Treatment of Psychiatric and Behavioral Problems in Individuals with Mental Retardation

EXPERT CONSENSUS GUIDELINES UPDATE

For Mental Retardation/Developmental Disability Populations

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Target Audience

This activity has been designed to meet the educational needs of physicians, pharmacists, and registered nurses involved in the management of patients with psychiatric and behavioral problems in populations with mental retardation/developmental disability.

Statement of Need/Program Overview

This activity explores issues surrounding the assessment, diagnosis, and treatment of behavioral problems and psychiatric disorders in populations with mental retardation/developmental delays. Participants will receive practical clinical guidance on the assessment and diagnosis of behavioral and psychiatric disorders in this population, review psychosocial and pharmacologic treatment strategies, and examine tactics to manage common behavioral problems and treatment-refractory symptoms.

Statement of Purpose

To provide clinical guidance on assessment, diagnosis, and appropriate treatment strategies for behavioral problems in populations with intellectual disabilities.

Educational Objectives

After completing this activity, the participant should be better able to:

- Discuss practical clinical guidance on the assessment and diagnosis of behavioral problems and psychiatric disorders in populations with mental retardation.
- Review available psychosocial treatment strategies, including recommendations for selecting the most appropriate interventions for different types of problems depending on the severity of symptoms and level of mental retardation.
- Review general principles for medication management in this population.
- Articulate specific recommendations for medication strategies to manage a variety of common behavioral problems in this population.
- Specify recommendations for dealing with treatment-refractory symptoms.

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Treatment of Psychiatric and Behavioral Problems in Individuals with Mental Retardation:

An Update of the Expert Consensus Guidelines

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INTRODUCTION

Clinicians need up-to-date information on assessing and treating psychiatric and behavioral problems in mental retardation (MR). This is important for several reasons:

- MR is relatively common, occurring in 1%–2% of the population.
- Psychiatric and behavioral problems occur in individuals with MR at 3 to 6 times the rate in the general population.[1–3]
- Psychiatric and behavioral problems create significant morbidity and make it more difficult to provide services.
- These problems place greatly increased burdens on caregivers.
- MR is often associated with medical/neurologic conditions that require medication treatment, increasing the risk for drug-drug interactions (eg, the prevalence of epilepsy may be as high as 40% in those with profound MR).[3]

This clinical guide has three purposes:

- To summarize the recommendations from the *Expert Consensus Guidelines on the Treatment of Psychiatric and Behavioral Problems in Mental Retardation*[4]
- To update the guideline recommendations with data from recent published research
- To help clinicians become more aware of the needs of individuals with MR and their families and caregivers

Survey of the Experts

Because the research literature provides very limited guidance on how best to manage psychiatric and behavioral problems in individuals of different ages with different severities of MR, a survey was undertaken to answer key questions not adequately answered by existing research literature and other guidelines.[5–7] The results, in conjunction with recommendations from the treatment literature, were used to develop the *Expert Consensus Guidelines*, which were published in 2000.[4] The survey:

- Was completed by 48 experts on psychosocial treatment and 45 experts on psychopharmacology.
- Had a response rate of 87%.
- Used a 9-point scale slightly modified from a format developed by the RAND Corporation for ascertaining expert consensus on the appropriateness of medical interventions.[8]
- Contained 48 questions that asked about 922 options.
- Covered general diagnostic and management issues as well as specific psychosocial and medication treatments.
- Produced data that were analyzed statistically with confidence intervals to determine the experts' consensus on first-line, second-line, and third-line options.

A list of the experts, a description of methodology, and information on guidelines for other psychiatric disorders developed using this methodology are available in other publications[9] and on the *Expert Consensus Guidelines* Web site (www.psychguides.com).

Review of the Literature

We reviewed literature on the psychopharmacologic treatment of psychiatric and behavioral problems in MR and updated the guideline recommendations to include recently published findings and information on medications not available at the time of the original survey. The reference list includes a number of the key citations. A full list of the citations we reviewed is available from the editors on request.

Needs of Individuals and Families

We provide guidance to help clinicians be more aware of the concerns of individuals with MR and their families. We solicited feedback from a number of key advocacy and support organizations (see page 13) and have incorporated their suggestions for clinicians on how to deliver the best care possible.

Expected Audience

The target audience for this monograph includes physicians, psychologists, nurses, social workers, pharmacists, teachers, rehabilitation and speech therapists, as well as family members and other caregivers. It is hoped that the recommendations presented here will help all these individuals work more effectively as a multidisciplinary team to serve the needs of this population.

Types of Interventions Discussed

This update to the *Expert Consensus Guidelines* first reviews the assessment and diagnosis of psychiatric and behavioral problems in individuals with MR. It then provides an overview of available psychopharmacologic, behavioral, and other nonpharmacologic interventions that may be helpful for such problems.

Limitations and Advantages of the Guidelines

These guidelines can be viewed as an expert consultation, to be weighed in conjunction with other information and in the context of the relationship between each individual and his or her clinician. The recommendations do not replace clinical judgment, which must be tailored to the particular needs of each clinical situation. We describe groups of individuals and make suggestions intended to apply to the average person in each group. However, individuals will differ greatly in their treatment preferences and capacities, in their history of response to previous treatments, their family history of treatment response, and their tolerance for different side effects. Therefore, the experts' first-line recommendations will certainly not be appropriate in all circumstances.

Guideline 1: Diagnosis and Assessment

1A. Target Population: Individuals with MR* and Psychiatric/Behavioral Problems

- There is significantly subaverage intellectual functioning (IQ of 70–75 or lower) evident before age 18 years.
- There are limitations in adaptive skills and functioning in at least two areas (eg, communication, self-care, social skills, self-direction, health, and safety).
- There are significant psychiatric or behavioral problems.
- The diagnosis of MR requires that the impairment in IQ preceded and is not directly related to the psychiatric disorder.

**Based on criteria from the DSM-IV-TR[10] and the American Association on Mental Retardation[11]*

1B. Most Pertinent DSM-IV-TR Diagnoses

When one of the following disorders can be diagnosed in an individual with MR, it may be an appropriate target of pharmacologic or behavioral treatment or a combination of the two.

- Schizophrenia
- Psychosis not otherwise specified (NOS)
- Bipolar disorder, manic or depressed phase
- Major depressive disorder
- Obsessive-compulsive disorder
- Mood disorder NOS
- Posttraumatic stress disorder
- Generalized anxiety disorder
- Anxiety disorder NOS
- Conduct disorder
- Attention-deficit/hyperactivity disorder (ADHD)
- Impulse control disorder NOS
- Pervasive developmental (autistic spectrum) disorders accompanied by behavioral or emotional problems
- Pica
- Stereotypic movement disorder (with or without self-injurious behavior)
- Insomnia/sleep disorder

Be Mindful of Difficulty in Diagnosing Mental Disorders in MR

There has been much controversy concerning how reliably one can make specific DSM-IV-TR[10] diagnoses in individuals with MR, especially in those with more severe impairment in intellectual functioning.[12] Because empiric data on this question are lacking, we posed this question to our expert panel. The majority indicated that it is often not possible to diagnose specific DSM-IV-TR disorders (other than autistic disorder) routinely and reliably in those with more severe MR. It is thus often necessary to focus primarily on problematic behaviors rather than a specific DSM diagnosis as a target for treatment in such individuals. Several efforts have recently been undertaken to help clinicians improve psychiatric diagnosis in MR.

A new manual, *Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation,*[13] was published in 2001 by the Royal College of Psychiatrists in London. It provides operationalized criteria for diagnosing psychiatric disorders and behavioral problems in this population, cross-referencing ICD-10 and DSM-IV.

Also in 2001, the European Association for Mental Health in Mental Retardation published *Practice Guidelines for the Assessment and Diagnosis of Mental Health Problems in Adults with Intellectual Disability.*[14] These guidelines, based on current evidence and consensus opinion, discuss epidemiology, assessment procedures, and clinical features of a number of specific psychiatric disorders.

The National Association for the Dually Diagnosed, in association with the American Psychiatric Association, is developing a *Diagnostic Manual for People with Intellectual Disabilities* to enable clinicians to more effectively identify mental disorders in this population. It uses the same diagnostic classification and coding system as the DSM-IV-TR with modified criteria based on behavioral equivalents. Publication is anticipated in 2005.

1C. Key Principles in Diagnosis

- Treatment should be based on the most specific DSM-IV-TR diagnosis possible.
- As the level of MR becomes more severe, it is increasingly difficult to make specific DSM-IV-TR diagnoses (other than autistic disorder) reliably.
- When only a tentative nonspecific DSM-IV-TR diagnosis can be made, the clinician may need to focus on one or more behavioral symptoms as the target(s) of treatment.
- Even when a specific diagnosis can be made with confidence, the clinician should also assess for behavioral symptoms that may be appropriate targets of treatment.

1D. Behavioral Problems

The following problems may be targets of psychopharmacolgic and/or behavioral treatment in the context of a DSM-IV-TR diagnosis or on their own if the clinician is unable to make a more specific diagnosis:

- Self-injurious behavior
- Physical aggression toward people or destruction of property
- Impulsivity/hyperactivity
- Suicidal ideation/behavior
- Sexually aggressive behavior
- Sexual self-exposure/public masturbation
- Social withdrawal
- Excessive dependency
- Noncompliance/oppositional behavior

1E. Assessment Methods

The experts recommended the following methods for evaluating individuals with MR:

- Functional behavior assessment
  - Interview with family/caregivers
  - Direct observation of behavior
  - Functional assessment behavior rating scales
- Ongoing assessment of treatment effects and side effects
  - Repeated direct observations of behavior
  - Repeated behavior rating scale assessments
- Medical history and physical examination
- Standard psychiatric diagnostic interview (more highly recommended for mild/moderate MR)

Laboratory tests, standardized psychometric tests, and indirect measures completed by other informants may also be useful.

1F. Identifying and Managing Stressors

As part of the initial assessment and treatment plan, clinicians should evaluate for stressors that often trigger or exacerbate psychiatric or behavioral problems in individuals with MR.[1,2,15]

- Interpersonal loss or rejection
  - Loss of parent, caregiver, or friend
  - Breakup of romantic attachment
  - Being fired from a job or suspended from school
- Environmental
  - Overcrowding, excessive noise, disorganization
  - Lack of satisfactory stimulation
  - School or work stress
- Parenting and social support problems
  - Lack of support from family, friends, or partner[16,17]
  - Destabilizing visits, phone calls, or letters
  - Family chaos
  - Neglect
  - Hostility
  - Physical or sexual abuse
- Transitional phases
  - Change of residence, school, or work
  - Developmental landmarks (eg, onset of puberty)
- Illness or disability
  - Chronic medical or psychiatric illness (more common in MR than in the general population)
  - Serious acute illness
  - Sensory deficits
  - Difficulty with ambulation
  - Seizures
- Stigmatization
  - Taunts, teasing, exclusion, being bullied or exploited
- Frustration
  - Due to inability to communicate needs and wishes
  - Due to lack of choice about residence, work situation, diet
  - Because of realization of deficits

Helping the individual, family, and caregivers deal with or eliminate stressors may sometimes be the primary target of treatment and often facilitates whatever other psychosocial or medication treatments are necessary.

1G. Informed Consent

After the diagnostic evaluation is completed and before beginning treatment, clinicians give appropriate information to individuals with MR and their caregivers and obtain informed consent. Because requirements about informed consent vary in different jurisdictions and settings, please consult applicable regulations for your specific state and type of treatment setting. The following general suggestions may be useful.[18,19]

- Informed consent is obtained from the individual (if he or she has the capacity to give it) or from a legally authorized representative before beginning any treatment (medication or other intervention), or as soon as possible after emergency treatment.
- Appropriate information on the proposed treatment (eg, purpose, benefits, risks, adverse effects, right to refuse, alternatives) is given before consent and on an ongoing basis during treatment.
- Consent is voluntary.
- Even if informed consent is not mandatory, giving individuals and their caregivers information and obtaining their assent to treatment is desirable and often leads to better treatment outcomes.
- Materials are available to help educate individuals with MR about their medicines and consent/assent procedures from Project MED (Medication EDucation for Consumers). These 8 booklets provide information on the following topics in a format that is easy to understand.

  Patients' Rights and Responsibilities
  Anticonvulsant Medicines
  Antipsychotic Medicines
  Antidepressant Medicines
  Antimanic Medicines
  Antianxiety Medicines
  Stimulant Medicines
  Other Behavior Medicines (blood pressure medicine, naltrexone, vitamins, and over-the-counter)

  Forms for ordering booklets from Project MED can be downloaded from the Web site www.projectmed.org. Booklets cost $1.50 each plus shipping and handling.

GUIDELINE 2: PSYCHOSOCIAL TREATMENT

2A. General Principles

- Enlist the cooperation of the individual and family.
- Use a multidisciplinary team approach.
- Ensure that there is continuity of care (eg, case coordination).
- Structure the physical and psychosocial environment to meet the individual's needs.
- Facilitate timely access to care (eg, information, transportation, finances, health care).
- Reduce psychosocial stressors.
- Enhance psychosocial supports.
- Select residential arrangements to suit functional level.
- Ensure placement in the least restrictive environment possible.

2B. Recommended Prevention and Intervention Methods for Psychiatric Disorders and Target Behavior Symptoms

Strategies	Goal	Example
Environmental changes	Reduce chances for emergence or exacerbation of problem behaviors by rearranging physical and/or social conditions that seem to provoke them	Changes in activities (eg, restructure tasks to be easier to complete) Changes in work, social groupings, or routines Changes in physical environment (eg, noise, temperature, lighting, crowding)
	Identify and manage stressors that exacerbate psychiatric disorders or behavior problems (see Guideline 1F)	Enrichment of environment through social or sensory stimulation
Education for individual and/or family	Teach ways to manage behavioral and psychiatric problems that may accompany developmental disabilities	Provide appropriately worded educational materials (eg, Project MED booklets [see Guideline 1G]) Refer to consumer advocacy and support groups (see p. 13) Behavioral training for parents, teachers, and staff Social and communication skills training Instruction in coping (self-control) skills
Applied behavior analysis (changing antecedents and consequences of target behaviors)	Build appropriate functional skills and reduce problem behavior	Accelerating and decelerating differential reinforcement procedures Response interruption for problem behavior Time out (unless the function of the target behavior is to escape/avoid)

The experts also recommended *cognitive-behavior therapy* (focusing on underlying thought processes; biased perceptions; and unrealistic expectations, attitudes, and emotions) for major depressive disorder, posttraumatic stress disorder, obsessive-compulsive disorder, and prominent anxiety symptoms in individuals with mild-to-moderate MR. They recommended *classical behavior therapy* (eg, in vivo or imaginary exposure) for generalized anxiety disorder and prominent anxiety symptoms. Consult references 20–24 for more detailed discussion of psychosocial interventions.

2C. Dealing with Insomnia

Sleep problems are common in individuals with MR.[25,26] They can cause considerable difficulty in themselves and can exacerbate (or be exacerbated by) psychiatric or behavioral problems. The experts recommended a number of sleep hygiene strategies.

- Establish a bedtime routine.
- Have regular bedtime and wake-up times.
- Provide education about good sleep hygiene.
- Restrict caffeine intake.
- Avoid environmental disruptions.
- Restrict naps.
- Restrict substance use.
- Promote exercise if appropriate.
- Relax with bath and/or reading at bedtime.
- Avoid hunger or meals at bedtime.
- Reduce stimulation and activities during the evening.
- Rule out other causes for insomnia (eg, sleep apnea, alcohol, nicotine, decongestants, beta blockers, antidepressants).[5]

2D. Dealing with Weight Problems

Individuals with MR are at increased risk for excessive weight gain. In addition, many of the medications that are used to treat psychiatric and behavioral problems can affect weight (eg, psychostimulants and topiramate are associated with weight loss, whereas some of atypical antipsychotics are associated with weight gain[27–31]). Clinicians should discuss the importance of avoiding weight gain with families and caregivers. A number of strategies can help manage weight problems and may make it possible for individuals to stay on medication that is helpful for behavioral problems.

- Obtain baseline height and weight before beginning a new medication.
- Structure meal times before medicine starts.
- Provide the right foods (vegetables, high fiber) instead of high calorie fatty foods.
- Encourage "fun" exercise (eg, working out on a trampoline, walks in the park, bicycling, swimming).
- Monitor height and weight (including waist girth) regularly.[30,31]
- If on an atypical antipsychotic, monitor glucose and lipid levels according to current guidelines.[30,31]

Guideline 3. General Principles of Medication Use

3A. Before Prescribing Medication, Assess:

- Medical pathology
- Psychosocial and environmental conditions
- Health status (including ruling out pain)
- Current medications (including over-the-counter)
- Presence of any psychiatric condition
- History, previous intervention, and results
- A functional analysis of behavior

The decision to use a psychotropic medication and choice of medication are generally more straightforward in the presence of an identifiable psychiatric diagnosis (Guideline 1B). If it is not possible to make a reliable specific diagnosis, medication selection should be based on specific behavioral symptoms as the target of treatment (Guideline 1D). However, even when a specific diagnosis can be made with confidence, clinicians should also assess for behavioral symptoms that may be targets of treatment.

3B. Strategies for Medication Management

The Centers for Medicare and Medicaid Services (CMS, formerly the Health Care Financing Administration [HCFA]) take great interest in this area (see their Web site for information and regulations[5]). We asked the experts how to apply CMS regulations and precautions in clinical settings. The general recommendations presented here are based on the CMS *Safety Precautions*,[5] consensus statements,[18] and the experts' responses to questions on dosing strategies, use of blood levels, and indications for hospitalization. Individuals with MR may be at higher risk for certain side effects, including antipsychotic-induced movement disorders (eg, dystonias, dyskinesias),[32,33] neuroleptic malignant syndrome,[34] weight gain,[27–31] and symptoms (tics, dysthymias, irritability) associated with psychostimulant treatment.[35] Individuals with MR, especially those with concomitant behavioral problems, are more likely to be receiving multiple medications, increasing the risk of adverse drug interactions.[36–39]

Dosing strategies

- Keep medication regimen as simple as possible. Consider use of once-a-day dosing and extended-release formulations (eg, divalproex XR) when possible.
- Start low and go slow—use lower initial doses and increase more slowly than in individuals without MR.
- Use the same (or lower) maintenance and maximum doses as in individuals without MR.
- Periodically consider gradual dose reduction (at the same rate or more slowly than in individuals without MR).
- Avoid frequent drug and dose changes unless there is a valid reason for the change (eg, no response, adverse effects).

Evaluating treatment effects

- Collect baseline data before beginning medication.
- Evaluate medication efficacy by tracking specific index behaviors using recognized behavioral measurement methods (eg, frequency counts, rating scales).
- Evaluate the medication's effect on functional status.

Evaluating side effects

- Monitor for side effects regularly and systematically (at least once every 3 to 6 months and after any new medication is begun or the dose is increased). A standardized assessment instrument can be helpful in monitoring for side effects.[18]
- If an antipsychotic is prescribed, assess for tardive dyskinesia at least every 3 to 6 months.
- If on an atypical antipsychotic, monitor for changes in weight and glucose and lipid levels per recently released guidelines.[30,31]
- If the individual is on more than one medication, monitor for drug interactions.

Polypharmacy

- Avoid using two medications from the same therapeutic class at the same time (intraclass polypharmacy, eg, two SSRIs).
- Using two or more medications from different therapeutic classes at the same time (interclass polypharmacy) may be appropriate and needed in certain situations (eg, psychotic or bipolar depression, partial response to one drug, comorbid conditions).

Other medication practices to avoid

- Long-term use of benzodiazepine antianxiety agents (eg, diazepam) or shorter acting sedative hypnotics (eg, zolpidem)
- Use of long-acting sedative hypnotics (eg, chloral hydrate)
- Use of anticholinergics without extrapyramidal symptoms
- Higher than usual doses of psychotropic medications
- Use of phenytoin, phenobarbital, primidone as psychotropics
- Long-term use of prn medication orders
- Failure to integrate medication with psychosocial interventions

Use of blood levels of medication

Blood levels may be helpful in the following situations:

- Serious side effects or nonresponse to usual doses
- Concern about compliance
- Worsening behavior
- To check for possible variation in metabolism and elimination
- When individual is taking a combination of medications, is at risk for seizures, or has difficulty communicating side effects

Review of the medication regimen

- Review regimen regularly (at least every 3 months and within 1 month of drug/dose change) to determine if medication is still necessary and if lowest optimal effective dose is being used.
- See the individual at each review.
- Consult with caretakers and the multidisciplinary team.
- Consider possibly reducing the number of psychotropic medications, even if medication-free status is not possible.
- Use a continuous quality improvement model.
- Incorporate a mechanism for flagging cases of greatest concern.

Indications for hospitalization

- Risk of suicide, significant self-injury, or harm to others
- Acute psychotic symptoms

3C. When to Include Medication in the Initial Treatment Plan

CMS (HCFA) General Safety Precaution #4 recommends that, before using medication to manage psychiatric or behavioral symptoms, clinicians should intervene in the least intrusive and most positive way. Although the CMS recommendation recognizes that the use of medication is sometimes the least intrusive and most positive intervention, it does not specify the circumstances when medication would be an appropriate part of the initial treatment plan. To help clinicians operationalize Safety Precaution #4, we present the experts' ratings of the appropriateness of including medication in the initial treatment plan in various situations.

Clinical situation	Medication is definitely recommended as part of initial treatment for	Consider including medication as part of initial treatment for
For DSM-IV disorders	Schizophrenia Bipolar disorder, manic or depressed phase Major depressive disorder Psychotic disorder NOS Obsessive-compulsive disorder	Mood disorder NOS Panic disorder ADHD Stereotypic movement disorder with self-injurious behavior
For target symptoms in the absence of a specific DSM-IV disorder	Suicidal ideation/behavior	Self-injurious behavior Interpersonal aggressive behavior Hyperactivity
Factors that suggest the need for medication as part of the initial treatment plan	History of behavioral deterioration when off medication Self-injurious behavior with risk of lasting harm Aggression to others that poses a physical risk Very severe symptoms Previous good response to medication Lack of response to psychosocial interventions Symptoms that interfere significantly with individual's ability to participate in education and/or rehabilitation	Family history of good response to a psychiatric medicine Symptoms that have persisted for more than a few weeks Symptoms that are very disruptive to family or other residents

3D. Reasons for Long-term Medication Treatment

CMS (HCFA) Safety Precaution #8 recommends that, unless clinically contraindicated, periodic attempts be made to reduce the dose of medication gradually to determine whether the person's psychiatric or behavioral symptoms can be treated with a lower dose or the medication can be discontinued altogether. However, CMS does not specify what clinical contraindications would make one cautious about reducing dose or attempting to discontinue the medication. This is a very important question in clinical practice because attempts to titrate down and discontinue treatment with psychotropic medications can be detrimental and even dangerous in some cases. Therefore, we asked the experts which psychiatric disorders are likely to require long-term maintenance medication and which circumstances would suggest that attempts at dosage reduction would be contraindicated.

DSM-IV disorders for which long-term maintenance medication is	
Usually necessary	**Sometimes necessary**
Schizophrenia Bipolar disorder, manic and depressed phases Major depressive disorder, frequently recurrent	Psychotic disorder NOS Obsessive-compulsive disorder

Clinical factors that contraindicate dose reduction or discontinuation	
Often	**Sometimes**
Continued presence of symptoms that make medication withdrawal risky (eg, psychosis, aggression) Individual relapsed during previous attempt to discontinue medication History of very severe symptoms History of severe self-injurious behavior History of aggressive behavior that poses a risk to others	Symptoms did not respond to previous medication treatment, but have responded now Concern that the individual will not respond as well if medication needs to be restarted in the future History of persistent symptoms (for more than a month or two) History of lack of response to psychosocial interventions

Guideline 4: Initial Selection of Medications

4A. Selection of Medications for Psychiatric Disorders

The same medications are used to treat specifically diagnosed psychiatric disorders in individuals with MR as in the general population. The experts' recommendations given here for treating psychiatric disorders in individuals with MR agree with those in previous expert consensus surveys for treating individuals without MR.[40]

Condition	Preferred medications
Bipolar I disorder, manic episode*	
Classic, euphoric mania	Divalproex or lithium alone or combined with newer atypical antipsychotic (AAP)
Mixed/dysphoric or rapid cycling mania	Divalproex alone or combined with newer AAP
Bipolar II disorder, hypomanic episode*	Divalproex or lithium
Bipolar disorder, depressive episode*	
Nonpsychotic depression†	Lithium and/or lamotrigine; lithium + antidepressant (AD); divalproex + AD or lamotrigine‡
Psychotic depression	Newer AAP + mood stabilizer (ie, lithium, divalproex, or lamotrigine) + AD
Schizophrenia	
If compliant with oral medication	Newer AAP
If noncompliant with oral medication	Long-acting depot antipsychotic (preferably atypical)
Numerous failed trials of other antipsychotics	Clozapine
Psychosis NOS	Newer AAP
Major depressive disorder	Selective serotonin reuptake inhibitor (SSRI)
Posttraumatic stress disorder	SSRI
Obsessive-compulsive disorder	SSRI
ADHD	Psychostimulant

**Recommendations updated based on a recent Expert Consensus survey[41] and research in the general population[42]*
†Consider the possibility that ADs may worsen rapid cycling.
‡Titrate lamotrigine dose slowly and monitor for rash. Discontinue lamotrigine if rash occurs because it may progress to Stevens-Johnson syndrome.

4B. Selection of Medications for Target Symptoms

We asked the experts about choice of medications when the following symptoms are present in an individual for whom a specific DSM-IV diagnosis cannot be made. We posed a situation in which the symptoms had not responded adequately to appropriate behavioral and environmental interventions and remain severe and persistent enough that medication treatment is definitely indicated.

Condition	Preferred medications
Self-injurious behavior	Newer AAP Anticonvulsant/mood stabilizer*
Physical aggression to people or property	Newer AAP Anticonvulsant/mood stabilizer
Nonaggressive agitation	Anticonvulsant/mood stabilizer
Suicidal ideation/behavior	SSRI
Anxiety	SSRI Buspirone
Hyperactivity	Psychostimulant
Insomnia	Trazodone

**Agents with combined anticonvulsant and mood stabilizing properties (see Guideline 4D for recommendations for specific agents)*

4C. Preferred Medications for Psychiatric or Behavioral Problems in an Individual with Comorbid Epilepsy

- Divalproex
- Carbamazepine

4D. Preferred Medications Within Different Classes

We asked the experts to give their highest ratings to medications with the best combination of effectiveness, tolerability, safety, and the least likelihood of causing further cognitive impairment.

Class of medication	Preferred medications
Antipsychotic* for psychotic symptoms, self-injurious behavior, and aggressive or destructive behavior	Risperidone Olanzapine
Mood stabilizer/anticonvulsant for self-injurious behavior and aggressive or destructive behavior	Divalproex Carbamazepine
Antidepressant for depression, self-injurious behavior, aggressive or destructive behavior, nonaggressive agitation, and anxiety	SSRI *(Consider venlafaxine or duloxetine for depression)*
**Quetiapine received higher second-line ratings. Two other newer atypical antipsychotics, ziprasidone and aripiprazole, were not yet available at the time of the survey.*	

4E. Literature Review*

Methodology. We performed a literature search for information on a number of psychotropic medications searching under the *name of the drug* plus *mental retardation*, *developmental disabilities*, *pervasive developmental disorders*, or *autism/autistic disorder*. The most striking finding is the extremely limited research base in this area and the very small number of placebo-controlled trials. This doubtless reflects the methodologic difficulties of performing studies in this population (eg, heterogeneity of the severity of MR, difficulty of psychiatric diagnosis, recruitment problems) as well as a lack of resources. Clearly there is a need for high quality controlled studies to improve our understanding of the most effective and safest medication treatments for this population. For general reviews on the treatment of behavioral problems and the use of different classes of agents, readers are referred to a number of review articles.[43–47] The literature supports the experts' recommendations for specific psychiatric disorders and target behaviors.

Mood stabilizers/anticonvulsants. The experts recommended use of mood stabilizers/anticonvulsants for bipolar disorder (manic and depressive phases), self-injurious or aggressive behavior, and agitation, and to treat psychiatric or behavioral problems that occur in individuals with epilepsy. Among the mood stabilizers, the experts considered divalproex the agent of choice (rated first line by 90% or more), followed by carbamazepine. These recommendations reflect findings in the literature. Divalproex was found to be effective in treating aggressive, self-injurious, and disruptive behavior.[48–50] Lindenmayer and Kotsaftis reviewed the literature on divalproex in the treatment of violent and aggressive behavior in patients with MR, organic brain syndromes, and dementia (17 reports involving 164 patients).[48] They reported promising findings, with an overall response rate of 77.1%. However, because most of these reports were open studies or case series, there is a significant need for controlled studies in this area. An open trial also found that divalproex was beneficial for patients with autism spectrum disorders, particularly those with affective instability, impulsivity, and aggression or a history of EEG abnormalities or seizures.[51] An extended-release formulation of divalproex is now available, which has been reported to be better tolerated with fewer side effects than the delayed release formulation, and also has the advantage of once-daily dosing.[52,53] Controlled studies are needed.

Atypical antipsychotics. The experts recommended the newer AAPs for schizophrenia and other psychotic symptoms (eg, psychosis NOS, psychotic depression) and for self-injurious or aggressive behavior. Among the AAPs, the experts considered risperidone the antipsychotic of choice (rated first line by over 90%) and also gave first-line ratings to olanzapine, with quetiapine a high second-line option. Ziprasidone and aripiprazole were not available at the time of the original survey and were, therefore, not included. Risperidone has received by far the most study and is the only AAP for which there are data from randomized controlled trials in patients with MR. It has been reported to be effective in the treatment of aggressive, self-injurious, and disruptive behaviors.[54–58] Uncontrolled studies have been done with olanzapine[28,59] and ziprasidone.[60] Findings suggest that at least some of the atypical antipsychotics may be effective in reducing hyperactivity, aggression, and repetitive behaviors in autistic disorder.[61] The largest number of studies have looked at risperidone. An 8-week, multisite, randomized double-blind trial comparing risperidone and placebo in 101 children was recently completed by the Research Units on Pediatric Psychopharmacology Autism Network.[62] It found that risperidone was effective and well tolerated for the treatment of tantrums, aggression, or self-injurious behavior in children with autistic disorder. In keeping with the experts' recommendations, there is support in the literature for the use of clozapine for treatment-resistant symptoms.[63]

Psychostimulants. More research on psychopharmacotherapy in MR has focused on ADHD than other disorders.[3] The experts' recommendation of psychostimulants for ADHD and hyperactive behavior reflects findings in the research literature.[64–66] Atomoxetine was not available at the time of the survey and no controlled studies in MR have yet been published.

SSRIs. The experts recommended SSRIs for major depressive disorder, posttraumatic stress disorder, obsessive-compulsive disorder, and for suicidal ideation/behavior and anxiety that does not meet criteria for a DSM-IV-TR disorder. These recommendations reflect findings that the SSRIs are effective for anxiety and depression.[3,43,67] Preliminary findings also suggest that SSRIs may be helpful for self-injurious behavior,[3] and these are reflected in the high second-line ratings they received for this indication.

**A full list of the citations reviewed is available from the editors (Email: eks@ls.net).*

Guideline 5: Inadequate Response to Initial Medication Treatment

5A. Recommended Steps Before Making a Change in the Medication Regimen

- ***Ensure adequate duration of medication trial***
  - For antipsychotic, 3–8 weeks
  - For mood stabilizer, 1–3 weeks
  - For SSRI, 6–8 weeks
  - Use the longer durations if partial response
- ***Ensure adequate dose of medication***
- ***Ensure adequate blood levels of medications (if applicable)***
- ***Evaluate for compliance problems***
- Reevaluate the diagnosis (Guideline 1B)
- Assess for the presence of side effects
- Manage environmental problems and stressors (Guideline 1F)
- Optimize nonpharmacologic interventions (eg, adequate behavioral treatment [Guideline 2])
- Get more information from other informants
- Order additional laboratory studies (eg, thyroid function) if applicable
- Assess for substance use

5B. General Strategies When There Is Inadequate Response to Initial Treatment

Clinical response	Recommended strategy
No response	Switch to different agent
Partial response	Add an adjunctive agent

If the individual has had no response to a medication after a trial that is adequate in duration and dose (see Guideline 5A), the experts recommended tapering the original medication and switching to a different medication to avoid unnecessary polypharmacy. This reduces the risk of added side effects and adverse drug interactions. If the individual has had a partial response, the experts believe it may be preferable to add a medication to the already existing treatment rather than eliminate it altogether to avoid losing whatever benefit the individual is obtaining from the original treatment. Partial response to a single medication can be an indication for rational polypharmacy.

5C. Selecting the Next Medication When There Is Inadequate Response to Initial Treatment

The table presents the experts' recommendations for agents to switch to, depending on the current treatment and the indication for which it is being used.

The current treatment is	Being given for	If there is no response, switch to
Newer AAP	Psychosis	Different newer AAP
	Self-injurious behavior Aggressive/destructive behavior	Anticonvulsant/mood stabilizer Different newer AAP
Conventional antipsychotic	Psychosis	Newer AAP
	Self-injurious behavior Aggressive/destructive behavior	Newer AAP Anticonvulsant/mood stabilizer
Anticonvulsant/mood stabilizer	Self-injurious behavior Aggressive/destructive behavior	Newer AAP Different anticonvulsant/mood stabilizer
SSRI	Nonpsychotic depression	Different SSRI
	Self-injurious behavior Aggressive/destructive behavior	Anticonvulsant/mood stabilizer Newer AAP
Buspirone	Anxiety	SSRI
Benzodiazepine	Anxiety	SSRI

5D. Selecting Adjunctive Medication When There Has Been Only a Partial Response to Initial Treatment

The table presents the experts' recommendations for adding agents depending on the current treatment and the indication for which it is being used. The editors note, however, that if the initial response is very limited, it may make sense to titrate down slowly and try to discontinue the first medication once the individual is stabilized because the benefit may no longer outweigh the risk of added side effects or drug interactions. This is a way of avoiding unnecessary polypharmacy.

The current treatment is	Being given for	If there is partial response, add
Newer AAP	Self-injurious or aggressive/ destructive behavior	Anticonvulsant/mood stabilizer
Anticonvulsant/mood stabilizer	Self-injurious or aggressive/ destructive behavior	Newer AAP
SSRI	Nonpsychotic depression	*(Consider adding an anticonvulsant/ mood stabilizer, lithium, or a different antidepressant)*
	Self-injurious or aggressive/ destructive behavior	Anticonvulsant/mood stabilizer Newer AAP
Buspirone	Anxiety	SSRI

Guideline 6: Working with Individuals with MR and Their Families

Key Points for Clinicians to Keep in Mind*

- Remember the person is first, the disability is second.
- Use words that are easy to understand. "People first" language is clear and respectful.
- Talk to the adult person, not his or her assistant.
- Allow enough time for questions and concerns to be raised.
- Provide a way for people to ask a question if one occurs to them after they leave your office or clinic.
- Involve individuals and families to the greatest extent possible in all aspects of decision making, asking for input about the severity and nature of problems and their perceived need for intervention.
- Provide individuals and families with written materials (and/or refer to Web sites) that provide appropriate information about their illness and the medications being recommended.
- Provide followup and compliance directions in writing or alternative formats if needed.
- Be prepared to consult with other members of the person's team. Your interdisciplinary skills can be the key to the best outcomes.
- Emphasize person- and family-centered strategies that reflect positive behavior support.
- Provide services and programs within the most normative settings and natural environments possible.
- Identify and refer to comprehensive supportive services (eg, speech or occupational therapy, assistance with housing or finances, supported employment).
- Tailor interventions to fit typical real-life routines and settings (eg, at home, school, in the community).
- Elicit information from the person and his or her family or caregivers concerning outcomes that are important to them.
- In evaluating for aggressive or disruptive behavior problems, clinicians, parents, and caregivers should be aware that some genetic syndromes are more prone to behavior problems (behavioral phenotypes).
- Refer individuals and families to appropriate support groups where they can discuss their experiences and concerns with others who might have been in similar situations.

**We would like to thank The Arc, the Autism Society of America, the National Fragile X Foundation, the National Association for the Dually Diagnosed, the National Down Syndrome Congress, the National Down Syndrome Society, TASH, and others for providing feedback and suggestions for this section and the document as a whole.*

Advocacy and Support Organizations

The Arc of the United States

National organization of and for people with cognitive, intellectual and developmental disabilities and their families that works to include people with these disabilities in all communities. Advocates for services and supports for these individuals and their families and fosters research and education regarding prevention of MR in infants and young children. Its 140,000 members include individuals with intellectual disabilities, family members, professionals in the field of disability, and other concerned citizens.

1010 Wayne Ave., Suite 650
Silver Spring, MD 20910
301-565-5456
http://www.thearc.org

Autism Society of America

Mission is to promote lifelong access and opportunity for all individuals within the autism spectrum and their families to be fully participating members of their community. Promotes education, advocacy at state and federal levels, active public awareness, and research.

7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814-3067
301-657-0881 or 800-3-AUTISM
www.autism-society.org

Best Buddies International, Inc.

Organization dedicated to enhancing the lives of people with MR by providing opportunities for one-to-one friendships and integrated employment.

100 SE Second Street, Suite 1990
Miami, FL 33131
305-374-2233
www.Bestbuddies.org

Epilepsy Foundation

Organization committed to the prevention and cure of epilepsy. Goals are to broaden and strengthen research, provide easy access to reliable information, and assure access to appropriate medical care.

4351 Garden City Drive
Landover, MD 20785
Phone: 800-332-1000 or 301-459-3700
www.epilepsyfoundation.org

National Fragile X Foundation

Mission is to unite the fragile X community to enrich lives through educational and emotional support, promote public and professional awareness, and advance research toward improved treatments and a cure for fragile X syndrome.

PO Box 190488
San Francisco, CA 94119
925-938-9300 or 800-688-8765
www.fragilex.org

The National Association for the Dually Diagnosed (NADD)

Organization for professionals, care providers, and families to promote understanding of and services for individuals with developmental disabilities and mental health needs. Mission is to advance mental wellness for persons with developmental disabilities by promoting excellence in mental health care. Provides educational services, training materials, and conferences.

132 Fair Street
Kingston, NY 12401
845-331-4336
www.thenadd.org

National Organization on Fetal Alcohol Syndrome (NOFAS)

Dedicated to eliminating birth defects caused by alcohol consumption during pregnancy, the leading known preventable cause of mental retardation and birth defects, and to improving the quality of life of affected individuals and their families. Provides national and community-based public awareness campaigns; a national curriculum for medical and allied health students; training workshops for professional and lay audiences; peer education and youth outreach initiatives; and an information, resource, and referral clearinghouse.

900 17th Street, NW, Suite 910
Washington, DC 20006
202-785-4585 or 800-66NOFAS
www.nofas.org

National Down Syndrome Congress (NDSC)

Works to create a national climate in which all persons will recognize and embrace the value and dignity of persons with Down syndrome. Operates the NDSC Center, a clearinghouse for up-to-date information on topics of interest to people with Down syndrome, family members, friends, professionals, and others. Publishes the Down Syndrome News and the Down Syndrome Headline News.

1370 Center Drive, Suite 102
Atlanta, GA 30338
800-232-NDSC or 770-604-9500
www.ndsccenter.org

National Down Syndrome Society (NDSS)

Mission is to benefit people with Down syndrome and their families through national leadership in education, research, and advocacy. Largest nongovernmental supporter of Down syndrome research in the United States. Provides information about Down syndrome and referral to local parent support groups and other resources.

666 Broadway
New York, NY 10012
212-460-9330 or 800-221-4602
www.ndss.org

TASH

International association of people with disabilities, their family members, other advocates, and professionals. Mission is to promote full inclusion and participation of persons with disabilities in all aspects of life and to eliminate physical and social obstacles that prevent equity, diversity, and quality of life. Known for its major annual conference and other training opportunities. Membership benefits include publications and opportunities for networking and participation in national and international disability rights efforts.

29 W. Susquehanna Avenue, Suite 210
Baltimore, MD 21204
410-828-8274
www.tash.org

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POSTTEST

1. Which of the following is true of the diagnosis of DSM-IV-TR mental disorders in patients with mental retardation?
   A. It is best done with a structured clinical interview.
   B. It is best done with a standardized rating scale.
   C. It is more difficult in mild than in severe mental retardation.
   D. It is very often difficult to do reliably in patients with more severe MR.
   E. A DSM-IV-TR diagnosis must be made before beginning treatment.

2. The following DSM-IV-TR diagnoses are all a first-line indication for medication treatment except:
   A. Schizophrenia
   B. Bipolar disorder, manic phase
   C. Bipolar disorder, depressed phase
   D. Posttraumatic stress disorder
   E. Major depressive disorder

3. The target symptom least likely to be treated with medication is
   A. Suicidal ideation or behavior
   B. Self-injurious behavior
   C. Social withdrawal
   D. Aggressive behavior
   E. Hyperactivity

4. The most important psychosocial techniques in assessing and treating behavior problems in patients with mental retardation include all of the following except:
   A. Functional behavior assessment
   B. Cognitive-behavioral therapy
   C. Applied behavior analysis
   D. Environmental changes
   E. Education for individual and family

5. Which of the folllowing are useful in dealing with insomnia?
   A. Established bedtime and wake-up times and routines
   B. Restrict caffeine and substance use
   C. Avoid environmental disruptions and daytime naps
   D. Relax with bath and/or reading at bedtime
   E. All of the above

6. All of the following are important principles in the medication management of patients with mental retardation except:
   A. Higher than usual maintenance doses are often necessary
   B. Start low in initial dosage
   C. Go slow in raising dosages
   D. Monitor side effects carefully
   E. Avoid long-term prn dosing

7. Indications for rational polypharmacy include:
   A. Bipolar disorder
   B. Psychotic depression
   C. Partial response to a single medication
   D. Comorbid conditions
   E. Any of the above

8. Factors that suggest the need for medication as part of the initial treatment plan for a patient with mental retardation and behavioral problems include:
   A. History of behavioral deterioration when previously off medication
   B. Self-injurious behavior with risk of lasting harm
   C. Aggression to others that poses a physical risk
   D. Lack of response to psychosocial interventions
   E. All of the above

9. Which class of medications should be avoided as maintenance therapy in patients with mental retardation?
   A. Benzodiazepines
   B. Atypical antipsychotics
   C. Mood stabilizers
   D. Psychostimulants
   E. Selective serotonin reuptake inhibitors

10. Which clinical factors might contraindicate semi-annual attempts at dose reduction?
    A. Continued presence of symptoms that make medication withdrawal risky
    B. Individual relapsed during previous attempt to discontinue medication
    D. History of very severe symptoms
    D. History of severe self-injurious or aggressive behavior that poses a risk to self or others
    E. All of the above

11. Mood stabilizers/anticonvulsants are often useful in the treatment of which of the following in a patient with mental retardation?
    A. Bipolar disorder, manic phase
    B. Bipolar disorder, depressed phase
    C. Self-injurious behavior
    D. Aggression or agitation
    E. All of the above

12. An atypical antipsychotic is often useful in the treatment of which of the following in a patient with mental retardation?
    A. Schizophrenia
    B. Self-injurious behavior
    C. Physical aggression
    D. Bipolar disorder, manic phase
    E. All of the above

13. A selective serotonin reuptake inhibitor (SSRI) is often useful in the treatment of which of the following in a patient with mental retardation?
    A. Bipolar depression
    B. Major depressive disorder
    C. Posttraumatic stress disorder
    D. Obsessive-compulsive disorder
    E. All of the above

14. When treating an individual with MR with an atypical antipsychotic, which of the following should be monitored for regularly?
    A. Weight
    B. Tardive dyskinesia and other movement disorders
    C. Lipid levels
    D. Glucose levels
    E. All of the above

Evaluation Form

Treatment of Psychiatric and Behavioral Problems in Individuals with Mental Retardation
Expert Consensus Guidelines Update for Mental Retardation/Developmental Disability Populations
Project ID: 2258-ES-2

Postgraduate Institute for Medicine (PIM) respects and appreciates your opinions. To assist us in evaluating the effectiveness of this activity and to make recommendations for future educational offerings, please take a few minutes to complete this evaluation form. You must complete the evaluation form and posttest to receive acknowledgment of participation for this activity.

Please answer the following questions by circling the appropriate rating:

	Outstanding	Good	Satisfactory	Fair	Poor
Extent to Which Program Activities Met the Identified Purpose					
• To provide clinical guidance on assessment, diagnosis, and appropriate treatment strategies for behavioral problems in populations with intellectual disabilities.	5	4	3	2	1
Extent to Which Program Activities Met the Identified Objectives					
After completing this activity, the participant should be better able to:					
• Discuss practical clinical guidance on the assessment and diagnosis of behavioral problems and psychiatric disorders in populations with mental retardation.	5	4	3	2	1
• Review available psychosocial treatment strategies, including recommendations for selecting the most appropriate interventions for different types of problems depending on the severity of symptoms and level of mental retardation.	5	4	3	2	1
• Review general principles for medication management in this population.	5	4	3	2	1
• Articulate specific recommendations for medication strategies to manage a variety of common behavioral problems in this population.	5	4	3	2	1
• Specify recommendations for dealing with treatment-refractory symptoms.	5	4	3	2	1
Overall Effectiveness of the Activity					
• Was timely and will influence how I practice	5	4	3	2	1
• Will assist me in improving patient care	5	4	3	2	1
• Fulfilled my educational needs	5	4	3	2	1
• Avoided commercial bias or influence	5	4	3	2	1

Impact of the Activity

The information presented: *(check all that apply)*

☐ Reinforced my current practice/treatment habits ☐ Will improve my practice/patient outcomes
☐ Provided new ideas or information I expect to use ☐ Enhanced my current knowledge base

Will the information presented cause you to make any changes in your practice? ☐ Yes ☐ No

If yes, please describe any change(s) you plan to make in your practice as a result of this activity:

How committed are you to making these changes? (Very committed) 5 4 3 2 1 (Not at all committed)

Future Activities

Do you feel future activities on this subject matter are necessary and/or important to your practice? ☐ Yes ☐ No

Please list any other topics that would be of interest to you for future educational activities:

Followup

As part of our ongoing quality improvement effort, we conduct postactivity follow-up surveys to assess the impact of our educational interventions on professional practice. Please indicate your willingness to participate in such a survey:

☐ Yes, I would be interested in participating in a follow-up survey
☐ No, I'm not interested in participating in a follow-up survey

Additional comments about this activity:

If you wish to receive acknowledgment of participation for this activity, please complete the posttest by selecting the best answer to each question, complete this evaluation verification of participation, and fax to: (303) 790-4876.

Posttest Answer Key

1	2	3	4	5	6	7	8	9	10	11	12	13	14

Request for Credit

Name_____ Degree_____

Organization_____ Specialty_____

Address_____

City, State, ZIP_____

Telephone_____ Fax_____ E-mail_____

I certify my actual time spent to complete this educational activity to be:

☐ I participated in the entire activity and claim 1.25 (CME), 0.12 CEUs (pharmacy), or 1.5 CNA/ANCC (nursing).

☐ I participated in only part of the activity and claim _____ credits.

Signature_____ Date Completed_____

Notes

Notes