# Pain in children with developmental disabilities: Development and preliminary effectiveness of a pain training workshop for respite workers

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Genik, L. McMurtry, M. Breau, L. Lewis, S. Freedman-Kalchman, T. 2018. Pain in children with developmental disabilities: Development and preliminary effectiveness of a pain training workshop for respite workers. Clinical Journal of Pain - 34(5), p.428-437.
https://doi.org/10.1097/AJP.0000000000000554

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This research was funded by a faculty start up grant at the University of Guelph and was conducted as Lara Genik's Master's Thesis research project within the Pediatric Pain, Health, and Communication (PPHC) Lab under the supervision of Dr. C. Meghan McMurtry. Lara is a current trainee within the Pain in Child Health Strategic Training Program and held an Ontario Graduate Scholarship while completing her Master's degree. Findings from this research have been presented at the Ontario Association for Developmental Disabilities Research Special

Interest Group Annual Research Day (April 2016), and the 11th International Symposium for Pediatric Pain (July 2017).

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## Abstract

Pain in children with intellectual disabilities (ID) is common and complex, yet there is no standard pain training for their secondary caregivers. *Objectives:* determine perceived pain training needs/preferences of children's respite staff (Phase One) and, use this information combined with extant research and guidelines to develop and pilot a training (Phase Two). *Methods:* In Phase One, 22 participants responded to questionnaires and engaged in individual interviews/focus groups about their experiences with pain in children with ID, and perceived training needs/preferences. In Phase Two, 50 participants completed knowledge measures and rated the feasibility of, and their own confidence and skill in, pain assessment and management for children with ID immediately before and after completing a pain training. They also completed a training evaluation. *Results:* Participants viewed a pain training as beneficial. Their ideal training involved a half-day, multifaceted in person program with a relatively small group of trainees incorporating a variety of learning activities, and an emphasis on active learning. Phase Two results suggested that completion of the 3 – 3.5 hour pain training significantly increased respite workers' pain-related knowledge (large effect sizes: $r$=.81-.88), as well as their ratings of the feasibility of, and their own confidence and skill in, pain assessment and management in children with ID (moderate to large effect sizes: $r$=.41-.70). The training was rated favorably. *Discussion:* Training can positively impact respite workers' knowledge and perceptions about pain assessment and management. As such, they may be better equipped to care for children with ID in this area.



*Keywords:* children with intellectual disabilities; pain; education; respite workers; pain assessment and management

## Introduction

For many children with intellectual disabilities (ID), the experience of pain may be more common compared to those who are typically developing given increased prevalence of health problems, injury, and need for medical procedures [1]. Not only is pain a negative experience for children with ID, its presence also greatly impacts their ability to function adaptively (e.g., use communication skills; [2]). Proper pain assessment and management is crucial to promote positive health-related quality of life, and optimize these children's functioning on a day-to-day and long-term basis.

Unfortunately, there are many challenges associated with effective assessment and management of pain in children who have ID. For example, these children are often incapable of providing self-reports of their pain [3], and instead rely on caregivers for making pain assessment and management-related decisions [4]. This can be particularly difficult as children with ID often exhibit pain behaviors that can be difficult to interpret (e.g., stereotyped movements, unique sounds; [5,6]) . While pain assessment tools have been developed to assist caregivers (e.g., the *Non-Communicating Children's Pain Checklist* for children with ID who are nonverbal*;* [2,7]), these have focused solely on primary caregivers (e.g., parents) and healthcare professionals.

Literature on pain assessment and management abilities of non-medical, non-primary caregivers of children with ID is sparse. This is problematic given these caregivers' frequent involvement, potentially inaccurate pain-related beliefs, and lack of pain education. For example, respite care is common and allows primary caregivers to take a break from the demands of raising children with special needs [8–10]. In a study comparing respite workers to inexperienced undergraduate students, respite workers believed a higher percentage of children with severe ID sensed less pain than children without ID [11]. This finding contrasts with research suggesting

that children with ID experience pain, but may express it differently than those without ID [6]. Given the paucity of research in this area, it is unclear how beliefs of respite workers might impact their work with these children. In the aforementioned sample, frequency analyses revealed that only a small minority of respite workers reported having pain-related training [11]. Lack of training could also impact respite workers' ability to provide effective pain assessment and management, as knowledge about the science of pain is required in addition to knowing about the individual child and this population of children [12].

**Study Rationale and Purpose**

At present, there is no pain-related training program for caregivers specific to the needs of children with ID. Further, the field has a limited understanding of secondary caregivers' experiences and perceived training needs in this area. As such, a two phase study was developed to: (a) gather information from stakeholders involved in respite care for children with ID, and (b) develop and pilot an empirically-informed training program for respite workers about pain in children with ID.

**Objectives/Hypotheses**

**Phase One.** The objectives for Phase One were to gather information about pain assessment/ management experiences and perceived training needs/preferences from employees within children's respite organizations via interviews, focus groups, and questionnaires. Use of interviews and focus groups allowed researchers to access more in depth information that may not otherwise be captured in a questionnaire. Given the exploratory nature of these objectives, specific hypotheses for this phase were not generated.

**Phase Two.** Objectives for Phase Two were to: (a) use the suggestions and needs expressed during Phase One in combination with extant research and guidelines (e.g., *IASP Core*

*Curriculum for Professional Education in Pain;* [22]) to create an empirically-informed pain training for respite workers, and (b) conduct a small single-arm pilot study with respite workers investigating the initial efficacy of the pain training. It was hypothesized the training would lead to increases in participants': (a) pain-related knowledge and (b) self-rated perceptions of the feasibility of and their perceived confidence and skill in pain assessment and management in children with ID. It was expected that participants' opinion of the program would be favourable.

## PHASE ONE

## Methods

### Participants

Using convenience sampling, participants for Phase One were recruited through children's respite organizations in Southwestern Ontario until data saturation was reached. Organizations closest to (city where research was conducted) were contacted first. Interested organizations sent initial recruitment emails to eligible staff. Participants needed to be over the age of 18, proficient in English and either (a) managers in respite-related program positions, or (b) respite workers who actively provide care to children with ID in any setting (e.g., family home, community, group homes). Speaking with these two types of staff allowed for identification of issues at both institutional and staff levels.

Participants consisted of 22 individuals ($M_{age}$: 37.10; $range_{age}$: 20 - 59; 19 female, 81.8% European/White; 13.6% Black/African/Caribbean) from three respite organizations in Southwestern Ontario. Seventeen front line children's respite workers participated in one of two focus groups (*n's of focus groups* = 5 and 12; $M_{age}$: 35.80; $SD_{age}$: 11.76; $range_{age}$: 20 - 59; 14 female). Five individuals in respite-related management positions participated in individual interviews ($M_{age}$: 42.75; $SD_{age}$ = 13.96; $range_{age}$: 29 - 58; 5 female). Length of employment in

respite settings varied substantially ($M_{years}$ = 9.5; $range_{years}$ = 0.6 - 30). Most participants interacted with children with ID at least once a week (95.5%), and rated their level of direct involvement as high (on a scale from 0 = Not At All Involved – 10 = Highly Involved, $M_{rating}$ = 9.29). Staff to child ratios varied (e.g., 1:1, 2:1), as did the types of support provided to the children (e.g., personal care, daily life skills) and setting (e.g., weekend respite, part/full day recreational programs).

**Procedures**

Clearance from the institution's Research Ethics Board was obtained. After providing consent, participants completed a demographics questionnaire, and a questionnaire on the feasibility of, and their perceived confidence and skill in, pain assessment and management. Individuals then participated in either a 1-1.5 hour interview or focus group [13,14]. During these interviews, participants were asked about general organization information (e.g., types of programs, training received), workers' pain-related beliefs and experiences with children with ID (e.g., how common are painful incidents for children during respite care, what challenges have you experienced with pain assessment and management in respite care) and perceived pain training needs/preferences (e.g., what information would be most useful to staff, what training format would be most useful). Questions were derived from research topics in the literature (e.g., pain-related beliefs [11]) and related experience of the research team. Interviews and focus groups were facilitated by the lead researcher with an accompanying research assistant [15,16]. Interview and focus guides are available upon request to the corresponding author.

Following the interview or focus group, participants were asked to complete a questionnaire about: (a) value, interest in and importance of pain training for respite workers, and (b) formatting and content preferences of the training program (e.g., group size). Participants received a fact sheet about pain in children with ID and could enter a draw for a $15 gift card.

***Recording, Field Notes and Transcription.*** Interviews and focus groups were audio-recorded [14]. Verbatim transcription by a research assistant [17] was later verified by an additional research assistant, and reviewed by the lead researcher. A research assistant present at the focus groups and interviews took field notes [14], noting conversations and general observations, which were expanded upon within 24 hours of the data collection.

**Materials**

All participants were asked to complete the following questionnaires in addition to contributing responses to questions during the interview/focus group in which they participated.

***Demographics Questionnaire.*** The data gathered from participants included age, gender, ethnicity, employment position, years employed in a respite (or similar) position, and experience with children who have ID.

***Self-Report Measures of Feasibility, Confidence and Perceived Skill.*** Six self-report ratings regarding pain assessment and management for children with ID were gathered. Participants were asked to rate each of the following on a scale of zero to ten for children with ID: 1) how feasible participants thought it would be to [assess, manage] pain; 0 = *Not Feasible At All*, 10 = *Highly Feasible*, 2) participants' perceived level of confidence in their pain [assessment, management] abilities; 0 = *Not Confident At All*, 10 = *The Most Confident Possible*, and 3) participants' perceived level of skill in [assessing, managing] pain; 0 = *Not Skilled At All*, 10 = *The Most Skilled Possible*. These numeric rating scales were used to assist in the quantitative standardization of participant responses; a scale from zero to ten allows for more variance and room for change in participant responses as compared to a smaller rating scale. These questions have been successfully used in previous research and have shown sensitivity to

change in a randomized controlled trial following pain training intervention in comparison to a non-pain related training intervention [18].

***Pain Training Specifics Questionnaire.*** This researcher-generated questionnaire was designed to gather critical information about pain training formatting and objectives of the training workshop. Some questions had a zero to ten scale ranging from 'strongly agree' to 'strongly disagree' (e.g., "Information provided at a pain training program would be applicable to my work."), while others were open-ended (e.g., "What types of activities would be beneficial to include?").

## Analytic Approach

### Quantitative Analyses

Demographic data, participant ratings of feasibility, confidence and perceived skill, and responses from the Pain Training Specifics Questionnaire were analyzed using frequency and descriptive analyses (e.g., mean, standard deviation). When coding was required, research assistants were trained on a researcher-generated coding scheme with practice coding responses to a minimum criterion of substantial agreement (>.60 kappa; [19]). Cohen's Kappa was used to calculate reliability between coders with the data and indicated very good reliability overall ($M$ = .82; Median = .81; range: .75 to .93). All data were double coded; discrepancies were resolved through consensus among the coders and primary investigator.

### Qualitative Analyses

Interview and focus group data were analyzed together, as inspection showed a high degree of similarity. All data were coded according to the study objectives and categories or themes which emerged from the data [20]. Decisions regarding what to include in the analyses were informed by how often a given topic arose in discussion, existing empirical literature, and

prior experience of the lead researcher (i.e., first-hand experience as a respite worker). Recommended procedures regarding reliability in qualitative research were used (e.g., documented content and thematic analysis processes and interpretation decisions; cross-checking field notes; regular consultation between researchers; [15,16]). Paraphrasing, rather than quotes is used in the results section when providing specific examples of topics raised by participants, as participants did not provide consent to have direct quotes used.

***Thematic Analysis.*** Thematic analysis using the phases outlined by Braun and Clarke [17] was used for questions associated with participants' subjective experiences related to pain when supporting children with ID. First, the lead researcher familiarized herself with the data and kept notes about general ideas (Step One: Data Familiarization). Next, the lead researcher systematically reviewed each question and the entire data set three times, extracting relevant data to develop lists of initial codes (Step Two: Generating Initial Codes), which were then organized into broader themes by similarity (Step Three: Searching For Themes). Initial themes were further refined (Step Four: Reviewing Themes) to ensure that all themes were clearly identifiable, distinct, and meaningful. Finally, the themes, sub-themes and other salient characteristics of the data were defined and formally named (Step Five: Defining and Naming Themes). Where possible, names and definitions of themes followed pain research terminology.

***Content Analysis.*** An inductive, qualitative content analysis using the phases outlined by Elo and Kyngas [21] (preparation, organization, and reporting) was used for questions specifically related to creating the training. The lead researcher familiarized herself with the data and took notes while reading through the transcribed data and then generated categories from the notes. These initial categories were then grouped into broader categories, using terminology from the associated disability and pain literature (e.g., pain experience versus expression [6]).

Subcategories were also used when needed. Next, the lead researcher developed category descriptions; these were reviewed by another researcher who had been present for all interviews/focus groups.

## Results

Results from the questionnaires and focus groups/interviews are discussed below. For qualitative data, results described in terms of 'themes' were related to thematic analyses; results in terms of 'categories' were related to content analyses.

### Participant Experiences with Pain In Children with ID

***Perceived Pain Prevalence.*** Two themes emerged related to participants' experiences of how common pain is for children with ID in respite. Some participants believed pain was very common, while others believed it was not. Participants indicated that prevalence of pain may vary depending on the respite setting (e.g., week-long respite versus day program). Participants noted that pain likely occurs more than they know, and elaborated on the difficulty of truly knowing how common pain is for these children.

Thematic analyses also suggested that in a respite context, children with ID seem to most often experience: (a) pain that occurs as a result of unintentional injuries (e.g., falling), and/or (b) pain that does not have a visible, external cause (e.g., headaches, gastrointestinal-related pain), with the latter being the most difficult to assess. Participants reported believing that children could show substantial variations in: (a) ability to tolerate varying intensities of pain, (b) [what participants believed to be] subjective experience of typically non-painful stimuli, and (c) [what participants believed to be] subjective experience and corresponding behavioral expression (or lack thereof) related to self-injurious behavior.

***Strategies Used when Assessing and Managing Pain for Children with ID.*** Three themes emerged related to pain assessment strategies for children with ID: (a) knowing or reviewing a child's history (e.g., consulting the child's profile), (b) observing a child's behavior (e.g., learning a child's pain cues), and (c) reviewing information from others (e.g., parent report). Two themes emerged for attempts at pain management: (a) psychological strategies (e.g., talking a child through a situation) and, (b) physical strategies (e.g., using ice or a cool cloth). Participants recognized the unique contribution of different strategies, and the benefits of using more than one simultaneously (e.g., when assessing pain, watch the child's behavior for clues, re-read the child's profile). They mentioned that pain assessment and management can feel like trial and error, particularly when they do not know a child well.

***Challenges Related to Pain in Children with ID.*** Participants described several challenges related to pain in children with ID. One theme was communication difficulties, including challenges with: (a) children who have limited verbal and/or cognitive abilities, (b) inadequate information about a child (e.g., pain history), and (c) challenges in knowing what behavioral signs to watch for during observational pain assessment. The second theme involved challenges related to pain management, particularly when certain strategies may not be available or effective (e.g., requirement of a medication protocol).

**Pain-Related Knowledge and Skills**

***Pain Assessment and Management: Perceived Feasibility, Confidence and Skill.*** Participants rated both pain assessment ($M$ = 8.00; range: 3-10) and management ($M$ = 7.32; range: 5 - 10) for children with ID as quite feasible. Self-reported confidence and skill in pain assessment ($M$ = 6.14; range: 2 - 10 and $M$ = 6.05; range: 2 - 10, respectively) and confidence

and skill in management (*M* = 6.55; range: 4 - 10, and *M* = 6.20; range: 2 - 10, respectively) for children with ID were moderate.

***Perceptions of Respite Workers' Pain-Related Knowledge.*** Participants' perceptions of the typical amount of pain knowledge possessed by respite workers ranged from (a) minimal-to-none, (b) a great deal, or (c) variable levels of pain knowledge. None of the participants had heard of pain training designed for respite workers supporting children with ID. Thematic analysis also revealed that participants thought that pain-related experience (and concomitant knowledge) could be gained: (a) on the job, (b) indirectly in other training they receive (e.g., management strategies in first aid certification), and (c) through personal experience (e.g., parenting).

**Preferences for a Pain Training**

Participants' ratings related to their perceived value, interest and importance of pain training specific to respite workers was high (10 = Strongly Agree/Extremely Important; range of mean ratings = 8.82 - 9.59).

***Format.*** Participants preferred in-person (66.7%) or hybrid (in person and online; 28.6%) pain training. Exclusively online training workshops were less preferred (4.8%). Ideal group size for a pain training ranged from eight to 38 (*M* = 14.60). On average, participants indicated that 5.20 hours for a pain training was desirable. Management stressed consideration of feasibility (e.g., booking staff time) and funding training programs.

Participants identified three main components of a successful training program: (a) considering general aspects of a training program (e.g., format; an engaging presenter); (b) addressing needs and wants of those attending, and (c) incorporating a variety of learning activities. Participants discussed the importance of utilizing both passive (e.g., videos, giving

real-life examples) and interactive (e.g., hands on, discussion, role playing) activities. Interactive activities were preferred by 68.8% of participants compared to only 23.4% of participants who indicated that passive activities would be beneficial. All participants indicated they would like to receive a certificate of completion and handouts to reference.

***Content.*** Participants believed it would be ideal to focus on: (a) general pain knowledge, (b) pain assessment, and (c) pain management. Participants discussed simple, adaptable tools that would be helpful, including step-by-step tools/protocols/decision trees and individual child profiles highlighting pain-related information. Some strategies were deemed less useful, depending on the setting (e.g., due to medication administration limitations) or less novel if the strategies have been addressed in other trainings (e.g., some physical strategies may be provided in first aid). They also indicated variable levels of comfort in using different pain management strategies; with comfort seeming to be linked to factors including knowledge of a given strategy, frequency of use, beliefs, experiences, rapport or experience with a given child, tools and resources available.

When asked about the most important thing to include in pain training, 78.8% of responses were related to provision of information and tools about pain assessment and management, 18.2% of responses suggested that an aspect of the training format (e.g., in person format) was most important, and 3.0% of responses were unclear.

***Desired Outcomes, Barriers, and Facilitators.*** A content analysis highlighted two categories of desired outcomes: (a) more organization support for pain training and use of related strategies and (b) increased confidence, skill and/or knowledge related to pain, pain assessment, and pain management. Potential barriers to the use of information from the pain training in workplace settings included: (a) the organization (e.g., policies), (b) individual staff members

(e.g., comfort with using certain pain management strategies, individual beliefs, time required to learn new information and skills), and (c) children being supported (e.g., child's communication abilities, communication between caregivers). To facilitate use of information, it was suggested that content be simple, broad, easy to remember (e.g., creating mnemonics), and adaptable.

## PHASE TWO

### Methods

#### Participants

Again, convenience sampling was used to recruit participants from children's respite organizations in Southwestern Ontario. Organizations closest to the city where the research was conducted were contacted first. Two organizations agreed to host a free pilot pain training and sent out study information letters and consent forms ahead of time for review by eligible respite workers attending the pain training. Eligible participants had to: (a) be over the age of 18 years, (b) be proficient in English, and (c) currently providing respite care to children with intellectual disabilities under age 18. Participating in the research study was optional (i.e., individuals could attend the training but not participate in the research study); all individuals present at the pilot trainings were eligible and chose to take part. There was no overlap of participants in Phase One and Phase Two.

Participants consisted of a sample of 50 individuals ($M_{age}$: 33.20; $SD_{age}$: 9.84; $range_{age}$: 20 - 59; 46 female; 42% European/White; 32% Black/African/Caribbean; 14% South/West/Southeast Asian). Twenty-six individuals participated in Pilot 1 ($M_{age}$: 39.70; $SD_{age}$: 9.03; $range_{age}$: 27 - 59; 24 female) and 24 individuals in Pilot 2 ($M_{age}$: 26.63; $SD_{age}$: 5.23; $range_{age}$: 20 - 42; 22 female). Years of employed respite experience was 8.3 years on average ($range_{years}$ = 1 - 41), with most interacting often/very often with children with ID (93.8%) and a

high degree of direct involvement with children with ID (95.8%). According to a priori guidelines on sample size required in pilot studies [23], this sample size was sufficient for a pilot study investigating the efficacy of an intervention (detecting a large effect at power of .80 and alpha of .05; [24]) and providing an effect size estimate for future intervention trials.

**Procedures**

After providing consent, participants completed: (a) a demographics questionnaire, (b) two pain-related knowledge measures specific to children with ID, and (c) ratings of perceived feasibility of, and confidence and skill in, assessing and managing pain in children with ID. Individuals then participated in a 3.5-hour interactive pain training with a 30-minute refreshment break at the midpoint. Following the training, participants were asked to complete post-measures for (b) and (c), described above, and a training evaluation. Participants received an informational fact sheet about pain in children with ID, the resources provided at the training, and an opportunity to enter a $15 gift card draw (odds of winning: 1 in 10).

**Materials**

***Demographics Questionnaire.*** Demographic data gathered in Phase Two was analogous to Phase One.

***Pain Knowledge Questionnaire.*** There are no established measures for assessing pain knowledge in respite workers, or pain knowledge specific to children with ID. Thus, the researchers used two pain knowledge questionnaires: (a) an adapted published measure and (b) a researcher-developed measure. Both measures and their corresponding scoring methods were found to be responsive to knowledge and attitude change in a randomized control trial of pain training with undergraduate students [18].

(a) The adapted pain knowledge questionnaire was based on the *Pediatric Pain Knowledge and Attitudes Questionnaire Revised (PPKAQ-R),* herein referred to as the *Adapted PPKAQ* [25]. The questionnaire was substantially adapted to suit the present study, with removal of three items identified as problematic for reliability in the initial validation study [25], and items not relevant to respite workers (*n* = 49/71 items; e.g., those related to post-operative analgesic drugs). Relevant items were adapted as needed. Eight questions about children with ID were created by the researchers, resulting in 26 items on the final adapted questionnaire. As in the original measure, participants responded on a 5-point Likert scale ranging from disagree (1 point) to agree (5 points; maximum 130 points).

(b) The *Questionnaire for Understanding Pain in Children with Intellectual Disabilities - Caregiver Report (QUPID-C;* [18]) is a 35 item true/false and multiple choice questionnaire developed using Chapter 43 (Pain Issues in individuals with Limited Ability to Communicate Due to Cognitive Impairment) of the IASP Core Curriculum [22], in tandem with existing research in the field. The questionnaire assesses general pain-related knowledge, as well as comprehension of specific pain assessment and management issues. One 'point' is attributed for every correct response (maximum 35 points).

***Measures of Feasibility, Confidence and Skill.*** This measure is identical to that which was used in Phase One.

***Pain Training Evaluation Questionnaire.*** This researcher-developed questionnaire was modeled after existing training evaluation questionnaires and included ten ratings about aspects

of the training (e.g., format, content, group size, ; 0 = *strongly disagree* to 10 = *strongly agree*) and open-ended questions about what participants liked or disliked.

### Pain Training

Format and content emphasized in the training was based on: (a) results from Phase One; (b) information from Chapter 43 of the IASP Core Curriculum Pain information which itself was derived from pain-related research literature; and (c) researcher experience (e.g., from design and delivery of previous similar pain trainings, respite care provision). Training materials are available on request to the corresponding author. The training consisted of an interactive, in-person training specific to children with ID in respite settings focusing on what pain is, pain expression, how to assess pain, and relevant pain management strategies. The same researcher facilitated both trainings, and used a presentation with notes to provide consistent information. Interactive activities included group tasks and discussions. Participants received assessment resources which they could use or adapt [e.g., the Faces Pain Scale - Revised, a self-report tool measuring pain intensity; [26]; Non-Communicating Children's Pain Checklist - Postoperative Version; [5]); and a link to the Pediatric Pain Profile, a behavior-rating scale to help with pain assessment in children with severe disabilities [27].

## Analytic Approach

### Missing Data

When participants were missing data on a given variable or item needed for a specific analysis, their data were excluded from the corresponding analysis only.

### Demographic Differences

All demographic data collected in Phase Two were analyzed using the same frequency and descriptive analyses as in Phase One. Given the small sample size, data were considered to be normally distributed if standardized skewness and kurtosis values were less than 2.58 [28].

Participant age ($M_{agePilot1}$: 39.70; $M_{agePilot2}$: 26.63; $t$ (36.88) = 6.12, $p < .001$), years employed in a respite organization for children with ID ($M_{yearsPilot1}$: 11.73; $M_{yearsPilot2}$: 4.63; $t$ (29.97) = 3.34, $p < .01$), and level of direct involvement caring for children with ID ($M_{directcontactPilot1}$: 9.88; $M_{directcontactPilot2}$: 8.48; $t$ (23.33) = 3.62, $p < .01$) were significantly different between Pilot 1 and Pilot 2. Given these demographic differences, analyses of the outcome measures (knowledge, feasibility, confidence, skill; described below) were also conducted by group[1].

**Effect of Training**

***Pain Knowledge.*** After total scores were calculated for both the adapted PPKAQ and the QUPID-C, paired samples t-tests were used to determine whether there was a difference between pain-related knowledge before and after the training program (hypothesis a). Effect sizes were calculated using Pearson's correlation coefficient *r*, as it is a standardized measure and could therefore be compared both across studies and between different measures [28]. As the current study was exploratory in nature with clear, hypotheses-driven, a-priori analytic plans, no statistical correction for multiple comparisons (e.g., Bonferroni correction) was used for the paired samples t-tests.

***Feasibility, Confidence, and Skill Ratings.*** First, descriptive statistics (e.g., ranges) of the feasibility, confidence and skill ratings, and their inter-relationships were examined. Considering the number of correlations conducted, only those with a $p$ value of $p < .001$ were considered to be significantly related. These variables were examined for normality by reviewing skewness and kurtosis values, and transforming them into z scores. In order to examine pre-post

[1] In general, the pattern of results was identical whether the groups were analyzed together or separately. Significant differences between the two pilot training groups only existed in the following instances: (1) when examining both groups individually, Pilot 1's assessment feasibility ratings, $M_{pre}$: 8.40, $M_{post}$: 9.04, $t(24) = -1.73$, $p = 0.96$ did not change significantly from pre to post, and (2) while the training was rated favourably in both groups, many of these training satisfaction ratings varied significantly between groups, such that Pilot 1 had higher ratings than Pilot 2 (see notes in Table 3).

ratings of perceived feasibility of, confidence in, and skill in assessing and managing pain in children with ID (hypothesis b), paired samples t-tests were used, following the same guidelines as described above for the two knowledge measures.

### Training Program Evaluations

Data from the training program evaluations were analyzed using frequency and descriptive analyses.

## Results

### Knowledge Measures

On average, participants' scores on both knowledge measures were significantly higher following completion of the pain training, [adapted PPKAQ: $t(37) = -11.71$, $p < .001$, $M_{prescore}$: 99.93, $M_{postscore}$: 114.04 ; QUPID-C: $t(37) = -8.32$, $p < .001$; $M_{prescore}$: 21.20, $M_{postscore}$: 26.78] These analyses yielded large effects of $r = .88$ and .81 respectively (Table 1).

### Ratings of Feasibility of, Confidence in, and Skill in Pain Assessment and Management of Children with ID

Feasibility ratings often did not correlate significantly with other self-report rating variables. However, a number of positive correlations existed between the confidence and skill ratings (Table 2). The strongest correlations were between confidence and skill within a given pain domain (i.e., assessment, treatment) suggesting that if perceived skill levels are high then perceived confidence will also be high. Pre-training ratings of feasibility, confidence and skill were not significantly correlated (at $p < .001$) with participants' ratings at post-training.

Ratings about feasibility of, and participants' perceived confidence and skill in, assessing pain in children with ID increased significantly following the pain training [feasibility: $M_{pre}$: 8.02, $M_{post}$: 8.88, $t(47) = -3.06$, $p < .01$; confidence: $M_{pre}$: 6.33, $M_{post}$: 8.26, $t(48) = -6.81$, $p <$

.001; skill: $M_{pre}$: 6.63, $M_{post}$: 8.10, $t(48) = -4.80$, $p < .001$]. Similarly, participants' beliefs about feasibility of, and their perceived confidence and skill in managing pain in children with ID also increased significantly following the pain training [feasibility: $M_{pre}$: 7.77, $M_{post}$: 8.82, $t(45) = -3.97$, $p < .001$; confidence: $M_{pre}$: 7.10, $M_{post}$: 8.37, $t(46) = -4.99$, $p < .001$; skill: $M_{pre}$: 6.96, $M_{post}$: 8.29, $t(46) = -5.34$, $p < .001$]. All of these analyses yielded large effects ($r$ = .51 - .70), with the exception of the assessment feasibility ratings, which was a medium sized effect ($r$ = .41; [24]).

**Participants' Endorsement/Opinion of the Program**

Overall, participants positively endorsed the value and format of the pain training ($M_{range}$ = 8.61 - 9.15; mode for all questions = 10; 10 = *Strongly Agree*; see Table 3).

## Discussion

**Phase One Results**

While extant literature suggests children with ID may experience pain more commonly than children without ID [29], participants expressed variability in what they thought was the frequency with which children in respite care experience pain. They also suggested, however, that they may not always recognize when a child with ID is in pain. This concern is consistent with the history of inadequate pain assessment and treatment for children with ID (e.g., [30–32]). Participants also discussed relevant topics such as children with ID's pain tolerance and subjective experience and expression with sensory stimuli. The empirical literature on these topics is limited. Research evidence has quite strongly opposed the notion of pain insensitivity among those with ID, but it is still unclear whether these children have attenuated, different, or slower reactions to pain (e.g., [33,34]).

Similar to previous findings [29], participants described pain related to unintentional injury and pain without a "visible cause" (e.g., headaches, gastro-intestinal pain) as the most

common and the most difficult to assess. Consistent with the literature on other caregivers (e.g., [3,35]), participants described pain assessment for children with ID as being challenging due to several factors including the child's verbal and cognitive abilities. Understanding pain assessment and its complexities is critical to provide accurate pain assessment and monitoring pain management efforts [36,37].

Despite the challenges expressed, participants were able to identify some important and empirically sound assessment (e.g., behavioral observation) and management (e.g., provide pain medication) strategies [38]. However, the specifics are unclear (e.g., do they know what particular behaviors to watch for? Do they understand how to properly apply the management strategies?). Participants' knowledge of different strategies combined with a potential lack of understanding suggests that these caregivers are, at a minimum, applying an assessment/management strategy that is possibly appropriate and, at best, taking a comprehensive approach as has been recommended in the literature [39].

Participants' opinions regarding pain-related knowledge of respite workers were variable. Although all participants agreed that there was no formal pain training designed for them, they described experience (e.g., on the job, personal) as playing a key role in learning how to assess and manage pain in children with ID. Experience may give respite workers strategies and ideas; however, it is unclear whether this experience could also have negative effects (e.g., learning inappropriate strategies). This lack of health-related education specific to children with ID and the potential problems and implications of this (e.g., lack of comfort working with children with ID; ability to effectively care for children with ID) have also been echoed in research with nurses and parents of children with ID [40]. Despite variability in the baseline of perceived pain-related knowledge of respite workers, the concept of a pain training was very well received. Participants

were highly interested in and saw great value in this type of information. Again, the similarity between participants' interest in relevant training and perceived needs and those of nurses in another recent study is notable (e.g., knowledge that is practical and can be applied to their work setting [40]). Although social desirability cannot be ruled out entirely, given the level of engagement and interest in the focus groups and interviews, these ratings are thought to accurately reflect their opinions on the topic.

Participants expressed a number of preferences and ideas related to developing a pain training. They preferred an in person training format, which is consistent with research suggesting that groups will be able to perform a skill or task better if they learn about it together (e.g., [41]). In addition, they favoured interactive activities related to case studies, role plays and hands on experiences. Efficacy of active learning has been empirically demonstrated (e.g., teaching communication skills to physicians; e.g., [42,43]).

**Phase Two Results**

As hypothesized and consistent with past research (e.g., [44–46]), participants' pain knowledge on both measures increased significantly following completion of the pain training. While participants from the first pilot training group had more experience than those in the second, both groups demonstrated a significant increase in knowledge. These findings suggest that pain training could be an effective and appropriate method of providing this information to respite caregivers with varying levels of experience. What remains unclear, however, is whether this increase in knowledge will translate into practice, or sustain over time.

Participants' ratings of confidence and skill were often positively correlated, suggesting that those with higher perceived skill also have higher confidence in pain assessment and management. As hypothesized and consistent with similar research (e.g., [47]), these ratings

increased significantly following training. Interestingly, participants' pre and post self-report ratings were not significantly correlated (at $p < .001$). This may support the influence that external variables (e.g., training provision) have on participants' perceptions of feasibility and their own confidence and skill in pain assessment and management. Perhaps further exposure, education and discussion about the issue of pain in children with ID can improve caregivers' perceptions of these three areas. Skill ratings, however, are only participants' perceptions. Research on the relation between nurses' pain knowledge and perceived competence found that while 63% could provide accurate estimates of their knowledge level, 37% could not, providing either under- or over-estimates [48]. The extent to which participants' ratings accurately reflect their actual skills in pain assessment and management is unknown. If their perceived skill is over-estimated, the corresponding higher confidence is unwarranted and concerning.

Despite some differences between training satisfaction ratings between groups, participants' evaluations of the pain training (e.g., content, format) were highly favourable. Combined with the use of international guidelines, the positive evaluation suggests that the training included appropriate and empirically based information that met the needs and preferences of respite workers. Importantly, some differences in endorsement/opinion of the program between pilot groups were noted. This may demonstrate the variability of organization and group preferences to training material. Participants also indicated that they planned to incorporate what they learned into their work [$M = 9.01$ (out of 10)]. It will be important to investigate how the training is incorporated into their work in future research.

**Strengths and Limitations**

This was the first study to develop and conduct preliminary testing on pain training tailored to secondary caregivers who support children with ID outside of healthcare settings.

Importantly, Phase One of this research study incorporated both qualitative and quantitative methodology to gather opinions about pain in children with ID, perceived pain training needs, and preferences directly from a set of stakeholders. This approach is similar to participatory, action-based research, involving co-construction of research by including stakeholders in the research development process [49,50]. Pre-determined interview and focus group questions and probes ensured consistency across interviews and focus groups; strategies highlighted in established qualitative methodology (e.g., [15,16]) were used during analyses to maximize validity and reliability (e.g., ensuring the data was saturated before ceasing data collection, keeping an audit trail). The training program in Phase Two was constructed based on extant research literature and pre-identified needs and preferences gathered directly from children's respite staff and management, helping to ensure the program's credibility and relevance to its audience. This pilot study allowed the researchers to explore feasibility and initial effectiveness of the training and identify challenges to be addressed prior to conducting a larger study. Given the adequate sample size, information from this pilot study can be used for a power analysis in planning a rigorous large-scale intervention study [23]. Both phases of the study involved staff from more than one organization in order to gain perspectives and a sense of the suitability of the training from individuals with differing experiences, and opinions.

Despite the strengths listed above, there are also a number of limitations to consider. In Phase One, the focus groups and interviews were time-limited, and the researchers were unable to verify themes and content categories with participants (e.g., via member-checking). The lead researcher of the project is not only a pain researcher but also has extensive first-hand experiences providing care for children with ID in a variety of respite care settings. These experiences would have likely impacted the lens through which she viewed the data from the

focus groups and interviews. The pilot program in Phase Two did not include a control group or long term/follow up assessment of participants' knowledge. It also did not examine actual behavior. A large number of participants skipped or missed at least one questions in both the PPKAQ and QUPID-C knowledge measures at pre- and/or post-training ($n$ = 12/50). In the future, it will be important to reduce the amount of missing data. Importantly, there were significant age differences between the two pilot groups. While it would be important to control for this in future analyses, this variability may also help improve the generalizability of the study. In both phases, social desirability was not examined, and so it is possible that some responses (e.g., in focus groups, ratings on self-report measures) were inflated. Further, there are limitations in both phases related to the use of convenience sampling and generalizability, although data saturation was reaching in phase one. Similarly, there are limitations related to the use of newer measures with limited information about psychometric properties. As is often the case, 0-10 ratings (e.g., feasibility, confidence and skill ratings) were treated as interval data but are arguably ordinal. Finally, limited information about the children being cared for (e.g., severity of disability, age, risks for pain) is not available and may be relevant to better understanding the context in which these participants work.

**Future Directions and Conclusions**

In addition to learning more about respite workers' pain-related experiences and perceived need for pain-related training, this research study involved the development of a pain training directed towards respite workers who care for children with ID. Ensuring that respite workers have access to accurate information specific to pain in children with ID is critical to improving the pain-related care of these children. Results suggested that completion of the pain training can increase pain-related knowledge of these caregivers, as well as their perceptions of

the feasibility of, and their confidence and skill in pain assessment and management in children with ID. Further, various aspects of the training's content and format were rated favourably. Future research should continue to evaluate this training using larger, diverse samples in a randomized controlled trial. Longer term follow-ups may also be implemented in the study design to explore the impact of knowledge over time. The impact of this program on actual care of children with ID should also be explored (e.g., using direct observations). Fostering increased pain-related knowledge in these caregivers could help to reduce the amount of pain experienced and thus increase the quality of life of children with ID.

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