A Checklist for Coordinators & Supervisors

Psychiatric and Behavioral Problems in Individuals with Intellectual Disability

This checklist is based on ***Treatment of Psychiatric and Behavioral Problems in Individuals with Mental Retardation: An Update of the Expert Consensus Guidelines (2004)*** by M. C. Aman, M. L. Crismon, A. Frances, B. H. King, and J. Rojahn, which summarized the recommendations of a panel of national experts. The checklist was developed for Service Coordinators, Program Managers, QMRP's, and others who coordinate and supervise care for individuals with intellectual disability. It was adapted from the expert consensus guidelines, with permission of the publisher, by the DC Health Resources Partnership at Georgetown University–University Center for Excellence in Developmental Disabilities.

When to Use This Checklist

This checklist is intended to help you coordinate and supervise the care of individuals with co-occurring intellectual disability and psychiatric/behavioral problems. **For mandatory requirements, consult the Developmental Disability Administration's guidelines.**

Individuals with co-occurring intellectual disability (ID) and psychiatric/behavioral diagnosis have:*

- ☐ Significantly subaverage intellectual functioning (IQ of 70-75 or lower) evident before age 18 years.**
- ☐ Limitations in adaptive skills and functioning in at least two areas (such as communication, self-care, social skills, self-direction, health, and safety).
- ☐ Significant psychiatric or behavioral problems.
- ☐ Note that the diagnosis of ID requires that the impairment in IQ precedes and is unrelated to the psychiatric disorders.

ASSESSMENT

Key Principles in Diagnosis

- ☐ Effective treatment is most likely when there is an accurate and specific diagnosis
- ☐ As the level of ID becomes more severe, it is increasingly difficult to make psychiatric diagnoses other than autistic disorder, but it is still extremely important
- ☐ The two diagnostic manuals to be familiar with are the DSM-IV-TR (current *Diagnostic Style Manual of the American Psychiatric Association*) and the DSM-ID (*Diagnostic Style Manual for Intellectual Disability*) by NADD and the American Psychiatric Association
- ☐ Sometimes treatment is focused on improvement of target symptoms. 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

**Based on criteria from the DSM-IV-TR and the American Association on Intellectual and Developmental Disorders.*
***Editor's note: Many of these guidelines are also applicable to individuals with cognitive limitations acquired in adulthood (as in traumatic brain injury).*

Assessment Continued

Common Behavioral Problems

- ☐ 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

Formal Assessment

- ☐ The Functional Behavior Assessment should clarify the specific purpose that *each* behavior is serving for the individual (escape from demands, communication, protest, need for sameness, self-soothing, comfort in repetitive behavior, etc). The assessment should include:
  - Interviews with direct caregivers
  - Direct observation of behavior in the natural environment*
  - 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 ID)
- ☐ Laboratory tests, standardized psychological tests, and indirect measures completed by other informants may also be useful

*__Editor's Note:__ *Best practice for functional assessment includes, whenever appropriate, analog observation conditions.*

KEY STRATEGIES IN PSYCHOSOCIAL TREATMENT

General Principles of Intervention

- ☐ Enlist the cooperation of the individual and family and/or other caregivers
- ☐ Use a multidisciplinary team approach
- ☐ Ensure that there is continuity of care (e.g., case coordination)
- ☐ Structure the physical and psychosocial environment to meet the individual's needs
- ☐ Facilitate timely access to care (e.g., 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

Identifying and Managing Stressors

Eliminating stressors may sometimes be the primary target of treatment or an important component of the overall treatment plan. Common stressors that may set off behavioral or psychiatric symptoms include the following:

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 and/or other caregivers, friends, or partner
- ☐ Destabilizing visits, phone calls, or letters
- ☐ Chaos related to family or caregiver
- ☐ Neglect
- ☐ Hostility
- ☐ Physical or sexual abuse

Transitional phases

- ☐ Change of residence, school, or work
- ☐ Developmental landmarks (e.g., onset of puberty)

Illness or disability

- ☐ Chronic medical or psychiatric illness (which is more common in ID than in the general population)
- ☐ Serious acute illness
- ☐ Sensory problems like hearing or vision loss
- ☐ Difficulty with walking
- ☐ Seizures

Stigmatization

- ☐ Taunts, teasing, exclusion, being bullied or exploited

Frustration

- ☐ Due to inability to communicate needs and wishes
- ☐ Due to lack of choices (about specific activities, diet, work, etc.)
- ☐ Because tasks are too hard
- ☐ Because the individual is aware of areas of deficits

Change the Environment

- ☐ Rearrange physical and/or social conditions that seem to provoke the individual
- ☐ Identify and manage stressors that exacerbate psychiatric disorders or behavior problems
- ☐ Change the activity (e.g., restructure tasks so they are easier to complete)
- ☐ Change work, social groupings, or routines
- ☐ Change the physical environment (e.g., noise, temperature, lighting, crowding)
- ☐ Enrich the environment through social or sensory stimulation

Key Strategies in Psychosocial Treatment Continued

Teach the Individual

- ☐ Instruction to permit a functional communication system needs to be a ***priority***. Alternative, augmentative, and visual strategies should be considered
- ☐ Social communication skills training
- ☐ Instruction in coping (self-control) skills

Teach the Caregivers

- ☐ Assure that the caregivers have the skills necessary to foster the individual's functional communication (including visual communication strategies)
- ☐ Teach skills to manage behavioral and psychiatric problems that may accompany developmental disabilities
- ☐ Provide appropriately worded educational materials (e.g., booklets about medication and consent procedures written for individuals with ID)
- ☐ Refer to consumer advocacy and support groups
- ☐ Behavioral training for family, teachers, and staff

Other Treatment Methods Include:

- ☐ **Applied Behavior Analysis** works by changing antecedents and consequences of target problem behaviors, building appropriate functional skills, and providing systematic reward of desirable behavior
- ☐ **Cognitive-Behavior Therapy** in individuals with mild-to-moderate ID (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
- ☐ **Classical behavior therapy** (including gradual exposure to whatever elicits the fear) in some instances of specific fears

COMMON PROBLEMS

Dealing with Insomnia

Sleep problems are common in individuals with ID. They can cause considerable difficulty in themselves and can exacerbate (or be exacerbated by) psychiatric or behavioral problems. The experts recommend 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 (e.g., sleep apnea, alcohol, nicotine, decongestants, beta blockers, antidepressants)

Dealing with Weight Problems

- ☐ Individuals with ID 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, for example, psychostimulants and Topamax (topiramate) are associated with weight loss, whereas some atypical antipsychotics such as Zyprexa and Risperdal are associated with weight gain
- ☐ 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 issues
- ☐ 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 (e.g., working out on a trampoline, walks in the park, bicycling, swimming)
- ☐ Monitor height and weight (including waist girth) regularly
- ☐ If on an atypical antipsychotic, monitor glucose and lipid levels according to current guidelines

GENERAL PRINCIPLES OF MEDICATION USE

Although medication is under the purview of treating physicians, it is important for care coordinators and others to understand the issues involved.

In general, before medication is prescribed, the following should be assessed:

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

Behavioral Symptoms as the Target of Treatment

- ☐ The decision to use a psychotropic medication and choice of medication are generally more straightforward in the presence of an identifiable psychiatric diagnosis
- ☐ 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
- ☐ However, even when a specific diagnosis can be made with confidence, clinicians should also assess for behavioral symptoms that may be targets of treatment

Strategies for Medication Management

- ☐ The general recommendations presented here are based on the CMS *Safety Precautions* consensus statements and the experts' responses to questions on dosing strategies, use of blood levels, and indications for hospitalization
- ☐ Individuals with ID may be at higher risk for certain side effects, including
  - movement disorders induced by antipsychotic medication such as
    - dystonias (in which sustained muscle contraction causes twisting and repetitive movements or abnormal postures)
    - dyskinesias (with involuntary movement such as tongue rolling)
  - neuroleptic malignant syndrome (a rare, life-threatening reaction to medication that includes fever, muscle rigidity, change in mental status and other medical findings)
  - weight gain
  - symptoms associated with psychostimulant treatment (tics, depression and irritability)
- ☐ Individuals with ID, especially those with behavioral problems, are more likely to be receiving multiple medications, increasing the risk of adverse drug interactions

Recommended Dosing Strategies

- ☐ Keep medication regimen as simple as possible. Consider use of once-a-day dosing and extended-release formulations
- ☐ Start low and go slow—use lower initial doses and increase more slowly than in individuals without ID
- ☐ Use the same (or lower) maintenance and maximum doses as in individuals without ID
- ☐ Periodically consider gradual dose reduction (at the same rate or more slowly than in individuals without ID)
- ☐ Avoid frequent drug and dose changes unless there is a valid reason for the change (e.g., 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 (e.g., 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
- ☐ If an antipsychotic is prescribed, assess for tardive dyskinesia (involuntary movements) at least every 3 to 6 months
- ☐ If on an atypical antipsychotic, monitor for changes in weight, and blood glucose and lipid levels
- ☐ 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 (this is called *intraclass* polypharmacy, e.g., two SSRIs, like Prozac and Zoloft)
- ☐ In contrast, using two or more medications from different therapeutic classes at the same time (*interclass* polypharmacy) may be appropriate and needed in certain situations (e.g., psychotic or bipolar depression, partial response to one drug, comorbid conditions)

Other Medication Practices to Avoid

- ☐ Long-term use of benzodiazepine antianxiety agents such as Valium (diazepam) or shorter acting sedative hypnotics such as Ambien (zolpidem)
- ☐ Use of long-acting sedative hypnotics (tranquilizers such as chloral hydrate)
- ☐ Use of anticholinergics (a class of muscle relaxant) when the individual does not have extrapyramidal symptoms (tremor, restlessness, involuntary movement, slurred speech)
- ☐ Higher than usual doses of psychotropic medications ("psychoactive drugs" affecting the mind or mood or other mental processes)
- ☐ Use of Dilantin (phenytoin), phenobarbital, Mysoline (primidone) as psychotropics
- ☐ Long-term use of *prn* medication orders
- ☐ Failure to integrate medication with psychosocial interventions

Use of Blood Levels to Monitor 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 an 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
- ☐ The prescribing doctor should see the individual at each review
- ☐ Consult with caregivers 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 are
  - Risk of suicide
  - Significant self-injury or harm to others
  - Acute psychotic symptoms

Recommended Steps Before Changing the Medication Regimen

- ☐ **Ensure adequate duration of medication trial**
  - For antipsychotic such as Clozapine, Risperdal and Zyprexa, 3-8 weeks
  - For mood stabilizer such as Lamictal, Seroquel, 1-3 weeks
  - For SSRI such as Prozac and Zoloft, 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
- ☐ Assess for the presence of side effects
- ☐ Manage environmental problems and stressors
- ☐ Optimize other interventions (e.g., adequate behavioral treatment)
- ☐ Get more information from other informants
- ☐ Order additional laboratory studies (e.g., thyroid function) if applicable
- ☐ Assess for substance use

KEY POINTS 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 to 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 follow-up 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-centered 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 (e.g., speech or occupational therapy, assistance with housing or finances, supported employment)
- ☐ Tailor interventions to fit typical real-life routines and settings (e.g., at home, school, in the community)
- ☐ Elicit information from the person and his or her family and/or other caregivers concerning outcomes that are important to them
- ☐ In evaluating for aggressive or disruptive behavior problems, clinicians, family and caregivers should be aware that some genetic syndromes have known behavior problems (behavioral phenotypes), e.g., Prader-Willi syndrome, Williams syndrome, Fragile X syndrome
- ☐ 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

Key Resource for this Checklist: *Treatment of Psychiatric and Behavioral Problems in Individuals with Mental Retardation: An Update of the Expert Consensus Guidelines Update (2004)* by Michael C. Aman, PhD, M. Lynn Crismon, PharmD, FCCP, Allen Frances, MD, Bryan H. King, MD, and Johannes Rojahn, PhD. Adapted with permission.