

## CARING FOR CHILDREN WITH INTELLECTUAL DISABILITIES PART 2

Table 1

*Coding scheme for participants' factors considered when making pain assessment decisions.*

Variables	Description	Examples
Pain Behavior/ Expression/ Response	Behavior or response of the child is mentioned. This behavior or response may be more general or specifically related to physical movement of one's body, behavioral responses (e.g., physically withdrawing), or a verbal/vocal response (does not need to be use of words). The participant may have mentioned that they considered a behavior that was present OR absent from the scenario.	→ Holding arm → No screaming
Pain History/ Knowledge	Response mentions consideration of previous pain history/experience with pain/pain behaviors (may or may not be from the vignette).	→ History of pain → Knowing the child has headaches
General History/ Knowledge	Response mentions general knowledge/history of the child (may or may not be from the vignette). These would not explicitly be related to pain history/knowledge but rather to the child's likes/dislikes, temperament, etc.	→ Child's age → Knowing that the child is nonverbal
History/ Knowledge (Type Unclear)	Response mentions reference to the history/knowledge in general, however the specific aspect of the child's history that is being referred to is unclear (i.e., could not decipher from pain history vs. general history).	→ History → How often does this happen
Environmental/ Situational Context	Response includes explicit mention of an environmental or external factor (e.g., something related to the direct surroundings of the scenario) which may have contributed to their ratings of the child's pain intensity. These factors would all involve aspects of the	→ Contextual cues → Setting

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situation beyond the child's immediate response to and experience of a painful event, but may have contributed to increased distress overall.

Consideration of other (alternate) explanations for behavior	In considering pain intensity, individual considered additional/alternate explanations for behavior in the vignette aside from the suggested pain source given in the vignette. In other words, these explanations could take the place of an argument for pain experience of the child (e.g., maybe the child didn't want to go to bed).	→ The child does not have a headache - they may actually have a stomach-ache → The child may be anxious
Consideration of specific pain source and/or the severity of this (specific to vignette)	Response mentions a specific pain source (e.g., the child fell) or the level of severity associated with an injury/physical damage (e.g., there was no bruising) that is specific to an individual vignette. Any of these responses would need to be related to the pain source from the vignette, but may or may not be in explicit reference to the child in the vignette itself.	→ A shot is painful → Severity of fall
Unrelated/ Unclear	Response is either unclear as to the meaning or unrelated to factors one would consider when determining intensity of pain a child is experiencing. Cannot effectively code into another given category without adding additional interpretation of the response.	→ Witnessing event/witnessing the act → Pattern changed

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Table 2

*Coding scheme for the types of actions the participants would take for the child in each vignette.*

Type of Action	Definition	Examples
Assessment:		
<ul style="list-style-type: none"> <li>General</li> </ul>	<p>Suggestion of further assessment/observation of the situation (e.g., external factors) or the child (e.g., behavioral response, physical examination). Note that this would involve passive action and only observation - no explicit mention of asking the child about their pain should be made.</p>	<p>→ Assess level of pain → Determine the cause</p>
<ul style="list-style-type: none"> <li>Asking Child/ Self-Report</li> </ul>	<p>Specific mention of referring to the child to learn more through asking questions, otherwise communicating with child</p>	<p>→ Ask questions to find out what hurts → Ask where it hurts</p>
<ul style="list-style-type: none"> <li>Asking Others</li> </ul>	<p>Suggests the need to refer to a second party who may or may not have been present (e.g., parents/guardians, doctors, etc.) to get another opinion or suggestion about action to take.</p>	<p>→ Call parents to ask their opinion</p>
Pain and Distress Management:		
<ul style="list-style-type: none"> <li>Pharmacological</li> </ul>	<p>Suggestion of using a form of medication (over the counter or prescribed) to help manage pain the child may be experiencing. Also include suggestions of investigating whether pharmacological pain management protocols exist for the child.</p>	<p>→ Give medicine they usually take → See if there is a medication protocol</p>
<ul style="list-style-type: none"> <li>Physical</li> </ul>	<p>Suggestion of using a pain management strategy</p>	<p>→ Physical</p>

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	that involves physical touch or application of something (non-pharmacological)	comfort → Ice
• Psychological	Suggestion of using a pain management strategy that is psychological in nature (i.e., a strategy that might target the child's thoughts/cognitions about the event, emotional response etc.) involving strategies using language, physical presence (but not physical touch), distraction, breathing, etc. This might include the use of objects (e.g., therapeutic toy as a distraction). If reference is made to physical contact the strategy would NOT fall under this category.	→ Distraction → Sit with child
• Modification of Setting/ Environmental Factors	Explicitly states active physical modification of the setting or situation in order to address the issue (may not be explicitly related to pain management)	→ Find a quiet area → Take breaks when doing activities
• Other – Management Strategy Unclear	Suggestion of use of a specific management strategy is clear, however the type of strategy used is unclear (e.g., cannot decipher whether strategy would involve physical or psychological strategies; the strategy appears to involve more general behavior management rather than what might help decrease the pain intensity)	→ Try to get rid of the pain → Give comfort
Reporting - Inform Caregiver of the Event	Suggest the need to inform another individual about what has occurred either verbally or through some form of incident report. Individuals being informed of the situation could include parents/guardians, supervisors, etc.	→ Tell parents → Complete incident report
Consulting Resources	Suggests reviewing protocols or care plans of the	→ Review child's

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child (e.g., to determine next steps, see if this is something that usually occurs, etc.). This is different from Assessment – Asking Others because while the participants are still seeking information about an action they might take next, they are not directly speaking to a caregiver or another person. Instead they are reviewing protocols/information sheets etc. Note that this does not include pharmacological aspects such as checking to see if there is medicine available for the child. This category only accounts for non-pharmacological incidences.

care plan  
→ Review child history

No Action/Do Nothing

Participant indicates that they would do nothing or not take any action

→ No action needed

Unclear/Unrelated

Description of action that is too vague to place in another category; the exact purpose of the type of action may not be clear (e.g., this could involve reporting, management, etc. but this is unclear)

→ Once you know the problem, take further action  
→ Continue with appropriate care

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Table 3

*Percentage of participant responses for the first factor considered when making a pain assessment decision for different sources of pain collapsed across vignettes and separated by child's verbal ability in vignette.*

Coding Category	Unspecified Pain Source			Headache			Flu Shot			Falling Down			Arthritis			Insulin Injection		
	Full	V	NV	Full	V	NV	Full	V	NV	Full	V	NV	Full	V	NV	Full	V	NV
1. Pain Behavior/ Expression/Response	44.4	42.9	45.7	57.4	65.3	50	51.9	46.4	57.6	20.5	23	17.8	44.5	46.4	42.3	51.9	46.2	57.1
2. Pain History/Knowledge	1.9	3.6	0	18.5	19.2	17.9	5.6	3.6	7.7	0	0	0	27.8	17.9	38.5	9.3	15.4	3.6
3. General History/Knowledge	18.5	21.4	15.4	1.9	3.8	0	14.8	14.3	15.4	3.7	3.8	3.6	3.7	3.6	3.8	14.8	15.4	14.3
4. History/ Knowledge (Type Unclear)	1.9	0	3.8	3.7	0	7.1	0	0	0	0	0	0	7.4	7.1	7.7	1.9	3.8	0
5. Environmental/ Situational Context	13.0	14.3	11.5	5.6	3.8	7.1	3.7	7.1	0	3.7	0	7.1	0	0	0	0	0	0
6. Consideration of other (alternate) explanations for behavior	5.6	3.6	7.7	0	0	0	0	0	0	0	0	0	1.9	3.6	0	0	0	0
7. Consideration of specific pain source and/or the severity of this (specific to vignette)	1.9	3.6	0	0	0	0	13.0	17.9	7.7	61.1	61.5	60.7	1.9	3.6	0	5.6	3.7	7.1
8. Unrelated/Unclear	11.1	10.7	11.5	9.3	3.8	14.3	5.6	3.6	7.7	9.3	7.7	10.7	5.6	7.1	3.8	7.4	7.7	7.1

*Note:* When percentages in a given column do not add up to 100%, the remainder of the data was missing (i.e., participants left a blank response); Full sample (non-discriminating from verbal abilities of child in scenario; Full),  $N = 54$ ; Verbal (V),  $N = 26$ ; Nonverbal (NV),  $N = 26$

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Table 4

*Percentage of types of actions endorsed by participants for different sources of pain collapsed across vignettes.*

Coding Category	Unspecified Pain Source	Headache	Flu Shot	Falling Down	Arthritis	Insulin Injection
Assessment:	(28.3)	(21.5)	(5.1)	(29.1)	(40.6)	(4.5)
1. General	14.6	9.1	3.2	19	17.6	2.7
2. Asking Child/Self-Report	8.8	10.2	1.9	8.9	18.5	1.8
3. Asking Others	4.9	2.2	0	1.2	0	0
Pain and Distress Management:	(43.8)	(40.3)	(72.2)	(29.2)	(42.9)	(73.4)
4. Pharmacological	0	11.8	1.3	0	3.4	0
5. Physical	3.5	2.7	7.7	14.9	3.4	3.5
6. Psychological	21.7	18.8	62.6	14.3	26.9	68.1
7. Modification of Setting/Environmental Factors	18.6	7	0.6	0	9.2	1.8
8. Other – Management Strategy Unclear	18.1	25.3	18.1	22.6	4.2	11.5
9. Reporting - Inform Caregiver of the Event	4.4	2.7	1.9	11.9	6.7	1.8
10. Consulting Resources	1.3	2.2	0	0	0	0
11. No Action/Do Nothing	0	0	0	0	1.7	4.4
12. Unclear/Unrelated	4	8.1	2.6	7.1	8.4	4.4

*Note:* When percentages in a given column do not add up to 100%, the remainder of the data was missing (i.e., participants left a blank response)