

# Addressing Detection of Dementia in Individuals with Intellectual/Developmental Disability (I/DD) and Dementia

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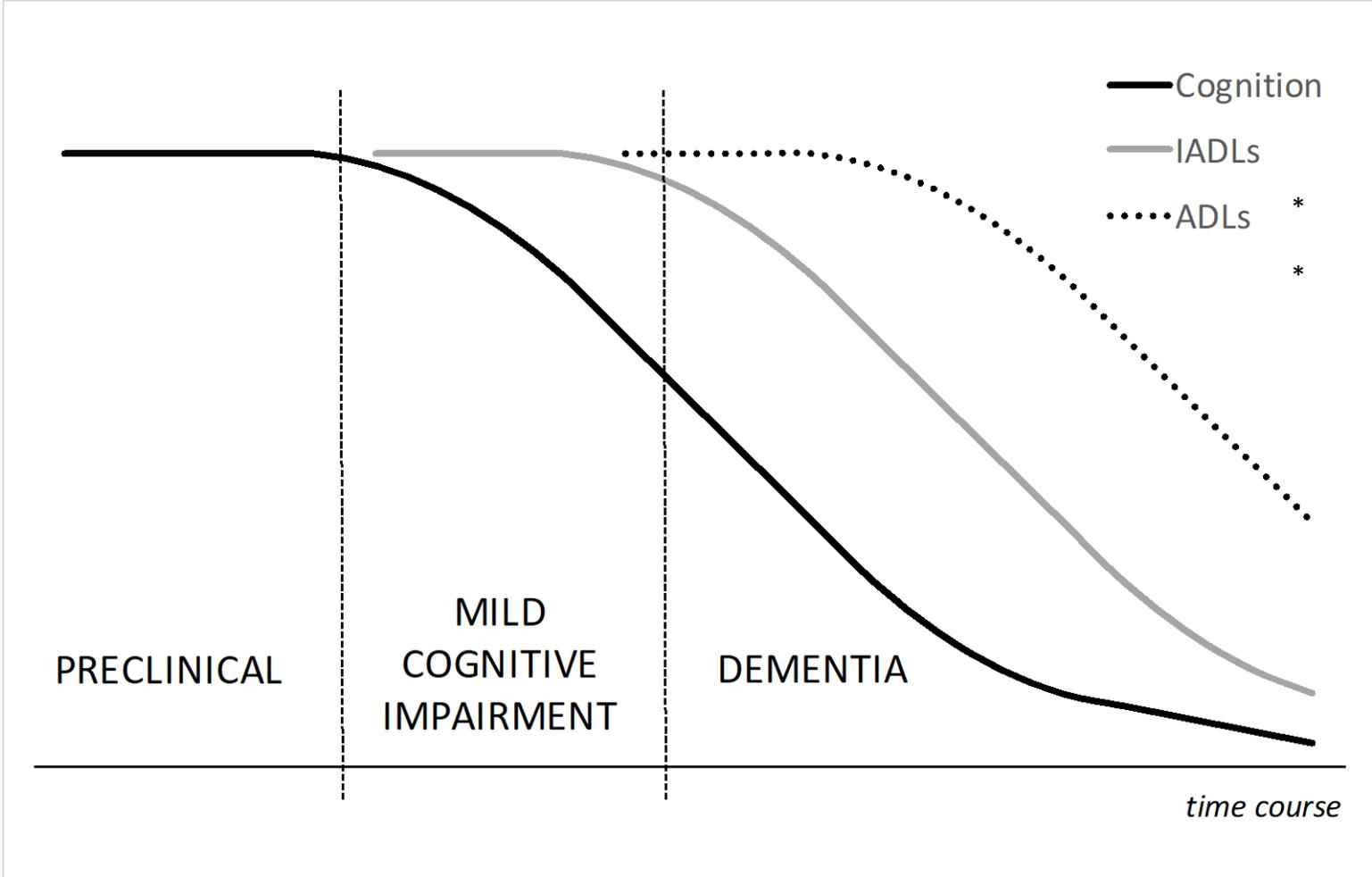


# Objectives

- Describe how behavioral and psychological symptoms of dementia (BPSD) manifest in persons with intellectual/developmental disability
- Describe the pharmacological options that may help address BPSD in persons with intellectual/developmental disability
- Develop an approach to managing BPSD that includes behavioral & environmental interventions as primary and psychotropic medications as secondary



# Overview of dementia



\* change from baseline in instrumental activities of daily living (IADLs) or personal activities of daily living (ADLs)



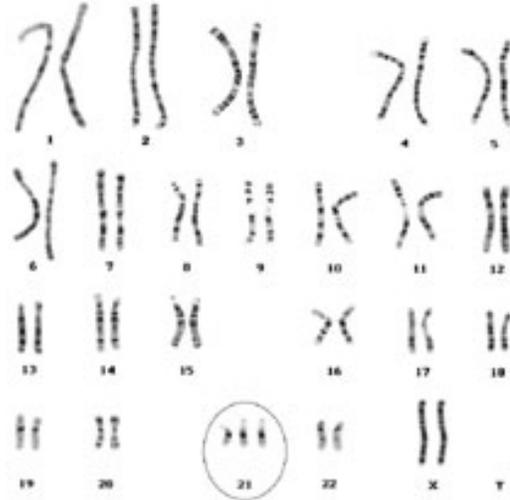
# Causes of mild cognitive impairment (MCI) and dementia

- Alzheimer's disease
- Lewy body disease / Parkinson disease
- stroke (vascular dementia)
- frontotemporal dementia
- alcohol
- traumatic brain injury
- mixed

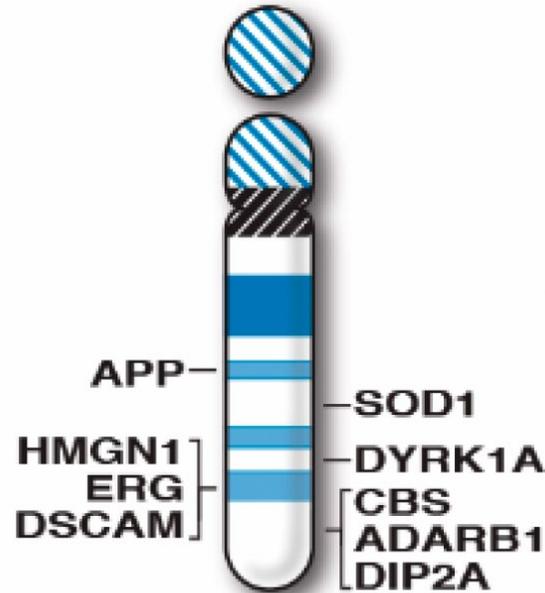


# I/DD and dementia: the example of Down syndrome

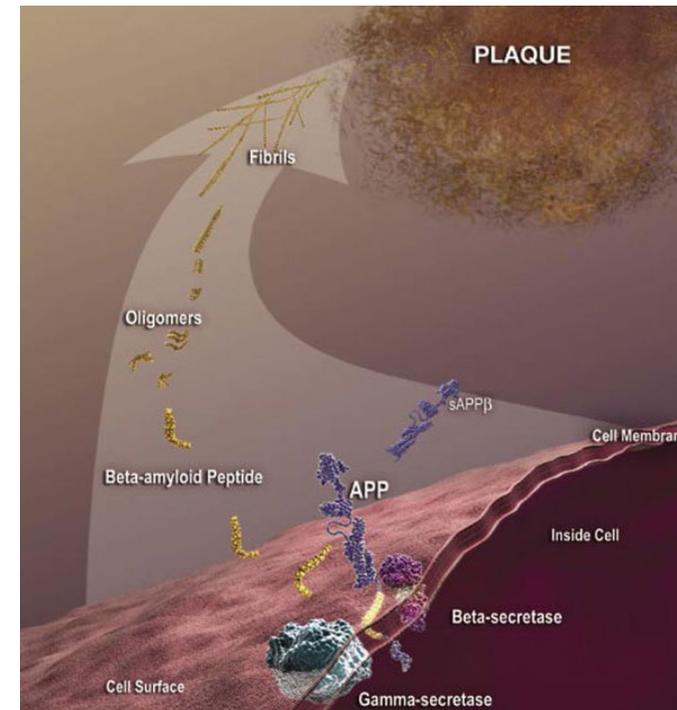
trisomy 21



APP gene on  
chromosome 21



amyloid plaque



# Behavioral & psychological symptoms of dementia (BPSD)

- as categorized by the NTG-EDSD\*:
  - behavior and affect
  - sleep-wake patterns
  - other notable significant changes observed by others

\* NTG-EDSD = National Task Group (NTG) Early Detection Screen for Dementia ([www.aadmd.org/ntg/screening](http://www.aadmd.org/ntg/screening))



# NTG-EDSD & BPSD: behavior & affect\*

- appears depressed
- withdraws from social activities
- withdraws from people
- loss of interest in hobbies and activities
- seems to go into own world
- shows lethargy or listlessness
- talks to self
- appears uncertain, lacks confidence
- does not know what to do with familiar objects
- increased impulsivity
- appears anxious, agitated, or nervous
- shows verbal aggression
- shows physical aggression
- temper tantrums, uncontrollable crying, shouting
- wanders
- obsessive or repetitive behavior
- hides or hoards objects

\* described as: *always been the case, always but worse, new symptom in the past year*



# NTG-EDSD & BPSD (cont'd)

## Sleep-wake changes:

- excessive sleep
- inadequate sleep
- wakes frequently at night
- confused at night
- sleeps during the day more than usual
- wanders at night
- wakes earlier than usual
- sleeps later than usual

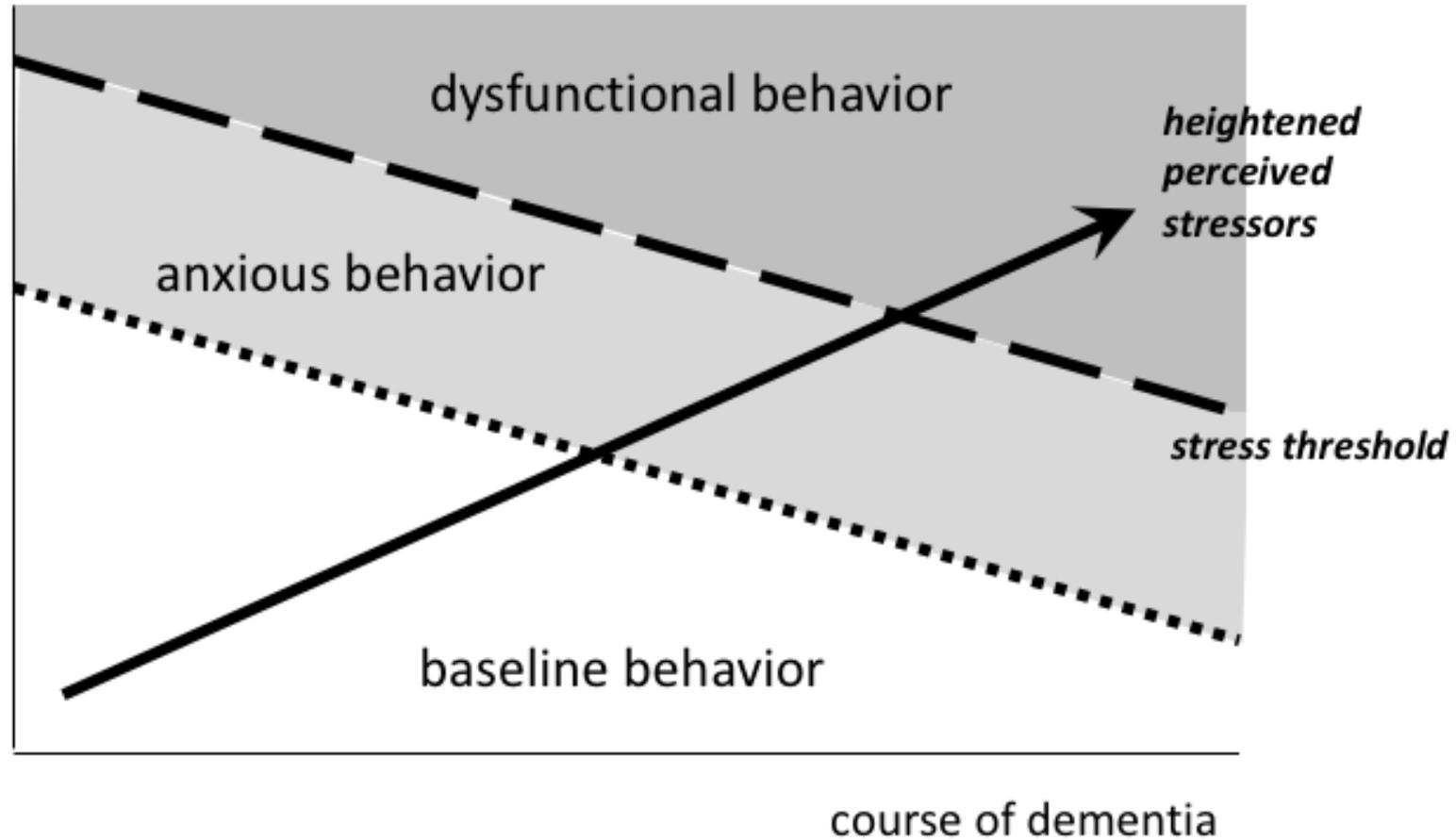
## Other changes:

- personality: for example, subdued when was outgoing
- friendliness: for example, now socially unresponsive
- attentiveness: for example, misses cues or is distracted
- weight: weight loss or weight gain
- abnormal movements



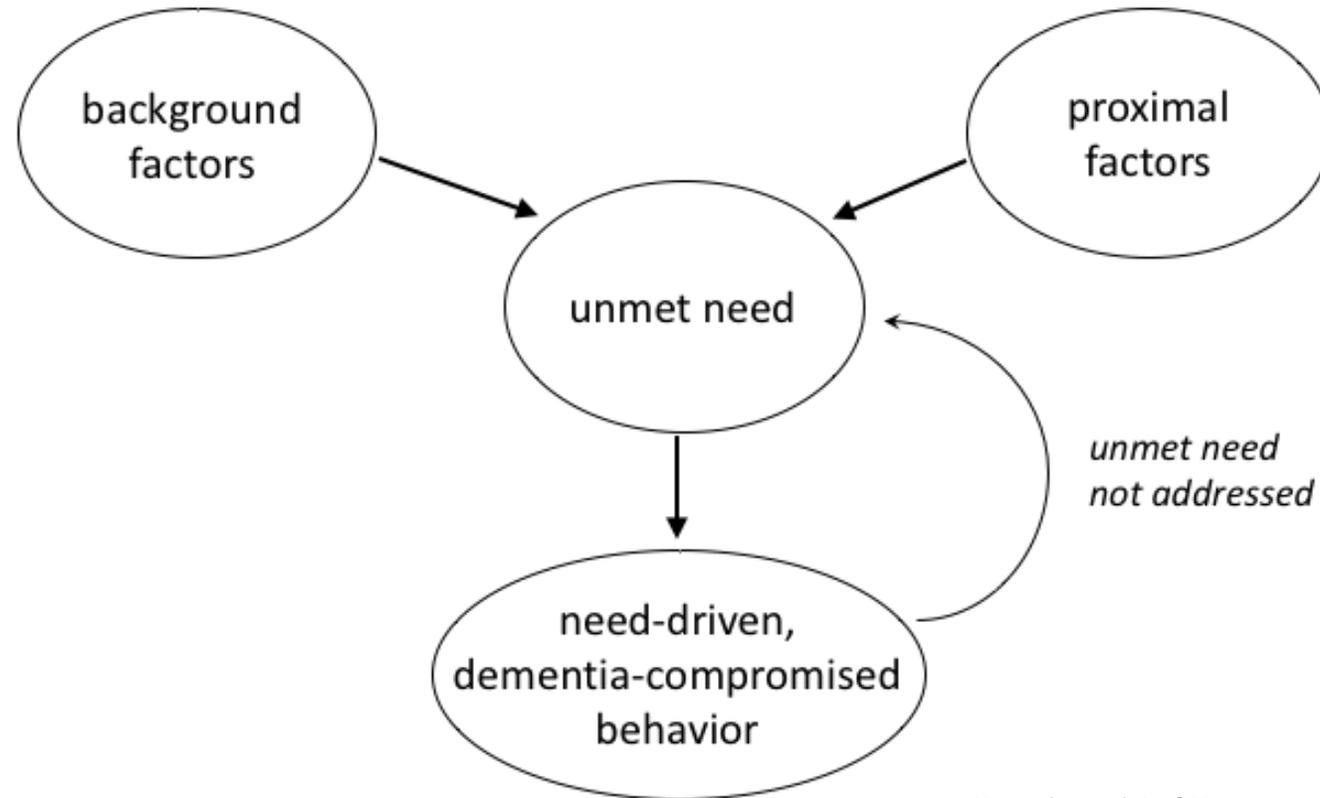
# Why do BPSD arise? (1)

Progressively lowered stress threshold model



# Why do BPSD arise? (2)

## Unmet needs model



Kovach et al *J of Nursing Scholarship* 2005;37:134-140.



# Assessment of BPSD (1)

- for each BPSD:
  - timing: how often? how long does symptom last? how long has it been present?
  - severity: dangerous? distressing? at risk of escalating?
  - antecedents: precipitants? patterns?
  - consequences: how do caregivers respond? what works and doesn't work?
  - history: new behavior? if not new, is it different?
- screen for all BPSD



## Assessment of BPSD (2)

- review medication list & other substances
- consider medical contributions
- screen for abuse
- screen caregivers for depression, e.g., PHQ-2
- use a structured tool such as the NTG-EDSD



# Medications that can worsen cognition or cause BPSD

- anticholinergic medications:
  - antihistamines
  - bladder agents
  - tricyclic antidepressants
- opioid pain medications
- antipsychotics
- benzodiazepines
- antiepileptic drugs

Moran et al., *Mayo Clin Proc* 2013;88(8):831-40



# Medical problems that can worsen cognition or cause BPSD

- sensory deficits: hearing loss\*, vision loss\*
- metabolic disturbances: electrolyte abnormalities, hypo/hyperglycemia, B12 deficiency, hypothyroidism\*
- sleep problems: sleep apnea\*
- other: constipation, urinary retention, pain\*

\* especially common in adults with Down syndrome

Moran et al., *Mayo Clin Proc* 2013;88(8):831-40



# Overview of management

- address medical, environmental & psychosocial problems that may contribute to behaviors, including pain
- discontinue or reduce doses of problematic medications
- consult occupational therapy or physical therapy
- caregiver education & support
- behavioral & environmental interventions
- psychopharmacological interventions
  - use when behavioral & environmental measures have failed, or when behavior poses a threat to patient or others
- most of the studies are in persons with dementia due to AD who do not have I/DD

American Psychiatric Association, *Practice Guideline for the Treatment of Patients With Alzheimer's Disease and Other Dementias*, 2e (2007); Moran et al., *Mayo Clin Proc* 2013;88(8):831-40



# Try non-pharmacological interventions first

Review the clinical response to nonpharmacological interventions prior to nonemergency use of an antipsychotic medication

*The American Psychiatric Association Practice Guideline on the Use of Antipsychotics to Treat Agitation or Psychosis in Patients with Dementia (2016)*



# Environmental & behavioral interventions

- revise care plans to emphasize skill maintenance over skill acquisition
- continue or increase community participation
- standardize daily routines
- decrease demanding situations at home and other settings
- modify the environment to promote safety and support ADLs
- change activities to those suited to maintaining attention and interest
- increase activities such as music, tactile participation (e.g., gardening), exercise, being read to
- sleep hygiene



# Medication options for cognition

- cholinesterase inhibitors
  - donepezil has been studied the most in persons with I/DD and dementia
  - some evidence that donepezil may help slow cognitive decline and might improve quality of life
  - but also associated with side effects: nausea/vomiting, diarrhea, insomnia, fatigue, muscle cramps, loss of appetite, dizziness, syncope, urinary incontinence
- randomized controlled trials have these to be ineffective in persons with I/DD and dementia:
  - memantine
  - vitamin E

Prasher et al., *Degenerative Neurological & Neuromuscular Disease* 2016;6:85-94.



# When to turn to medications for BPSD

Nonemergency antipsychotic medication should only be used for the treatment of agitation or psychosis in patients with dementia when symptoms are severe, are dangerous, and/or cause significant distress to the patient (*emphasis added*)

Before treatment, the potential risks and benefits from antipsychotic medication should be assessed by the clinician and discussed with the patient, surrogate decision maker, or other family member

*The American Psychiatric Association Practice Guideline on the Use of Antipsychotics to Treat Agitation or Psychosis in Patients with Dementia (2016)*



# Medication options for behavioral problems

- almost no studies in persons with I/DD and dementia
- have to extrapolate from either studies of persons with dementia without I/DD or those with I/DD without dementia
- in general, limited benefits with significant potential for side effects
- best evidence base for:
  - atypical antipsychotics: risperidone, olanzapine, and aripiprazole (based on studies of dementia without I/DD)
  - antidepressants: citalopram, sertraline, trazodone (based on studies of dementia without I/DD)
  - antiepileptic drugs (based on studies of I/DD without dementia)
- **all choices are off-label usages and some choices have significant safety concerns; tolerability is lower in persons with I/DD**



# Antipsychotics

- **atypical antipsychotics**
  - risperidone
  - olanzapine
  - aripiprazole
  - quetiapine
- **typical antipsychotics**
  - haloperidol



# Comparative effectiveness review of antipsychotics for BPSD (not I/DD)

Effect in dementia	aripiprazole	olanzapine	quetiapine	risperidone
overall	++	+	+	++
psychosis	+	+/-	+/-	++
agitation	+	++	+/-	++

++ moderate or high evidence of efficacy

+ low or very low evidence of efficacy

+/- mixed results



# Safety concerns with antipsychotics

- death (FDA black box warning)
- weight gain
- Diabetes
- Stroke
- extrapyramidal symptoms
- Sedation
- falls
- cognitive impairment
- persons with I/DD more likely to have side effects



# Guidelines for prescribing antipsychotics

- prescribe only one antipsychotic at a time
- used the lowest effective dose possible
- use higher doses only with caution and with close supervision
- limit use of add-on medications to treat side effects of antipsychotics
- monitor the response to medications: if not effective after 4 weeks, taper off
- decrease/discontinue 4 months after starting; withdraw gradually to prevent recurrence of symptoms

Prasher et al., *Degenerative Neurological & Neuromuscular Disease* 2016;6:85-94; *The American Psychiatric Association Practice Guideline on the Use of Antipsychotics to Treat Agitation or Psychosis in Patients with Dementia* (2016)



# Other medication options to consider

- based on studies of persons with dementia without I/DD:
  - antidepressants
  - benzodiazepines
  - dextromethorphan
  - prazosin
  - acetaminophen
  - other pain control strategies
- based on studies of persons with I/DD without dementia
  - lithium (but likely to be poorly tolerated by older adults)

