Bibliography

I. Assessment and Diagnosis for DD/MI Population

   Provides an analysis of over 20 measurement tools used to assess mental health concerns in adults with intellectual disabilities. The report provides information on purpose, psychometric properties, as well as informational reliability and validity of tools when available.

   Provides listing of approved scales and tools for MI/DD population, by type. It should be noted that each of these scales and instruments has its advantages and disadvantages. Some produce valid and reliable results, and are in common usage. Others may not be standardized for the MI/DD population, or may be difficult to use (if not inappropriate to use) in certain ranges of retardation. NAMED: OHIO-MIMR-Report

   Proposes that model evaluations incorporate a multi-method approach including the following:
   - personal/social history (e.g. recording of recent stressors);
   - physical examination and medical history;
   - evaluation of current medication and possible side effects or interaction effects;
   - psychiatric evaluation;
   - FBA

   This article includes recommendations for assessment tools: DASH-II (Diagnostic Assessment for the Severely Handicapped – II), the ADD (Assessment of Dual Diagnosis), and the REISS Screen. These instruments have taken symptoms for the various diagnostic categories in the DSM and translated them into descriptions of behaviors that have been associated with particular diagnostic categories. This kind of assessment can also help sort out which behaviors are manifestations of a psychiatric disorder and which behaviors are a result of learning. Functional behavioral assessments need to be conducted for the latter when identified.

Patients with milder levels of disability can use self-report measures and can be diagnosed using standard criteria with little modification. For those with more severe disability, diagnosis...often requires the use of residual categories. Atypical clinical presentation, including maladaptive behaviors, lent support for "behavioral equivalent" substitutes of standard criteria. Typical pharmacological agents were effective for depression and electroconvulsive therapy for treatment-resistant bipolar disorder.


Systematic assessments of real-world functioning were related to performance on neurocognitive and functional capacity measures. Of the six rating scales evaluated in this study, the Specific Levels of Functioning (SLOF) assessment was the best. Use of a single rating scale provides an efficient assessment of real-world functioning that accounts for considerable variance in performance-based scores.


Presence of traumas was assessed through Allen’s trauma history screen...administered to key informants. Though they have been less studied by the literature regarding predictors of mental illness in people with intellectual disability, traumatic experiences seem to play a more important role in psychopathology than life events.


QABF-MI has robust psychometric properties and may be useful as a screening tool for determining the nature of the variables that maintain maladaptive behavior exhibited by individuals with serious mental illness.


DM-ID offers a broad examination of the topic, including a description of each disorder, a summary of the DSM-IV-TR diagnostic criteria, a review of the literature and research and an evaluation of the strength of evidence supporting the literature conclusions, a discussion of the etiology and pathogenesis of the disorders, and adaptations of the diagnostic criteria for the ID population. An abridged clinical manual is also available.


   Brief training interventions may improve awareness of mental health problems, but further research is needed to understand the referral process and to demonstrate the role of training in influencing actual staff behavior.


   The assessment of emotional disorders such as anger, depression and stress among people with an intellectual disability has traditionally used one of three methodologies: ratings by a significant other, a clinical interview or self-report. Despite the widespread use of all three methodologies, there is little research into their equivalence. This paper assesses the convergence among these three approaches for 147 people with a mild or moderate intellectual disability across the affective domains of anger, depression and stress. The results showed the overlap among the three methods to be consistently low, although limited convergence was found between self-report and clinical interview. Ratings by work supervisors discriminated least clearly between anger, depression and stress while self-report was the most discriminating between these three overlapping but conceptually distinct states. Suggestions are made for ongoing research into the methodologies of assessing affective states among people with an intellectual disability.

This population-based study included comprehensive individual assessments with each person. A two-stage process was used for diagnosis of affective disorders. Factors independently associated with depression were investigated through logistic regression analysis. The point prevalence was higher than that reported previously for the general population; DC-LD yielded 3.8% for depression and 0.6% for mania. Additionally, 1.0% had bipolar disorder currently in remission, and 0.1% first episode of mania currently in remission. Similar to general population findings, depression was associated with female gender, smoking, number of preceding family physician appointments, and preceding life events. Important differences were the association of not having a hearing impairment, and the trends for not living in deprived areas, and being married. Unlike general population findings, not having daytime occupation and obesity were not independently associated; nor was previous long-stay hospital residence, severity of ID, or sensory impairments. This study has found a high point prevalence of affective disorders in adults with ID. The factors associated with depression have differences to general population findings. An understanding of this is important in order to develop appropriate interventions, public strategy and policy, to reduce existing health inequalities.


The purpose of this research was to develop the Anxiety, Depression, and Mood Scale (ADAMS), an instrument intended to fill this gap. We developed a preliminary rating scale that included 55 symptom items. We examined the factor structure of these items by an exploratory factor analysis of behavior ratings on 265 individuals. A five-factor solution emerged that was both statistically sound and clinically meaningful. These factors were labeled “Manic/Hyperactive Behavior,” “Depressed Mood,” “Social Avoidance,” “General Anxiety” and “Compulsive Behavior.” We validated this solution by conducting a confirmatory factor analysis on ratings of 268 additional individuals. Model fit was acceptable. Internal consistency of the subscales and retest reliability for both the total scale and the subscales was high. Interrater reliability was satisfactory. The validity of the ADAMS was assessed with a clinical sample of 129 individuals with mental retardation who were seen in a psychiatric clinic; this provided additional support for the subscales. The ADAMS appears to be a psychometrically sound instrument for screening anxiety, depression and mood disorders among individuals with mental retardation.

The psychometric properties of the Self-Report Depression Questionnaire (SRDQ) were evaluated, extending a previous assessment of this instrument. Data from two independent studies (Esbensen, 2004; Seltzer & Krauss, 1989) were pooled to generate a sample of 192 individuals with primarily mild or moderate mental retardation. Reliability estimates of this questionnaire were good to excellent and corroborated prior findings. In addition, the measure was found to have sound validity as evidenced by convergent validity, discriminant validity, and predictive validity and by comparing individuals with and without clinical diagnoses of depression. Thus, the SRDQ appears to be a reliable and valid measure of depressive symptomatology for individuals with mild or moderate mental retardation. Screening procedures are suggested.


Despite further published papers and other studies in progress, the method of diagnosis for people with severe and profound ID remains debatable, with some authors advocating adherence to standard criteria, others suggesting adding criteria to the standard ones and yet others believing that substitute criteria are called for. However, for those with mild to moderate ID, a consensus is emerging that standard diagnostic criteria are appropriate. There has been progress in examining some of the symptoms which might constitute depression in people with ID. New diagnostic criteria issued by the Royal College of Psychiatrists are to be welcomed. There is an assumption in much of the research that symptoms of behaviour commonly termed challenging or maladaptive must be atypical symptoms of depression, but none of the studies reviewed demonstrate this effectively. This is compounded by methodological flaws in the way that depressed samples are arrived at for further study. Although new rating scales have emerged, there is as yet no gold standard diagnostic tool for depression amongst people with ID. It is suggested that, given these difficulties, the validity of the conceptual frameworks for depression is still in doubt. It remains the case that large-scale, collaborative, prospective studies are called for.


Empirical literature examining the emotional lives of adults with severe and profound mental retardation is limited. One area to have received attention is mood. It is proposed that the utility of assessment of mood extends beyond psychiatric diagnosis to issues such as the appraisal of quality of life for individuals with limited or no expressive language. Two themes related to the assessment of mood are evident in contemporary literature. First, attempts have been made to clarify presentation of affective disorders, especially depression, and to improve assessment of depressive symptomatology in adults with mental retardation. A review of current methods for assessing depression indicates significant problems with reliability and validity. There is a need to develop appropriate assessment methods for use in relation to adults with severe and profound mental retardation who are unable to self-report and behavioral methodology might be useful in this respect. Second, there is an emerging argument that presentation of depression in adults with mental retardation, particularly in individuals with severe disabilities, includes
challenging behaviors, referred to as “atypical symptoms.” Methodological and conceptual issues related to this argument warrant closer examination. Finally, it is noted that research drawing on more rigorous methodology is required to interpret the emotional states of individuals with severe and profound mental retardation.


The purpose of this article is the presentation of a multidimensional guideline for the diagnosis of anxiety and anxiety-related behavior problems in people with intellectual disability (ID), with a substantial role for the nurse in this diagnostic process. Design And Methods: The guideline is illustrated by a case report of a woman with ID with severe problems. Findings: It appears that a multidimensional diagnostic approach involving multidisciplinary team efforts can result in a more accurate diagnosis and improved subsequent treatment. Practice Implications: Nurses should be engaged in the diagnostic process because of their ability to make direct observations and to actively participate in carrying out all parts of the guideline.

23. Boyd, C et al. (2010) Clarifying Multimorbidity Patterns to Improve Targeting and Delivery of Clinical Services for Medicaid Populations High-priority patterns of multimorbidity. Based on hospitalization rates and costs; The impact of mental illness and substance abuse on per capita costs and hospitalization rates;

24. Sullivan, Willima F, MD, CCFP, PhD, et al Primary care of adults with developmental disabilities *Canadian consensus guidelines*. Knowledgeable health care providers participating in a colloquium and a subsequent working group discussed and agreed on revisions to the 2006 guidelines based on a comprehensive review of publications, feedback gained from users of the guidelines, and personal clinical experiences. Most of the available evidence in this area of care is from expert opinion or published consensus statements (level III). **Main message** Adults with DD have complex health issues, many of them differing from those of the general population. Good primary care identifies the particular health issues faced by adults with DD to improve their quality of life, to improve their access to health care, and to prevent suffering, morbidity, and premature death. These guidelines synthesize general, physical, behavioural, and mental health issues of adults with DD that primary care providers should be aware of, and they present recommendations for screening and management based on current knowledge that practitioners can apply. Because of interacting biologic, psychoaffective, and social factors that contribute to the health and wellbeing of adults with DD, these guidelines emphasize involving caregivers, adapting procedures when appropriate, and seeking input from a range of health professionals when available.
II. Service Design and Utilization


   
   This paper examines the complexity and challenges in providing effective delivery of physical and mental health care to people with developmental disabilities. The paper highlights a model of service delivery that focuses on “behavioral” crisis intervention and prevention which leads to a comprehensive set of interdisciplinary services and supports as well as a network of community linkages that facilitate the delivery of services.

   
   When adults have a medical home, their access to needed care, receipt of routine preventive screenings, and management of chronic conditions improve substantially.

   
   Results suggest that outcomes may be different for higher and lower functioning individuals with ID on a specialized inpatient unit, and some clinical measures may be more sensitive to changes in patients with more severe disabilities.

   
   People with ID (especially severe ID) have reduced access to general psychiatric services. General psychiatric inpatient care is unpopular especially with carers but can be improved by providing specially trained staff and in-reach from community ID teams. Opportunities may exist to enhance the care of people with borderline intellectual functioning within general psychiatric services...The weight of research is accumulating to suggest that provision of general psychiatric services without extra help is not sufficient to meet the needs of people with ID.

The value of utilizing objective monitoring systems incorporating operationalized signs and symptoms of hypothesized mental health concerns in individuals with developmental disabilities is now well accepted by interdisciplinary teams supporting these individuals. This article articulates in detail the establishment and implementation of an objective monitoring system to track cyclic changes in mood in individuals with developmental disabilities and bipolar disorder. Implementation of this system creates the opportunity for care-providers, individuals with developmental disabilities and/or their substitute consent-providers to make informed decisions regarding treatment decisions to optimize quality of life in individuals affected by this complex illness.


The presence of co-occurring psychiatric disorders among individuals with developmental disability (DD) requires clinicians to adjust and modify standard mental health assessment and treatment planning. In particular, assessment includes input from a multi-disciplinary team and as a result, diagnosis is frequently a synthesis of data from many different points of view. Treatment planning and implementation commonly include a collection of highly specialized, individualized programs that focus on the long term management of both disorders. Crises and recurrence of mental disorders are commonplace in part due to the presence of ongoing risk and vulnerability factors for mental disorders. As a result, the need for emergency interventions, specialized respite services, hospitalization and other transition services is extensive. The quality, availability and access to these services vary considerably. Many programs are concentrated in metropolitan or university-based centers and pose hardships based on geographic distance. The availability and utilization of services is affected by political, economic, socio-cultural and psychological forces that impact both the willingness to use services and the distribution of professionals trained and qualified to manage individuals with dual diagnoses. The complex interaction between each of these factors determines the structure, function, and capacity for innovation built into current service models.

8. Cubic, Barbara. Interdisciplinary Training to Promote Integrated Care (Webinar). Team based competencies domains: Roles and responsibilities, Communication, Team work (relationship building skills)

Project ADAPT tested a multifaceted intervention to improve the diagnosis and treatment of depression in older adults in rural (mostly primary care) sites. Under the program, providers received training, education, and ongoing consultation and support; agreed to use a standardized protocol for depression care; and designated an existing staff member as an onsite specialist who coordinated all depression-related care. The program enhanced access to screening and treatment and improved communication about depression among providers, leading to earlier diagnosis of the disease. See AHRQ Innovations Profile.


Compared to the control group, the intervention group showed an improvement in levels of depression, positive feelings about the self, and lower levels of automatic negative thoughts after the intervention. These changes were maintained at one month follow-up. These results demonstrate that intervention programmes are effective for the treatment of depression among people with ID.


Seventy-three adults with ID screened for adequate receptive vocabulary were interviewed as part of a larger study. They reported on cognitive constructs relating to depressed mood. In addition, comparisons were made between adults with ID and diagnosed major depression and a matched group of adults with ID and no psychiatric diagnoses in order to determine if these groups differed on the cognitive constructs associated with the two cognitive theories of depression. The cognitive variables examined were all significantly correlated with depressed mood in the direction predicted by their respective cognitive theory. Internal consistencies were good or excellent for most instruments, with the exception of those measuring hopelessness and attributions. In addition, significant differences were obtained between groups of individuals with and without co-morbid major depression on all variables except for hopelessness.

The present study examined the use of a progressive delayed concurrent schedule to teach tolerance to reinforcer delays with three adults with a dual-diagnosis of mental illness and mental retardation. Participants were initially given a series of choices between a sooner smaller reinforcer available immediately or a larger delayed reinforcer available after various delays ranging up to 5 min. During one of two alternating training conditions, participants were asked to choose between a sooner smaller reinforcer and a larger reinforcer at progressively increasing delays. During the other training condition, identical choices were available but participants were also provided a rule by the experimenter informing them that it was better to select one of the options over the other. Results showed that during baseline all three participants made frequent impulsive choices and selected the sooner smaller reinforcer most often, even at short delay values. However, following training, all participants’ preferences reversed. Furthermore, the effects were enhanced via the delivery of the rule by the experimenter. A 6 month follow-up consisting of rule removal and rule reversal demonstrated the durability of the training procedures over time. Implications for the enhancement of self-control via rule governed behavior is discussed.

13. Developing best practices for behavioral and mental health treatment for individuals with developmental disabilities: Maryland’s efforts.

We describe efforts by providers and stakeholders in Maryland to develop Best Practices for behavioral and mental health treatment for individuals with developmental disabilities. The Maryland initiative was characterized by inclusion of expert opinion and stakeholder experience to achieve consensus on Best Practices for the treatment of individuals dually diagnosed with a developmental disability and mental health or behavioral problems. An innovative, open space technology format was used during the Maryland Best Practices Conference that was held in February 2004. The planning and processes that resulted in the Maryland initiative are discussed and highlight the impact of these efforts. Results of the conference, workgroups and survey suggest many strengths in current practice as well as areas in need of development.


This study aims to reduce the incidents of restraints by applying a nontraditional consultation process in which a university-based team focused on patient consultations to collect data on treatment interventions and milieu approaches and conditions, as well as staff interactions. CONCLUSIONS. The efforts resulted in restraint reduction from 36 episodes per month to 0 episodes per month as well as precipitating a change in unit climate and care approaches on a specialized unit for patients with developmental disabilities and mental illness. PRACTICE IMPLICATIONS. Reducing the use of restraints involving multiple restraint incident patients is possible with a team-based approach and a specific intervention plan.

By identifying risk factors and treatment challenges related to individuals with both mental illnesses and developmental disabilities in the justice system, nurses can address these clients’ unique needs and prevent recidivism.

16. *Michigan Department of Community Health, 2011 Guide to Prevention and Positive Behavior Supports in A culture of Gentleness* This informational document is intended to provide examples and definitions of prevention and positive behavior supports and techniques in a culture of gentleness and to encourage the use of these approaches before implementing intrusive or restrictive interventions.


A review of 36 studies of outcomes over time for nearly 5,000 people with intellectual and developmental disabilities moving from large institutions to community living arrangements found high consistency in positive change in daily living skills for the movers.


This initial snapshot of services and associated costs raises many questions yet appears to offer some evidence of how people with dual diagnosis are being supported by IDS, MH and BHMCOs. For example, the data collected indicate a younger and less intellectually compromised population than the traditional program models have been serving. It is possible that service delivery models need to be more closely examined and modified to serve a population with different needs. With at least half of the individuals served by the IDS system taking psychotropic medications, this is a problem that needs to be addressed across systems. The people surveyed seem to be primarily diagnosed with mood disorders at about twice the rate of the general population.


For the “high risk” individuals reviewed, it appears that the service system was ineffective and that available resources were primarily dedicated to crisis management. This approach can often inflate costs with little return, including failed placements. A framework for collaboration between the separate mental retardation and mental health agencies that is proving to be successful. While barriers still exist in terms of adequacy of financial resources, and a lack of clinically trained and available practitioners, significant strides have been made in access to mental health inpatient services and to follow-up community outpatient services. There are lessons learned that may be useful to future policy discussions.


Youth and young adults aged 16 to 24 who have dual diagnoses of a serious mental health condition and a developmental disability experience significant challenges as they transition to adulthood. Responding to the identified lack of information about effective interventions with young people with dual diagnoses, the research team developed an exploratory qualitative study. The purpose of the study was to identify and describe best practices for transition to adulthood services for young people aged 16 to 24 who are dually eligible for mental health and developmental disability services.


III. Prevalance


   The findings from the present study suggest a strong relationship between severe behavioral problems, degree of intellectual disability and presence of psychiatric disorders in a large sample of adults with intellectual disabilities.

2. NCI Data Brief The 2008-2009 National Core Indicators Consumer Survey Report (see www.nationalcoreindicators.org for the full report) provides descriptive and outcome data on 11,569 adults (18 years and older) receiving publicly financed developmental disabilities services in 26 states and four sub-states entities. This Data Brief explores characteristics and responses of individuals who had dual diagnoses of intellectual disability (ID) and mental illness and contrasts them with characteristics and responses of individuals who had a diagnosis of ID only.


   Many behavior problems may be (unconventional) symptoms of psychiatric disorders or reflect a difficult life situation caused by a psychiatric disorder, or that a difficult life situation may contribute to both psychiatric disorders and behavior problems in individuals with intellectual disability.


   Compared the effects of a first-generation (i.e. haloperidol) and a second-generation (i.e. risperidone) antipsychotic drug with those of placebo in adults with intellectual disability who have a recent history of disruptive behavior. Aggressive challenging behavior in people with intellectual disability was reduced regardless of whether the treatment consisted of placebo or active medication.


   For individuals taking prescribed psychiatric medications at referral, psychiatric medication polypharmacy and same-class psychiatric medication polypharmacy were reduced by discharge. Modifications in the profile of medications prescribed generally reflected expert consensus guidelines. The overall findings suggest that this model of provision of specialized psychiatric outpatient services for individuals with IDD may be one approach to improve the quality of mental health care for this underserved population.

The prevalence of mental ill-health in adults with intellectual disabilities is around 40% using assessment measures that are specifically aimed at this population.


This exploratory study explored the relevance and availability of treatment practices for individuals with developmental disabilities (DD) and depression from the perspectives of professionals who work with this population. Additionally, potential areas of advancement in the field with regard to developing best practices were explored from the sixty professionals who participated in an online survey consisting of 15 questions on current treatment practices for depression among individuals with DD. Overall, the research findings indicate that individuals with DD and depression are an underserved population due to the lack of understanding and unsuccessful attempts by professionals in differentiating between co-occurring diagnoses. The difficulties involved with detecting depressive symptoms and diagnosing depression among individuals with DD have led to minimal progress in the development of empirically supported depression treatments. The research findings reflect the need for increased attention to differentiate depression from factors associated with DD and develop realistic treatment approaches for treating depression while managing the challenges associated with DD.


The prevalence rate of Alzheimer’s disease (AD) in people with Down’s syndrome (DS) increases significantly with age. However, the nature of the early clinical presentation, course and incidence rates of dementia are uncertain. The aims of the present study were to investigate the characteristics of age-related clinical changes and incidence rates for dementia in a population-based sample of people with DS aged 30 years and older at the age of risk for dementia. A modified version of the Cambridge Examination for Mental Disorders of the Elderly informant interview was used to determine the extent and nature of changes in memory, personality, general mental functioning and daily living skill 18 months after a similar assessment. At the time of the first assessment, the initial changes reported were predominately in behaviour and personality. At the second assessment, overall estimated incidence rates for frontal-like dementia were high (0.24), mainly in the younger groups, with incidence rates of AD, meeting both ICD-10 and DSM-IV criteria, of 0.04 predominately in the older groups. The present authors have hypothesized that the observed personality changes and the high estimated incidence rates of frontal-like dementia in the younger groups may indicate that functions served by the frontal lobes are the first to be compromised with the progressive development of Alzheimer-like neuropathology in people with DS.
9. NCI Data Brief Autism. The 2008-2009 National Core Indicators Consumer Survey Report (see www.nationalcoreindicators.org for the full report) provides descriptive and outcome data on 11,569 adults (18 years and older) receiving publicly financed developmental disabilities services in 26 states and four sub-state entities.

This update explores characteristics and responses of individuals who had a diagnosis of autism spectrum disorder (which includes Autism, Asperger Syndrome, and Pervasive Developmental Disorder) and contrasts them with characteristics and responses of individuals who did not. Of the total respondents for whom diagnostic information was available (10,629), 10.6% (N=1,128) had diagnosis of autism spectrum disorder, while 89.4% (N=9,501) did not. As a proportion of the total number of individuals with developmental disabilities responding to the 2008-2009 NCI surveys, the percentage of individuals with autism spectrum disorder varied among the states from 4.0% in Wyoming to 18.9% in New Jersey. It is important to note that the broader diagnostic category was used in the 2008-2009 survey. A higher proportion (10.6%) of the sample in 2008-2009 had an autism spectrum disorder diagnosis compared with 7.1% of the sample diagnosed with autism (using the stricter definition) in the 2006-2007 data.


www.aadmd.org/ntg/thinker ● www.rrtcadd.org/ ● www.aaidd.org Primary support for the National Task Group was provided by the American Academy of Developmental Medicine and Dentistry, the Rehabilitation Research and Training Center on Aging with Developmental Disabilities-Lifespan Health and Function at the University of Illinois at Chicago, and the American Association on Intellectual and Developmental Disabilities.

Identification, Screening, and Diagnosing. The National Task Group considers the need for early and valid identification of individuals showing signs and symptoms of cognitive impairment and dementia as an important first step in managing this age-associated challenge. What is proposed is the application of a metric (that is, a ‘screen’) on the behavior of individuals at-risk or suspected of evidencing changes associated with cognitive or functional decline. The National Task Group examined a number of instruments in use for assessing behavior and indicating whether the changes are due to a disease or organic process leading to dementia. One of the instruments examined appeared to have the most utility for use by direct support staff and family caregivers as a ‘first-instance’ screen. The Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQID), developed by Dr. Shoumitro Deb at the University of Birmingham, which is used in various parts of the world, is an informant-based instrument which would enable agencies to record change in behaviors typically noted as indicators or warning signs for dementia, and also might be useful for the cognitive impairment aspect of the annual wellness visit screening enabled by the Affordable Care Act.