Mental Retardation (MR) is a general term for a relatively common, life-long condition in which differences in cognitive and adaptive development occur because of abnormalities of brain structure or function. Medically, MR should not be thought of as a diagnosis but rather as a symptom of neurologic dysfunction, like weakness or spasticity. The presence of MR has impact on many aspects of the lives of children, their families, and their communities and is an important health and social issue.

Definitions

There are currently 2 commonly used formal definitions of MR. The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) defines MR by 3 coexisting features (1) significantly subaverage intellectual functioning accompanied by (2) deficits or impairments in adaptive functioning that are (3) evident before age 18. The definition of the American Association on Mental Retardation (AAMR) contains essentially the same 3 core components but also lists key assumptions that are essential to application of the definition. These address the importance of appropriate assessment with respect to elements such as age, culture, language, and environment; the need to delineate strengths as well as limitations and to identify support needs; and the potential for persons with MR to improve with respect to life functioning if provided with the appropriate supports for a sustained period.

Degrees of MR are additionally described within the DSM-IV, based on numerical IQ scores and assuming associated adaptive deficits. These ranges reflect the degree of deviation of the IQ from a mean of 100, with 15 points representing 1 standard deviation (SD) on measures such as the Wechsler Scales. In mild MR, IQ is 2 to 3 SD below the mean; in moderate MR, 3 to 4 SD below the mean; in severe MR, 4 to 5 SD below the mean; and in profound MR, IQ is more than 5 SD below the mean. In contrast, the AAMR does not subclassify MR based on IQ ranges but focuses on whether support needs in the various adaptive skill areas are intermittent, limited, extensive, or pervasive, the ILEP classification system.

Terminology

Debate about the terminology of developmental disability in general and mental retardation in particular continues, and practitioners can feel at times that they are in a linguistic minefield. In some countries, mental retardation has been largely discarded in favor of learning disability or intellectual disability because the term mental retardation is regarded by some as pejorative. Others argue that mental retardation has a definition, unlike alternative terms, and should therefore ensure clarity of communication. A study by Panek and Smith, in the Midwestern United States, found that there was some evidence favoring mentally challenged as a term, although the difference in how positively it was seen in comparison to the other terms was not large. This author’s experience has been that poorly timed use of the term mental retardation can harm therapeutic relationships and that the use of alternatives is generally preferable when speaking with affected individuals and their families. These include mentally challenged and development delay. Developmental delay is defined by some as applying only to children under 5 years of age and mental retardation to older children, but the reality is that each is often applied outside those age ranges. If a practitioner uses mental retardation, it is best to clarify with families their interpretation of the term and their feelings about it, rather than assuming a shared understanding. Regardless of which term is used, good communication requires that any
term be accompanied by appropriate explanation, including how it applies to the child’s developmental profile, and by information about prognosis, to the degree that it is known and sought by the family.

**Epidemiology of MR**

The prevalence of MR is generally quoted as roughly 1%, although cohorts defined only by IQ will range from 2% to 3%. A recent review of the epidemiology of MR in children indicated that actual measured prevalence varies considerably, with ranges as high as 9.7% in 1 series of 10- to 14-year-olds.9 This variance reflects differences in the populations studied, case definition, and study design. The same review noted that based on a normal distribution of intelligence, MR would be expected to be in the mild range 75% to 80% of the time but that the reported prevalence of children with IQs in the moderate to profound range may be somewhat higher.9 MR is found more commonly in boys than girls in a 1.4:1 ratio.

Based on available population figures and a 1% prevalence, there are currently approximately 6 million American and 560,000 Canadian children under the age of 14 years with MR.

**Etiology**

Efforts to identify the cause of a child’s MR are important because this may improve the recognition of associated health issues (eg, progressive supravalvular aortic stenosis in the child with Williams syndrome) or have genetic implications for the affected individual and his family (eg, tuberous sclerosis or Fragile X). In some cases, a treatable condition may be identified and the neurodevelopmental outcome improved (eg, lead poisoning). Families typically seek to know the cause of their child's developmental differences and this knowledge may assist them in understanding their child and in accessing support systems. Children with severe to profound MR will most commonly be identified as having developmental differences before the age of 6 years and will typically have had some investigation with respect to causation in early childhood. However, milder degrees of MR may not be recognized until a child encounters difficulties in the academic setting, and a search for the etiology will therefore be initiated later. In addition, in cases of MR in which no etiology has been determined, the hunt for causation becomes an ongoing process.

A review of the history and a thorough physical examination can aid in identifying the possible etiology. The interview should cover family history; prenatal, perinatal, and neonatal events; past medical history of both neurologic and other conditions; a review of systems; and a detailed history of development and behavior. Information about the child’s physical, social, and family environments as well as interventions accessed to date is also important. The physical examination should be comprehensive because clues to the etiology may be found in virtually any system. Growth abnormalities, skin markings, unusual facies, skeletal differences, and cardiac or genitourinary anomalies are examples of findings that may suggest syndromes associated with MR. The physical examination should include testing of vision and hearing, both as part of the search for etiology and because of the higher prevalence of comorbid sensory deficits in children with MR.

Findings may immediately suggest to the clinician an associated syndrome or disorder. If not, pattern recognition may be enhanced by the use of resources such as the Online Mendelian Inheritance in Man website,10 which provides a search engine into which one can list clinical findings, including the presence of MR, and receive a list of possible diagnoses. The neurodevelopmental profile itself can sometimes provide a clue to etiology. For example, some children with MR have a coexisting nonverbal learning disorder pattern, which should lead the clinician to consider causes such as velocardiofacial or Williams syndromes,11 among others.

Studies vary with respect to the reported likelihood that an etiology can be established for developmental delay and/or MR with yields from 10% to 81%.7,12 There is consensus that the history and the physical examination are the most critical elements of the investigation. Next most helpful is genetic testing. Fragile X syndrome has a reported frequency of 1% in children with milder delays and 4.1% of those with more significant MR.13 Chromosomal abnormalities on routine cytogenetic studies are reported to be present in 2.93% to 11.6% of children with delayed development.7 For children with MR and other findings or a suggestive family history, there may be additional yield from assessment for subtelomeric abnormalities via fluorescent in situ hybridization or the use of comparative genomic hybridization.13 Genetic testing should be considered even in the absence of dysmorphic features because these are absent in 4 of 10 children with MR and chromosomal abnormalities.13

The diagnostic yield for metabolic studies, electroencephalogram, thyroid function testing, and lead screening in children with isolated mild mental retardation (ie, those without abnormalities on examination or diagnostic red flags in the history) is low.7 The yield for abnormalities on neuroimaging, especially with magnetic resonance imaging, in children with MR is relatively high. One study with children under 5 years reported abnormal findings in 13.9% when imaging was done for “screening” and 3 times higher when there were focal neurologic findings or head growth abnormalities.7 However, it is not clear that finding cerebral dysgenesis or localized minor brain structure differences is actually truly answering the underlying question, “Why does this child have MR?” One is often left asking either “Is this relevant?” or “Why, then, did this brain develop differently?” Such findings also rarely affect management or outcome. Neuroimaging, moreover, is not without cost or risk. In this population, computed tomography (CT) scan and magnetic resonance imaging often require sedation and general anesthesia, respectively. For cranial CT scans in children, the lifetime risk of cancer related mortality, cited as 0.07% for a cranial CT scan of a 1-year-old,14 should be factored into decision making.

In the absence of additional indications for metabolic assessment or neuroimaging, therefore, it is this author’s prac-
tice to limit offered investigations to chromosome assessment and molecular analysis for Fragile X for children in this age range newly diagnosed with MR. These genetic tests should be undertaken only after full discussion with the family (and the child, where appropriate) of the medical, emotional, and social implications of abnormal results. Consultation with a geneticist may be helpful in more complex cases and if more detailed chromosomal testing is being considered.

When children do not have an identified etiology for their mental retardation, it is important that they be followed because some may later develop features that reveal an underlying diagnosis. Periodic physical examination is indicated to monitor for changes such as new cutaneous findings; differences in pubertal development; or changes in hearing, vision, or growth that could lead to relevant diagnoses.

### Comorbidities

Children with MR are at a significantly increased risk for a wide variety of comorbid conditions and should be actively screened for these on a periodic basis.

### Etiology-Specific Comorbidities

Subsets of children with MR have recognized syndromes or medical conditions that are associated with certain comorbidities. Children with Down syndrome, for example, need to be monitored for hearing impairment, visual difficulties, atlantoaxial instability, celiac disease, hypothyroidism, and so on. Children with Williams syndrome may have progressive supravalvular aortic stenosis or other cardiac conditions, abnormalities related to calcium metabolism, and differences in growth. Associations that have developed around specific conditions often maintain up-to-date resources for professionals (eg, National Down syndrome Society) on their Internet websites. Physicians can access condition-specific growth charts and health maintenance check lists to assist them.

### Autism

The relationship between autism and mental retardation is complex. It is estimated that 20% to 30% of children with MR also have autism spectrum disorder. It can be harder to determine whether autism is present or not in children with MR. Stereotypies such as rocking or atypical hand movements are common in children with more severe degrees of MR, as is the lack of pretend play. In and of themselves, these do not make a diagnosis of autism, which should be reserved for situations in which there is a clear difference in the quality of social and communicative behaviors. A marked reduction in the frequency of attempts to communicate can be a particularly helpful finding because those are normally present even in situations of severe and profound MR.

Reversing the equation, a significant number of children with diagnosed autism also meet criteria for MR. Children with classical autism have a reported prevalence of MR of 70% to 80%. Within the broader modern conceptualization of “autism spectrum disorder,” the percentage of affected children with comorbid MR is significantly lower. There is a risk of overestimating the presence of MR with early intelligence tests. The prognostic strength of measures of intelligence in the autistic population is lower than in delayed but otherwise typical children. Improvement in IQ is more commonly observed in the autistic group. Many individuals with autism, however, show adaptive behavior that is impaired more than would be expected for a given level of intelligence.

### ADHD

Prevalence rates for ADHD in school-aged children vary considerably. Brownell and Yogendran reported prevalence in Manitoba of 1.52% overall, whereas Blanchard and coworkers reported a figure of 6.9% based on the 2003 National Survey of Children’s Health in the United States. The prevalence of ADHD in children with MR is reported in the 9% to 15% range. ADHD can compromise the progress of children with MR, interfere with integration within schools, and add stress at home. The diagnostic criteria for ADHD do not change in the context of MR, but behavior needs to be interpreted with respect to the child’s developmental profile and not just his/her age. The child with MR and ADHD can benefit from both nonpharmacologic and pharmacologic interventions. Children with MR are somewhat less likely to respond to stimulant medications than other children or may require higher doses, but these remain first-line options in view of their low rate of significant side effects. There is some evidence that treatment with methylphenidate may improve some aspects of cognitive functioning in children with MR and ADHD. When children with MR and comorbid ADHD have disruptive behaviors that are seriously interfering with their function, consideration can be given to other medications, such as alpha-agonists or atypical antipsychotics. It should be noted, however, that these remain “off-label” uses for these medications. Risperidone, in particular, has been shown to compare favorably with methylphenidate for the management of ADHD in children and adolescents with MR. At this time, there is no information available regarding the use of atomoxetine specifically in individuals with MR. This author has had success using atomoxetine with some children with MR and ADHD, including some with comorbid autism. A limiting issue with the use of this preparation and some other formulations used to treat ADHD can be the inability of some children with MR to swallow an intact capsule or refrain from chewing sprinkled medications. In such cases, consultation with a behavioral psychologist to teach the child to swallow pills can be effective.

### Sensory Impairments

Sensory deficits are present in 2% of children with milder degrees of MR and 11% of children with severe MR. Diagnostic caution is advisable where there is severe sensory impairment because there is a risk of underestimating intelligence if it is assessed without consideration of the sensory difficulty. Such assessment is best performed by those experienced in assessing intelligence and adaptive behavior in the context of visual or hearing impairment.
Cerebral Palsy

Cerebral palsy is reported in 6% to 8% of children with mild MR and up to 30% of children with severe MR. As with sensory impairment, the presence of cerebral palsy may affect the assessment of intelligence, particularly when there is impairment of upper-limb function. Verbal intelligence is more straightforward to assess if children are reliably verbal. Assessment of nonverbal/performance intelligence is more challenging, but there are tools designed to assess visual/spatial learning without the motor component (eg, test of Visual Perception Skills–Revised).

Other Mental Health Disorders

The rates of psychiatric and behavioral disturbances among children with MR have been estimated as high as 80%. Parents may need additional support in developing optimal behavior-management strategies. Other caregivers and teachers may also need to have clear behavior strategies in place. The principles of behavior management for children with MR are the same as for others. The key differences are that behavior needs to be interpreted with respect to the developmental level and that it may be harder to determine the function of behaviors. Where there is challenging behavior, it can be very helpful to apply the basic ABC approach of analysis, which looks at (A) antecedents of the behavior (ie, what was going on at the time the behavior occurred?) (B) behavior (ie, exactly what happened?) and (C) consequences to the behavior (ie, what was accomplished through the behavior and how did others respond to it?).

Sometimes assessing behaviors using the ABC format will show that there are antecedent conditions that predict undesired behaviors. Some children, for example, may be upset with unexpected transitions and therefore act out. It may be noted with respect to consequences that noncompliance generated disruptions are inadvertently being reinforced when children do not have to stick with low-interest activities. Challenging behavior in children with more severe degrees of MR may be seen to occur when there is a communication gap. Careful analysis of behavior can identify potential modifiable environmental factors, clarify skills that need to be taught to allow a child another way to express himself or solve a problem, and help caregivers determine whether their responses are helping or not over time.

The use of psychopharmacologic agents to modify the behavioral profile of children with MR is a growing and somewhat controversial area. As alluded to previously, most agents are being used “off label” either with respect to the age of the recipient or the indication, and many of them are relatively unstudied. Individuals with MR are less likely to be consulted with respect to their medication preferences, and decision making is almost always done by proxy. Therefore, greater caution is needed in prescribing. Nonetheless, judicious and targeted use of medications can improve the function and lives of children and youth with MR and mental health concerns.

A number of the atypical antipsychotics are in use to manage difficult behavior in children and youth with MR. Most are relatively unstudied for this purpose. There is more information about risperidone than the others, including evidence for effectiveness in improving disruptive and conduct disorders in children with MR. The more common side effects include weight gain and somnolence. Weight gain can be dramatic. Extrapyramidal dysfunction and tardive dyskinesia are much less frequent with the atypical antipsychotics but can occur. There is some evidence that valproic acid may be helpful for aggression, self-injury, and other affective symptoms in individuals with MR, but studies have been performed primarily in adults.

Mood disorders such as anxiety and depression can occur in children and youth with MR and may be more frequent. Social isolation and emerging insight into differences can contribute to this enhanced susceptibility. Assessment for mood disorders may need to rely more on observed behavioral change than on self-report in individuals with severe MR. Children and youth with MR can also have comorbid obsessive-compulsive disorder, Tourette syndrome, and other tic disorders, as well as posttraumatic stress disorder, eating disorders, and personality disorders. The pharmacologic treatment of these will be similar to that for children who do not have MR. There is significant debate with respect to the efficacy of cognitive behavioral therapy in assisting individuals with MR and mental health concerns. Individual children or youth with MR can be assessed to see whether they have the component cognitive skills for cognitive behavioral therapy, which include awareness of emotion, the ability to link events and emotions, and the ability to engage in cognitive mediation.

Sleep Disorders

Sleep problems, including circadian rhythm disturbances, are common in children with MR. Sleep problems may be organic in origin (eg, sleep apnea associated with Down syndrome), behaviorally driven, or related to lifestyle. Underlying physical contributors, such as obesity, tonsillar enlargement, and gastroesophageal reflux, should be addressed. In general, behavioral and lifestyle approaches are preferred as first-line interventions for nonorganic sleep problems. Children with MR often lack sufficient exercise or may be permitted to nap beyond the typical age. Co-sleeping (ie, allowing the child to sleep for all or part of the night in the parental bed) is also somewhat more common in this group and may compromise sleep hygiene. If a sleep problem is severe and behavioral interventions unsuccessful, medication support may be required. Where possible, it should be used only short term. There are very few quality studies of the short-term or long-term safety or effectiveness of medications for children’s sleep disorders. That being said, this author has found that melatonin can be helpful, typically in doses of 2 to 6 mg. The impact appears to be primarily on sleep latency. Other options to induce sleep include clonidine or trazodone. A more challenging problem is when a child wakes repeatedly or for long periods during the night. Controlled-release melatonin and trazodone may help with this.
Educational Needs of Children and Youth With MR

The last few decades have seen a move away from the previous paradigm of separate education for individuals with MR in favor of a more inclusive approach. The rationale given for this is both philosophical and educational. It is easier to make the philosophical arguments about the need to value and include all members of a community than it is to pin down the impact on outcome. Attempts at meta-analyses of different educational studies have been inconclusive. Nonetheless, most American and Canadian school systems actively pursue an inclusive approach to special education at this time, and this has been generally welcomed by people with MR and those who advocate with and for them.

One of the desired goals of inclusive education is to improve the social experience of the child with MR. Unfortunately, inclusion alone does not appear to achieve adequate social integration, especially as children move into the middle and later elementary school years. Children with MR are more likely to be rejected by peers. Therefore, structured approaches to help students with and without MR to relate more positively to one another may be needed. As students get older, they appear to be more likely to find their deepest friendships among others with identified special needs and should have opportunities to socialize together.

Common Problem Areas at School for Children With MR

It is the author’s experience that the following are potential concerns for the child with MR at school, regardless of whether inclusive or segregated approaches are used.

Boredom

Mainstream schools are naturally built around a traditional academic model and have finite resources. It can be challenging for them to provide a sufficiently varied and interesting program for children with MR. This is especially true for those children with more severe degrees of learning difficulty. There is a risk of boredom if a child’s program remains inappropriately locked into a confined academic model. Some children spend time tracing letters or doing repetitive worksheets year after year in well-intentioned attempts to include them in “academic” activities. Boredom may present as withdrawal behaviors, such as increased stereotypies, self-talk, or disruptive behavior. An escalation in these activities should prompt a review of school programming to ensure sufficient novelty.

Insufficient Communication Intervention

Most children with MR have significant differences in their communication skills and need to be actively working on these throughout their education. Periodic assessment of the child’s communication intervention needs is critical, including support for articulation, comprehension, verbal expression, pragmatic use of language, and the need for alternative routes of communication for those whose expressive skills are limited. Communication skills have a huge impact on the quality of life of individuals with MR and must remain a priority for intervention.

Inadequate Opportunity to Build Functional/Adaptive Skills and Leisure Skills

Long-term outcome for individuals with MR can be significantly improved through the development of leisure skills. Active skills are of particular importance and are less likely to develop without planning. This leaves children dependent on passive, typically electronic, experiences such as watching TV. Leisure activities provide an opportunity to develop social skills and physical fitness and improve function and should be part of students’ individualized plans. Educational programs for children with MR should include introduction to a variety of leisure activities, such as card games, board games, walking/hiking with others, bowling, swimming, painting, making crafts, and so on. Many household skills are both functional and recreational, such as cooking, baking, and sewing. Students can be supported in pursuing areas of interest and developing them into hobbies, which in the long run may help them connect with others. Teaching these skills along with the key components of social skills are very appropriate components of individualized program plans for students with MR. Grooming, manners, and knowing how to maintain relationships are all skills that individuals need to thrive within communities. It may take longer for some individuals with MR to learn these skills, and their early introduction into the individual’s curriculum and reinforcement over time can be extremely helpful.

Sexuality/Puberty Issues in Youth With MR

Most individuals with MR go through puberty on a typical schedule. Those with underlying central nervous system problems such as hydrocephalus may have precocious puberty. Intervention in such cases to prevent an early onset of menses may be helpful because it can allow further time to develop self-help skills that will assist with menstrual hygiene. Although parents are often quite anxious about puberty issues, most individuals negotiate this stage without major difficulty. In general, girls who are able to handle their toileting hygiene will manage their menstrual hygiene. Some will need reminders and prompts, which can be easily incorporated into a daily schedule.

Physicians can help families monitor for complications of menstruation such as premenstrual mood or behavior changes. If the timing of periods is unpredictable, flow is excessive, or there are significant premenstrual behavioral issues, consideration can be given to the use of an oral contraceptive. This will often reduce the amount of flow and mood variability and also offers the security of predictable menses. Menstrual suppression through the use of depot medroxyprogesterone or of an oral contraceptive regimen with fewer scheduled periods per year is also an option. However,
any decision related to menstrual manipulation must carefully weigh the risks and benefits. Long-term use of depot medroxyprogesterone, for example, has been associated with osteoporosis. The use of hormonal agents is also associated with increased risk of stroke. The quality of life of the individual with MR must be carefully considered, and substitute decision making must always have the well being of the individual for whom the decisions are being made as the highest priority.

Parents still inquire about sterilization for their adolescent daughters with MR. This is a complex issue. Paransky and Zurawin have published an excellent review on this subject. If the concern behind such a request relates to menstrual management, strategies such as those discussed earlier can be introduced. If the concern is risk of pregnancy, balanced discussion about the likelihood of a young woman’s being sexuality active should occur. Individuals with MR have the same rights to be sexually active as others but are at a higher risk for being coerced. Sterilization is not a substitute for adequate protection of a vulnerable population, but refusing to ever consider sterilization as a possible contraceptive option for someone on the basis of their intellectual ability is also not reasonable. Consultation with a gynecologist experienced in assisting young women with MR can be invaluable when issues pertaining to menstruation and contraception arise. In challenging situations, an ethics consultation may also help the involved parties reach consensus.

Only a minority of young men and women with MR will be infertile, typically because of chromosomal abnormalities (e.g., males with Down syndrome,) and most will show evidence of typical sexual feelings. Sexuality education can be more challenging in this population but is important. Resources for sexuality education need to be individualized to match the level of understanding of the young person. For example, to help individuals with limited ability to understand the more abstract issues, the “bathing suit rule” can be helpful for teaching about appropriate touch. Very simply, young people can be taught that they should not touch other people in the areas typically covered by their bathing suit nor should they allow others to touch them in the areas that would typically be covered by a bathing suit. A good directory for relevant resources can be found at the website for the National Dissemination Center for Children with Disabilities.

Parents and teachers commonly express concerns about masturbation, particularly when it occurs in public settings. The concern is so common that physicians should ask about it as part of their review at visits. In most cases, education about privacy and redirection are sufficient to deal with the issue. Teaching strategies such as social stories may also be of assistance.

Parents may be concerned about the risk for sexual abuse or coercion of their children with MR. There is some evidence that programs for persons with MR can improve knowledge regarding sexual abuse, but to date there is little information about whether they change outcome. One study of a sexual abuse–prevention program for adults with MR found that the participating women improved in their knowledge of the taught skills but failed to exhibit them in follow-up probes. This suggests that appropriate supervision remains the key preventive strategy.

### Healthy Active Living for Children and Youth With MR

Children, youth, and adults with MR are at increased risk of obesity and poor fitness. In some cases, there is a direct relationship with underlying medical disorders, such as Prader-Willi and Bardet-Biedl syndromes. In most cases, however, it is because of a lack of opportunity for exercise, too much passive recreation, and poor eating habits. Children with MR may have difficulty accessing many recreational sports programs. Although the earliest levels of sport-related programs, such as T ball, can be successfully inclusive, many community programs quickly become competitive and are less welcoming. There are, however, in many areas recreational opportunities that can accommodate individuals with developmental differences. In some communities, recreational therapists can help find ways to include children. Some community recreation programs have financial assistance available to provide an aide to assist with integration within the program. Some areas will have special programs for children and youth with developmental disabilities, such as therapeutic horseback riding or the Special Olympics Program. It is important is to encourage all families to take a shared family approach to healthy active living.

Growth charts that have been assembled specifically to assess the growth of children with conditions, such as Down syndrome, should be regarded with caution. They may be based on populations that are, in fact, prone to obesity because of the previous factors and may not reflect healthy body proportions. It may help to use a body mass index chart to interpret the growth information.

### Planning for the Future

Just as it is important to start teaching leisure and adaptive skills early, it is also important to plan for job-related skills, particularly for those individuals in the mild to moderate MR categories. The communication, grooming, and etiquette skills previously described are important. So too is learning about the fundamentals of employability such as punctuality, appropriate attire, and work place behavior, along with exposure to different community settings that might offer work opportunities. This is more straightforward for individuals who are best matched within a sheltered or supportive work environment. Many individuals with mild MR, however, can match to a more independent work setting if they have an opportunity to develop the necessary skills. The list of possible opportunities is long, and having experts in vocational placement working with high schools is particularly helpful.
Funding/Resources and Supports for Families

Families with children with MR often encounter extra expenses. Some of these will relate to extra health care needs. Others are because of delays in the development of self-help skills such as toilet training and the ongoing need for babysitting/supervision, supports for recreation, and therapies that may not be provided through the public system. Physicians should ensure that families have access to current information about funding opportunities available to them as well as the relevant information for federal taxes. Families benefit from having ongoing contact with an informed social worker because funding situations and rules often change.

Families may also benefit from being connected with national or local support groups such as the Canadian Association for Community Living, the AAMR, the Canadian Down Syndrome Society, and so on. The list of such organizations is huge, contact routes often change, and it may be hard for practitioners to keep up. The Internet is generally the easiest route for families and professionals to access up-to-date information regarding such organizations.

The Role of Support Teams

Children with MR are individuals with varying needs. The skills of a variety of professional and community caregivers may be needed to assist both child and family. Children with MR may benefit from assessment and intervention support from a speech/language pathologist. Fine-motor, self-help, and other adaptive skills are in the domain of the occupational therapist (OT), and OT assessment can be of considerable benefit.43 Speech/language pathologists and OTs often work together to provide technical access/augmentative communication support for children with difficulty in motor and/or verbal output. Physical therapist assessment is indicated for children with significant motor deficits and can support modification of activities to allow fitness to develop. A recreational therapist’s role has been described already and can be helpful when available. Caregivers and teachers of children with challenging behaviors may benefit from a consultation with a behavioral psychologist to assist with optimizing strategies for home, school, and community settings. Families experiencing stress related to raising a child with a developmental difference may benefit from counseling services. Social Services/social work supports can help families negotiate the many systems with which they will find themselves involved.

The list of potentially involved persons is extensive. Teachers, other school personnel, administrators, physicians, nurses, and members of a child’s family and community also play a role on the support team. Given the complexity of the situation, it is important to think about what makes services work best for families. The work of the CanChild Centre for Childhood Disability Research is instructive and worth review by anyone working in the field of developmental disabilities and rehabilitation.44 This group has developed a Keeping It Together tool to assist families with organizing the information they receive and support them when interacting with different service providers. This is important because families typically find that they do a lot of case management themselves, and instruction and support in how to best do this, including how to maintain documentation, communicate effectively with others, actively participate in case conferencing, and so on, can be very helpful.

The vast majority of children and youth with MR live with their families of origin. It is important to recognize the critical importance of the family in the immediate, short term, and long term outcome of children. Service providers should assist families in choosing their own priorities and should avoid contributing to overload and confusion. Working together to formulate individualized family service plans can be extremely helpful. This is a much broader concept than the Individualized Educational Plan a child might have at school because it takes into account the many dimensions of the individual child’s life and that of his/her family.

Prognosis

Parents of children with developmental disabilities typically seek predictions from very early on about adult outcomes. Concerns about the future may increase as children enter the school system and are seen to differ from their peers. At all levels of severity of MR, there will be a seeming widening over time of the developmental gap. Parents may worry that this represents deterioration, particularly if they have understood a child to be running “1 year behind” and are then told that he is “2 years behind” because of the slower rate of development.

Parents need to understand that predictions early in life generally have to be somewhat nonspecific and that the prognosis for an individual child becomes clearer over time. Adaptive skill development, which can have significant influence on independence and employability, varies and does not always match with IQ. Outcomes depend on other variables as well and, in particular, on the presence of comorbid conditions such as autism, cerebral palsy, sensory impairments, and disruptive behavior disorders.

The severity of a child’s MR can give a general indication of expectations. This is related to the differences in learning and adaptive function but also to the fact that comorbidities increase in frequency with the severity of MR.

Individuals with mild MR can generally be expected to develop good self-help skills, and most will develop some academic skills. Some adults with mild MR achieve independent living and employability. Children who would be described in the DSM-IV system as having moderate MR commonly have more limited academic development but may achieve early reading and mathematic skills. As adults, most individuals with moderate MR need supported living and employment. Children with severe MR typically do not develop academic skills, and their self-help and daily living skills may require ongoing supervision and/or support. Adults with severe MR do not live independently. Some can work successfully in sheltered workshops. Children with profound MR typically have limited verbal communication skills and need support for self-help and daily...
living skills. As adults, some are able to do basic self-help skills such as feeding or dressing, but others remain dependent on support for all activities.

The usefulness of subcategorizing mental retardation is that it allows informed listeners to get a general sense of an individual's expected level of function. However, within the category of MR and within described subclassifications, there is room for enormous individual variability. Only very broad statements can or should be made about prognosis until an individual's strengths and needs have been identified and supported and sufficient time has passed to allow a sense of the developmental trajectory. It is critical that physicians recognize the influences that expectations and intervention have on outcome and avoid conveying an unduly negative outlook. In each contact, moreover, physicians should practice in a way that recognizes the importance of this message from the Canadian Association for Community Living: "All persons have inherent capacity for growth and expression. Every person has the right to be nourished physically, intellectually, socially, emotionally and spiritually."45

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