

Medical Care of Adults with Mental Retardation

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Persons with mental retardation are living longer and integrating into their communities. Primary medical care of persons with mental retardation should involve continuity of care, maintenance of comprehensive treatment documentation, routine periodic health screening, and an understanding of the unique medical and behavioral disorders common to this population. Office visits can be successful if physicians familiarize patients with the office and staff, plan for difficult behaviors, and administer mild sedation when appropriate. Some syndromes that cause mental retardation have specific medical and behavioral features. Health issues in these patients include respiratory problems, gastrointestinal disorders, challenging behaviors, and neurologic conditions. Some commonly overlooked health concerns are sexuality, sexually transmitted diseases, and end-of-life decisions. (*Am Fam Physician* 2006;73:2175-83, 2184. Copyright © 2006 American Academy of Family Physicians.)

► **Patient information:** A handout for caregivers of persons with mental retardation, written by the authors of this article, is provided on page 2184.

Approximately 1 percent of the general population has mental retardation.¹ The U.S. Surgeon General has identified “glaring” health disparities in the availability of good health care for adults with mental retardation compared with the general population.² These disparities are caused in part by inadequate compensation and a lack of experience among health care professionals in meeting the needs of this population.² Increasing numbers of persons with mental retardation are living into adulthood, and primary care physicians are needed to direct the medical support necessary for successful community integration.

Although persons with developmental disabilities are designated in different ways (e.g., “intellectually disabled”), this article focuses on the subset of patients with mental retardation (*Table 1*^{3,4}).

General Health Care Guidelines

For physician office visits, patients with mental retardation should be accompanied by a person who is familiar with them and the purpose of the visit. Providing caregivers in advance with a referral sheet documenting

the information expected for each office visit can be helpful (*Figure 1*). For patients with destructive or challenging behaviors, physical and emotional trauma can be minimized and the effectiveness of the evaluation enhanced by providing mild sedation (e.g., lorazepam [Ativan], 1 to 8 mg). Additional components of successful primary care office visits are listed in *Table 2*.

Patients with mental retardation often have multiple and sometimes complicated medical problems. Maintaining continuity of care and a complete record of all medical interventions is vital. To help keep each patient’s medical records current, caregivers should be reminded to ask consulting physicians to complete and return documentation related to all medical care provided away from the primary care physician’s office. Furthermore, accurate data collection by caregivers is crucial in identifying disorders, monitoring treatment response, and documenting behavioral problems.

Routine periodic health screening should be offered to patients with mental retardation as it is for other adults. The Massachusetts Department of Mental Retardation

SORT: KEY RECOMMENDATIONS FOR PRACTICE

<i>Clinical recommendation</i>	<i>Evidence rating</i>	<i>References</i>
Offer routine, periodic health screening to persons with mental retardation.	C	5
Avoid the use of psychotropic medications for new challenging behaviors until an attempt has been made to rule out potential medical and environmental causes (except when harmful to self or others).	C	52
Consider a conservatorship, and document end-of-life issues for adults not mentally capable of making medical decisions.	C	60

A = consistent, good quality patient-oriented evidence; B = inconsistent or limited quality patient-oriented evidence; C = consensus, disease-oriented evidence, usual practice, expert opinion, or case series. For more information about the SORT evidence rating system, see page 2105 or <http://www.aafp.org/afpsort.xml>.

publishes prevention guidelines more specific to this population (http://www.guidelines.gov/summary/summary.aspx?doc_id=4201).⁵ Healthy lifestyles and avoidance of high-risk behaviors should be encouraged. Physical activity, often lacking in this population,⁶ can improve quality of life for many.⁷ Participation in Special Olympics also should be encouraged, with appropriate screening for event-specific limitations (e.g., atlantoaxial instability in persons with Down syndrome). Genetic evaluation may be helpful in defining specific syndromes.⁸ This aids physicians in directing genetic family counseling and anticipating associated medical (Table 3)⁹ and behavioral (Table 4)¹⁰⁻¹⁸ disorders.

Up to 50 percent of patients coming from institu-

tions may have a history of hepatitis A or B infection.¹⁹ Screening and vaccination for hepatitis B should be considered.⁵

Oral Hygiene

Oral hygiene often is neglected in adults with mental retardation,²⁰ and obtaining access to good dental care can be difficult.²¹ Periodontal disease is common and can be a source of discomfort, fever, and challenging behaviors, especially in persons with communication difficulties. Hospitalization may be necessary to provide adequate dental care for persons unable to tolerate outpatient settings.²² Physicians should emphasize regular dental evaluations and consider mild sedation for outpatient dental visits.

Skin Care

Patients with decreased mobility or incontinence are at increased risk of skin breakdown. Caregivers should be counseled on appropriate skin care, and physicians should evaluate patients routinely for skin breakdown.

Persons with tracheotomy and percutaneous endoscopic gastrostomy (PEG) sites may have chronic colonization with bacteria such as methicillin-resistant *Staphylococcus aureus*.²³ Communicable disease guidelines for this population address treatment concerns and encourage integration into community or residential programs (<http://www.in.gov/isdh/dataandstats/epidem/2004/sep/guidelines.pdf> and http://www.cdph.state.co.us/dc/epidemiology/co_mrsa_schools5_03.pdf).

Respiratory Concerns

Persons with mental retardation, particularly those with Down syndrome, often have obstructive sleep apnea.²⁴ However, many are unable to tolerate continuous positive airway pressure. For persons who require treatment,

TABLE 1
Definitions of Developmental Disabilities and Mental Retardation

Developmental disabilities

Severe chronic mental or physical disabilities that manifest before a person reaches 22 years of age, are likely to continue indefinitely, and result in substantial functional limitations in three or more of the following areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, or economic self-sufficiency³

Mental retardation

Identifies a subset of persons who have developmental disabilities with below-average general intellectual functioning (below 65 to 75) as measured through standardized general aptitude evaluation tools, such as the Wechsler Intelligence Scales or Stanford-Binet Intelligence Scales (mild, 50 to 69; moderate, 35 to 49; severe, 20 to 34; profound, less than 20)

Is present before 18 years of age

Accompanies two or more deficits in adaptive behavior used for everyday living (e.g., communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, work) as determined by a structured evaluation tool such as the Vineland Adaptive Behavior Scales.⁴

Information from references 3 and 4.

Patient Encounter Form

Please bring this sheet to each visit.

Patient name: _____ Date of birth: _____ Date of visit: _____

Conservator name: _____

Contact information: _____ Name of person filling out form: _____

Relationship to patient: _____

Complete list of medications (or copy of the current medicine administration record): _____

Medication allergies/intolerance: _____

Reason for visit/chief concern: _____

Date of onset: _____

What are the symptoms? _____

How have the symptoms changed? _____

What treatments have been tried? _____

What were the results? _____

If this is a follow-up visit:

How has the patient improved? _____

How has the patient become worse? _____

Any side effects of treatment? _____

Specific questions to ask the doctor: _____

Care plan/physician recommendations: _____

Figure 1. Encounter sheet for caregivers of patients with mental retardation to fill out before each physician visit.

surgical intervention such as uvulopalato-pharyngoplasty or genioglossal advancement may be helpful.²⁵

Gastrointestinal and Feeding Disorders

Many patients with intellectual and physical disabilities develop swallowing difficulties, which can lead to choking, aspiration, malnutrition, and poor hydration.²⁶ Aspiration is particularly common in patients with neuromuscular disorders, is often silent,²⁷ and may lead to significant pulmonary pathology (e.g., aspiration, bronchitis, pneumonia) and even

TABLE 2
Components of a Successful Examination of the Patient with Mental Retardation

- Gradually desensitize the patient to the office and staff through short social visits.
- Minimize environmental noise (e.g., intercom pages, loud music).
- Tell the patient what you are doing as each area is being examined.
- Include the patient in the decision-making process as much as possible.
- Plan ahead for how to cope with potentially challenging behaviors.
- Consider sedating the patient before medical evaluations (e.g., 2 mg of lorazepam [Ativan] two to three hours before visit).

TABLE 3

Medical Phenotypes of Specific Disorders in Persons with Mental Retardation

<i>Disorder</i>	<i>Possible medical phenotypic expression</i>
Cerebral palsy	Gastrointestinal: drooling, swallowing disorders Neuromusculoskeletal: chronic pain (lumbosacral, hip, leg), muscle spasticity, seizures, osteoporosis, scoliosis Pulmonary: recurrent infections secondary to aspiration Urinary: incontinence
Cri du chat syndrome	Cardiac: ventricular and atrial septal defects Orthopedic: scoliosis Pulmonary: recurrent upper respiratory infection with otitis media
Down syndrome	Cardiac: adults without apparent congenital heart disease may have valvular disease including mitral valve prolapse and aortic regurgitation Dermatologic: seborrheic dermatitis of scalp and face, eczema of hands and feet, tinea infections including onychomycosis Endocrine/metabolic: hypothyroidism, diabetes, obesity ENT: recurring cerumen impactions, hearing loss, upper airway obstruction, obstructive sleep apnea Gastrointestinal: GERD, often with Schatzki's ring and Barrett's esophagus, celiac disease Neurologic: dementia, seizures Ophthalmic: strabismus, cataracts, decreased visual acuity Orthopedic: atlantoaxial instability, patellar subluxation, hip disease, osteoporosis
Neurofibromatosis 1	Cancer: neurofibrosarcoma Cardiovascular: hypertension Neurologic: tumors may develop in the brain, on cranial nerves, or on the spinal cord Orthopedic: enlargement and deformation of bones, scoliosis
Prader-Willi syndrome	Dermatologic: leg edema or ulceration, lesions on head and anterior legs from skin picking ENT: obstructive sleep apnea Gastrointestinal: gastroparesis, acute idiopathic gastric dilatation Metabolic: insulin resistance, hyperlipidemia, hypertension, growth hormone deficiency, water intoxication, obesity Neurologic: exaggerated responses to standard dosages of anesthetic and sedative agents Orthopedic: scoliosis, osteoporosis
Rett syndrome	Cardiorespiratory: prolonged QT interval, episodic apnea or hyperpnea Gastrointestinal: drooling, GERD, swallowing difficulties caused by oropharyngeal and gastroesophageal incoordination, constipation with functional megacolon, gallbladder dysfunction Neuromusculoskeletal: seizures, gait apraxia and truncal ataxia, scoliosis, osteoporosis
Tuberous sclerosis	Cardiac: congestive heart failure, hypertension Dermatologic: facial, unguinal angiofibromas Neurologic: seizures, obstructive hydrocephalus Ophthalmic: retinal hamartomas or phakomas Orthopedic: cystic defects in the metacarpals, metatarsals, or phalanges; erosions of the tufts of the distal phalanges Pulmonary: fibrosis, pneumothorax

ENT = ear, nose, and throat; GERD = gastroesophageal reflux disease.

Information from reference 9.

death from respiratory infection.²⁸ Hypoxemia occurring during oral feedings can be identified by monitoring the patient with pulse oximetry.²⁹

Speech pathology consultation with a fluoroscopic swallowing study can document the presence of aspira-

tion and indicate dietary changes or postural changes during swallowing to minimize aspiration. Because of a limited evidence base, the use of a feeding tube to avoid aspiration with oral feeding is controversial³⁰; however, malnutrition may require nutritional supplementation

through a PEG tube.³¹ Patients who experience aspiration from reflux may benefit from fundoplication or placement of a jejunostomy tube.³²

A person with poor verbal skills may have difficulty communicating discomfort related to gastroesophageal reflux disease (GERD). Particularly prevalent in persons with Down syndrome, GERD may cause unexplained sore throat, choking, cough, or changes in behavior.³³ Esophagogastroduodenoscopy may be better tolerated and require less patient cooperation than radiographic procedures. It also provides more specific information about the degree of inflammation and pathology and allows for intervention (e.g., dilatation of a Schatzki's ring).

Constipation and fecal impaction are common in persons with mental retardation³⁴ and may lead to unexplained changes in behavior. These conditions may be caused by an innate predisposition, but medical causes or medication side effects should be considered. There is limited evidence for an ideal treatment regimen in this population. Nonetheless, proactively regulating bowel

movements may be more helpful than waiting for symptoms of constipation to be reported by caregivers.

Women's Health Issues

Menstrual discomfort can be a source of agitation and aggression, including self-injurious behavior.³⁵ When medication fails to control dysmenorrhea or there are serious menstrual hygiene problems, surgery may be a reasonable option.³⁶ It should not be assumed that persons with mental retardation are not sexually active; reproduction and sexually transmitted diseases should be considered. Surgical or medical interventions affecting reproductive ability require an awareness of relevant ethical issues and should be completed only after appropriate consideration of applicable local, state, and federal laws.³⁷

Neurologic Disorders

Seizures in persons with mental retardation are likely to be severe, occur often, and be difficult to control³⁸; increase as the degree of psychomotor retardation increases³⁹; and decrease life expectancy by up to 20 years.⁴⁰ When

TABLE 4

Behavioral Phenotypes of Specific Disorders in Persons with Mental Retardation

Disorder	Behavioral phenotype	Specific interventions
Angelman's syndrome ¹⁰	Absence of speech but with paroxysmal laughter and smiling; fascination with water; sleep disturbance	Requires close supervision when around water; melatonin
Prader-Willi syndrome ^{11,12}	Obesity, food-seeking and food-hoarding behaviors; antisocial with temper tantrums; obsessive-compulsive features such as skin picking, ordering impulsivity; labile affect; psychosis; sleep disturbance	Group psychotherapy; SSRIs
Williams syndrome ¹³	Overly friendly and highly sensitive to rejection; impulsivity; incessant chatter; fearful and worrisome; has few friends	Intervention for anxiety
Fetal alcohol syndrome ¹⁴	ADHD; inappropriate sexual behavior and sexually offending behaviors (e.g., touching, incest); substance abuse; anxiety disorders, depression, mania; sleep disorders; aggression, conduct disorders, oppositional defiant disorders, adjustment disorders; visual-motor/visuospatial coordination deficits; speech/language impairments	Psychosocial intervention; stimulants; SSRIs; atypical antipsychotics; mood stabilizers
Down syndrome ¹⁵	Depression; obsessional slowness; obsessive-compulsive disorder; autism; dementia after 50 years of age	Psychosocial intervention; SSRIs
Rett syndrome ¹⁶	Repeated movements, hand stereotypy, facial twitches; social interaction (autistic-relating) problems; mood disturbance, fear, anxiety; insomnia; autistic behaviors	SSRIs, risperidone (Risperdal), melatonin
Fragile X ¹⁷ syndrome	Hyperarousal, anxiety, ADHD, aggression, autism	SSRIs, stimulants, clonidine (Catapres), atypical antipsychotics, mood stabilizers
Phenylketonuria ¹⁸	Autism, ADHD, agoraphobia	Maintenance of phenylalanine-free diet

SSRI = selective serotonin reuptake inhibitor; ADHD = attention-deficit/hyperactivity disorder.

Information from references 10 through 18.

Mental Retardation

obtaining information from caregivers about new onset of seizures in patients taking metoclopramide (Reglan) or neuroleptics, physicians must be careful because extrapyramidal signs and tardive dyskinesia may be mistaken for seizures. Furthermore, physicians should incorporate surveillance for these medication-related movement disorders in patients taking these medications. The Abnormal Involuntary Movement Scale is available online at <http://www.atlantapsychiatry.com/forms/AIMS.pdf>.

Many persons with mental retardation, especially those with Down syndrome, do not have predictable responses to pain. Therefore, pain is an unreliable indicator for the presence or severity of many disorders,⁴¹ resulting in delayed diagnosis and intervention and an increased risk of morbidity and mortality.⁴² Given the uncertainty of individual pain perception and response, new onset of pain must be evaluated thoroughly.

Musculoskeletal Conditions

Neuromuscular scoliosis is common among persons with mental retardation, especially those with cerebral palsy. Bracing is unlikely to be effective in stabilizing this type of scoliosis. Consultation with an orthopedic subspecialist for significant curvature is important because surgical intervention may be required to limit curve progression, respiratory compromise, and pain.^{43,44}

Contractures can develop in persons who do not have use of their lower extremities. Symptomatic relief can be provided by surgical interventions such as tendon lengthening, tendon release, or osteotomy.

Spasticity is a common source of discomfort.⁴⁵ Oral muscle relaxants can provide mild improvement⁴⁶ but

often have complications such as sedation.⁴⁷ Physical therapy, prolonged stretching, splinting, and serial casting can be effective, but some patients may require more invasive interventions such as site-specific botulinum toxin (Botox) injections or use of a baclofen (Lioresal) pump.

Osteoporosis is common, particularly among non-weight-bearing patients⁴⁸; as many as 50 percent of adults with mental retardation have osteoporosis or osteopenia.⁴⁹ Conditions associated with an increased risk of osteoporosis include cerebral palsy, Down syndrome, use of antiepileptics, special diets (e.g., ketogenic diet for seizure control), and hypogonadism.⁵⁰ Aggressive evaluation of traumatic injuries with radiographic studies may be justified even when there are few physical findings. Furthermore, osteoporosis and use of antiepileptics may predispose patients to degenerative disk disease with spinal cord compromise, leading to functional decline.⁵¹

Behavioral and Psychiatric Interventions

For persons unable to communicate adequately, a change in behavior may be the first indication of a problem. An unrecognized medical disorder or environmental change should be considered before concluding that a new challenging behavior, or an exacerbation of a previous behavior, is caused by an underlying psychiatric disorder (*Table 5*).⁵² Given the relationship between mental retardation and family violence and abuse,⁵³ family dynamics also should be evaluated carefully when challenging behaviors are most prevalent in the home.

Neuropsychiatric disorders such as obsessive-compulsive disorder, attention-deficit/hyperactivity disorder, and mood disorders can occur in persons with mental retardation and, when left untreated, may lead to more challenging behaviors. Although some etiologies of mental retardation may have associated behavioral phenotypes (*Table 4*),¹⁰⁻¹⁸ most challenging behaviors are caused by the same neuropsychiatric disorders that affect the general population⁵⁴ and respond to the same treatments. One notable exception is benzodiazepine therapy, which can precipitate paradoxical reactions of increased irritability and aggression in 10 to 15 percent of patients with mental retardation.⁵⁵

Once pharmacologic or behavioral intervention is deemed appropriate and informed consent has been obtained, the goal is to minimize physical and emotional trauma to the patient and caregivers while maximizing community integration. Counseling and psychotherapy should be considered

TABLE 5

Triggers for Challenging Behavior in Persons with Mental Retardation

Type of stressor	Examples
Transitional phase	Change of teacher or residence; adolescence; retirement of patient
Interpersonal loss or rejection	Loss of parent, job, romantic partner
Environmental	Stress at group home or day program
Family, social support problems	Neglect from family, friends, caregivers; abuse
Medical or psychiatric illness	Tooth pain; depression
Anger, frustration	Being teased; inability to complete tasks

Information from reference 52.

TABLE 6

Topics to Address Regarding Relationships, Sexuality, and Protection from Harm in Persons with Mental Retardation

Protection from harm

Alcohol and drug use
Physical, emotional, and sexual abuse
Pregnancy
Sexually transmitted diseases

Relationship development

Respecting the boundaries of other persons
Setting boundaries

Sexuality

Appropriate and inappropriate behaviors
Appropriate and inappropriate dress
Appropriate and inappropriate places for behavior (e.g., masturbation)

for persons with mild to moderate mental retardation.⁵⁶ Except for short-term intervention in patients determined to be potentially harmful to themselves or others, medications should not be used to restrict behaviors. Treatment should be directed at an underlying medical condition, environmental change, or psychiatric disorder.

Because many persons with mental retardation have greater access to their community than others, they should be educated about the inappropriate use of illicit drugs and alcohol.⁵⁷ It also is important to provide patients and caregivers with information on relationship development, sexuality, sexual abuse, pregnancy prevention, and protection from sexually transmitted diseases (Table 6).^{58,59} Sexually offending behavior is concerning, but a number of interventions are available (Table 7).⁵²

TABLE 7

Challenging Behaviors in Patients with Mental Retardation

<i>Challenging/target behavior</i>	<i>Interventions</i>
Sexually offending behavior (e.g., inappropriate touch, public masturbation, hypersexuality, sexual abuse)	Remove prejudice toward healthy, nonoffensive sexual expression; behavioral therapy; psychotropic therapy (identify and treat any comorbid psychiatric disorders; SSRIs, cimetidine [Tagamet], spironolactone [Aldactone], risperidone [Risperdal], medroxyprogesterone [Provera], leuprolide [Lupron])
Self-injuring behavior (e.g., skin picking, head banging, biting)	Risperidone, SSRIs, valproic acid (Depakene), naltrexone (ReVia)
Stereotypy behavior (e.g., repetitive, nonpurposeful movement in persons with pervasive [autistic] spectrum disorders; rocking; hand flapping)	SSRIs, risperidone (2 to 4 mg twice a day), clonidine (Catapres)
Aggression or destruction Cyclic—consider bipolar disorder and migraine headache syndrome Poor impulse control disorder—sudden, unexplained aggression that resolves as quickly as it develops Temporal lobe seizure—sudden, unexplained aggression that resolves as quickly as it develops; associated with a change in sensorium before, during, or after behavior outbursts	Risperidone, valproic acid, clonidine, propranolol (Inderal), buspirone (BuSpar)
Sleep disturbance (may be a symptom of a mood disorder)	Trazodone (Desyrel), zolpidem (Ambien), diphenhydramine (Benadryl), melatonin
Hyperactivity (e.g., autism, ADHD, akathisia if using neuroleptic drugs, side effect of phenobarbital)	Methylphenidate (Ritalin), clonidine, valproic acid, risperidone
Attention deficit (e.g., ADHD, autism)	Methylphenidate, clonidine, bupropion (Wellbutrin)
Repetitive behavior patterns (e.g., becomes “stuck” in an activity, such as hand washing) Obsessive-compulsive disorder—appears stuck in an activity; when redirected, goes back to previous activity and becomes stuck again Autism—becomes stuck in an activity; when redirected, goes to new activity and may become stuck in that	SSRIs, risperidone
Miscellaneous—talking aloud to themselves	Not pathologic, intervention not warranted

SSRI = selective serotonin reuptake inhibitors; ADHD = attention-deficit/hyperactivity disorder.

Information from reference 52.

Legal and End-of-Life Issues

Informed consent and capacity for medical decision making can be difficult to assess. It should not be assumed that all adults with mental retardation are unable to make medical decisions. If there are questions about this issue, physicians should consider a formal competency evaluation. Furthermore, families of adults with mental retardation often fear that they will outlive a caring support system; thus, end-of-life concerns are best discussed before a time of crisis develops. Specific end-of-life requests and preferences should be documented. These include religious ceremonies and wishes for final disposition of the body. Although parents have the authority to make medical decisions for their minor children, adult patients with mental retardation who lack adequate medical decision-making capacity should have a conservator appointed to act in their best interest.⁶⁰ Ideally, this would be a parent or other knowledgeable family member. Although conservators do not have the power to make a living will, individual and family preferences about treatment objectives and parameters for resuscitation efforts can be documented to help guide surrogate decision makers in their absence.

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