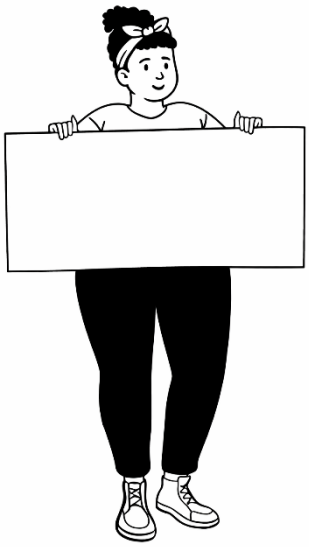
THE OHIO STATE UNIVERSITY
NISONGER CENTER

Detecting Emotional Distress in Adults with Profound Intellectual Disability

Toolkit for caregivers, family members, clinicians, educators, and Direct Support Professionals



Individuals with profound intellectual disability feel emotions.

They can experience mental health conditions,
even if they cannot express this verbally or physically.

They communicate through individualized, subtle cues
in their face, body, sounds, and behaviors.

YOUR DAILY OBSERVATIONS ARE THE MOST IMPORTANT TOOL FOR DETECTING DISTRESS!

Use the following tools to develop a personal profile with individualized communication strategies, and track emotional patterns to detect changes that may indicate distress:

- **Visual Communication Profile:** *This template describes how the individual shows comfort, discomfort, and distress to help team members learn about the person.*
- **Daily or Weekly Observation Checklist:** *This worksheet may be used regularly to collect data, monitor changes over time, and respond to emotional concerns or needs.*
- **Decision-Making Guide:** *This flowchart may be used to ask core questions when concerns or needs are seen in the data and determine how to proceed.*

Walton, K.M., Bacherini, A., Lowery, T., Munir, A., Cobranchi, C., Barnhill, L.J., Havercamp, S.M., and the Nisonger RRTC on Health and Function (2025). Current Methods and Future Prospects in the Detection of Mental Distress in Individuals with Profound Intellectual and Multiple Disabilities. *Journal of Developmental and Physical Disabilities*. https://doi.org/10.1007/s10882-025-10036-6

Visual Communication Profile

Describe How This Person Shows Comfort, Discomfort, and Distress

To be completed by interdisciplinary team members during individualized support plan meetings (e.g., caregivers, family, educators, DSPs, PCPs, clinicians).

1. Person's Baseline Profile

Name: _____

Date: _____

Primary caregiver(s) and/or support team member(s) completing this profile:

2. Communication – Circle or Highlight All That Apply and/or Add Your Own Information

Shows likes & dislikes, or expresses opinions	Uses face and/or body movement for expression	Uses vocalizations and sounds for expression
Does not show likes & dislikes, or does not express opinions	Does not use face and/or body movement for expression	Does not use vocalizations and sounds for expression

Notes:

3. Comfort Cues When Content or Calm – List specific signals, as these vary widely by person:

Facial expressions: (e.g., soft eyes, relaxed mouth)

Body posture & muscle tone: (e.g., loose, leaning toward others)

Vocalizations: (e.g., humming, happy sounds, calm breathing)

Behavioral signs: (e.g., exploring objects, smiling, engaging)

Environmental preferences: (favorite people, places, sensory inputs)

4. Discomfort or Distress Cues – List specific signals, as these vary widely by person:

Facial expressions: (e.g., grimace, frown, startled look, flushed face)

Eyes: (e.g., wide eyes, looking away, rapid blinking)

Jaw/tongue movements: (e.g., grinding, biting, clenched jaw)

Body posture & tone: (e.g., stiff, curled up, shaking, pulling away)

Vocalizations: (e.g., whining, yelling, sudden silence)

Behavioral signs: (e.g., aggression, refusing food, withdrawal, pacing, self-injury)

Known triggers: (people, places, noises, routines, sensory factors, medical issues)

5. Comfort Strategies That Help – List individualized calming supports:

Sensory strategies: (e.g., favorite foods, weighted blanket, dim lights, soft textures)

Social supports: (favorite people, preferred interaction style)

Environmental adjustments: (quiet space, predictable schedule, reduced demands)

Activities that soothe: (interests, hobbies, music, motor movements)

Simple Support Strategies

- Maintain consistent routines
- Reduce sensory overload
- Offer calming sensory input
- Provide predictable transitions
- Increase comforting social interactions
- Offer favorite activities or objects
- Ensure access to familiar caregivers
- Use soft, slow, clear communication
- Be patient and give extra time
- Document what helps

6. Action Plan for Care Team – If these distress cues appear, we should:

Distress Cues	Actions
•	
•	
•	
•	
•	

7. When to Contact Medical/Mental Health Providers – Describe emergency situations or signs to seek help.

8. Who to Contact – List team members (name and relationship) and how to make contact in emergencies.

Person/Provider	Contact Information
•	
•	
•	
•	
•	

Daily/Weekly Observation Checklist – *Track behavior changes that are not typical or out of the norm.*

A. Body and Movement

☐	Increased muscle tension or rigidity	☐	Restlessness or reduced movement
☐	Shaking, trembling, or stiff posture	☐	Protecting a body part (may signal pain)

B. Face and Eyes

☐	Frowning, tightened face/cheeks (grimace)	☐	Tearfulness or widened eyes
☐	Reduced facial expression or "flat" affect	☐	Change in eye contact or gaze avoidance

C. Sounds and Vocalizations

☐	More or less vocalizations (whines, groans, grunts, yelling)	☐	Distressed or unusual sounds
☐	Sudden reduction in vocalizations	☐	Repetitive vocal patterns

D. Behavior and Routine

☐	Changes in sleep (more/less)	☐	New self-injury, aggression, or avoidance
☐	Changes in appetite or eating	☐	Increased startle responses
☐	Withdrawal from enjoyed activities	☐	Regression in skills

E. Social and Environmental Clues

☐	Avoiding certain people or places	☐	Seeking comfort from certain caregivers more than usual
☐	Distress during transitions	☐	Other:

Contact a clinician, mental health provider, or interdisciplinary team member when:

- A new change lasts more than 3 days
- The behavior is severe or escalating
- The person shows signs of pain, trauma triggers, or sudden regression
- Caregivers feel unsure about the cause
- The environment is unsafe or causing distress

Decision-Making Guide

As a team, discuss three core questions to guide your response after detecting emotional concerns or needs.

Core Questions – Before assuming a "disability-related behavior," ask:

1. **Could this be a medical or secondary health issue?**

   ➢ **If yes → seek medical evaluation** ➢ **If no → proceed to next question**

   Look for:
   - Pain (very common)
   - Physical need (e.g., hunger, thirst, needs bathroom, soiled or wet, temperature)
   - Illness, infection, injury
   - Upset stomach, constipation, or other gastrointestinal (GI) issue
   - Seizures or sleep issues
   - Medication changes or side effects

2. **Could this be an environmental issue or a sensory trigger?**

   ➢ **If yes → Functional Behavior Analysis** ➢ **If no → proceed to next question**

   Check for:
   - Loud noises, bright lights, crowds
   - Food sensitivities
   - Feeling dirty, unclean or uncomfortable
   - Unfamiliar caregivers
   - Overstimulation or under stimulation
   - Unpreferred activity or persons
   - Loss or separation from familiar people
   - Unanticipated changes in routine or setting

3. **Could this be emotional or mental distress?**

   ➢ **If yes → seek psychiatric evaluation** ➢ **If no → repeat the questions**

   Examples:
   - Loss of interest in preferred activities
   - Reminders of traumatic events
   - Atypical mood, increased irritability, aggressive behaviors
   - Social isolation
   - Changes in temperament or typical communication style

THE OHIO STATE UNIVERSITY
NISONGER CENTER

THE OHIO STATE UNIVERSITY

NISONGER CENTER

The contents of this paper were developed as part of a Rehabilitation Research and Training Center (RRTC) on Health and Function awarded to The Ohio State University (OSU) Nisonger Center through a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant numbers 90RTHF0006-01-00 and 90RTHF0002-01-00). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this paper do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the Federal Government.

Recommended citation: Detecting Emotional Distress in Adults with Profound Intellectual Disability. (2026). The Ohio State University Nisonger Rehabilitation Research and Training Center on Health and Function.

https://go.osu.edu/RRTC