Areas of Special Concern in Behavioral Health Services for Children and Adolescents

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TDMHSAS BEST PRACTICE GUIDELINES

Intellectual Disability and Comorbid Psychiatric Disorders
In Persons Under 22 Years of Age

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Introduction

Psychiatric disorders are frequently comorbid with Intellectual Disability (ID). Prevalence estimates of psychiatric disorders in Intellectual Disability range from 30 percent to 70 percent Virtually all categories of psychiatric disorders have been reported. Often, particularly in those with more severe intellectual disability, specific psychiatric diagnoses cannot be made yet, behavioral symptoms significantly compromise optimal daily functioning by interfering with adaptive, communication, social, learning, recreational and/or motor activities.

Key Principles in Children with ID

There are several key principles that should guide the care of children/adolescents with Intellectual Disability (ID) and comorbid psychiatric disorders or challenging behaviors.

- Children/adolescents with ID can have the full range of psychiatric disorders seen in the general population. Indeed, there is a 3-5 fold greater prevalence of psychiatric disorders in individuals with ID.
- Children's behavior must be seen in a developmental context. The child's behavior/attention/interactions may be inappropriate for his/her chronological age but entirely appropriate for his/her developmental age.
- Psychiatric disorders may be under-diagnosed because
  i) professionals feel challenging behaviors are part of the child's cognitive delay or disorder and warrant no further investigation;
  ii) the child's communicative or cognitive skills interfere with symptom reporting;
  iii) caregivers are not familiar with the range of symptoms or behaviors of the individual;
  iv) disorders such as depression may present differently in children, including those with ID, than in adults.
- Communicate the working diagnosis with the family or caregivers. The psychiatric diagnoses in people with intellectual disabilities tend to accumulate and travel with them for years, so help them sort through which diagnoses are active, and which ones are not.
- Many children/adolescents with ID may not clearly fit DSM diagnostic criteria. In this case, systematic but empiric approaches to "target" symptom management are necessary.

- Comorbid medical disorders often present as behavioral change. Attention to possible conditions such as gastresophageal reflux, dental pain, infections, medication side-effect, seizures, constipation and other disorders is important. Treatment of the comorbid disorder(s) may alleviate the behavioral symptoms.
- Stress may lead to behavior symptoms. Removing the source of stress may do much to diminish challenging behaviors.
- The appropriateness and effectiveness of behavioral therapies varies with the child's developmental age.
- Pharmacological intervention is only one component of a therapeutic package which may also include a wide range of psychotherapies, environmental changes and other contextual interventions.
- Children/adolescents (and adults) with ID may experience greater side effects from psychotropic medications than those without ID. A basic strategy of "Start low, go slow" is warranted (lower starting doses, increase more slowly.)
- Closer monitoring for treatment effect and side effect in children/adolescents with ID is required, compared to adults without ID. Rates of response are often poorer and side effects more frequent than in individuals without ID.
- Relatively little psychotropic medication research has been done in children/adolescents with ID. Studies are predominately open trials, case reports or controlled trials with small samples. Risperidone is an exception.
- Studies of long-term benefits or side effects are not available.

Assessment and Diagnosis

The psychiatric diagnostic evaluation of persons who have ID is in principle the same as for persons who do not have ID. Diagnostic approaches are modified, depending on the child's cognitive level and communication skills. For persons who have mild ID and good verbal skills, the approach does not differ much from diagnosing persons with typical cognitive skills. The poorer the communication skills, the more one has to depend on information provided by caregivers familiar with the child and on direct behavioral observations.

Psychiatric and behavioral assessment and diagnosis of persons with ID includes:

- Comprehensive assessment of ID.
- Comprehensive history and physical examination, child and caregiver interviews, medical record review, completion of relevant laboratory tests and psychological testing, behavioral inventories and diagnostic formulation.

Criteria for Diagnosis of ID (Based on DSM-IV-TR and AAIDD criteria)

Criteria	Definition
Significantly subaverage general intellectual functioning	IQ approximately 70 or below
Accompanying significant limitations in measured adaptive functioning in at least two areas:	Communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety
Age of onset	Must be evident before 18 years of age
Levels of severity (DSM-IV-TR)	Mild IQ 50-55 to approximately 70 Moderate IQ 35-40 to 50-55 Severe IQ 20-25 to 35-40 Profound IQ below 25
Levels of supports needed (AAIDD)	Intermittent, Limited, Extensive or Pervasive
Be cautious in interpreting low IQ in the presence of a psychiatric disorder	Low IQ must precede and not be a direct result of psychiatric disorder or behavior symptoms

Assessment of individuals with ID and behavioral problems and/or suspected psychiatric disorders includes:

Comprehensive History from Parent/Caregiver

- Presenting symptoms/behaviors.
- Assessment of functioning, including communication.
- Treatment history.
- Prior medications responses.
- Prior behavioral interventions.
- Placements and supports.
- Family/household dynamics.
- Past evaluations.

Interview (where appropriate) and Observation of Child/Adolescent

- Ample time should be allotted for the child interview. Sufficient time may be needed to put the child at ease.
- The interview should be adapted to the child's communication skills.
- Clear and developmentally appropriate language should be used.
- Reassurance and support should be provided.
- Leading questions should be avoided.

- The interviewer should attempt to ensure the child understands all questions and communications.
- Mental status may be assessed from observation and context of conversation/interaction, rather than by formal mental status examination.
- Nonverbal expression and activity should be considered, possibly as communication.

Medical Review

- Developmental history.
- Past medical history, including medical diagnoses and treatments.
- Family history
- Social history, including living context.
- Educational history
- Physical examination
- Neurodevelopmental examination

Laboratory Studies

Laboratory and radiologic studies should be guided by history and examination and may include chromosomal analysis or chromosomal microarray, fragile-X by DNA analysis, amino acid and organic acid studies, and other appropriate tests for inborn errors of metabolism. If there is concern for underlying metabolic disorder, a pediatric genetics and/or child neurology consultation should be obtained. If there is concern about seizure disorder, structural brain abnormality or progressive neurological disorder, a child neurology consultation should be obtained.

Psychological Testing

Intellectual Disability must be assessed using standardized, full scale measures of intelligence. Acceptable instruments include the Wechsler Adult Intelligence Scale, 4th Ed. (WAIS-IV), Wechsler Intelligence Scale for Children, 4th Ed. (WISC-IV), Kaufman Assessment Battery for Children, 2nd ed. (K-ABC-II) and the Stanford-Binet Scales, 5th Ed. Brief forms of these are not acceptable for the purposes of diagnosis. A diagnosis of ID should never be made solely on the basis of an IQ score. Evaluation of adaptive behavior is also required. Frequently used measures of adaptive behavior include Adaptive Behavior Assessment System, 2nd Ed. (ABAS-II), Scales of Independent Behavior-Revised (SIB-R) and the Vineland Adaptive Behavior Scales, 2nd Ed (Vineland-II).

Psychological tests can provide additional support for the diagnosis of a psychiatric disorder. Rating and self report scales such as the Child Behavior Checklist (CBCL), Beck Depression Inventory (BDI), the Structured Clinical Interview (SCID), and the Behavior Assessment System for Children, 2nd Ed. (BASC-2) are highly reliable tools. Most instruments include guidelines for use with various populations and reading levels.

Evaluation of Stressors

Complete evaluation and individualized treatment requires attention to possible stressors that may be triggering or exacerbating the presenting problem in someone with ID. The stressors listed below may be more likely to occur in persons with ID, and cause difficulties for those who have reduced coping skills. Helping the individual, family, and caregivers deal with or eliminate stressors may sometimes be the primary target of treatment and often facilitates other treatment interventions.

Type of Stressor	Examples
Change	New school, job or residence
Interpersonal	Loss of family member, friend, job; taunting, teasing, bullying, other social exploitation
Environmental	Crowding, noise, lack of stimulation, lack of privacy, work or school-related stress
Parenting or Social Support	Lack of support from others; disruptive visits or contacts; neglect, hostility, physical or sexual abuse; sibling issues; domestic violence; parent/caretaker stress
Illness/Disability	Chronic or recurrent illness, serous acute illness, sensory deficits, seizures, recurrent constipation, GERD, occult fracture or musculoskeletal injury, occult pain, medication side effects; changing disability such as declining mobility, dysphagia
Frustration	Communication problems, lack of choice, awareness of disability
Trauma	Persons with ID have higher rates of victimization

Diagnosis and Identification of "Target" Symptoms

Children and adolescents with ID are vulnerable to the same major psychiatric conditions as people without intellectual disabilities. It is essential to gather information about possible comorbid conditions and environmental factors which may be contributing to the target symptoms as children and adolescents with ID are likely to have difficulties presenting their own history.

Keep in mind that similar to typical children, children with ID rarely self refer. They are brought by family or caregivers who are usually concerned about particular behaviors.

Consider whether the target symptoms are due to developmental delay, symptoms consistent with a specific developmental disorder, symptoms of a medical condition or signs of psychopathology requiring a psychiatric diagnosis.

As the level of ID becomes more severe, it is increasingly difficult to make specific DSM-IV-TR diagnoses (other than autistic disorder) reliably. [Autistic disorder is a common comorbid condition in people with ID, and the reader is referred to the chapter on Autism Spectrum Disorders in these guidelines.]

The psychopharmacologic and/or behavioral treatments of children and adolescents with intellectual disabilities and suspected Psychiatric Disorders should be based on the most specific DSM-IV-TR diagnosis possible. If the treatment does not work to resolve the presenting problem, consider that the diagnosis may not be correct and that additional information not present at the outset may lead to a new diagnosis.

When there is not a psychiatric syndrome such as a mood disorder or, more rarely, a psychotic disorder, then 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 in the absence of a firm diagnosis.

The following are some of the more common problems that may be targets of behavioral or psychopharmacologic 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.
- Obsessive thoughts and obsessive compulsive behaviors.

Patient and Caregiver Interview

The child or adolescent may present with limited communication skills or may be shy to disclose relevant history. Information from parents and caregivers should always be sought in order to develop a more complete assessment, especially in those instances where the child or adolescent lacks adequate communication skills. Keep in mind that 90 percent of people with ID are in the mild categories and, especially for adolescents, may be able to present very pertinent parts of their history. They should be interviewed alone at some point, if possible. Attempts should be made to collect both anecdotal subjective information and more objective data, such as adaptive functioning, daily record keeping, or graphical data.

Treatment

General

Habilitation of persons with ID is based on the principles of normalization and community-based care, with additional supports as needed. Federal legislation, for example, the Individuals with Disabilities Education Act (IDEA), entitles children and adolescents with disabilities to a full range of diagnostic, educational and support services from birth to age 21. Specialized treatments are also provided if necessary for children and adolescents with additional severe visual and auditory impairment or motor disabilities.

The parents of children and adolescents with ID are entitled by these laws to receive support services and to be active participants in treatment planning. Some parents and older children are not fully aware of their rights to obtain services. The clinician has an important role in such instances to educate and, if needed, to refer to a "patient advocate" or "educational advocate."[2]

In recent practice, children and adolescents are educated in special classes in regular school or in inclusionary programs (in age appropriate regular classes, with additional supports as needed). In the United States, children with ID are now rarely if ever placed in residential institutions and seldom in separate schools.

Habilitation and treatment include:

- Specific treatment of the underlying condition, if known, to prevent or to minimize brain insults that result in ID (e.g., shunting in the case of hydrocephalus).
- Early intervention, education, and ancillary therapies (such as physical, occupational, speech and/or language therapies, *and behavior therapies*), family support, and other services, as needed.
- Treatment of comorbid physical conditions, such as hypothyroidism, congenital cataracts or heart defects in children with Down syndrome or treatment of seizures in persons with tuberous sclerosis.
- Treatment of comorbid mental disorders, including psychosocial interventions and pharmacotherapy.

Psychiatric

The psychiatric treatment of persons with ID and a comorbid mental disorder is generally the same as for persons without ID. However, persons with ID and a comorbid psychiatric disorder may have features that warrant special consideration; for example some persons with ID may be more sensitive to the disinhibiting effects of sedative/hypnotic agents and this needs to be taken into account in choosing a medication.

Psychotropic medication should be integrated as part of a comprehensive treatment plan that includes, appropriate behavior planning, behavior monitoring, and communication between the prescribing physician, therapists, and others providing supports, habilitative services, and medical treatment.

[2] In Tennessee, Support Training for Exceptional Parents (STEP) is the statewide family-to-family program providing free information, advocacy training, and support services to parents of children eligible to receive special education or related services. STEP can be reached at (800)-280-STEP.

Treatment including psychotropic medications should be based on the most specific DSM-IV TR diagnosis possible. When only a tentative non-specific DSM-IV TR diagnosis can be made, the clinician may need to focus on one or more behavioral symptoms as the target of treatment. There should be an effort, over time, to adjust medication doses to document ongoing need or the minimum dose at which a medication remains effective. The prescribing clinician may want to collaborate with a Board Certified Behavior Analyst regarding behavior analysis and treatment.

Psychotropic medication decisions need to be made with due consideration for potential problems of polypharmacy, and otherwise for negative impact on the individual's functioning and overall quality of life. Every effort should be made to avoid unnecessary compromise of cognitive, communicative, social, adaptive or motor function. Risk vs. benefit needs to be considered and continually reassessed, and justification for duration of treatment needs to be established periodically during the course of treatment.

Behavioral Emergencies

- Individuals will be evaluated for any contraindication for restraint or emergency medication.
- Possible medical causes for an acute behavioral exacerbation must be considered (e.g., other illness, injury, medication side effects).
- Reassessment of the diagnosis and the plan of treatment and support are indicated when there is an emergent behavioral episode.
- Restraint of any kind, where permitted, is used only when efforts at redirection or de-escalation have failed and the individual poses an imminent risk of harm to self or others.
- Emergency medications, where permitted, are given only after appropriate diagnostic assessment and other alternatives have been attempted or are contraindicated.

Psychotherapeutic Interventions

Psychotherapy can be effective for persons with ID toward realization of a variety of goals such as:

- Mitigation of stressors.
- Improved coping skills.
- Improved communication of feelings, problems, etc.
- Improved problem solving skills.
- Improved social and interpersonal skills.
- Reduction/elimination of maladaptive behaviors.
- Increase of adaptive behaviors.
- Understanding of disability and illness.
- Increased self-esteem.

Modality and Technique

Types of psychotherapy for persons with ID and a comorbid mental disorder may include:

- Individual.
- Applied behavior analysis (ABA).
- Group.
- Family therapy.

As with all psychiatric care, the approach to treatment of persons with ID and a comorbid mental disorder is generally the same as for the general population. Techniques typically utilized with persons with mental disorders can be considered potential interventions for persons who are dually diagnosed, with adaptations made as necessary, based on the needs and strengths of the individual. The approach to therapy may need to be more concrete, repetitive, and/or directive, and may need to incorporate visual and auditory aids. Role play can be effective, and behavioral techniques, such as positive reinforcement are very important.

Treatment should be appropriate for the individual's cognitive and communicative skills. Generally, the lower the cognitive and adaptive functioning of the child, the more extensive the needed modifications in technique. Some techniques are rarely appropriate for persons who function at the lower levels of ID.

Applied behavior analysis (ABA) is a widely used strategy for addressing behavior problems among patients with disorders such as ID, other developmental disabilities, and traumatic brain injury. It considers antecedents (environmental factors that appear to trigger unwanted behavior), the behaviors themselves, and consequences that either increase or decrease future occurrences of that behavior. A treatment program using a behavioral technique known as operant conditioning is then carried out to address the specific challenging behavior, such as self-injurious behavior.

The principles of ABA include:

- Indirect Assessment, such as interviewing family/caregivers; use of behavior rating scales.
- Direct observation of behavior.
- Functional analysis, i.e., a formal evaluation of the effects of specific environmental variables upon the behavior.
- Ongoing assessment of treatment effects by repeated direct observations of behavior, coupled with repeated behavioral assessments.

Residential Treatment Programs

Treatment of children and adolescents with Intellectual Disability should always be in the least restrictive environment possible. Residential treatment programs that serve children and adolescents with ID should only be considered if they are experienced in serving children with ID and children are protected in the setting. Children and adolescents with ID are easily victimized and need enhanced supervision and support. In groups they may need fewer distractions (e.g.small group size), a more psychoeducational rather than process therapy approach, developmentally appropriate language and adequate time to practice/rehearse.

Treatment Follow-up

It is essential to assess treatment effectiveness. Treatment goals as well as "target" symptoms must be established by the clinicians, family caregivers and where appropriate, the child.. Interdisciplinary collaboration of professionals and caregivers is essential. Follow-up includes repeated recipient interview/observation and obtaining comprehensive interim information. The risks vs. benefits of a treatment must be reevaluated on an ongoing basis throughout the course of treatment. When psychotropic medications are prescribed for the individual with ID and a comorbid mental disorder, the treating professionals should establish a plan to monitor for potential side effects as well as for continued efficacy and need for continued use of the medication. If the child or adolescent is not experiencing improvement, the accuracy and completeness of the diagnosis should be reviewed, as well as the consistency of implementation of treatment by the caregivers.

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