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Clinical Pearls in IDD Healthcare:

Understanding Behavioral Clues

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- Began nursing career in 2013
- Entered the IDD field in 2018, driven by advocacy and support for at-risk populations
- Served as Regional Director, Lead IDD RN, and Developmental Disability Professional (DDP) in Georgia
- Supported community and residential IDD provider agencies
- Joined IntellectAbility in 2021 as a Clinical Service Representative
- Assumed the role of Clinical Director in 2025



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HRST®

HEALTH RISK SCREENING TOOL

Academy

IDD SUPPORTER EDUCATION

Person Centered Services

A SHIFT IN SUPPORTER PERSPECTIVE

Productions

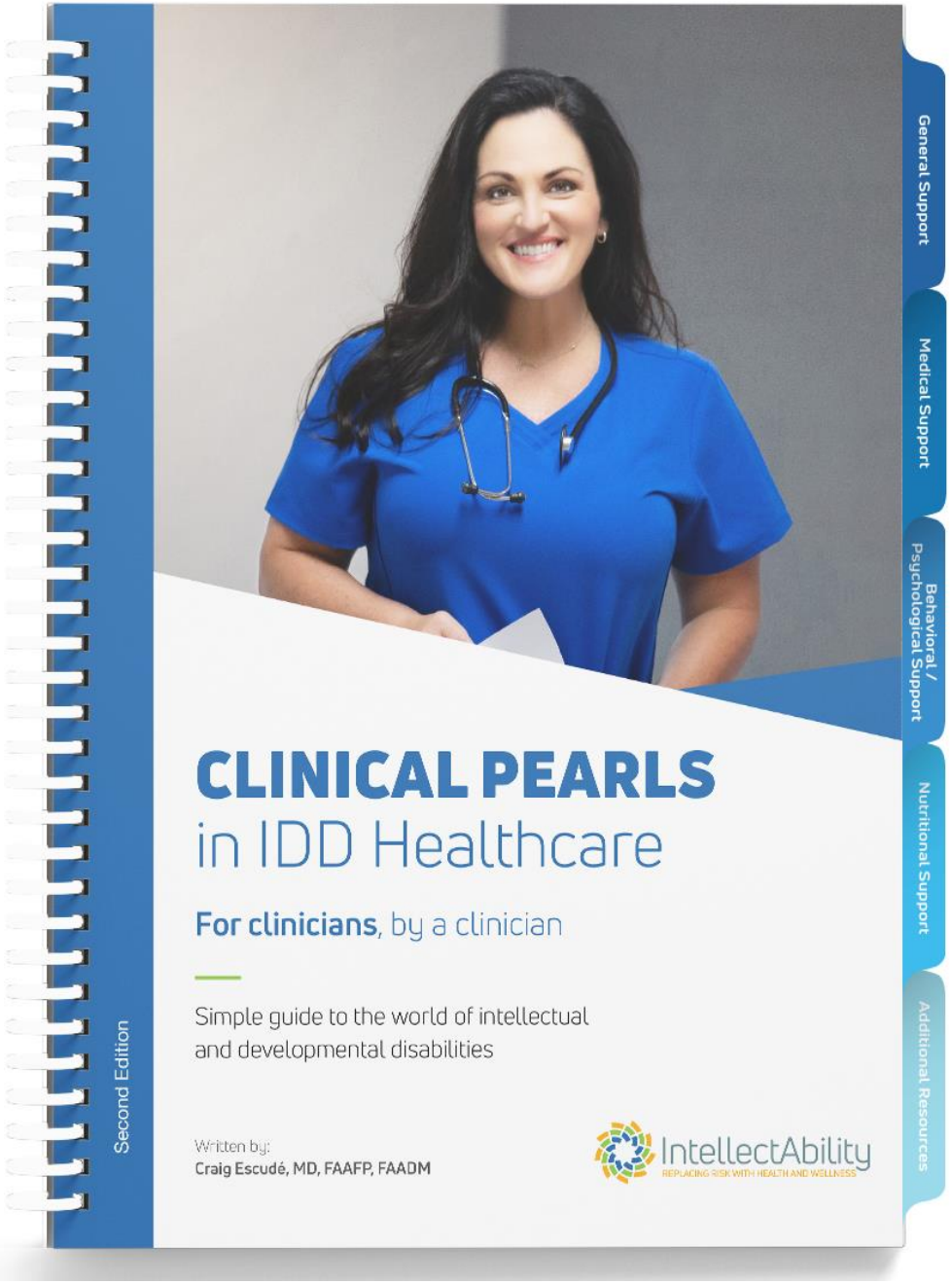
CUSTOM COURSE DEVELOPMENT

Objectives

- Identify medical, psychological, and communication-related causes of behavioral changes in people with IDD
- Recognize hidden pain, medication effects, and mental health conditions influencing behavior
- Examine behavioral considerations related to dual diagnosis, pica, and dementia
- Apply biopsychosocial principles to assessment, psychotropic prescribing, and individualized support



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Content Acknowledger

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What Are Clinical Pearls?

Small bits of free-standing, clinically relevant information based on experience or observation



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Who Are They For?

- Nurses
- Dentists
- Physicians
- Psychologists
- Physical therapists
- Occupational therapists
- Speech-language pathologists (SLPs)
- Direct Support Professionals (DSPs)
- Support teams
- Family supporters
- People with IDD



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How Can They Be Used?

- Assist with in-service trainings
- Presented by DSPs or nurses to physicians
- Educate family members and other supporters

Understanding Behavior

Because what we see is only part of the story

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Behavior Is Communication

- Behavior may communicate pain, fear, frustration, discomfort, or unmet needs
- A behavior's function is not always immediately apparent
- Behavioral changes should prompt curiosity, not assumptions

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Look Beyond the Behavior

- Do not attribute behavior to IDD rather than investigating other conditions
- Know the person's baseline
- Distinguish longstanding behaviors from new or worsening behaviors
- Never assume a behavior is simply "the way someone is"

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Know the Person's Baseline

- What is typical for this person?
- What has changed?
- When did it begin?
- Is the change persistent, worsening, or occurring in a pattern?
- What else changed at the same time?



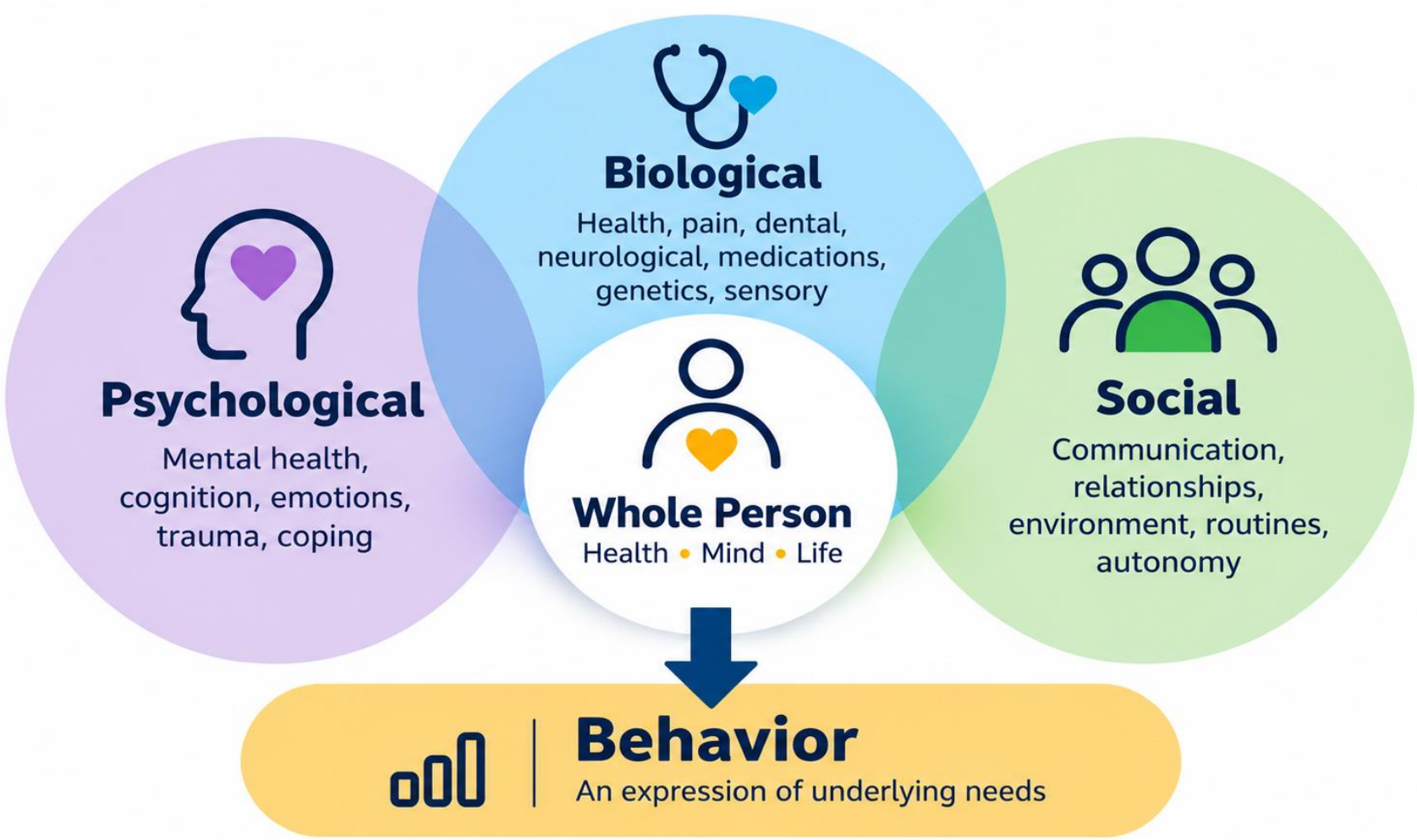
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Clinical Pearl #40: Medical Causes for Behaviors

- Gastrointestinal (GI) distress or reflux
- Earache, headache, sinusitis, or hearing/vision loss
- Dental issues
- Constipation
- Seizure disorder
- Urinary tract infection (UTI)
- Pneumonia
- Medication side effects and interactions

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The Biopsychosocial Model



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Behavioral Mysteries

What looks like a behavioral concern is often something more



The Refusal to Eat

- Sarah, 29, has limited verbal communication and recently began pushing food away, striking her face, and resisting toothbrushing.
- Staff believe she is becoming increasingly oppositional.

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Clinical Pearl #41: Dental Causes of Behavior

Behaviors that might indicate dental issues include:

- Putting hands in mouth*
- Hitting self in any area, including the mouth and jaw
- Physical or verbal aggression around mealtimes*
- Refusing to eat*
- Spitting out food

*Gastroesophageal reflux disease (GERD) can also cause similar symptoms. Dental exams should look for signs of GERD, including bad breath, tooth discoloration, erosions in the posterior teeth, and loss of enamel on the upper teeth



The Refusal to Eat

A dental examination identifies an abscessed molar.

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The Behavioral Outburst

- Michael, 24, speaks minimally and begins yelling and throwing objects whenever staff initiate a particular activity.
- Staff describe the behavior as task avoidance.

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Clinical Pearl #42: Communication Difficulties as a Cause of Adverse Behaviors

Strategies to identify communication barriers:

- Observe and document patterns, triggers, timing, and environmental factors
- Consider what the person might be trying to communicate:
  - Pain or discomfort
  - Unmet wants, needs, or preferences
  - Desire to leave a situation or be left alone
  - Difficulty understanding expectations or instructions
- Evaluate the person's typical communication methods

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The Behavioral Outburst

Michael's communication device is no longer functioning properly. He has been unable to express that the activity causes sensory distress.

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The Resistance to Care

- Linda, 47, has severe IDD and uses a wheelchair.
- She begins screaming and striking supporters during transfers and dressing.
- No injury has been reported.

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Clinical Pearl #43: Elusive Causes of Pain and Adverse Behaviors

Often-overlooked medical causes of pain or discomfort include:

- GI conditions, like constipation or gallstones
- UTIs
- Pressure injuries
- Fractures
- Arthritis
- Vision or hearing loss

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The Resistance to Care

Further evaluation identifies a hip fracture that had not been previously recognized.

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The Escalating Behavior

- Darrell, 35, begins pacing, yelling, and refusing community outings following a change in residential staff and daily routines.
- He also has a history of anxiety and difficulty sleeping.

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Clinical Pearl #44: Biopsychosocial Causes for Behavior

- Explore contributing factors:
  - Biological
  - Psychological
  - Social
- Consider next steps:
  - Restore familiar routines and consistent staffing when possible
  - Use reassurance during transitions
  - Evaluate sleep patterns, anxiety symptoms, and potential medical contributors
  - Monitor behavioral patterns, sleep quality, participation, and response to interventions

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The Escalating Behavior



Darrell is provided additional time and interaction with new staff, using reassurance and gradual transitions.

The support team reviews Darrell's responses to interventions and modifies supports as needed.

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The Loss of Interest

- Thomas, 32, has mild IDD and begins withdrawing from preferred activities, sleeping more, and becoming irritable with peers.
- His support team initially attributes the changes to his disability.

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Clinical Pearl #46: Mental Health Conditions in People with IDD (PWIDD)

Things to consider:

- Unusual change(s) in baseline behavior:
  - Changes in sleep and eating patterns
  - Engaging in self-harm
  - Lack of self-care
- Behavior occurs in all environments
- The person does not appear to have control over their behavior
- Go-to strategies have been ineffective
- Medical causes have been ruled out

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The Loss of Interest



Following a comprehensive assessment to rule out medical issues, Thomas is diagnosed with major depressive disorder.

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The Unexplained Decline

- Denise, 40, has IDD and has been prescribed multiple psychotropic medications over several years for aggression and agitation.
- Her original target symptoms are poorly documented, and she now experiences daytime sedation, confusion, and frequent falls.

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Clinical Pearl #47: Key Considerations When Prescribing Psychotropic Drugs to PWIDD

Essential steps of psychotropic medication use:

- Confirmed diagnosis for which psychotropics are indicated
- Behavior is severe and non-responsive to cognitive or behavioral therapy
- Medical causes of behavioral symptoms have been ruled out
- Potential benefits outweigh harm
- Discuss with the person and supporters
- Obtain consent

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Clinical Pearl #47: Key Considerations When Prescribing Psychotropic Drugs to PWIDD

Develop a treatment plan detailing:

- Targeted behavior/symptom: frequency and intensity
- Method of measuring therapeutic response
- Past responses to treatment, including any adverse effects or allergic reactions
- A treatment timeline and contingency plan if ineffective

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The Unexplained Decline

A comprehensive medication review identifies potentially unnecessary overlapping treatment and adverse effects that may be contributing to her functional decline.

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The Persistent Pica

- Marcus, 26, has moderate IDD and a history of pica.
- Staff report increased attempts to ingest paper, plastic, and other household materials despite enhanced supervision.

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Clinical Pearl #48: Pica Behavior in PWIDD

Potential causes of pica include:

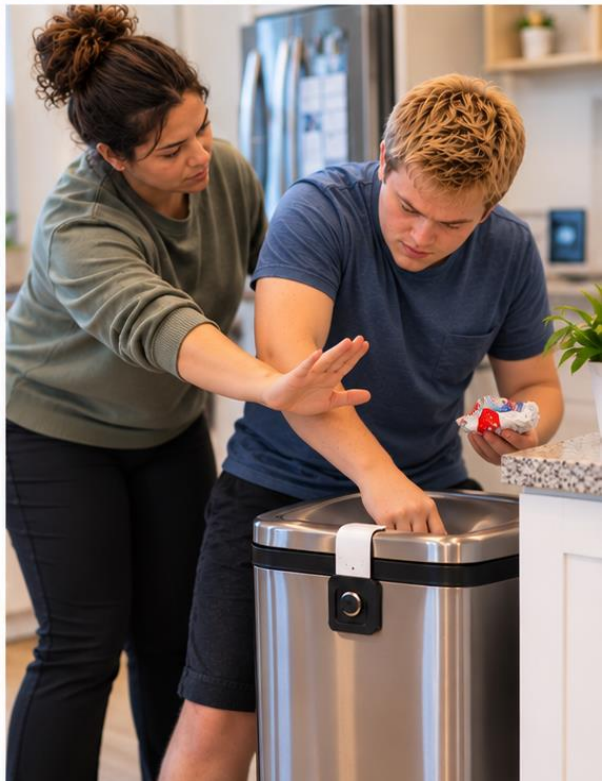
- Iron or mineral deficiency
- Chronic esophagitis
- GERD
- Chemical imbalance in the brain
- Obsessive-compulsive disorder
- Maternal deprivation, poverty, or neglect

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The Persistent Pica





Assessment identifies iron deficiency and GERD as possible contributing factors. The team awaits diagnostic testing results while maintaining safety precautions.

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The Change in Personality

- Emily, 41, has Down syndrome and begins to demonstrate increased irritability, difficulty completing familiar tasks, and changes in sleep.
- Her family is struggling to understand the changes in her behavior.

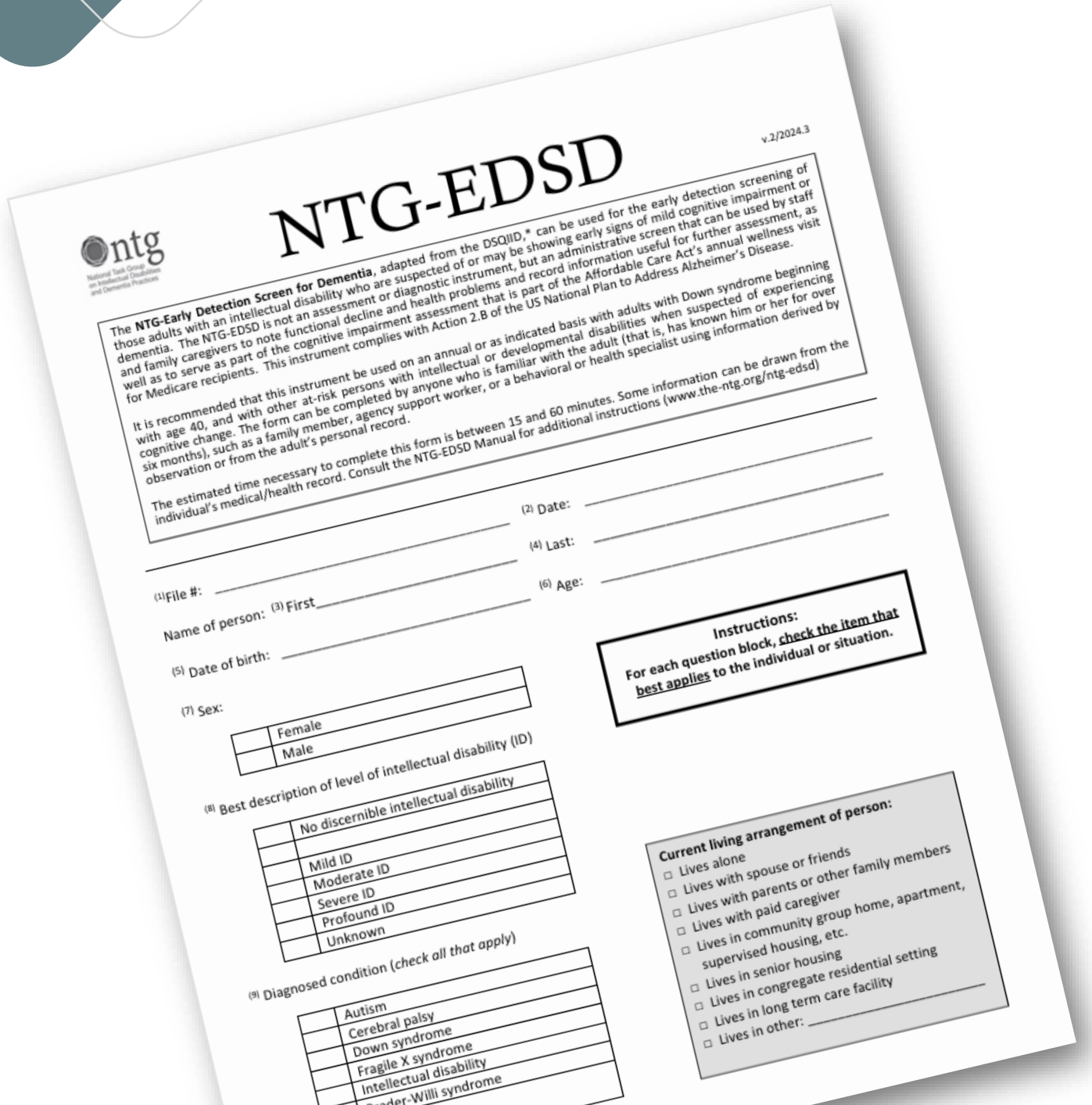
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Clinical Pearl #49: Dementia in PWIDD

Considerations for early identification:

- Know the risk factors
  - Down Syndrome, aging, history of a traumatic brain injury (TBI), and family history
- Establish and document the person's baseline
- Recognize early warning signs
  - Mobility issues, confusion, new-onset seizures, increased dependence, changes in sleep patterns, irritability, and loss of interest
- Rule out other potential contributors
  - Hypothyroidism, anemia, dehydration, medication side effects, depression/anxiety, sleep apnea, hearing or vision loss
- Screen for dementia early and often

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NTG-EDSD

v.2/2024.3

ntg
National Task Group on Intellectual Disabilities and Dementia Practices

The **NTG-Early Detection Screen for Dementia**, adapted from the DSQIID,* can be used for the early detection screening of those adults with an intellectual disability who are suspected of or may be showing early signs of mild cognitive impairment or dementia. The NTG-EDSD is not an assessment or diagnostic instrument, but an administrative screen that can be used by staff and family caregivers to note functional decline and health problems and record information useful for further assessment, as well as to serve as part of the cognitive impairment assessment that is part of the Affordable Care Act's annual wellness visit for Medicare recipients. This instrument complies with Action 2.B of the US National Plan to Address Alzheimer's Disease.

It is recommended that this instrument be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change. The form can be completed by anyone who is familiar with the adult (that is, has known him or her for over six months), such as a family member, agency support worker, or a behavioral or health specialist using information derived by observation or from the adult's personal record.

The estimated time necessary to complete this form is between 15 and 60 minutes. Some information can be drawn from the individual's medical/health record. Consult the NTG-EDSD Manual for additional instructions (www.the-ntg.org/ntg-edsd)

(1) File #: _____ (2) Date: _____

Name of person: (3) First _____ (4) Last: _____

(5) Date of birth: _____ (6) Age: _____

Instructions:
For each question block, check the item that best applies to the individual or situation.

(7) Sex:

- ☐ Female
- ☐ Male

(8) Best description of level of intellectual disability (ID)

- ☐ No discernible intellectual disability
- ☐
- ☐ Mild ID
- ☐ Moderate ID
- ☐ Severe ID
- ☐ Profound ID
- ☐ Unknown

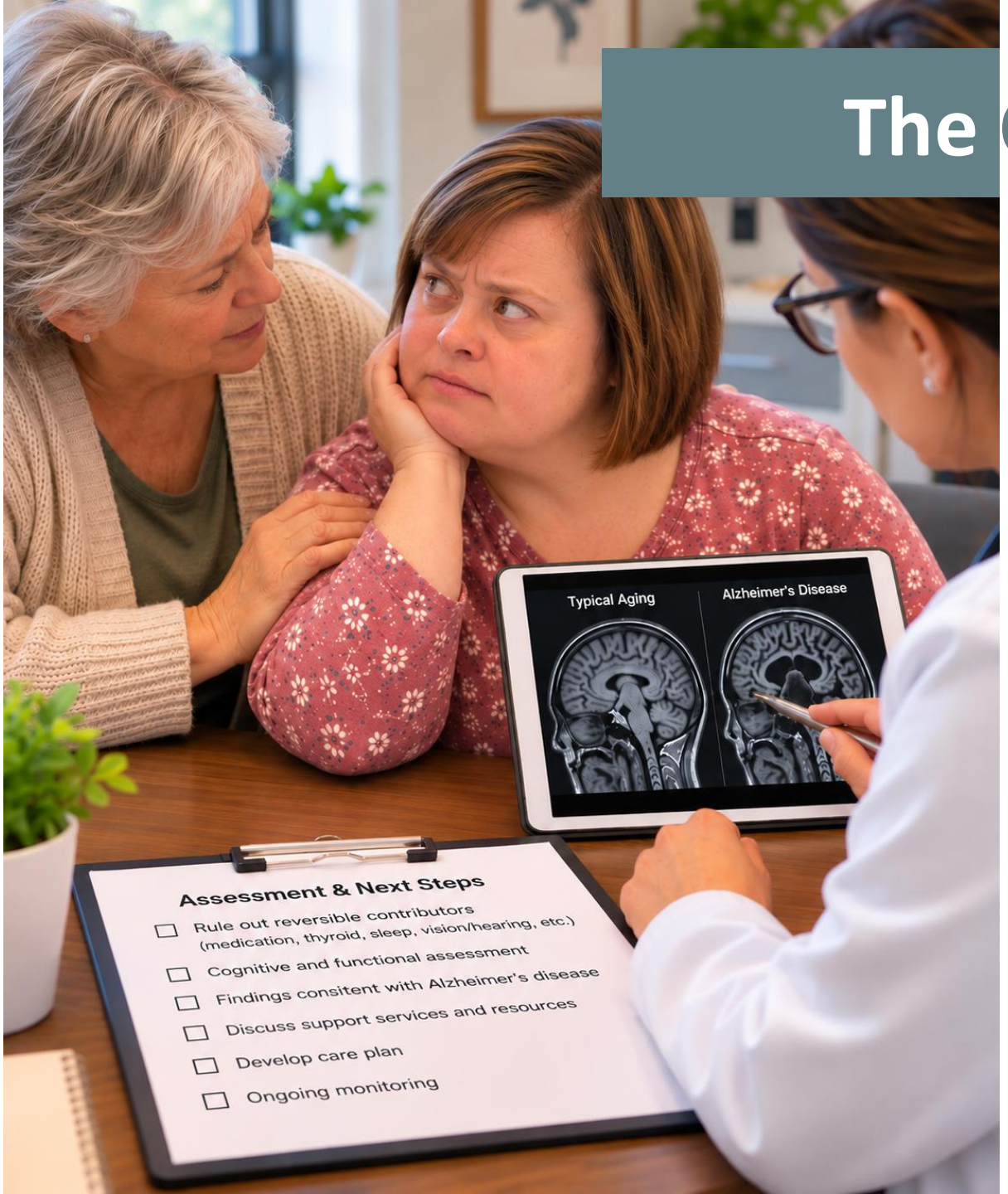
(9) Diagnosed condition (*check all that apply*)

- ☐ Autism
- ☐ Cerebral palsy
- ☐ Down syndrome
- ☐ Fragile X syndrome
- ☐ Intellectual disability
- ☐ Prader-Willi syndrome

Current living arrangement of person:

- ☐ Lives alone
- ☐ Lives with spouse or friends
- ☐ Lives with parents or other family members
- ☐ Lives with paid caregiver
- ☐ Lives in community group home, apartment, supervised housing, etc.
- ☐ Lives in senior housing
- ☐ Lives in congregate residential setting
- ☐ Lives in long term care facility
- ☐ Lives in other: _____

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The Change in Personality

A longitudinal assessment identifies cognitive and functional decline consistent with Alzheimer's disease, after evaluating potentially reversible contributors.

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Connecting the Clinical Pearls

Connecting what we know to what we do

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One Behavior, Multiple Possible Causes

Observed Behavior	Potential Contributor
Refusing meals	Dental pain, GERD, dysphagia
Pacing and agitation	Anxiety, medication side effects like akathisia, pain
Refusal of personal care	Trauma, abuse, musculoskeletal pain, communication barriers
Withdrawal	Depression, sedation, infection, dementia
Increased self-injury or aggression	Pain, sensory distress, unmet communication needs

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5 Questions to Ask When Behavior Changes

1. What changed from baseline?
2. What could hurt?
3. What could be influencing behavior?
4. Who needs to be involved?
5. How will we know it worked?





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Key Takeaways

- Behavior IS communication
- Know the person; recognize the change
- Rule out medical causes first
- Collaborate. Investigate. Advocate.

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