

# BEST PRACTICES FOR MEDICATION MANAGEMENT FOR CHILDREN, ADULTS AND SENIORS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

May 2018



**MEDICAL HEALTH HOMES**

*Promoting Integrated, Person-Centered Care for  
People with Intellectual & Developmental Disabilities*



## INTRODUCTION

Children and adults with intellectual and developmental disabilities have higher rates of medical problems and unmet health needs and are treated with psychiatric medications at high rates. About 30-40 % of people with intellectual and developmental disabilities (I/DD) meet criteria for a psychiatric disorder or have severe challenging behaviors such as self-injury or aggression. People with I/DD experience the full range of psychiatric disorders, including anxiety, depression, bipolar disorder, schizophrenia and post-traumatic stress disorder. The most common psychiatric disorders are anxiety and depression in adults and anxiety and ADHD in children.

There is growing concern about the extensive use of anti-psychotic medications, increased use of multi-drug regimens and a significant increase in psychoactive medication use in the treatment of individuals with I/DD. Though children and adults with I/DD often have complex symptoms and multiple medical conditions there is limited evidence that multi-drug regimens is best practice. Taking multiple medications increases the likelihood of drug interactions and other adverse effects. The use of complex multi-drug regimens may cause a cascade of problems in patients with I/DD who have fragile neurological and physical health.

This document is intended to inform clinicians of best practice recommendations and resources regarding the use of psychotherapeutic medications for the treatment of children, adults and seniors with intellectual and developmental disabilities. It is also intended to offer some basic information about the North Carolina disability service system. It is not intended to establish rigid standards of treatment but to assist in prescribing and monitoring the pharmacotherapy of the patient with an intellectual or developmental disability.

This document was developed by Community Care of North Carolina (CCNC) and the Medication Work group of the Medical Health Homes for People with I/DD initiative, a project funded by the North Carolina Council on Developmental Disabilities and a partnership of The Arc of NC, Easter Seals UCP NC and Autism Society of NC. A list of work group members can be found on page 31.

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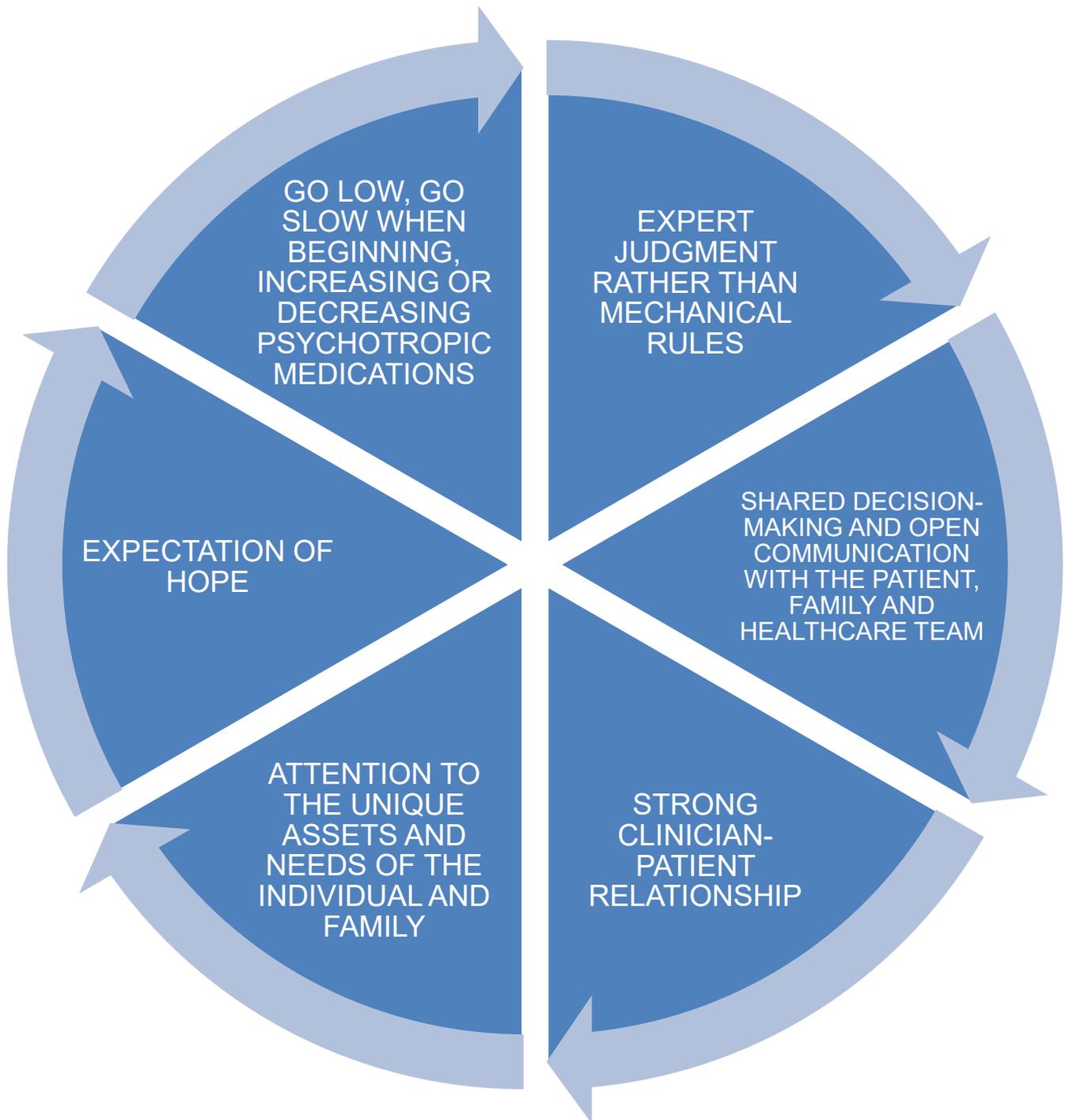
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## Disclaimer

These Guidelines are based on the current state of knowledge on effective and appropriate care, at the time of publication. These Guidelines may not apply to all patients; therefore, each guideline should be tailored to the individual patient, based on clinical judgment. Proper use, adaption, modifications or decisions to disregard these or other guidelines in whole or part, are entirely the responsibility of the clinician who uses these Guidelines. The authors bear no responsibility for the use of these Guidelines by third parties.

## GUIDING PRINCIPLES



## Comprehensive Assessment or Reassessment of Challenging Behaviors in the Context of Intellectual and Developmental

People with intellectual and developmental disabilities have different and perhaps limited ways to communicate their distress and pain. Many people with I/DD are referred for psychiatric care due to “problem” behaviors. When considering the use of medications or other interventions to address challenging behaviors an appropriate evaluation should address the following issues:

### CONSUMER STORY: COMPREHENSIVE ASSESSMENT OR REASSESSMENT OF CHALLENGING BEHAVIORS IN THE CONTEXT OF I/DD

**Jose** is a 42 y/o male with ASD, bipolar disorder and seizures. There is a family history of diabetes and hypertension. His brother reports that sometimes Jose has “behaviors” but it is difficult to identify a specific cause. Following a recent “aggressive episode” late at night Jose was evaluated in the local Emergency Department where he was prescribed clozapine, which can contribute to constipation. After several weeks his brother saw no improvement. During a regularly scheduled appointment with the neurologist, the family reported Jose had been complaining of dry mouth, stomach pain, and constipation. The neurologist referred Jose to a renal specialist, who ordered an ultrasound that revealed massive constipation. The renal specialist prescribed bowel medication and encouraged adequate fluid intake.

**These interventions resolved the physical complaints and “behaviors”.**

At the return appointment with the neurologist the clozapine was discontinued as it may actually have intensified Jose’s behaviors and physical symptoms.

**A) Medical/Physiologic** drivers of the behavior including, but not limited to, possible physical illness, sources of pain/discomfort, medication side effects. (*see Common Medical Issues*);

**B) The presence of (or lack of) contributing psychiatric comorbidities** including but not limited to mood disorders, anxiety disorders, psychotic disorders, and substance abuse/dependence disorders;

**C) Psychosocial/Environmental factors** including but not limited to assessment of the appropriateness of current environments, functional behavioral analysis, communication needs, and exposures to common modifiable stressors (e.g. sensory stressors, changes in routines/care providers).

**D) Abuse and Trauma:** Children and adults with I/DD are four to ten times more likely to be abused than the general population. People with DD tend to be abused more frequently, for longer periods of time, are more likely to be abused by a caregiver or someone they know and are more likely to remain in abusive situation. Signs of abuse may include sleep

problems, changes in eating habits, depression, anxiety, self-injurious behaviors, and suicide attempts.

This comprehensive assessment is most commonly accomplished through standard practice which should include collaboration between the primary medical provider/prescriber of psychiatric medication and other key non-medical providers (e.g., family, caregivers, educators, therapists).

Comprehensive assessment or reassessment may occasionally demand specialized consultation from medical subspecialists, I/DD behavioral specialists (e.g., psychologists, behavior analysts), Allied Health Professionals (e.g. speech/language pathologists, occupational therapists, physical therapists), or educational specialists.

Lack of access to specialized consultation should not serve as a barrier to standard/routine ongoing comprehensive assessment/reassessment.

**Common Medical Issues** that can cause irritability, altered mental status and externalizing behavior problems and may mimic acute mental illness are reviewed in section five (pages 9 and 10).

**A comprehensive assessment can include multiple sources of information and activities, including:**

COMPREHENSIVE ASSESSMENT COMPONENTS	
Detailed record review	Psychiatric interview
Informant interviews	Team collaboration
Symptom surveys	Input from other professionals, such as nursing, occupational therapy, physical therapy, direct support professionals
If possible, pre-appointment home visit and/or conference call	Detailed report
Direct patient examination	Follow-up review of the evaluation with family.
Office physical and neurological exam	



## BEHAVIOR CHANGES, CHALLENGES AND SUPPORTS

Each person with I/DD has a unique profile of strengths and challenges that impact their communication, including behaviors.

**Challenging Behavior** may be defined as “culturally abnormal behavior of a significant intensity, frequency or duration that physical safety of the person or others is placed at risk or is likely to significantly limit a person’s ability to be part of their community”. (Brown, Brown and Dibiasio, 2013)

Generally, these behaviors have occurred more than once and often have been happening repeatedly.

Challenging behaviors and many behaviors of concern are influenced by:

- **biological** (pain, illness, medication side effects, sensory sensitivities, challenges to executive functions and self-regulation (working memory, mental flexibility, and self-control), physical disabilities)
- **social** (challenges to communication, boredom, lack of social opportunities, challenges to social awareness, inconsistent approaches of caregivers, lack of training for caregivers, caregivers failing to provide for person's wishes and needs)
- **environmental** (exposure to impoverished environments or ones experienced as aversive (i.e. due to noise and lighting), limited choices/control, or limited access to preferred objects or activities)  
psychological (lack of meaningful engagement, difficulty coping with stress and change, limited skills for exercising control over one’s own life, feeling excluded, lonely, devalued, labelled, disempowered, living up to people's negative expectations)

### CONSUMER STORY: BEHAVIOR CHANGES, CHALLENGES AND SUPPORTS

**Jada** is a 63-year-old female, with moderate ID, seizure disorder and a history of UTIs. She lives with her mother who is 84-years old. Ms. Brown’s medical chart is extensive and documents that she has been seen by numerous health care professionals and had several in-patient hospitalizations, resulting in complicated medication regimes. Her mother reports recent behavior changes including crying, interrupted sleep, falls, and disorientation. Jada is presently taking two (2) antipsychotics. The family physician thinks a comprehensive evaluation is needed and has requested a psychiatric referral to evaluate her medications, possible dementia, and family support needs.

Comprehensive assessment considering the above factors will inform more effective treatment, which frequently needs to include multiple modalities (i.e. Speech and Language interventions, counseling, Applied Behavior Analysis (ABA) based interventions, and medications). Behavior change is most effective when we teach people what they *can* do to be safe and healthy and how to meet their needs rather than focusing on what they should *not* do. For example, a student with I/DD who assaults his teacher to gain escape from an academic task he finds difficult might be taught to change this “target behavior” by learning to ask for help or ask for a break.

Adaptive functioning can be described as how well a person meets what is expected in terms of personal independence and responsibility compared to others of similar age. It includes conceptual, social, and practical skills that all people learn in order to function in their daily lives. Adaptive behavior delays and deficits are part of the Intellectual Disability definition and are used to determine the level of severity.

### CONSUMER STORY:

#### COMMON MEDICAL ISSUES THAT CAN CAUSE IRRITABILITY, ALTERED MENTAL STATUS AND EXTERNALIZING BEHAVIOR PROBLEMS AND MAY MIMIC ACUTE MENTAL ILLNESS

**Thomas** is an 11-year-old male with Down syndrome. Recently he has shown an increase in agitated behaviors, increased appetite and occasional gagging after meals. Ongoing attempts to address his agitation resulted in the use of multiple high dose antipsychotics. However, medication interventions coupled with a change in his daily activities were ineffective. A review of Thomas’ medical history indicated that GI issues might be a problem. A referral for a GI evaluation revealed significant esophageal effects from GERD that had likely been present for some time. Thomas was also significantly constipated. By treating Thomas’ medical problems there was a marked decrease in his agitated behaviors. His mother describes him as a “new person”.

**COMMON MEDICAL ISSUES THAT CAN CAUSE IRRITABILITY, ALTERED MENTAL STATUS AND EXTERNALIZING BEHAVIOR PROBLEMS AND MAY MIMIC ACUTE MENTAL ILLNESS**

Common Medical Issues	Clinical Features and Detection	Medications that may contribute or cause the symptom	Other risk factors that may contribute to or cause the symptom
Constipation	Often missed on physical exam. Best detected through detailed bowel monitoring and charting, or KUB (abdominal x-ray) with request for specific comment on stool content. Risk of repeat incidents is high	Benzotropine Other anticholinergic drugs Opioid analgesics Antipsychotic medications Diuretics Iron supplements	Cerebral Palsy; Down Syndrome; Williams syndrome; Autism Not enough movement, fluid, fiber
Gastro-Esophageal Reflux	May be under-appreciated by informants. May notice burping, gagging or coughing when eating; complaints of sore throat or increased challenging behaviors or agitation around meals. Sometimes staff report “intentional vomiting.” Other indications can include: Increased hand mouthing; pica; agitation and restlessness in the middle of the night; & unplanned weight loss regardless of intake.	Fosamax Oral corticosteroids	Cerebral Palsy, Cornelia de Lange syndrome; Autism
Sedation or Fatigue	Person may become irritable and “refuse” activities due to fatigue and may even become aggressive when prompted. Also decreases ability to respond to non-medical interventions. May see reversal of sleep-wake cycle.	Benzodiazepines, hydroxyzine, diphenhydramine (sedation/lethargy), Beta blockers (fatigue/lethargy) Antipsychotics; PKU	Down Syndrome at increased risk due to hypothyroidism, hypotonia and dementia Children with Autism Spectrum Disorder at heightened risk for sedation
Infections (UTIs, URIs, Otitis, Skin.)	Infections are sometimes missed and can be very uncomfortable, then driving challenges behaviors. Infections can worsen existing movement disorders or cause a delirium if persistent.		Smith-Magenis Syndrome at increased risk due to impaired T-cell function Williams syndrome at up risk for UTI due to renal anomalies
Extra-Pyramidal Side-effects (EPS) dystonias, akathisia	Muscle stiffness (dystonias) may be painful. Akathisia (intensive motor restlessness) is often misinterpreted as “mania.” <i>Note that manic over activity is often excessive but goal directed while akathisia looks like the person is “jumping out of their skin” and cannot control urges to move.</i>	Metoclopramide, first and second generation antipsychotics	

<b>Common Medical Issues</b>	<b>Clinical Features and Detection</b>	<b>Medications that may contribute or cause the symptom</b>	<b>Other risk factors that may contribute to or cause the symptom</b>
Dental Problems	Dental pain can cause distress and fuel challenging behaviors. Individuals may need special help to tolerate dental procedures including sedation dentistry.	Anticholinergics (dry mouth) Antiepileptic medications	Prader-Willi syndrome at increased risk due to thick viscous saliva Fragile X syndrome due to high arched palate
Sleep Problems	Sleep problems and disorders such as sleep apnea may be caused by or worsened by medications. Some IDD syndromes confer risk for sleep problems including difficulty initiating or maintaining sleep.	Some antidepressants, steroids Pseudoephedrine Psychostimulants	Trauma, abuse, lack of activities or structure, daytime sleeping Angelman, Cornelia de Lange & Fetal Alcohol syndromes- common sleep problems Down Syndrome: high risk of obstructive sleep apnea Prader-Willi: high risk of sleep disorder due to weight Autism & Tuberous Sclerosis increased risk of sleep disorder
Confusion, delirium, encephalopathy	Medications can cause altered mental states that can be mistaken for “psychosis” such as when the person says things that sound odd or unusual. These states are also seen with transient skill loss or memory problems, “waxing and waning” level of alertness and purposeless repetitive behaviors.	Glyburide/glimepiride, Valproic acid/divalproex CNS polypharmacy	Delirium often associated with infection, especially in older population and people with cognitive impairment Rapid drug changes, discontinuation syndromes Vision & hearing problems can result in substantial changes in behavior
Headaches, Dizziness	Many medications cause headaches or even orthostasis (a drop in blood pressure on rising from a prone or seated position). Person may suddenly sit on the floor or may refuse activities, but may not be able to reliably describe these symptoms to others.	Beta blockers, trazodone, tricyclic antidepressants Antiepileptic medications	
Excessive food drive or dehydration	People with IDD may not control their own fluid intake and may become mildly dehydrated without caregivers noticing. Observe for dry skin, cracked lips, and monitor to insure adequate intake. Some medications increase appetite and then the person has challenging behaviors related to seeking food or liquids.	Lithium (caution with dehydration), mirtazapine, second generation antipsychotics, first generation antihistamines	Prader-Willi Syndrome

## THE IMPORTANCE OF LIFE TRANSITIONS

Life transitions: are important opportunities to review current medications, side effects, and health changes. It is also a chance to ensure that individuals, families and community providers are educated about current medications.

It is important to realize that not every person with I/DD receives formal disability services. In many cases the individual with I/DD may be reliant on themselves or family to monitor and report medication side effects, obtain refills, and raise drug related questions with their healthcare provider. Patient education and support is critical.

### **PRIMARY CARE PROVIDER AND PHARMACIST:**

**ASK** if the person with a developmental disability is receiving formal disability services. If no, and the person is in need of services:

- Individuals can apply for NC Medicaid online at the North Carolina's Department of Health and Human Services website: <https://medicaid-help.org/Primary-Information>
- Individuals can apply in person at their local Department of Social Services (DSS) office: <https://dma.ncdhhs.gov/medicaid/get-started>
- Contact the Call Center of the regional LME MCO to discuss eligibility, service options and community resources. To find more information on which LME MCO is linked to an individual's county of residence <http://www.ncdhhs.gov/providers/lme-mco-directory>
- The medication review process can help reduce medication errors that are especially common among individuals who have complex health care needs and interact with multiple healthcare providers.

### **CONSUMER STORY: THE IMPORTANCE OF LIFE TRANSITIONS**

**Sally** is a 23 y/o female with mild ID and a history of anxiety. Several months ago Sally moved from her family home to a group residential setting. Staff report that when Sally gets anxious she refuses to drink fluids and says "my heart hurts". During a recent conversation Sally was tearful and stated she misses her boyfriend. During a weekend family visit her sister noted that "Sally is not herself, she did not want to do anything, it was hard to wake her up and she was quiet most of the weekend". An appointment with her primary care provider revealed that Sally had low blood pressure and was dehydrated. Treatment focused on re-hydration and adequate nutrition. However, the following week Sally again appeared lethargic, at times agitated and tearful, and complained "my heart is wrong". The primary care provider suggested that Sally be monitored for hydration AND be evaluated for depression given her recent life transitions, including the loss of her boyfriend. Sally may benefit from individual or group therapy and medications.

- Develop a complete and accurate and current list of ALL medications an individual is taking (including non-prescription and alternative medications) including name, dosage, frequency, and route
- Compare this list with their medical record and to the list of medications obtained from the individual with IDD, family, disability provider and healthcare facility
- Review an up-to-date list of their prescribed medications at every appointment

Medication errors occur frequently when individuals are prescribed new medications or when they are admitted to or discharged from health care facilities.

**KEY TIMES OF LIFE TRANSITION:**

- School entry and exit: 0-4 year; 5-12 years; 14-18/21 years
- Residential /home changes: move away from family, move into new residence, new roommate
- Family changes: death of a caregiver; primary care giver now unable to provide care and a residential move is necessary
- Puberty can be a challenging time for a person with DD
- Age transitions: people with Down Syndrome may experience dementia at an earlier age and thus require medication review
- “Unexplained” or atypical behavior changes: crying, sleep, agitation, pain
- Annual individual support plan/person centered plan meeting for those receiving formal disability services: care coordinator should do a preliminary review of medications and request follow-up review if red flags are noted
- Annual Individual Education Plan meeting with the school system

Disability system: The primary point of contact varies, based on age, service needs, and community resources. Pages 21 – 23 provide additional information on the NC Disability Service System.

# **“Red Flag” Medication Review Guidelines for Individuals with Intellectual and Development Disabilities**

**Purpose:** To assist Prescribers and Pharmacists, with the identification of “Red Flag” criteria which may be potentially harmful to an individual with I/DD while reviewing their medications

**“Red Flag”** criteria indicate a need to review the individual’s clinical status in order to verify the medication regimen is accurate and appropriate. These parameters do not necessarily indicate that treatment is inappropriate, but they do indicate a need for further review.

For an individual with I/DD being prescribed a psychotropic medication, any of the following suggests the need for additional review of that individual’s clinical status:

<b>All Children, Adolescents, Adults, and Older Adults with I/DD</b>	
 <b>1: Absence of a thorough current and comprehensive assessment</b> (medical/physiologic drivers, psychiatric co-morbidities, psychosocial/environmental factors - see page 5 for detailed information) in the medical record at least every 6 months for children, at least every 1 year for adults, and at every transition point in a person’s life (see life transitions section on page 11).	<input type="checkbox"/> YES <input type="checkbox"/> NO
 <b>2: The prescribed psychotropic medication is not consistent with the evidenced-based principles of care</b> (see page 4 for Guiding Principles) for treating individuals with I/DD.	<input type="checkbox"/> YES <input type="checkbox"/> NO
 <b>3: Psychotropic polypharmacy (2 or more medications)</b> for a given mental disorder is prescribed <u>before</u> utilizing psychotropic mono-therapy (single medication).	<input type="checkbox"/> YES <input type="checkbox"/> NO
 <b>4: The psychotropic medication dose exceeds usual recommended doses***</b> (FDA and/or literature based maximum dosages – see Resources section for literature on medication dosages).	<input type="checkbox"/> YES <input type="checkbox"/> NO
 <b>5: The Prescriber (Primary Care Provider, Pediatrician, Psychiatrist, or Other Advanced Practice Provider) is not familiar with treating the I/DD population</b> , and is not working in collaboration or consultation with a Prescriber who is comfortable treating the I/DD population.	<input type="checkbox"/> YES <input type="checkbox"/> NO
 <b>6: Psychotropic medication therapy for longer than 6 months without re-evaluation</b> of the need for the medication.	<input type="checkbox"/> YES <input type="checkbox"/> NO
 <b>7: Psychotropic medication(s) prescribed without collaborating</b> with those who best know the individual with I/DD (family, caregivers) and those who provide long-term services and supports for each individual with I/DD.	<input type="checkbox"/> YES <input type="checkbox"/> NO
 <b>8: Prescribing psychotropic medication without a comprehensive treatment plan</b> that includes nonpharmacological interventions and other supports.	<input type="checkbox"/> YES <input type="checkbox"/> NO

<p><b>9: Prescribing of:</b></p> <ul style="list-style-type: none"> <li>• Two (2) or more concomitant stimulants <sup>*1</sup>, or</li> <li>• Two (2) or more concomitant alpha agonists <sup>2</sup>, or</li> <li>• Two (2) or more concomitant antidepressants <sup>3</sup>, or</li> <li>• Two (2) or more concomitant antipsychotics <sup>4</sup>, or</li> <li>• Two (2) or more concomitant mood stabilizers <sup>5</sup>, excluding those diagnosed with a seizure disorder</li> </ul> <p>* The prescription of a long-acting stimulant and an immediate release stimulant of the same chemical entity (e.g., methylphenidate) does not constitute concomitant prescribing.</p> <p><i>Note: When switching psychotropic medications, medication overlaps (where one medication overlaps with another medication for a period of time) and cross taper (slowly decreasing the dose of one medication while slowly increasing the dose of another medication) should occur in a timely fashion, generally within 12 weeks.</i></p>	<input type="checkbox"/> YES <input type="checkbox"/> NO
<b>Children and Adolescents with I/DD (0-20)</b>	
<p><b>1: Four (4) or more psychotropic medications prescribed at the same time</b> (medications being prescribed to deal with the side effects of the primary medication are not included in this count (i.e., benztropine, diphenhydramine, trihexyphenidyl)).</p>	<input type="checkbox"/> YES <input type="checkbox"/> NO
<p><b>2: Psychotropic medications are prescribed for children of very young age,</b> including children receiving the following medications with an age of:</p> <ul style="list-style-type: none"> <li>• Stimulants <sup>1</sup>: Less than three (3) years of age</li> <li>• Alpha Agonists <sup>2</sup>: Less than four (4) years of age</li> <li>• Antidepressants <sup>3</sup>: Less than four (4) years of age</li> <li>• Antipsychotics <sup>4</sup>: Less than four (4) years of age</li> <li>• Mood Stabilizers <sup>5</sup>: Less than five (5) years of age</li> </ul> <p><i>Note: Kids with I/DD of very young age are very susceptible to the behavioral side effects of these medications.</i></p>	<input type="checkbox"/> YES <input type="checkbox"/> NO
<p><b>3: Prescribing of chronic benzodiazepine <sup>6</sup> medication(s)</b> excluding children prescribed rectal diazepam (Diastat®) for seizure disorders.</p>	<input type="checkbox"/> YES <input type="checkbox"/> NO
<p><b>4: Antipsychotic medication(s) prescribed continuously without appropriate monitoring</b> of glucose and lipids at least every 6 months.</p>	<input type="checkbox"/> YES <input type="checkbox"/> NO
<b>Adults with I/DD (Age 21-54)</b>	
<p><b>1: Four (4) or more psychotropic medications prescribed at the same time</b> (medications being prescribed to deal with the side effects of the primary medication are not included in this count (i.e., benztropine, diphenhydramine, trihexyphenidyl)).</p>	<input type="checkbox"/> YES <input type="checkbox"/> NO
<p><b>2: Antipsychotic medication(s) prescribed continuously without appropriate monitoring</b> of glucose and cardiovascular risk at least every 1 year.</p>	<input type="checkbox"/> YES <input type="checkbox"/> NO

## Older Adults with I/DD (55 and older)

 <b>1: Three (3) or more psychotropic medications prescribed at the same time</b> (medications being prescribed to deal with the side effects of the primary medication are not included in this count (i.e., benztropine, diphenhydramine, trihexyphenidyl)).	<input type="checkbox"/> YES <input type="checkbox"/> NO
 <b>2: At least one (1) psychotropic medication and individual with I/DD has a history of repeated falls.</b>	<input type="checkbox"/> YES <input type="checkbox"/> NO
 <b>3: Individual with I/DD is having an acute change in cognition from baseline</b> and is prescribed one at least (1) medication that can harm an older adult's cognition: <ul style="list-style-type: none"> <li>• Antihistamines/anticholinergic medicines <sup>7</sup></li> <li>• Anti-anxiety (benzodiazepines <sup>6</sup>) and antidepressant medicines<sup>3</sup></li> <li>• Sleep aids <sup>8</sup></li> <li>• Antipsychotics <sup>4</sup></li> </ul>	<input type="checkbox"/> YES <input type="checkbox"/> NO

<sup>1</sup> Examples of **stimulants** include methylphenidate, (Ritalin®, Concerta®), dexamethylphenidate (Focalin®), lisdexamfetamine (Vyvanse®), and amphetamine mixed salts (Adderall®).

<sup>2</sup> Examples of **alpha agonists** include Guanfacine ER (Intuniv®) and clonidine ER (Kapvay®).

<sup>3</sup> Examples of **antidepressants** include Escitalopram (Lexapro®), Sertraline (Zoloft®), fluoxetine (Prozac®), and Trazodone.

<sup>4</sup> Examples of **antipsychotics** include Risperidone (Risperdal®), olanzapine (Zyprexa®), Aripiprazole (Abilify®), and Quetiapine (Seroquel®).

<sup>5</sup> Examples of **mood stabilizers** include Divalproex (Depakote®), lithium, Lamotrigine (Lamictal®), and carbamazepine (Tegretol®, Equetro®).

<sup>6</sup> Examples of benzodiazepines include lorazepam (Ativan®), diazepam (Valium®), alprazolam (Xanax®) and temazepam (Restoril®).

<sup>7</sup> Examples of **antihistamines/anticholinergic medications** include benztropine (Cogentin®), diphenhydramine (Benadryl®), and trihexyphenidyl.

<sup>8</sup> Examples of **sleep aids** include zolpidem (Ambien®), zaleplon (Sonata®), and eszopiclone (Lunesta®).

*This resource was adapted from the Psychotropic Medication Utilization Parameters for Children and Youth in Foster Care - 5<sup>th</sup> Version (March 2016) that was developed by the Texas Department of Family and Protective Services and The University of Texas at Austin College of Pharmacy. Any changes, and additional criteria were decided upon by the I/DD Medication Management Workgroup*



# Community Pharmacy Enhanced Services Network

*A Different Kind of Pharmacy for Patients Who Need a Higher Level of Care*

CPESN pharmacies bring a new dimension to the delivery of healthcare. Community pharmacists have unrivalled access to the complex patients that are your biggest challenge.

CPESN North Carolina pharmacists see their complex patients on average **35 times per year**. These same patients see their primary care physician only about **3.5 times per year**. Every one of these interactions is an opportunity to get more value from medications and alert physicians when new issues arise that could lead to readmission or a worsening of the patient’s condition.

## What is “enhanced” about CPESN North Carolina pharmacies?



### Services

CPESN pharmacies provide specialized services key to managing complex patients, such as medication reconciliation, non-English-labeling, adherence coaching, daily dose multi-medication blister packaging, 24hour emergency service, and home delivery/home visits.



### Relationship to the care team

Our pharmacists work hand-in hand with primary care physicians, care managers, and behavioral health providers, sharing information, improving compliance, and contributing to a shared, patient-centered care plan.



### Relationship with the patient

Community pharmacists know their local complex patients well, and enjoy a high degree of patient trust. This can open doors to non-compliant patients who aren’t doing well but are reluctant to accept additional help. CPESN pharmacies are focused on interventions that change patient behavior and lead to improved outcome

Accountability

Collaboration

Excellence

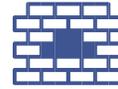
Innovation



## How can CPESN North Carolina pharmacies help you?



**Reduce readmissions** by identifying problems complex patients in time to make changes in literacy or treatment or medications.



**Boost value** by removing barriers to better with medication adherence, such as low health cognitive impairment.



**Improve patient satisfaction** – 98 percent of patients closely utilizing a CPESN pharmacy felt their care was your coordinated among multiple providers.



**Improve budget predictability** by working with complex patients to get more value from pharmaceutical spend.

### Improve Care and Maximize Your

CPESN delivers more attention, more more resources to complex patients in a effective, sustainable way that improves and lowers

#### For more information about CPESN contact:

Troy Trygstad, Pharm.D, M.B.A.,  
Vice President of Provider Pharmacy  
ttrygstad@cpe



Accountability

Collaboration

Excellence

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## OTHER CPESN PHARMACY SERVICES\*

**24-hour Emergency Service/On Call – Dispensing** – medication dispensing services offered after the normal business hours in urgent situations or special circumstances

**24-hour Emergency Service/On Call – Non-Dispensing** – non-medication dispensing services offered after the normal business hours such as DTP resolution or medication reconciliation in urgent situations or special circumstances

**Adherence Packaging** – unit dose packaging designed to assist patients with medication organization by incorporating date and time into the unit dose device

**Clozapine Dispensing and Monitoring** – ability to dispense clozapine via registration with registry and ongoing lab monitoring for patients

**Collection of Vital Signs** – ability to collect heart rate, respiration rate, temperature and blood pressure in your pharmacy for patients

**Compounding, Non-Sterile** – art and science of creating personalized, non-sterile medications

**Compounding, Sterile** – art and science of creating personalized, sterile medications

**Comprehensive Medication Review** – a review of patient medications, including prescription, over-the-counter, herbal medications and dietary supplements to identify, resolve, and prevent medication-related problems, including adverse events

**DME Billing – Medicare and Medicaid** – ability to bill both Medicare and Medicaid for durable medical equipment

**Home Delivery** – pharmacy-provided delivery service, regardless of cost to patient

**Home Visits** – act of sending a pharmacist or other qualified pharmacy staff member into a patient's home to complete a medication reconciliation/review or other medication-related service

**Immunizations – Non-Medicaid** – administration of vaccines in the pharmacy as authorized by protocol

**In Depth Counseling/Coaching** – additional counseling offered in the pharmacy, requiring a pharmacist or qualified staff member to step out of traditional pharmacy workflow in order to complete the activity

**Long-Acting Injections** – ability to administer injections for long-acting medications in your pharmacy; may require employment of non-pharmacy professional staff (nurse, etc.)

**Med Synchronization Program** – aligning all patient medications to be filled at the same time each month

**Multi-Lingual Staff** – employees a pharmacy staff member who can fluently speak languages other than English or has a contracted service with a vendor who can translate between the pharmacist/pharmacy representative and the patient or patient representative.

**Naloxone dispensing** – ability and willingness to dispense naloxone and deliver proper counseling for its use in narcotic overdose situations

**Nutritional Counseling** – delivery of education to help patients develop balanced diets that may also be tailored to individual chronic conditions

**Personal Medication Record** – ability to create a comprehensive list of current patient medications manually or from dispensing software

**Care Plan Development/Reinforcement** – document detailing patient information pertinent to helping a patient reach a particular healthcare goal

**Point of Care Testing** – ability to perform medical testing and deliver results in the pharmacy (HbA1c, cholesterol, blood glucose, etc.)

**Pre-filling Syringes for Oral Administration** – ability to fill individual-dosed oral syringes before medication is dispensed

**Presumptive Eligible (Medicaid) Medication Dispensing** – willingness to dispense medication based on “good faith” belief that the patient is eligible for Medicaid and is in the application process to be billed to Medicaid once actual eligibility is obtained

**Smoking Cessation Program** – educational program offered in your pharmacy designed to assist patients who desire to stop smoking

**Specialty Pharmacy Dispensing** – ability to dispense medications deemed “specialty drugs” based on the fact that they require specialized due to cost, treatment of a rare condition, requirement of special handling, use of a limited distribution network, or requirement of ongoing clinical assessment

**Standardized Assessments** – ability and willingness to administer questionnaire-based surveys to patients (i.e. pain assessment, PHQ-9, etc.)

**Long-term Care Chart Reviews** – evaluate medical charts for patients in residential care facilities such as nursing homes

**Disease state management programs** – educational programs offered in your pharmacy to enhance patient knowledge about chronic diseases (anticoagulation, cardiology, COPD/asthma, diabetes, hyperlipidemia, etc.)

## QUESTIONS YOU SHOULD ASK THE PRESCRIBER

Why are you planning to add this medication?

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What should we expect as a result of this addition?

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How long will it take for this medicine to work? How long will the individual be on it?

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What common side effects might we see?

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What red flags should we contact you about?

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Is the medication addictive? Can it be abused?

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Will labs need to be drawn before or while the individual is on this medication?

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Does this medication interact with any over-the-counter medications, food, activities, or with any of the individual's other medications?

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Concerns if the individual becomes pregnant?

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## NC DISABILITY SERVICE SYSTEM

The state agencies that are ultimately responsible for the design of the state system are:

### **Division of Mental Health, Developmental Disabilities and Substance Abuse Services (MHDDSAS)**

- <http://www.ncdhhs.gov/divisions/mhddsas>

### **Division of Medicaid Assistance (Medicaid)**

- <https://dma.ncdhhs.gov/>

**Local Management Entity (LME) Managed Care Organization (MCO)** manages the provider network, authorizes services, and provides care coordination in a “managed care model” for children and adults with MH, DD and SA. This includes the Innovations waiver and other behavioral health services and the registry of unmet needs in their catchment area.

**To find more information on which LME/MCO is linked to a county of residence:**

- <http://www.ncdhhs.gov/providers/lme-mco-directory>

## MEDICAID WAIVERS

**Community Alternatives Program for Children (CAP/C)** provides cost-effective home care for medically fragile children (through age 20) who would otherwise require long-term hospital care or nursing facility care.

- **DMA Clinical Policy and Programs CAP/C:**  
919-855-4340  
<https://www2.ncdhhs.gov/DMA/services/capc.htm/>

**Community Alternatives Program for Disabled Adults (CAP/DA)** is a Medicaid program that makes care at home a real possibility for people who face nursing home placement. The CAP/DA program waives certain NC Medicaid requirements to furnish an array of home and community based services to **adults with disabilities 18 years of age and older** who are at risk of institutionalization.

- **DMA Clinical Policy and Programs:**  
919-855-4340  
<https://www2.ncdhhs.gov/dma/services/capda.htm/>

## OTHER MEDICAID SERVICES

**Early Periodic Screening Diagnosis Treatment (EPSDT):** is a federal law that all medically necessary health care services are to be provided to Medicaid-eligible children under the age of 21. Services must be ordered by the child's physician or another licensed clinician. Prior approval from the Division of Medical Assistance may be required to verify medical necessity for some services. Covered services must be medically necessary and include periodic screening services, vision, dental and hearing services, medical and adaptive equipment and other necessary health care such as occupational, physical, speech and language therapy.

- **Medical Assistance Operations Section:**

919-855-4260

<http://dma.ncdhhs.gov/providers/programs-services/medical/Health-Check-Early-and-Periodic-Screening-Diagnosis-and-Treatment>

**Innovations Waiver:** North Carolina resource for funding services and supports for people with ID/DDs who are at risk for institutional care. This waiver provides community-based services and supports to promote choice, control, and community membership. The local management entity/managed care organization (LME/MCO) receives a set amount of money (capitation) each year to help people get I/DD services. There are a limited number of Innovation Waiver slots available that are managed by the LME MCO.

- **To learn more about Innovation Waiver services, contact your LME MCO.**

**Traumatic Brain Injury (TBI) waiver:** is a pilot waiver designed to provide more comprehensive services for adults with a TBI which occurred on or after their 22nd birthday.

The catchment area is Cumberland, Durham, Johnston, and Wake counties.

- Contact the **Alliance LME MCO** <https://www.alliancebhc.org/> and **NC DHHS Division of Medical Assistance** for additional information. <https://dma.ncdhhs.gov/>

**B 3 services** are available statewide and are intended to expand supports for individuals with complex needs who are eligible for Medicaid. Services for children and adults with IDD include community guide/navigation, de-institutionalization service array, in-home skill building, respite, supported employment, psychiatric consultation. *NC Innovations Waiver participants are eligible only for b3 Psychiatric Consultation.*

- **Contact the local LME MCO for more information.**

**Early Intervention/Infant Toddler Program:** part of the N.C. Division of Public Health. The Infant-Toddler Program provides supports and services for families and their children, birth to three who have special needs. Sixteen Children's Developmental Services Agencies (CDSAs) across North Carolina work with local service providers to help families help their children succeed. Services include: Service Coordination, physical, occupational and speech-language therapies, family support, special instruction, and assistive technology.

- Contact **NC ITP**  
919-707-5520  
or your local **CDSA** program  
<http://www.bearly.nc.gov/index.php/contact/cdsa>

## SERVICE PLANNING

**Individualized Education Program (IEP)** is a written document required for each child who is eligible to receive special education services. The IEP spells out the child's learning needs, the services the school will provide and how progress will be measured. The IEP is the responsibility of the Local Education Agency.

**Individual Support Plan (ISP)** is the written details of the supports, activities, and resources that an individual, Personal Agent or Service Coordinator, and other people of the individual's choice agree are important to or for achieving and maintaining personal outcomes. The ISP is required for anyone receiving services through the Innovations Waiver.

**Person-Centered Plan (PCP)** is the umbrella under which all planning for treatment, services and supports occurs. The PCP focuses on the strengths, interests and needs of an individual. The PCP is required for anyone receiving state funded services.

**Individual Family Support Plan (IFSP)** is a written treatment plan that maps out the early intervention (EI) services a child will receive, as well as how and when these services will be administered. It details the child's current levels of functioning, specific needs and goals for treatment. Local Children's Developmental Services Agencies (CDSAs) are available to help families, caregivers, and professionals serve children with special needs through the Infant Toddler Program.

- Contact your local CDSA program
- <http://www.bearly.nc.gov/index.php/contact/cdsa>

## GLOSSARY

### **DIAGNOSIS**

**Developmental Disability (DD)** means a disability that is manifested before the person reaches twenty-two (22) years of age, and

- is likely to continue indefinitely,
- results in substantial functional limitations,
- is attributable to intellectual disability or related conditions which include cerebral palsy, epilepsy, autism or other neurological conditions, and
- reflects the individual's need for assistance that is lifelong or extended duration that is individually planned and coordinated.

### **DD INCLUDES:**

- Intellectual Disability (ID)
- Autism Spectrum Disorder (ASD)
- Muscular Dystrophy
- Cerebral Palsy (CP)
- Fetal Alcohol Syndrome
- Traumatic Brain Injury (TBI)
- Down Syndrome
- Some other disorders (Prader-Willi, Fragile X)

### **INTELLECTUAL DISABILITY (ID)**

- Intellectual disability is a disability characterized by significant limitations both in **intellectual functioning** and in **adaptive behavior**, which covers many everyday social and practical skills.
- Generally, an IQ score of around 70 or less indicates a limitation in intellectual functioning
- Adaptive behavior includes three skill types:
  - Conceptual skills—language and literacy; money, time, and number concepts; and self-direction
  - Social skills—interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., wariness), social problem solving, and the ability to follow rules/obey laws and to avoid being victimized.
  - Practical skills—activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone.

## **MEDICATIONS AND RELATED TERMS**

**Adverse Drug Event-** refers to any injury occurring at the time a drug is used, whether or not it is identified as a cause of the injury.

**Adverse Drug Reaction:** Adverse drug reactions are caused by adverse drug effects and are an unintended consequence resulting from medication use; with adverse drug reactions, the drug must be causally related to the symptoms manifested, occur at usual doses, and are caused by the pharmacologic action of the drug; onset may be sudden or develop over time.

**Akathisia:** distressful feeling of restlessness, inability to be still, often described as something moving inside the body

**Allergic Reaction:** Symptoms which occur when your body's immune system becomes sensitized to a substance in the medication or the drug itself, and perceives it as a foreign invader and releases chemicals to defend against it, leading to the symptoms of rash, hives, swelling, or difficulty breathing

**Alpha agonists:** medications trigger contraction of smooth muscle throughout the body. They are especially active in the blood vessels, particularly the arteries, and have a vasoconstrictive effect.

**Alpha blocker agents:** relax certain muscles and help small blood vessels remain open. They work by keeping the hormone norepinephrine (noradrenaline) from tightening the muscles in the walls of smaller arteries and veins, which causes the vessels to remain open and relaxed. This improves blood flow and lowers blood pressure. Examples include Minipress (prazosin), Cardura (doxazosin)

**Antianxiety Agents:** work to treat the symptoms of anxiety in various ways including affecting the neurotransmitter GABA (benzodiazepines) or promoting skeletal muscle relaxation by affecting histamine receptors (hydroxyzine). Examples include Benzodiazepines Valium, Xanax, Klonopin, Ativan

**Anticholinergic agents:** medications which inhibit parasympathetic activity by blocking the neurotransmitter acetylcholine; anticholinergics are used for asthma, COPD, diarrhea, nausea, vomiting, Parkinson's disease and to decrease smooth muscle spasms (e.g., in the urinary bladder). Examples are Cogentin, Artane, and Benadryl.

**Anticonvulsants:** also commonly known as antiepileptic drugs or AEDs, with uses that include, but are not limited to, treatment of seizures, mood disorders, migraines and neuropathic pain. They should be used carefully, with consideration of medication interactions and potential side effects, especially for

some individuals with IDD. Examples include Depakote, Lamictal, Tegretol, Neurontin

**Antidepressants:** affect neurotransmitters in the brain such as serotonin, norepinephrine and dopamine and can be used to treat depression, anxiety, eating disorders and pain. Examples include Celexa, Prozac, Effexor, Wellbutrin

**Antiepileptic drugs (AEDs)** (see Anticonvulsants described above) Depakote, Lamictal, Tegretol, Neurontin

**Antihistamines:** a group of medications that affect histamine receptors and are used for a wide variety of indications, including treatment of allergic reactions, insomnia, treatment of extrapyramidal side effects from antipsychotics, nausea, motion sickness and vertigo. Examples include Benadryl, Vistaril, Unisom

**Atypical Antipsychotic:** also known as the newer antipsychotics or second generation antipsychotics; have similar efficacy to older antipsychotics and their prominent side effects are more likely to include, but are not limited to, weight gain, diabetes, high cholesterol /blood lipids. Examples include Abilify, Seroquel, Zyprexa, Latuda, and others.

**Concomitant:** describes a situation when two or more medications are given at or almost the same time.

**Desired medication effects:** All medications have pharmacologic effects, those which are desired (i.e. the reason for treating a disease/using the medication) as well as those effects which are not desired (side effects or adverse effects)

**Diabetes:** a disease in which blood sugar levels are too high. Can result in damage to eyes, nerves, kidneys, heart disease, or stroke

**Prediabetes:** blood sugar is higher than normal but not high enough to be called diabetes.

**Hyperlipidemia:** the presence of too much cholesterol, which is a naturally occurring waxy, fat-like substance that the body needs. High levels of cholesterol in the blood can increase risk of heart disease.

**Drug allergy:** abnormal reaction of your immune system to a medication that can include, but is not limited to, hives, rash or fever, and less commonly trouble breathing.

**Drug interaction:** occurs when two or more drugs react with each other and may result in an unexpected side effect.

**Drug Levels:** lab measurements used to look for the presence and amount of a medication in the blood.

**Drug sensitivity:** when the reaction to a medication is faster or there is a lower threshold to the effects of medications when compared to the response of others.

**Efficacy:** ability of a medication to achieve the desired effect.

**Extrapyramidal Symptoms / Side Effects (EPS):** there are four primary types of EPS

- a) **Pseudoparkinsonism or Parkinsonian Syndrome:** these symptoms look like Parkinson's Disease: tremor, shuffling gait, rigidity
- a. **Acute dystonic reaction:** bizarre, involuntary muscle spasms that can involve the head, face, back, arms or legs
- b. **Akathisia:** distressful feeling of restlessness, inability to be still, often described as something moving inside the body
- c. **Tardive Dyskinesia:** sucking or smacking of the lips, tongue thrust, purposeless movements in extremities; symptoms may take years to develop.

**Metabolic side effects/metabolic syndrome:** a group of conditions that increase risk for heart disease and diabetes, including high blood pressure, high blood sugar, high cholesterol and extra weight at the waist.

**Psychoactive/psychotropic medication:** medications that affect brain activities associated with mental process and behavior, including but not limited to antipsychotics, mood stimulators, ADHD meds, sleep aids, antidepressants, and anti-anxiety medications. Examples include Risperdal, Adderall, Ambien, Celexa, Klonopin

**Side Effects:** unwanted results of medication use.

**Stimulants:** used to stimulate the central nervous system by affecting the neurotransmitters norepinephrine and dopamine to treat ADHD, narcolepsy, depression, obstructive sleep apnea, shift-work disorder and obesity. Examples include Ritalin, Adderall, Vyvanse, Concerta

**Therapeutic Range:** a range of numbers given to use for evaluation of a specific number determined by lab test, sometimes for side effect evaluation or therapeutic efficacy.

**Typical Antipsychotic:** also known as the older antipsychotics or first generation agents; have similar efficacy to newer antipsychotics, side effects are more likely to include, but are not limited to, extrapyramidal symptoms and tardive dyskinesia. Examples include Haldol, Thorazine, Mellaril, and Prolixin

## RESOURCES

### **American Academy of Developmental Medicine and Dentistry**

- [www.aadmd.org](http://www.aadmd.org)

### **American Psychiatric Association Practice Guideline on the Use of Antipsychotics to Treat Agitation or Psychosis in Patients with Dementia**

- <http://ajp.psychiatryonline.org/doi/full/10.1176/appi.ajp.2015.173501>

### **Appropriate Use of Psychotropic Medications for People with IDD**

Vanderbilt Kennedy Center

- [www.iddtoolkit.org](http://www.iddtoolkit.org)

### **Autism Spectrum Disorder & Intellectual Disability Disorder: Psychotropic Medication Recommendations for Target Symptoms in Children and Adolescents**

University of South Florida

- [http://www.medicaidmentalhealth.org/assets/file/Guidelines/17-ASD%20&%20ID%20Guidelines%20\(w%20references\)%20%206.5%20x%209.5.pdf](http://www.medicaidmentalhealth.org/assets/file/Guidelines/17-ASD%20&%20ID%20Guidelines%20(w%20references)%20%206.5%20x%209.5.pdf)

### **Best Practices for Medication Management for Children & Adolescents in Foster Care**

Community Care of North Carolina

- <https://www.communitycarenc.org/media/files/foster-care-medication-management-oct.pdf>

### **Consensus guidelines for primary health care of adults with developmental disabilities, Canadian Consensus Guidelines**

- <http://www.surreyplace.on.ca/documents/Primary%20Care/Primary%20Care%20of%20Adults%20with%20Developmental%20Disabilities%20Canadian%20Consensus%20Guidelines.pdf>

### **Florida Best Practice Psychotherapeutic Medication Guidelines for Adult**

University of South Florida

- [http://www.medicaidmentalhealth.org/assets/file/Guidelines/Web\\_2015-Psychotherapeutic%20Medication%20Guidelines%20for%20Adults\\_Final\\_Approved1.pdf](http://www.medicaidmentalhealth.org/assets/file/Guidelines/Web_2015-Psychotherapeutic%20Medication%20Guidelines%20for%20Adults_Final_Approved1.pdf)

### **Mental Health Medications**

National institute of Mental Health

- [https://www.nimh.nih.gov/health/topics/mental-health-medications/index.shtml#part\\_149855](https://www.nimh.nih.gov/health/topics/mental-health-medications/index.shtml#part_149855)

### **Psychotropic Medication Utilization Parameters for Children and Youth in Foster Care**

Texas Dept. of Family and Protective Services

- [https://www.dfps.state.tx.us/Child\\_Protection/Medical\\_Services/documents/reports/2016-03\\_Psychotropic\\_Medication\\_Utilization\\_Parameters\\_for\\_Foster\\_Children.pdf](https://www.dfps.state.tx.us/Child_Protection/Medical_Services/documents/reports/2016-03_Psychotropic_Medication_Utilization_Parameters_for_Foster_Children.pdf)

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