SHARED LEARNING FORUM

H.E.L.P Framework for Pain and Distress

31-March-2023

PRESENTERS:

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Learning objectives

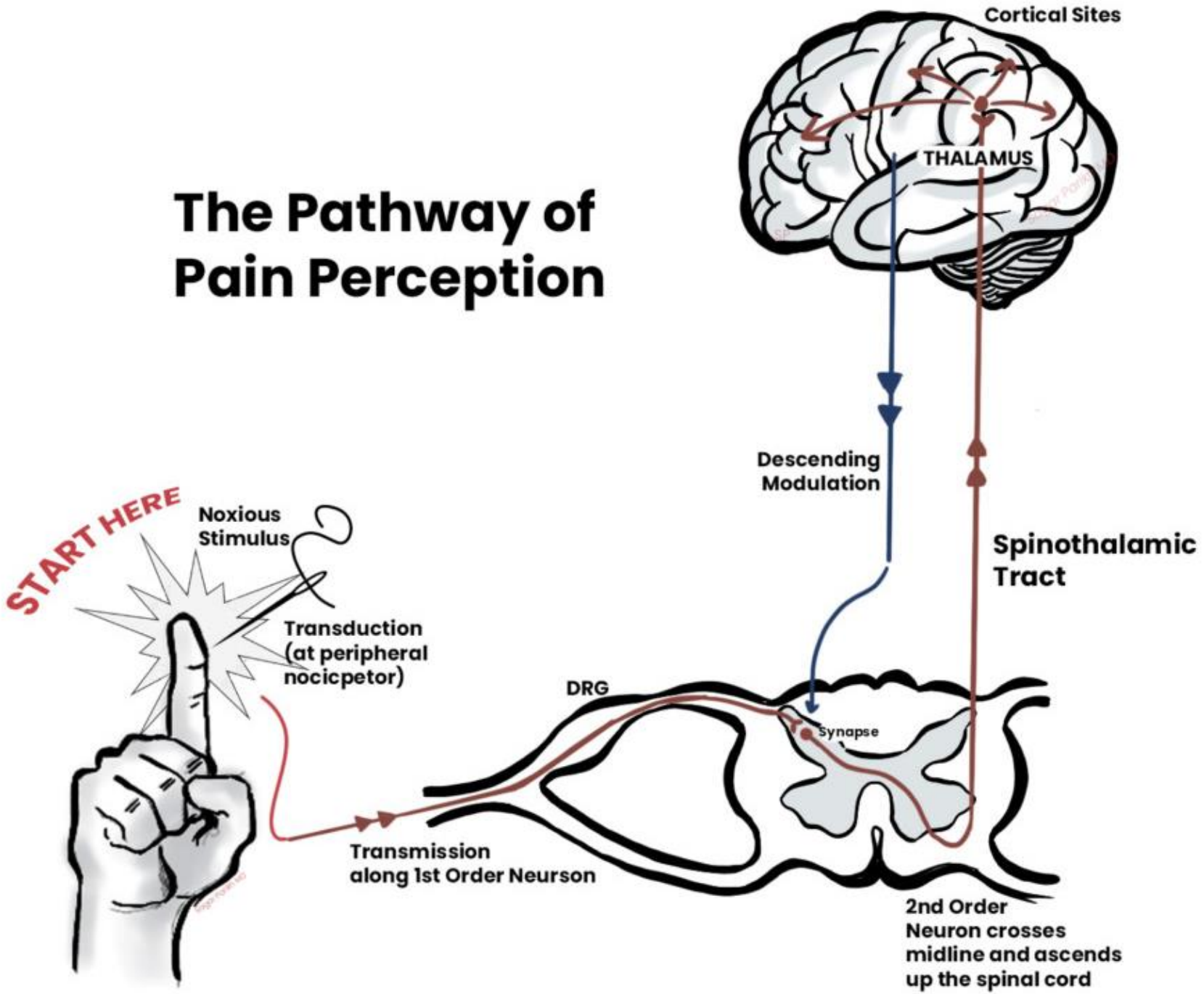
By the end of this session, Participants will be able to:

1. Apply the H.E.L.P framework in an approach for addressing pain and distress.
2. Implement tools and resources to gather information to be able to support health care assessments.
3. Use a case scenario to implement guidelines and tools.

What is pain?

- Pain is the body's warning signal something is wrong.

- Subjective, multi-dimensional and a highly variable individual experience.
  - "…an unpleasant sensory or emotional experience associated with actual or potential tissue damage or described in terms of such damage." *(International Association for the Study of Pain, 2010)*
  - "Pain is whatever the person says it is, exists whenever the person says it does" *McCaffery and Pasero (1979)*
  - "It is not the responsibility of clients to prove they are in pain; it is the clinician's responsibility to accept the clients report of pain" *Canadian & American Pain Society (2005)*


The Pathway of Pain Perception
Cortical Sites
THALAMUS
Descending Modulation
Spinothalamic Tract
START HERE
Noxious Stimulus
Transduction (at peripheral nocicpetor)
DRG
Synapse
Transmission along 1st Order Neurson
2nd Order Neuron crosses midline and ascends up the spinal cord

Types of Pain

- Examples of common types of pain are:
  - Acute pain
  - Chronic pain
  - Neuropathic pain
  - Nociceptive pain

O-P-Q-R-S-T

- **Onset:** The onset of pain can provide important clues to its origin. What was the casualty doing when the pain started? Did the pain come on gradually or suddenly?
- **Provocation:** What makes the pain worse and what relieves it – may be rest, position or medication.
- **Quality:** Ask the casualty to describe the pain in their own words – is it sharp, dull, constant, coming and going?
- **Radiation:** Does the pain spread to any other regions of the body?
- **Severity:** How severe is the pain? Use a verbal pain score to rate the pain. For adults the start point is 0 i.e no pain and end point is 10 –worst pain imaginable.
- **Timing:** How long has the casualty had the pain? Is it getting worse/better/staying the same over time?

https://www.firstaidforfree.com

Pain Context with IDD

- Health problems 2.5 times higher than neurotypical population
- Multiple complex medical problems may co-occur with communication difficulties.
- Health conditions may necessitate painful medical procedures.
- Overcoming communication differences could result in more timely and effective pain treatment.
- Little is known about ‘pain behavior’ in context of IDD.

Health Complexities with IDD

Complexities & Comorbidities

Medical

- Epilepsy
- Vision impairments/ cataracts
- Dental complications and disease
- Hearing loss/ ear infections
- Cardiac disorders (CHD, MVP)
- Respiratory disorders

Psychosocial

- Stress caused by change of routine
- Stress caused by social or situational anxiety
- Change in behaviour caused by pain
- Change in behaviour caused by anxiety

Pain

- Dental
- Constipation
- MSK Spasticity
- Scoliosis

Pain Context with IDD

- "…chronic pain is a significant problem for persons with an ID, with a proportion of service users living with daily pain for many years and experiencing limitations in daily functioning, emotional well-being, and quality of life." *(Walsh et al., 2011)*

- Frequency and severity of self-injury, aggression, and stereotypy highly correlated with the pain scores. *(Courtemanche et al., 2016)*

Trauma-informed Approach

- **Behaviour = Communication**

- Trauma-informed response
  - Active listening
  - Explaining before doing
  - Exploring what makes the Person feel safer
  - Accepting that it takes time to build trust
  - Offering choices
  - Taking time to obtain important info

Principle: Identify Cause

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Pain and Distress

ASSESS FOR PAIN AND ITS INTENSITY

With caregiver input and adapted tools, such as the Chronic Pain Scale for Nonverbal Adults with Intellectual Disabilities[74, 75] or the Non-Communicating Adult Pain Checklist[76, 77], assess for pain and its intensity.

Strongly Recommended

RECOMMENDATION STRENGTH | TYPES OF KNOWLEDGE | BACKGROUND

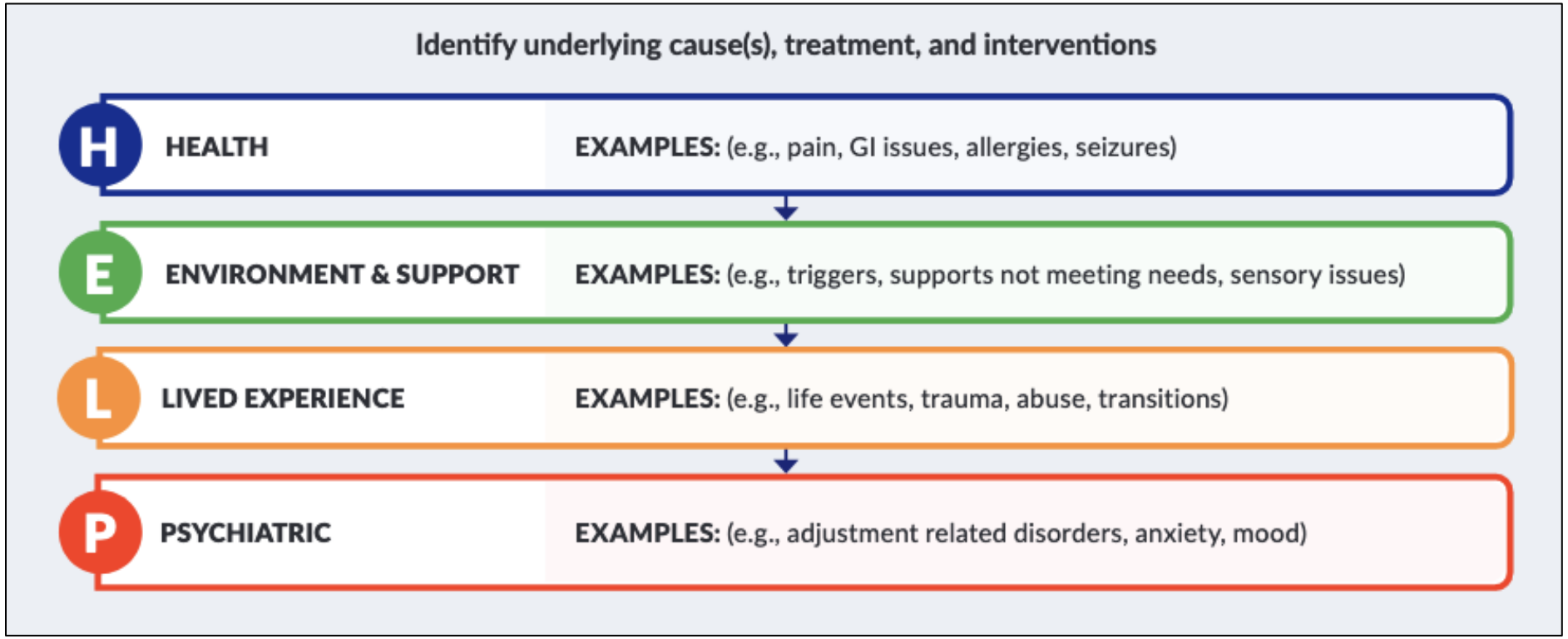
CONSIDER BEHAVIOURS THAT CHALLENGE

Employ a comprehensive and systematic approach to assessing behaviours that challenge that might be communicating pain or other causes of distress (see guideline Behaviours that Challenge).[14, 72, 81, 82]

Strongly Recommended

RECOMMENDATION STRENGTH | TYPES OF KNOWLEDGE | BACKGROUND

H.E.L.P.



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H.E.L.P.

https://ddprimarycare.surreyplace.ca/tools-2/mental-health/guide-to-understanding-behaviour

SURREY PLACE

Developmental Disabilities Primary Care Program

H HEALTH

People with IDD vary in their capacity to communicate to others that they are experiencing physical discomfort or are in pain. Many medical conditions present atypically in people with IDD, for example as a change in behaviour or daily functioning.

- Perform a complete review of systems, physical examination, and necessary investigations to determine whether emotional distress and concerning behaviours might be related to a medical condition or pain.

E ENVIRONMENT AND SUPPORTS

People with IDD are much more dependent on their environments for safety, security, meaning and quality of life. A mismatch between a person's unique developmental needs, supports and services provided or care provider understanding and expectations, can result in behaviours that challenge. Enabling environments to meet unique needs can diminish emotional distress and eliminate concerning behaviours including behaviours that challenge.[2,3]

- Identify and address a person's needs with input from an Occupational Therapist, Speech-Language Pathologist, Behaviour Therapist, ideally working in an interprofessional team.
- Some IDD conditions (e.g., autism) are associated with very specific needs. Consult syndrome-specific Health Watch Tables.[iii]

L LIVED EXPERIENCES

Adversity and traumatic life experiences are common in the lives of people with IDD. These might underpin ongoing emotional distress and remain unrecognized unless specifically identified.[4] Systems interventions (e.g., trauma-informed supports) and individual treatments (e.g., psychological therapies) need to be considered.

- Identify everyday stressors and investigate a person's lived experiences.
- Seek input from a social worker or similarly trained professional experienced in trauma and the IDD population.

P PSYCHIATRIC DISORDERS

A review of physical health, environments and life events, and implementation of needed interventions will diminish emotional and behavioural concerns, unless these are associated with psychiatric disorder.

- Assess remaining emotional and behavioural concerns and determine any change from baseline.
- If these changes from baseline suggest a psychiatric disorder, a diagnosis-specifc intervention (e.g., medication, psychological therapies) might be tried.
- If still concerned, make a referral to a developmental disability specialty service or use.
- Using the HELP approach, consider whether previous psychiatric diagnoses are still valid and treatments are appropriate.[2,3]

HEALTH - REVIEW POSSIBLE MEDICAL AND MEDICATION-RELATED CONDITIONS

Pain, injury or discomfort

PRACTICE TIP:
If the patient is unable to self-report, involve someone who knows the person well.

PRACTICE TOOL:
Pain Assessment of Adults with IDD[i], including CPS-NAID[9] for physical pain, and DisDAT[10] for physical, emotional, and psychological distress.

Ways the patient expressed distress in the past in response to painful injuries or painful procedures

- ☐ Verbally
- ☐ Points to place on body
- ☐ Non-specific behaviour disturbance:

Other:

Could pain, injury or discomfort (e.g., fracture, tooth abscess, constipation) be contributing to the behaviour change(s)?

- ☐ Yes
- ☐ No
- ☐ Possibly

Explain:

Completed pain assessments

Results:

DEVELOPED BY: Surrey Place Developmental Disabilities Primary Care Program

PAGE 2 of 8

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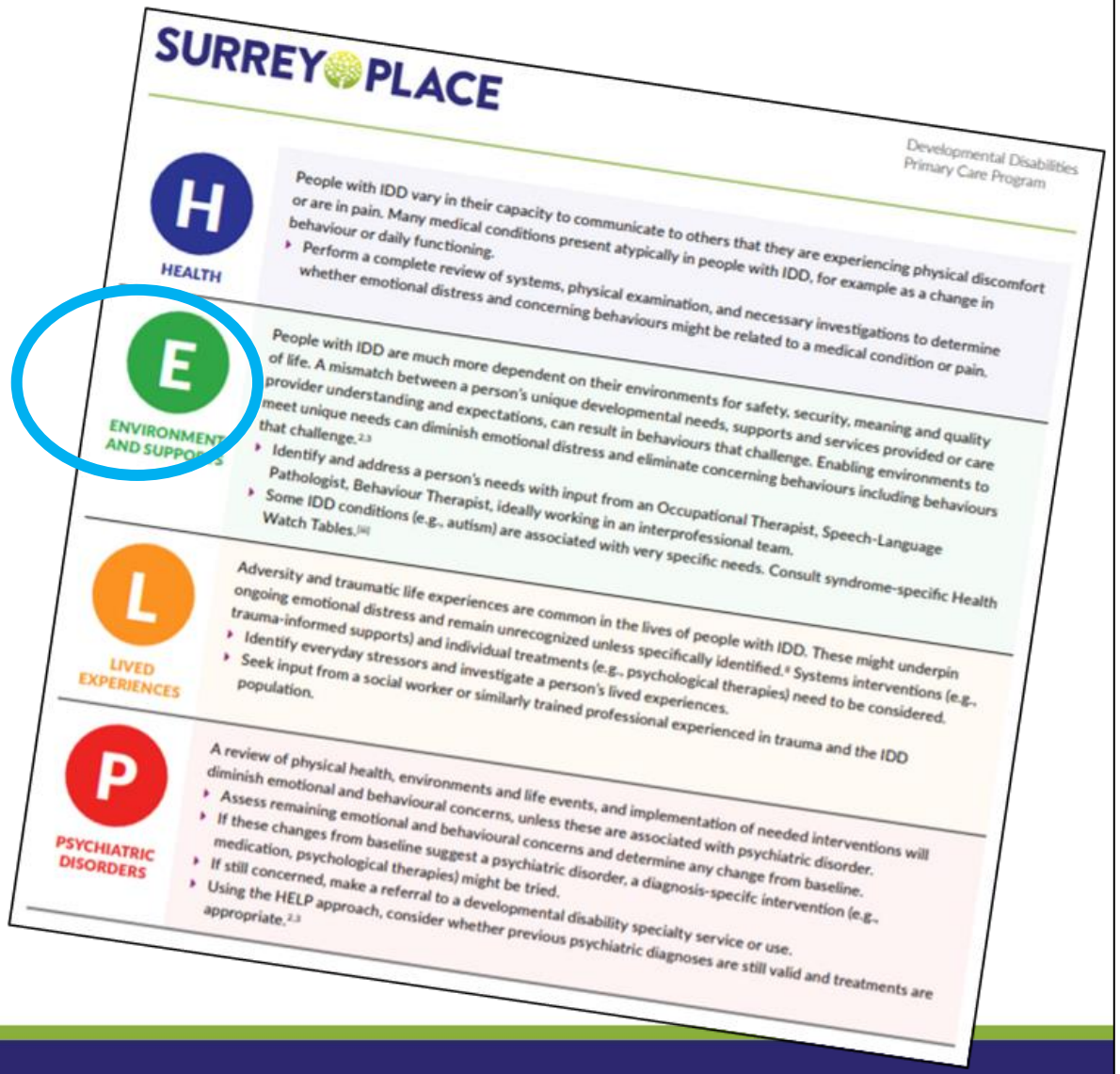

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Sensory impairments and communication needs

☐ Hearing impairments ☐ Vision impairments ☐ Communication difficulties	Accommodations and communication strategies:

Syndrome-specific needs

☐ Autism diagnosis ☐ Other diagnosed syndrome with a recognized biological basis:	Syndrome specific support needs:

Hypersensitivities

☐ Not observed ☐ Auditory (e.g., covers ears, dislikes thunderstorms) ☐ Visual (e.g., dislikes dark and bright lights) ☐ Other (e.g., tactile, olfactory, tase)	Accommodations:

H.E.L.P.

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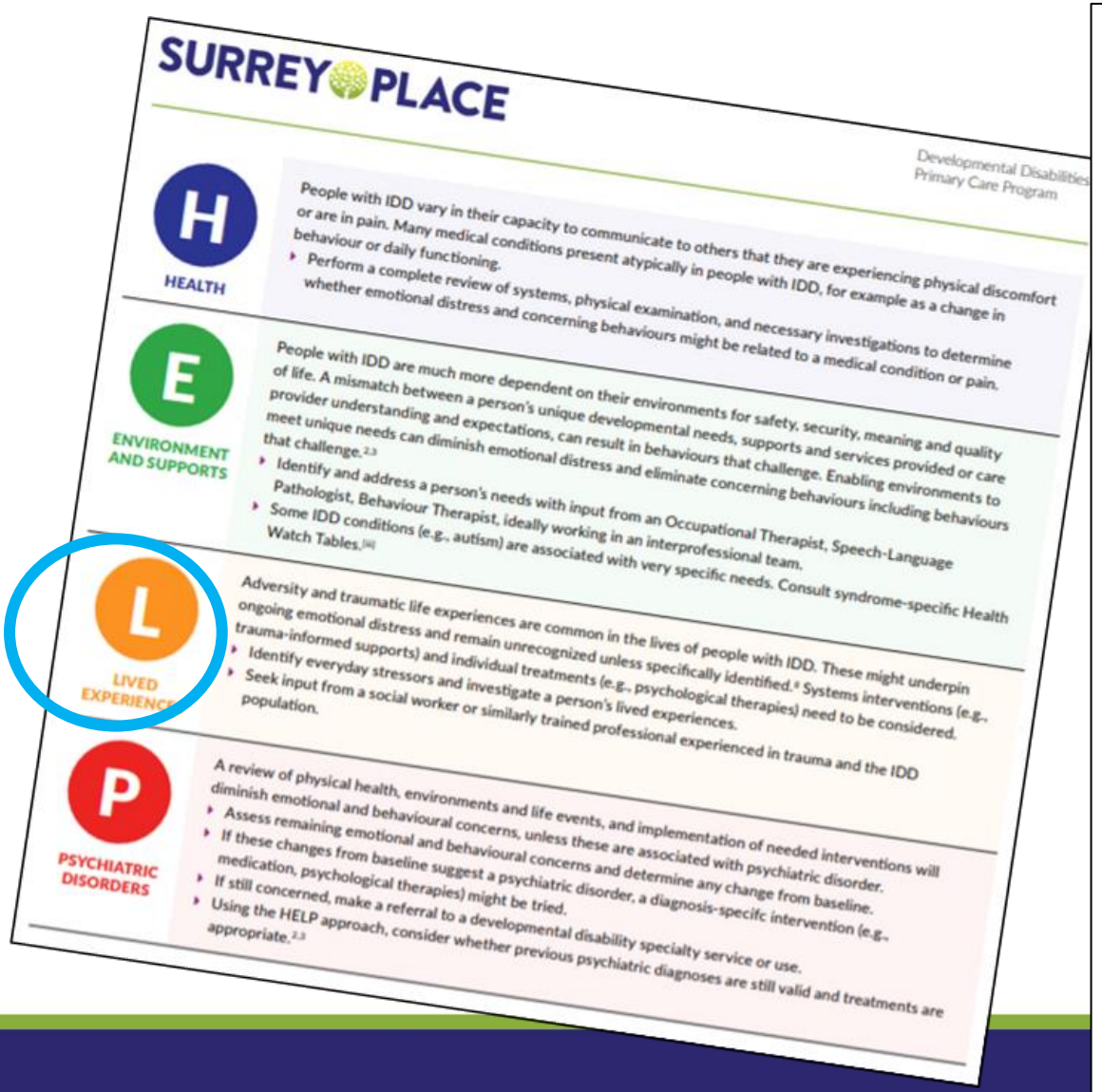

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LIVED EXPERIENCE - REVIEW LIFE EVENTS, TRAUMA, AND EMOTIONAL ISSUES

PRACTICE TIP:
Review with the patient and caregiver(s) familiar with the patient's past and present lived experience. Identify possible present or past causes of emotional distress. Seek input from a social worker or other professional experienced in trauma and IDD.

PRACTICE TOOL:
SHARE Transition Plan[vii]

Stresses from changes in

- ☐ Physical environment (e.g., home and work environments, such as relocation, renovations):
- ☐ Daily routines (e.g., change in programs, travel arrangements, mealtimes, staff shortages):
- ☐ Transition (e.g., change of seasons, youth to adulthood, or adult to retirement or end-of-life):
- ☐ Other:

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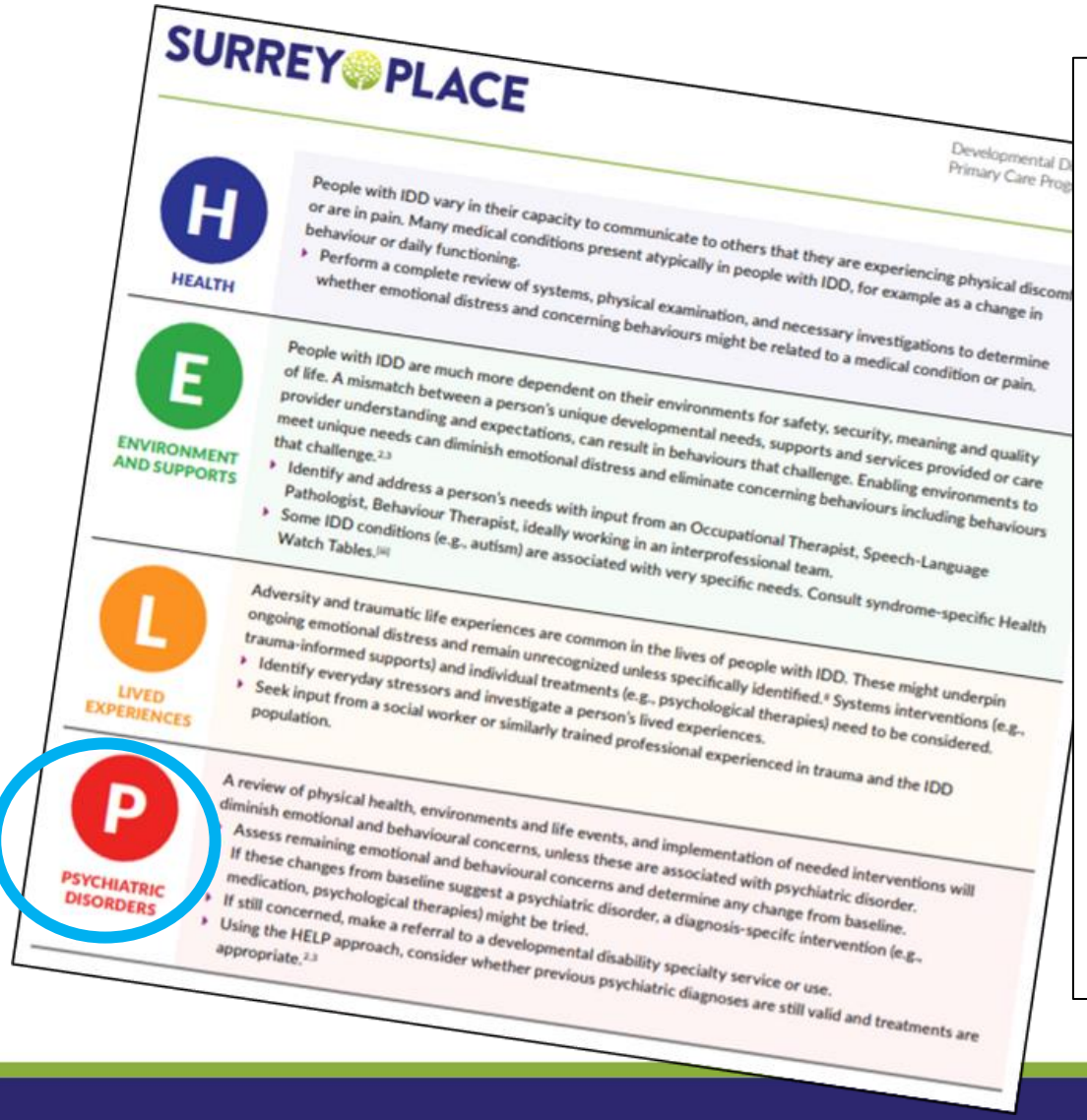

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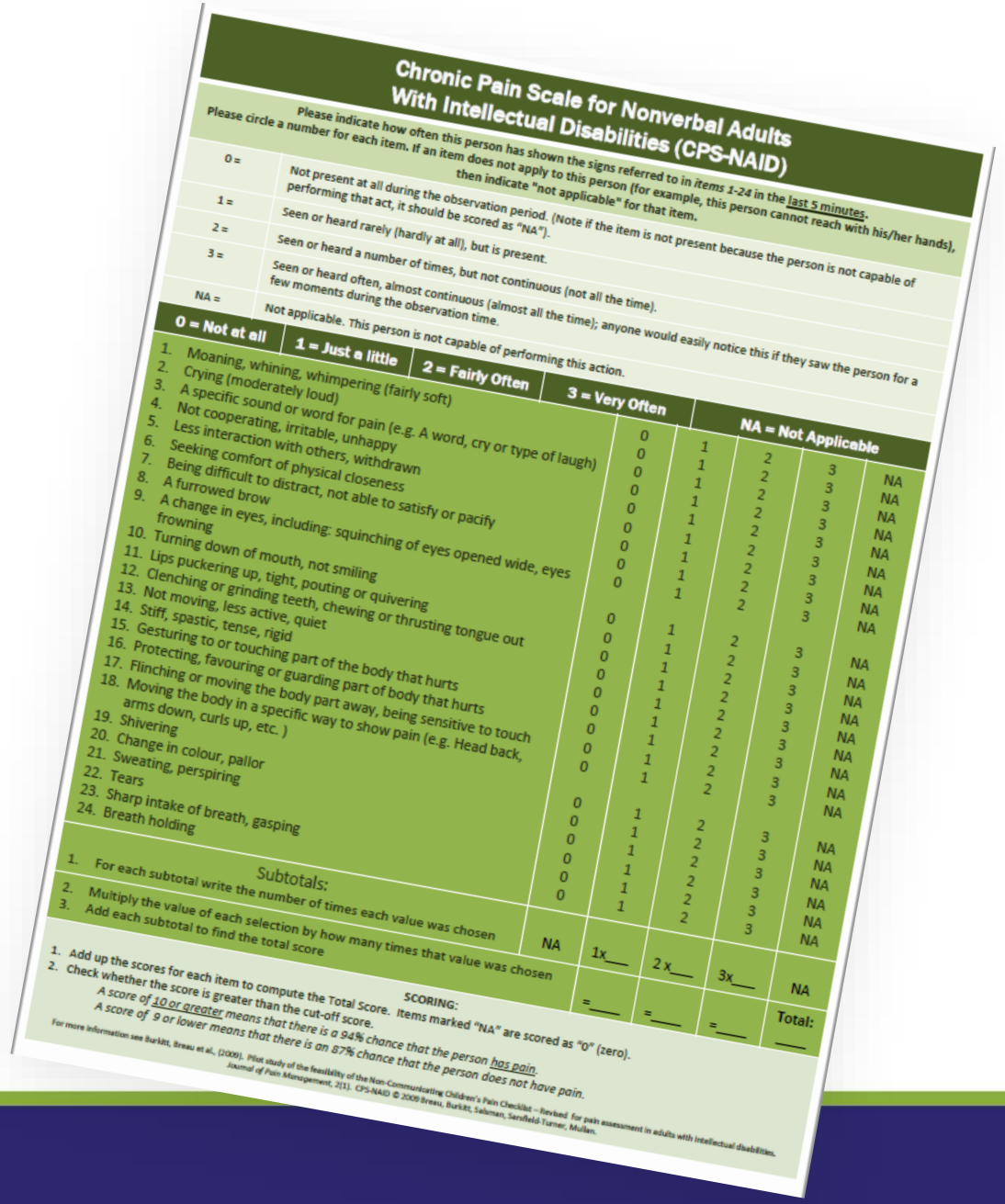
Previous hospital admission(s) for a psychiatric reason ☐ Yes ☐ No **Date:**

Describe

Recent deterioration or changes in **Date:**

- ☐ Functioning (e.g., Activities of Daily Living):
- ☐ Health problems or concerns (e.g., seizures, continence):
- ☐ Movement or mobility (e.g., slow, agitated, coordination):
- ☐ Cognition (e.g., attention, thinking, memory):
- ☐ Communication:
- ☐ Behaviour:
- ☐ Stamina:
- ☐ Sleep:

Pain Scales



Chronic Pain Scale for Nonverbal Adults With Intellectual Disabilities (CPS-NAID)

Please indicate how often this person has shown the signs referred to in *items 1-24* in the last 5 minutes. Please circle a number for each item. If an item does not apply to this person (for example, this person cannot reach with his/her hands), then indicate "not applicable" for that item.

0 = Not present at all during the observation period. (Note if the item is not present because the person is not capable of performing that act, it should be scored as "NA").
1 = Seen or heard rarely (hardly at all), but is present.
2 = Seen or heard a number of times, but not continuous (not all the time).
3 = Seen or heard often, almost continuous (almost all the time); anyone would easily notice this if they saw the person for a few moments during the observation time.
NA = Not applicable. This person is not capable of performing this action.

	0 = Not at all	1 = Just a little	2 = Fairly Often	3 = Very Often	NA = Not Applicable
1.	0	1	2	3	NA
2.	0	1	2	3	NA
3.	0	1	2	3	NA
4.	0	1	2	3	NA
5.	0	1	2	3	NA
6.	0	1	2	3	NA
7.	0	1	2	3	NA
8.	0	1	2	3	NA
9.	0	1	2	3	NA
10.	0	1	2	3	NA
11.	0	1	2	3	NA
12.	0	1	2	3	NA
13.	0	1	2	3	NA
14.	0	1	2	3	NA
15.	0	1	2	3	NA
16.	0	1	2	3	NA
17.	0	1	2	3	NA
18.	0	1	2	3	NA
19.	0	1	2	3	NA
20.	0	1	2	3	NA
21.	0	1	2	3	NA
22.	0	1	2	3	NA
23.	0	1	2	3	NA
24.	0	1	2	3	NA
Subtotals:					
1. For each subtotal write the number of times each value was chosen					
2. Multiply the value of each selection by how many times that value was chosen	NA	1x___	2 x___	3x___	NA
3. Add each subtotal to find the total score		=___	=___	=___	Total: ___

SCORING: Items marked "NA" are scored as "0" (zero).

1. Add up the scores for each item to compute the Total Score.
2. Check whether the score is greater than the cut-off score.
   A score of 10 or greater means that there is a 94% chance that the person *has pain*.
   A score of 9 or lower means that there is an 87% chance that the person does not have pain.

For more information see Burkitt, Breau et al., (2008). Pilot study of the feasibility of the Non-Communicating Children's Pain Checklist – Revised for pain assessment in adults with intellectual disabilities. *Journal of Pain Management*, 2(1). CPS-NAID © 2009 Breau, Burkitt, Saloman, Sandfeld-Turner, Mullen.

Non-Communicating Adult Pain Checklist*

Item	Score			
Vocal Reaction	Not at all	Just a little	Fairly Often	Very Often
Moaning, whining, whimpering (fairly soft)	0	1	2	3
Crying (moderately loud)	0	1	2	3
Screaming or yelling (very loud)	0	1	2	3
Emotional Reaction				
Not cooperating, cranky, irritable, unhappy	0	1	2	3
Agitated, being difficult to distract, not able to satisfy or pacify	0	1	2	3
Facial Expression				
Furrowed eyebrows, raising eyebrows	0	1	2	3
A change in eyes including (squinting of eyes, eyes opened wide, eye frowning)	0	1	2	3
Turning down of mouth, not smiling	0	1	2	3
Movements of the lips and tongue (lips puckering up, tight, pouting, quivering, teeth grinding, tongue pushing)	0	1	2	3
Body Language				
Moving more or less	0	1	2	3
Stiff spastic, tense, rigid	0	1	2	3
Protective Reaction				
Gesturing to or touching part of the body that hurts	0	1	2	3
Protecting, defending, or guarding part of the body that hurts	0	1	2	3
Flinching or moving the body part away, being sensitive to touch	0	1	2	3
Moving the body in a specific way to show pain (head back, arms down, curls up)	0	1	2	3
Physiological Reaction				
Change in facial color	0	1	2	3
Respiratory irregular responses (breath holding or gasping)	0	1	2	3
TOTAL (0-51) Greater score means greater pain				

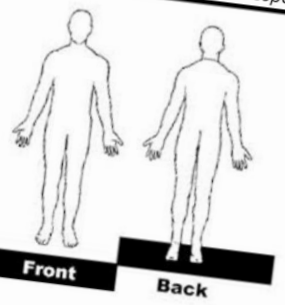
Pain Scales

Pain Assessment Visual Tool for _____ (Name of

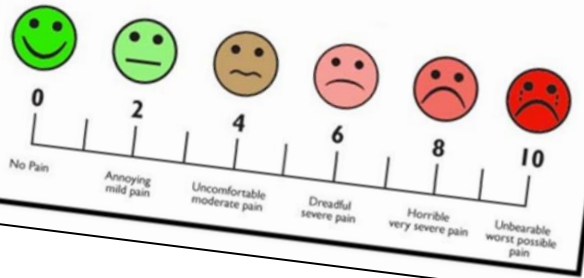
*Please show this visual to the person/client once or more if needed, during the shift:

- Ask the person to point to the face or number that shows how bad pain is.
- Document the date and time you asked, and describe the response in the Table be

"Where does it hurt?"



"How bad does it hurt?"



Distress and Discomfort Assessment Tool

DisDAT

v22

Please take some time to think about and observe the individual under your care, especially their appearar and behaviours when they are both content and distressed. Use these pages to document these.

We have listed words in each section to help you to describe the signs and behaviours. You can circle the or words that best describe the signs and behaviours when they are content and when they are distressed.

Your descriptions will provide you with a clearer picture of their 'language' of distress.

COMMUNICATION LEVEL * (Ring their level when well	unv
This individual is unable to show likes or dislikes	Level 0
This individual is able to show that they like or don't like something	Level 1
This individual is able to show that they want more, or have had enough of something	Level 2
This individual is able to show anticipation for their like or dislike of something	Level 3
This individual is able to communicate detail, qualify, specify and/or indicate opinions	Level 4

* This is adapted from the Kidderminster Curriculum for Children and Adults with Profound Multiple Learning Difficulty (Jones, 1994, National Portage Association).

FACIAL SIGNS

Appearance		
What to do	Appearance when content	Appearance when distressed
(Ring) the words that best fit the facial appearance. Add your words if you want.	Passive Laugh Smile Frown Grimace Startled In your own words:	Passive Laugh Smile Frow Grimace Startled In your own words:

Jaw or tongue movement		
What to do	Movement when content	Movement when distressed
(Ring) the words that best fit the jaw or tongue movement. Add your words if you want.	Relaxed Drooping Grinding Biting Rigid Shaking In your own words:	Relaxed Drooping Grin Biting Rigid Sh In your own words:

Appearance of eyes		
What to do	Appearance when content	Appearance when distressed
(Ring) the words that best fit the appearance of the eyes. Add your words if you want.	Good eye contact Little eye contact Avoiding eye contact Closed eyes Staring Sleepy eyes 'Smiling' Winking Vacant Tears Dilated pupils In your own words:	Good eye contact Little eye Avoiding eye contact Closed Staring Sleepy eyes 'Smiling' Winking Tears Dilated pupils In your own words:

BODY OBSERVATIONS: SKIN APPEARANCE		
What to do	Appearance when content	Appearance when distres
(Ring) the words that best fit the describe the appearance of the skin. Add your words if you want.	Normal Pale Flushed Sweaty Clammy In your own words:	Normal Pale Sweaty Clammy In your own words:

Edmonton Symptom Assessment System: (revised version) (ESAS-R)

Please circle the number that best describes how you feel NOW:

No Pain	0 1 2 3 4 5 6 7 8 9 10	Worst Possible Pain
No Tiredness (Tiredness = lack of energy)	0 1 2 3 4 5 6 7 8 9 10	Worst Possible Tiredness
No Drowsiness (Drowsiness = feeling sleepy)	0 1 2 3 4 5 6 7 8 9 10	Worst Possible Drowsiness
No Nausea	0 1 2 3 4 5 6 7 8 9 10	Worst Possible Nausea
No Lack of Appetite	0 1 2 3 4 5 6 7 8 9 10	Worst Possible Lack of Appetite
No Shortness of Breath	0 1 2 3 4 5 6 7 8 9 10	Worst Possible Shortness of Breath
No Depression (Depression = feeling sad)	0 1 2 3 4 5 6 7 8 9 10	Worst Possible Depression
No Anxiety (Anxiety = feeling nervous)	0 1 2 3 4 5 6 7 8 9 10	Worst Possible Anxiety
Best Wellbeing (Wellbeing = how you feel overall)	0 1 2 3 4 5 6 7 8 9 10	Worst Possible Wellbeing
No _____ Other Problem (for example constipation)	0 1 2 3 4 5 6 7 8 9 10	Worst Possible _____

Patient's Name _____

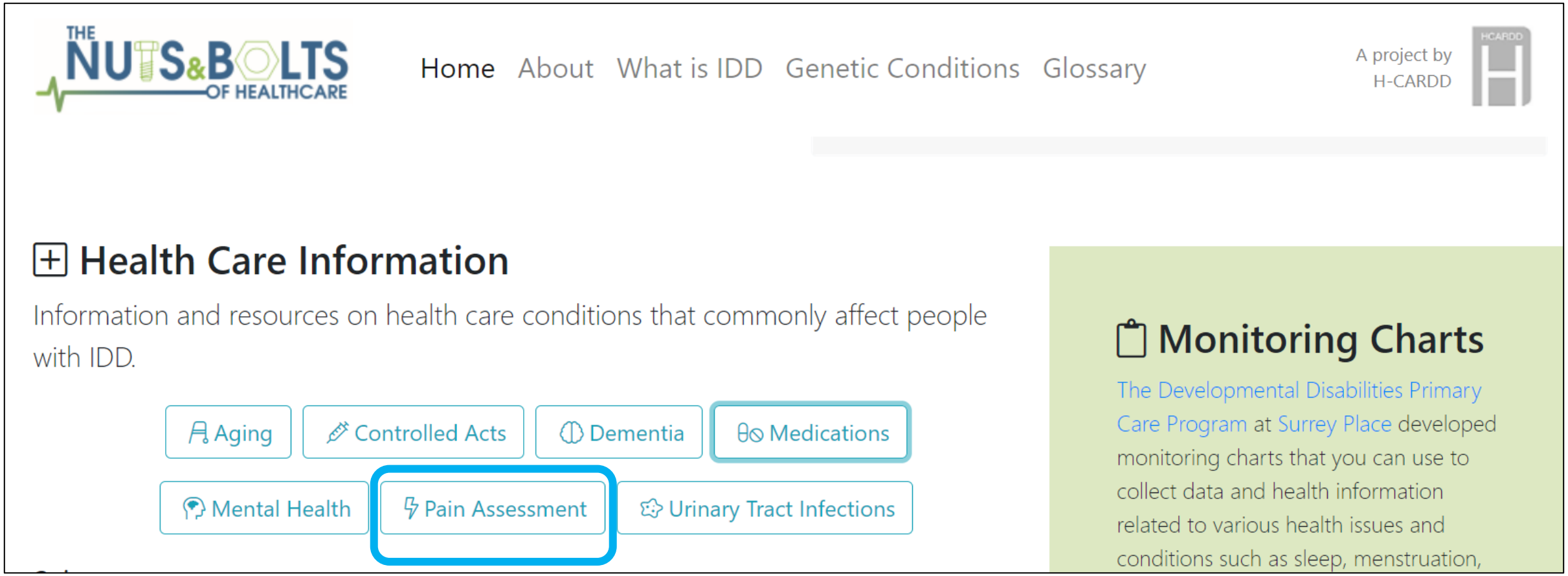
Date _____ Time _____

Completed by (check one):
- ☐ Patient
- ☐ Family caregiver
- ☐ Health care professional caregiver
- ☐ Caregiver-assisted

ESAS-r
Revised: November 2010

BODY DIAGRAM ON REVERSE SIDE

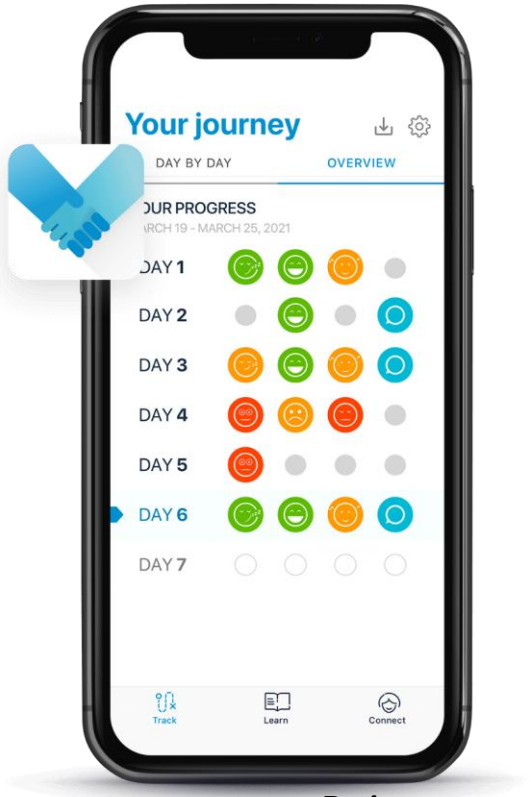
Support Health Care Collaboration



https://nutsandbolts.ddtoolkits.com

New / Future Tools

- Technological developments could offer new ways to understand/report pain, e.g.,
  - Smartphone Apps for caregivers based on unique acoustic characteristics of pain-related vocal responses
  - ‘Smart’ wearable shirts that enable continuous surveillance of vital physiological signs

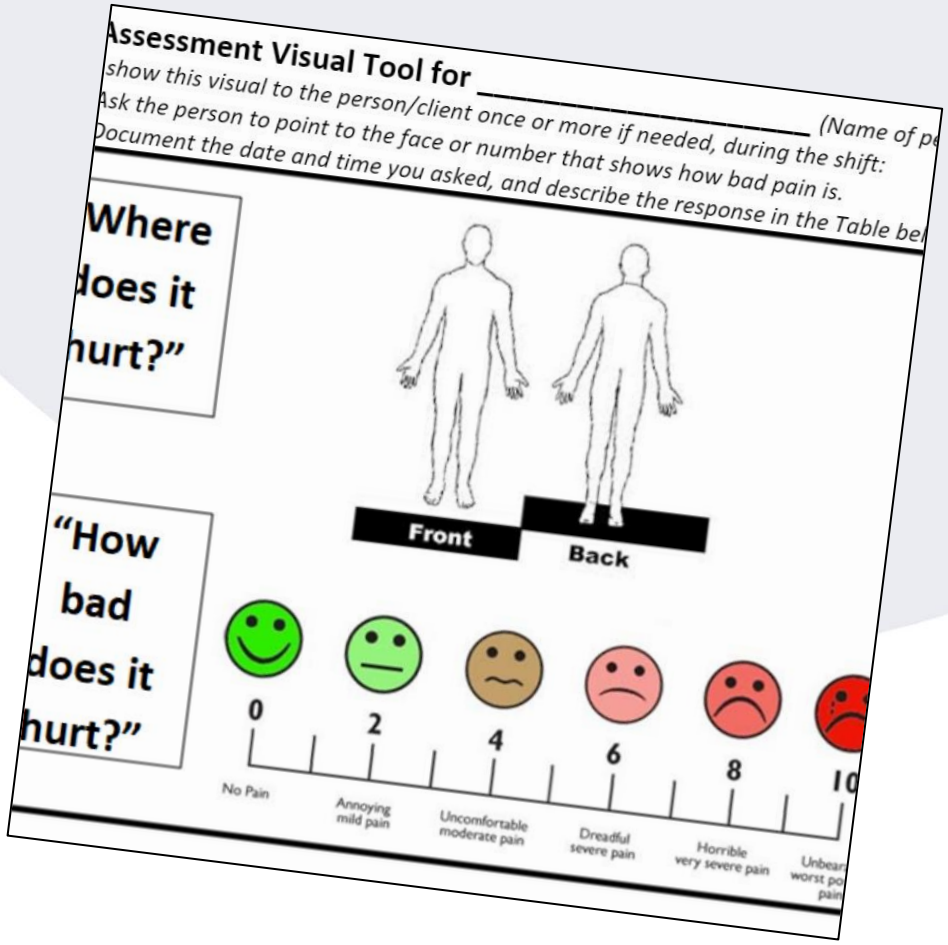


Pain.com

Why Collect Pain Data?

Communication

- Data collection and summary should be discussed with the person/SDMs, circle of support team and health care providers
- Crucial info to inform care plan/treatment



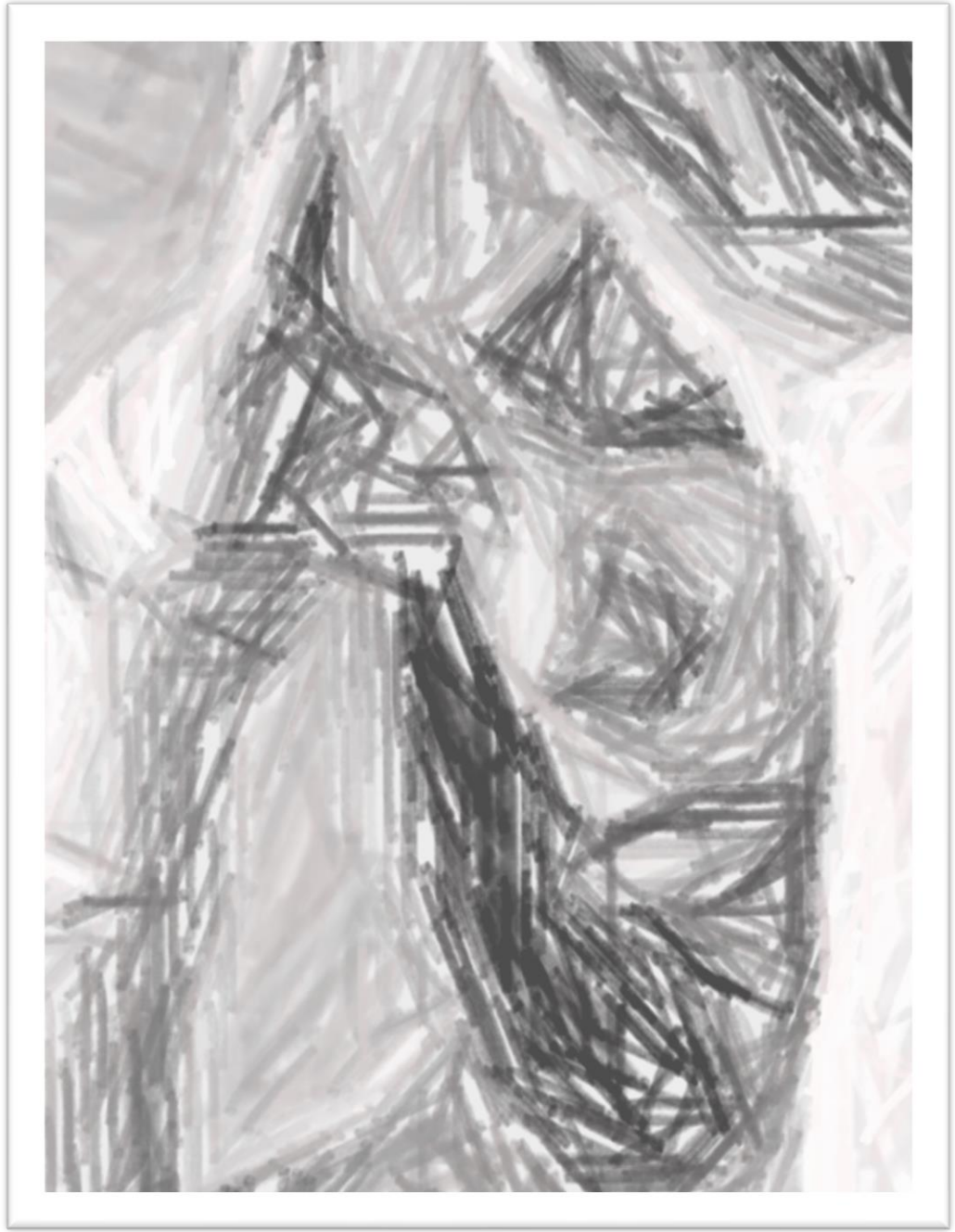
Examples of Types of Pain Medications

- Over-The-Counter pain relievers, (e.g., Tylenol, Advil, Voltaren)
- Opioids, (e.g., OxyContin, oxymorphone, Percocet)
- Corticosteroids, (e.g., prednisone)
- Antidepressants, (e.g., duloxetine, fluoxetine)
- Anticonvulsants, (e.g., gabapentin)
- Cannabidiol (CBD)

Non-pharmacological Examples

- Cold and heat
- Physical therapy
- Therapeutic massage
- Music

Case Presentation



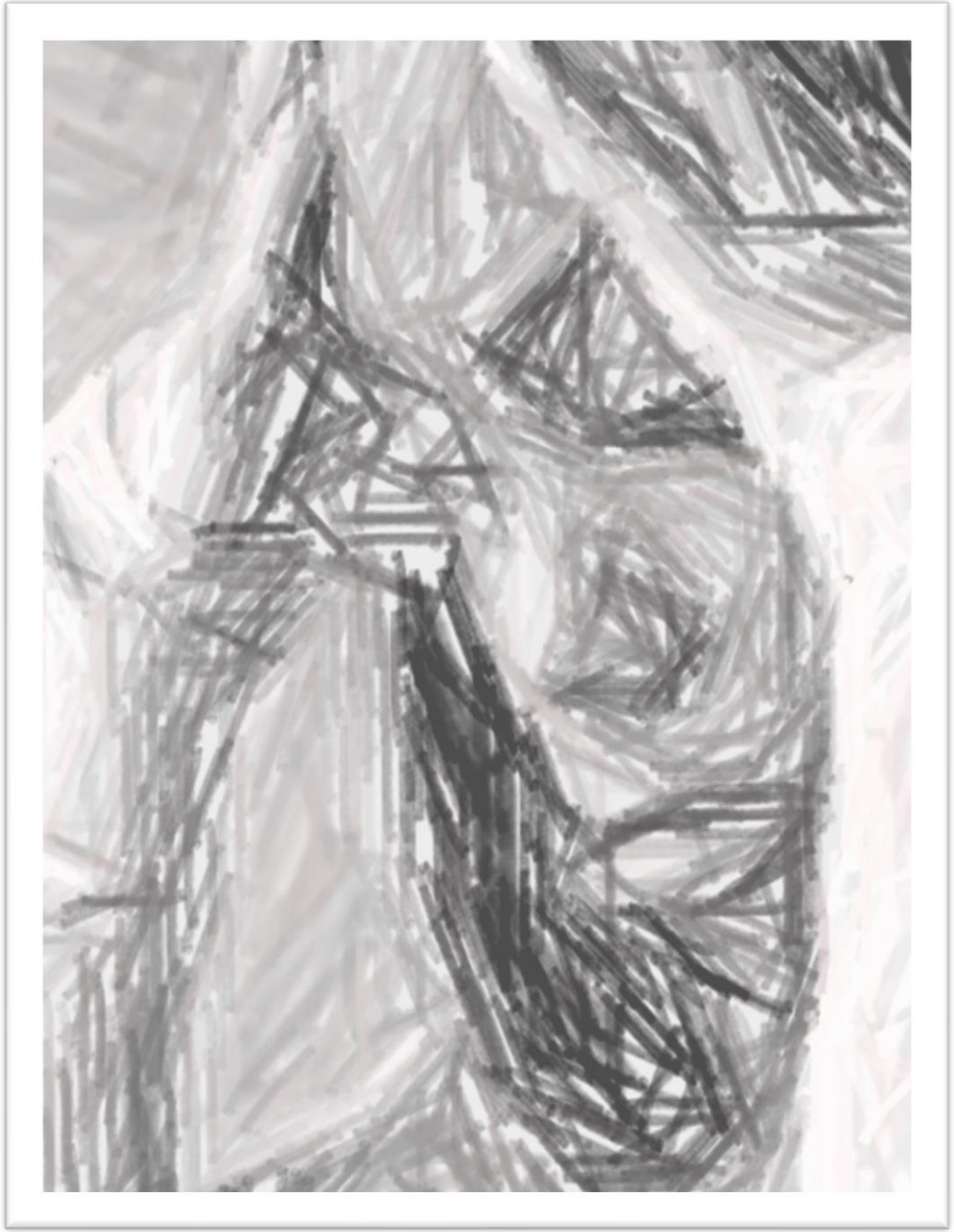
Reflection - Aatifa

- 43-year-old woman who is usually very affectionate, loves music, nature and lives in a supported-living urban setting.
- Her mother visits often and assists in supported decision making.
- Diagnoses: IDD of unknown cause in moderate range, diabetes type 2, GERD/reflux, arthritis, osteoporosis and schizophrenia.
- During the pandemic she was unable to access sleep dentistry.
- Medications: olanzapine, quetiapine, clonazepam, metformin, pantoprazole.
- She has increasing episodes of agitation and outbursts, with decreasing appetite and declining to return to day program activities.

Case Presentation

Clarifying Questions?

Support Strategies?



Q&A

Key Messages

- Integrate H.E.L.P.
- Pain assessment and monitoring tools are important.
- Specific resources could be helpful.
- Collaborative communication with circle of support including health care providers is important.

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Thank You

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