Pain Among Children with Intellectual Disabilities: Development and Preliminary Effectiveness of a Pain Assessment and Management Training Workshop for Respite Workers

by

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ABSTRACT

PAIN AMONG CHILDREN WITH INTELLECTUAL DISABILITIES: DEVELOPMENT AND PRELIMINARY EFFECTIVENESS OF A PAIN ASSESSMENT AND MANAGEMENT TRAINING WORKSHOP FOR RESPITE WORKERS

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Pain among children with intellectual disabilities (ID) is common and complex. There is no pain assessment and management training program for respite workers (RW) who frequently care for these children. Objectives: (1) determine RW's pain training needs and preferences, (2) develop and pilot a pain training program. Methods: Twenty-two RW described their experiences with pain in children with ID, their perceived training needs and preferences. Fifty other RW then completed knowledge measures and ratings before and after a pain training program, and a program evaluation. Results/Discussion: Participants viewed pain training as beneficial. Their ideal training program involved a half-day, multifaceted in person program utilizing active learning. Completion of the training significantly increased pain-related knowledge ($r = .81 - .88$), and pain assessment and management-related ratings ($r = .41 - .70$). The training was rated favourably. Future research should evaluate the program in a randomized controlled trial.
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Introduction

Pain is prevalent among children across settings and age groups (Fearon, McGrath, & Achat, 1996; Perquin et al., 2000; Peterson, Moreno, & Harbeck-Weber, 1993). For example, findings from one study suggested that everyday pains (e.g., bumps, cuts) were common among children aged three to seven in daycare and incurred on a wide variety of body parts approximately once an hour per child (Fearon et al., 1996). Chronic pain is also a common experience for children and adolescents (King et al., 2011; Perquin et al., 2000). Specifically, in one study, 25% of 6636 children between the ages of zero and 18 were found to be experiencing chronic pain (Perquin et al., 2000). As defined by the International Association for the Study of Pain (IASP; 2012), pain is “an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage” (Pain terms, para. 1). Pain is subjective in both experience (i.e., a person’s pain perception) and expression (i.e., a person’s communication of pain). The presence of pain should not be dismissed due to an inability to communicate verbally (IASP, 2012, Pain terms, para. 2). This note is particularly important because it negates past beliefs about individuals with intellectual disabilities (ID) being insensitive or indifferent to pain (Biersdorff, 1991). In fact, for many children who have ID, the experience of pain may actually be more common compared to those who are typically developing; individuals whose verbal communication is limited may be particularly at risk (Stallard, Williams, Lenton & Velleman, 2001; Breau, Camfield, McGrath & Finley, 2003).

Not only is the negative experience of pain common among children with ID, but its presence also greatly impacts their ability to function adaptively. For example, one study

1 ‘People with intellectual disabilities’ will refer to those individuals who express both lower levels of overall intellectual functioning and limitations in adaptive behaviour (e.g., social skills; AAMR, 2002).
indicated that when pain is present, children with ID maybe less likely to learn, consolidate, or use a number of adaptive functioning skills (i.e., communication, social, daily living, and motor skills; Breau, Camfield, McGrath & Finley, 2007). Thus, proper pain assessment and management is crucial for these children to promote positive health-related quality of life, and optimize their level of 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. Pertaining specifically to pain assessment, self-report has sometimes been seen as a gold standard method (Chen-Lim et al., 2012). This is challenging for many children with ID, who are often incapable of providing valid and reliable self-reports of pain (Chen-Lim et al., 2012). For this reason, caregivers are often responsible for assessing and reporting their children’s pain and making appropriate pain management decisions (Solodiuk et al., 2010). Further complicating this issue is that children with ID often exhibit pain behaviours (e.g., stereotyped movements, a unique sound; Breau, McGrath, Camfield, & Finley, 2002; Dubois, Capdevila, Bringuier, & Pry, 2010) that can be difficult to interpret, different from those of typically developing children, and idiosyncratic at an individual level (McGrath, Rosmus, Canfield, Campbell, & Hennigar, 1998; Fanurik, Koh, Schmitz, Harrison, & Conrad, 1999; Bottos & Chambers, 2006). While pain assessment tools have been developed to assist in caregivers’ pain assessment (e.g., the Non-Communicating Children’s Pain Checklist for children with ID who are nonverbal; Breau, Camfield, McGrath, Rosmus, & Finley, 2001), these have been focused solely on primary caregivers (e.g., parents) and health care professionals.

To date, little research on the pain assessment and management abilities of other caregivers who spend time with children who have ID has been conducted. This is problematic, as children with ID commonly spend time with other caregivers on a daily basis. For example,
Respite care is a common service designed to provide an opportunity for primary caregivers to take a break from the demands of raising children with special needs (Shelton & Witt, 2011; Hoare, Harris, Jackson, & Kerley, 1998; McNally, 1999). Respite care has been noted to have positive effects on all members within a family unit (Robertson et al., 2011). Further, these services are high in demand, so much so that demand often exceeds the level of available services (McConkey, Kelly & Craig, 2011).

When children with ID are in the care of respite workers, primary caregivers (e.g., parents) may not be available to identify when their children are experiencing pain and to what degree. In a study comparing respite workers to a group of inexperienced undergraduate students, respite workers believed a higher percentage of children with severe ID sensed less pain than children without ID (Genik, McMurtry & Breau, in prep.a). This is contrary to research suggesting that children with ID experience pain, but may express their pain differently than those without ID (Dubois et al., 2010). Although children’s verbal ability (i.e., whether they are verbal or nonverbal) did not seem to impact respite workers’ pain intensity ratings, respite workers believed that children with more severe ID had lower behavioural and emotional reactions to pain, and were less able to communicate their pain effectively compared to typically developing children (Genik et al., in prep.a). Given the paucity of research in this area, it is unclear how the beliefs of respite workers might impact their direct work with the children for whom they care. This may also depend on their level of pain-related training. In the same sample, frequency analyses revealed that only a small minority of respite workers reported having pain-related training (Genik et al., in prep.b). Lack of training could 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 (Hunt, Mastroyannopoulou, Goldman, & Seers, 2003). The unique considerations of pain assessment and management in individuals with ID are clearly communicated by inclusion of a specific chapter about pain in people with intellectual disabilities in the International Association for the Study of Pain’s (IASP) Core Curriculum (see Chapter 43 in Charlton, 2005).

In sum, not only does it appear that many respite workers lack pain-related training, but they may also hold inaccurate beliefs regarding pain in children with ID, and could, in turn, be missing important pain cues. It is therefore important to learn more about respite workers’ pain-related experiences with children they support and perceived pain-related training needs. It should also be determined whether these needs can then be addressed through the provision of empirically-informed educational programming. Knowledge of these experiences and perceived needs could inform a pain-related training program for respite workers which, in turn, could conceivably improve the level of care they can provide to children with ID.

Pain training programs have been successfully used for health care professionals, although these generally have not focused on unique populations such as children with ID. For example, an Interfaculty Pain Curriculum designed to educate pre-licensure students in health care-related fields (e.g., dentistry, medicine, nursing) about pain has been developed and found to improve participants’ scores on a pain-related knowledge and beliefs questionnaire (Hunter et al., 2008). Increased knowledge levels have also been found following pain education programming for physicians and nurses in hospital settings, and long-term care staff in seniors’ residences (e.g., Gagnon, Hadjistavropoulos, & Williams, 2013; Zhang et al., 2008). Similar studies have also assessed the impact of training programs on factors other than knowledge. For example, one study found that nurses reported feeling more credible and effective after completing a pain management training program (Dalton et al., 1998). Training programs for
respite workers providing care to older adults also demonstrate improved outcomes related to knowledge and attitudes on health-related topics. For example, a training program targeting respite workers who support those with Alzheimer’s disease led to significant increases in disease-specific knowledge, as well as more positive attitudes towards individuals who wander (Robinson, Kiesler, & Looney, 2003).

Objectives

This work is part of a series of novel studies on the development and evaluation of an empirically-informed training program about pain in children with ID for respite workers. This study was divided into two phases and is outlined below (also see Figure 1).

Phase One

Objectives

The objectives for Phase One were to gather information about pain assessment and management experiences as well as perceived training needs directly from employees within organizations that provide respite care services to children with ID. Given the qualitative nature of these objectives, specific hypotheses regarding participants’ experiences, needs and preferences were not generated. All analyses were descriptive and exploratory in nature.

Methods

Participant Recruitment

The primary method for recruiting participants for this study involved the help of organizations providing respite care for families in Southwestern Ontario. The lead researcher (LG) approached these organizations by telephone and/or email. After receiving information about the project and its purpose, organizations were asked about their interest in involvement. Interested organizations were asked to send out initial recruitment emails or letters to eligible staff. Participants needed to be over the age of 18, proficient in the English language 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. Potential participants were then given additional information about the study from a researcher and could formally choose to participate.

**Participants and Organizations**

Participants consisted of 22 individuals ($M_{age}$: 37.10; $range_{age}$: 20 - 59; 19 female) from three different respite organizations in Southwestern Ontario. Five individuals in respite-related management positions participated in individual interviews ($M_{age}$: 42.75; $range_{age}$: 29 - 58; 5 female). Seventeen individuals actively providing respite care to children with ID participated in one of two focus groups ($n$’s of focus groups = 5 and 12; $M_{age}$: 35.80; $range_{age}$: 20 - 59; 14 female). Additional demographic information regarding management and respite worker participants can be found in Table 1.

Participating organizations provided varying types of support to the children for whom they care (e.g., personal care, feeding, daily life skills, social activities), and offered different types of respite program options to families for children with ID (e.g., weekend/week long respite, holiday/seasonal care, part/full day recreational programs). Staff to child ratios varied, but were as high as one-to-one.

**Procedures**

When arriving for a focus group or interview, participants first reviewed the consent form and study information with a researcher (individually for interviews or in a group format for focus groups), and provided informed consent. Next, they completed a demographics questionnaire (see Appendix A), and a brief questionnaire on the feasibility of, and their perceived confidence and skill in pain assessment and management (see Appendix B).
Individuals then participated in either an interview (approximately 1 hour in length) or focus group (approximately 1 – 1.5 hours in length; Morgan, 1997; Mack, Woodsong, MacQueen, Guest & Namey, 2005) regarding perceived pain training needs of respite workers and ideal delivery of content. Interviews and focus groups were facilitated by the lead researcher (LG) with an accompanying research assistant, and researchers collected data until they felt that the data was saturated (Morse et al., 2002; Thyer, 2009).

Interviews and focus groups began with brief introductions of the participants and the researchers. Next, more general questions about pain among children with ID and the participants’ experiences with pain among this population were discussed. This was followed by a series of questions and probes related to participants’ perceived pain training program needs and ideas about training delivery. The same questions were discussed in both the interviews and focus groups (see Appendix C).

Following the interview or focus group, participants were also asked to complete a series of questions about: (a) their thoughts regarding the value, interest in and importance of a pain training program for respite workers, and (b) specific formatting and content preferences of the training program (e.g., preferred group size; see Appendix D). All completed questionnaires were submitted in an envelope at the end of the focus group or interview, and participants received an informational fact sheet about pain in children who have ID and an option to enter a gift card draw for a $15 Tim Horton’s gift card (odds of winning were one in 10).

**Recording, Field Notes and Transcription.** Interviews and focus groups were all audio-recorded (Mack et al., 2005). A research assistant took brief field notes during the focus groups and interviews (Mack et al., 2005), noting the conversations which took place as well as any more general observations. These field notes were later expanded upon in detail by the same
research assistant within 24 hours of an interview or focus group. Audio recordings were later transcribed verbatim by a research assistant (Braun & Clarke, 2003). Transcriptions were verified against the recordings by an additional research assistant, and reviewed by the lead researcher (L.G.). Field notes were also transcribed and reviewed.

**Materials**

All participants were asked to complete the following questionnaires and contribute responses to questions during the interview/focus group in which they participated (see Appendix C for the list of questions). A complete copy of each of these materials can be viewed in the Appendices.

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

*Self-Report Measures of Feasibility, Confidence and Perceived Skill (Pre-Interview/Focus Group).* Six self-report ratings regarding pain assessment (i.e., knowing whether someone is in pain) and management (i.e., helping to manage someone’s pain) for children with ID were gathered. As there were no suitable published measures, these tools were created by the researchers (see Appendix B). 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*. 

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Pain Training Specifics Questionnaire (Post-Interview/Focus Group). This questionnaire was predominantly quantitative, and designed to gather critical information about pain training formatting and objectives of the training workshop. As no suitable published measure was available, all questions were developed by the researchers. Some questions had a zero to 10 point scale ranging from ‘strongly agree’ to ‘strongly disagree’, while others were open-ended to allow for participants to contribute their unique ideas (see Appendix D).

Analytic Approach

A combination of both qualitative and quantitative analyses were used (described below).

Quantitative Analyses

Demographic data collected were coded and analyzed using frequency and descriptive analyses (e.g., mean, standard deviation) for the interviews, focus groups, and full sample. Participant ratings of the feasibility of, as well as their confidence and skill in pain assessment and management were also analyzed in this way using descriptive analyses.

Results from the Pain Training Specifics Questionnaire were described by coding the results as needed and using frequency analyses. For example, scaled ratings relating to general interest and perceived value of the pain training were described using means and ranges. Codes were generated for four of the open-ended questions [e.g., “What types of activities would be beneficial to include (e.g., case studies, group discussions, etc.)?”; see Appendix D, open ended question numbers: 3, 4, 6 and 7]. This process was conducted similarly to the content analysis described below, except that following the development of codes/categories, two research assistants were trained on the coding scheme. This was achieved through one initial round of practice coding with six to ten practice coding questions developed by the lead researcher (L.G.) which were designed to mirror the actual data. Coders were trained to a minimum criterion of
substantial agreement (> .60 kappa; Landis & Koch, 1977) before coding the actual data. Cohen’s Kappa was used to calculate reliability between coders and indicated very good reliability overall ($M = .82$; Median = .81; range: .75 to .93). Any discrepancies were resolved through consensus among the coders and primary investigator (L.G.). See Table 2 for the questions which were coded and the corresponding Cohen’s Kappa reliability values for the practice and final coding of each question.

**Qualitative Analyses**

Data gathered from the interviews and focus groups were collapsed and analyzed together, as inspection showed a high degree of similarity. Using the transcriptions, qualitative content analysis or thematic analysis was used depending on the question and its purpose (further elaborated on below and specified in Appendix C). In both of these cases, all data were coded according to the study objectives and categories or themes which emerged from the data itself (Morse & Field, 2005). For this reason, the raw data were reviewed throughout the qualitative process in order to remain grounded in the data (Kvale, 1996). Decisions regarding what to include in the analyses were informed by how often a given topic came up in discussion, researcher knowledge of empirical literature, and prior experience of the lead researcher, LG (i.e., five years of employment and volunteer respite care experience across a number of settings including group homes, day programs, in the community). In all of these cases, recommended procedures regarding reliability in qualitative research were used. For example, the content and thematic analysis processes were documented, as were any choices made regarding interpretations, content classifications, and what information to include/exclude (i.e., an audit trail; Morse, Barrett, Mayan, Olson, & Spiers, 2002). Further, multiple types of field notes were kept (i.e., condensed and expanded versions, field notes, running record of analyses and

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interpretations), and notes were cross-checked by both researchers who had been present for all interviews and focus groups (Thyer, 2009). The researchers present for the interviews/focus groups (L.G. and a research assistant) and the supervisor (C.M.M.) consulted with each other regularly regarding interpretation and classification to ensure mutual agreements were reached (Morse et al., 2002).

**Thematic Analysis.** A thematic analysis was used for questions associated with participants’ subjective experiences and stories related to pain when supporting children with ID. Questions analysed in this way had a larger emphasis on context of responses, aiming to search for common threads across the data related to participants’ thoughts and feelings about a given topic that may be specific to their experiences as a respite worker (e.g., “As care providers for children with ID, what sorts of challenges have you experienced/heard about regarding pain assessment or management with these children that could be addressed in a pain training program?”; see Appendix C; Vaismoradi, Turunen, & Bondas, 2013).

All thematic analyses were conducted using the phases outlined by Braun and Clarke (2006). Specifically, the process began by having the lead researcher (LG) familiarize herself with the data (Step One: Data Familiarization) and keeping notes about some general ideas regarding the data collected. This was an iterative and ongoing process both during and after data collection, and included several readings of the entire data set. Following this, the lead researcher (LG) systematically reviewed each question being used for the thematic analysis and the entire data set three times, extracting relevant data throughout and using these data to develop lists of initial codes (Step Two: Generating Initial Codes). The codes in these lists were then organised into potential broader themes by similarity (Step Three: Searching For Themes). The following were considered when deciding on themes: (a) the level of agreement between participants (e.g.,
did only one participant seem to think that something was an issue, or did the entire group see it as an issue?), (b) how much time a given topic was discussed within a focus group or interview, and (c) the frequency with which topics were discussed (i.e., was a topic discussed in more than one focus group or interview). Also taken into consideration, however, was the relevance of the themes to the overall research questions asked. As the initial codes were listed in a word document, the different codes were colour coded to visually represent different themes, and a series of mind maps were also developed to better visualize the themes and their relations with each other (e.g., at code, sub-theme and theme levels). These initial themes were then reviewed and further refined (e.g., some initial themes were collapsed together, eliminated, further broken down into subthemes; Step Four: Reviewing Themes) to ensure that the meaning of the data remained in the themes but also that the various themes were clearly identifiable and distinct from one another. The maps initially developed in the previous step were further refined and solidified here. 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 the terminology used in the pain research literature. A research assistant who was present at all focus groups and interviews and transcribed the data then followed the same process and reviewed the lead researchers’ themes and categories. Any discrepancies were discussed and a consensus was reached. The lead researcher’s supervisor (C.M.M.) also reviewed the final thematic maps. Quotes were not used, as participants were told during the consent process that their data would only be presented in aggregate form. However, when providing some specific examples in the results section, paraphrasing was used to demonstrate specific examples of topics raised by participants. Use of a thematic analysis enabled the researchers to: (a) summarize the key areas of interest/focus for secondary caregivers
in respite settings that emerged, (b) capture any unanticipated ideas about pain in children with ID in the context of respite care, and (c) incorporate and synthesize results for Phase Two (Braun & Clarke, 2006).

**Content Analysis.** A qualitative content analysis was used for questions specifically related to creation of the pain training program (e.g., “What sorts of things do you think would be helpful to include in a pain training program that would help respite workers to better support the children they care for and feel more confident in the care they provide? What sort of pain assessment information? What types of pain management information?”; see Appendix C) and participants’ identified goals/desired outcomes from a pain training program (e.g., “What sorts of goals/outcomes would you like to see after participating in/having your staff participate in a pain training program?”; see Appendix C). For content analyses, the phases outlined by Elo and Kyngas (2007; preparation, organization and reporting) were used by the lead researcher (L.G.), in collaboration with a research assistant and the supervisor (C.M.M.). The process began with the lead researcher (L.G.) reviewing the questions asked for the content analysis and the data to become fully immersed and familiar with it, making any notes about ideas and insights related to the data itself. An inductive approach was used to code the data. The researcher began by making notes while reading through the transcribed data and then freely generating categories associated with the notes. These initial categories were then grouped into fewer, more broad categories. Subcategories were also used when needed. When possible, the researcher labelled these broader categories using terminology from the associated pain literature. Following the creation of categories, the researcher then developed category descriptions. When this process was complete, a research assistant who was present at all focus groups and interviews and who transcribed the data also reviewed the process and any discrepancies were addressed. The lead
researcher’s supervisor (C.M.M.) also reviewed the final categories derived from the content analysis process. See Appendix E for the specific coding categories used when conducting frequency analysis for the four quantitative content analyses.

**Results**

Results from the questionnaires and focus groups/interviews are discussed below. Results are not presented in the same order as study procedures; specifically, components of the interviews/focus groups have been re-organized to facilitate flow from participants’ experiences related to pain in children with ID, to thoughts related to pain knowledge and need for training, and to specific formatting preferences related to a pain training. In some cases, respite workers used language that did not reflect that which is used in the pain research literature. The results have been described using terminology consistent with the literature but this does not alter the interpretation of the results. For example, participants often described pain without a visible cause as “internal pain”. As all pain is processed internally, researchers described this pain as “pain without a visible cause” in the results section. With respect to qualitative data, results described in terms of ‘themes’ are related to thematic analyses; results described in terms of ‘categories’ are related to content analyses; results referred to as ‘descriptive’ were summarized by the lead researcher (L.G.) from participant responses and used to further support quantitative analyses, and again reviewed by a research assistant. Quantitative analyses are prefaced with the term ‘quantitative’.

**General Observations of Participant Engagement and Interest**

From the lead researcher’s (L.G.) perspective, the majority of individuals who participated were very engaged with the researcher(s) during their focus group or interview. Both focus groups with respite staff seemed to be particularly invested and have high levels of interest
in the topic of pain in children with ID. In fact, the respite care staff were so eager to discuss these issues that often the lead researcher (L.G.) was concerned about having enough time to get through all of the questions.

Participant Experiences with Pain Among Children with ID

Pain: How Common? Two different themes emerged related to participants’ experiences of how common pain is for children with ID in respite care. Some participants believed that pain was very common, while others believed it was not. Participants indicated that prevalence of pain may vary depending on the type of respite setting. For example, compared to longer term respite settings (e.g., weekend or week long respite), pain may be less common in short term recreational programming (e.g., a day program), as children may stay home or be sent home if experiencing pain. Despite this, participants noted that pain likely occurs more than they know, and elaborated on the difficulty in 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., toothaches, headaches, stomach-aches). Participants unanimously agreed that this second type of pain was the most difficult to assess. Participants suggested that in relation to pain, children could show substantial variations in: (a) their ability to tolerate varying intensities without reacting, (b) their subjective experience of typically non-painful sensory stimuli (e.g., warm or cool cloth on forehead), and (c) their subjective experience and corresponding behavioural expression (or lack thereof) related to self-injurious behaviour.
**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 behaviour (e.g., learning a specific child’s pain cues), and (c) gathering or reviewing information from others (e.g., parent report). Two themes emerged for participant 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). For management, some participants noted that respite workers may be unaware that some care strategies they use may also manage pain (e.g., distraction), and thus unable to identify the specific type of strategy being used at a given time. Further, participants recognized the unique contribution of different strategies, as well as the benefits of using more than one simultaneously (e.g., when assessing a child with ID for pain, watch the child’s behaviour for clues, re-read the child’s profile, contact the parents). They mentioned that pain assessment and management can sometimes feel like a guessing game, or trial and error, particularly when they do not know a child well.

**Challenges Related to Pain in Children with ID.** Participants described a number of challenges related to pain among children with ID. One theme centered on communication difficulties, including challenges with: (a) communicating with children who have limited verbal and/or cognitive abilities, and (b) inadequate information provided to them from other caregivers about a child (e.g., pain history). A second theme involved challenges related to knowing what behavioural signs to watch for during observational pain assessment. The third and final theme involved challenges related to pain management. Participants indicated that it is often difficult to know what to do when a child is in pain, particularly when certain strategies may not be available or effective. For example, this may sometimes be the case for pharmacological...
strategies (e.g., requirement of a medical protocol; waiting for the medication to have an effect; concern regarding side effects). A child’s response to physical strategies such as ice or hugs may be impacted by his or her own sensory preferences. In other words, a child who responds well to weighted vests and deep pressure when in distress or overstimulated may respond better to hugs than a child who is hypersensitive to touch.

**Pain-Related Knowledge and Skills**

*Pain Assessment and Management: Perceived Feasibility, Confidence and Skill.* Table 3 outlines the descriptive statistics for these ratings. Quantitatively, ratings provided by management and respite workers were similar, but the former’s ratings were slightly lower. Participants rated both pain assessment and management for children with ID as quite feasible. However, self-reported confidence and skill in pain assessment and management for children with ID were more moderate.

*Perceptions of Respite Workers’ Pain-Related Knowledge.* There was no consensus on the typical amount of pain knowledge possessed by individual respite workers. Specifically, three themes emerging from the data suggested participants believed that ‘average respite workers’: (a) had minimal to no pain knowledge, (b) had a lot of pain knowledge, or (c) had variable levels of pain knowledge depending on the individual. None of the participants in the focus groups or interviews had heard of a pain training program designed for or available to respite care providers 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 (e.g., informal peer mentorship, gaining direct experience with a specific family or child, from children’s profiles), (b) through indirect experience with pain in other training they
receive (e.g., some physical management strategies may be taught in first aid certification), and (c) through their own personal lives (e.g., through parenting).

Preferences for a Pain Training Workshop

*General Interest and Perceived Value of Pain Training Workshops.* Quantitatively, participants’ ratings related to general interest in and perceived value of a pain training program were quite high (see Table 4). However, respite care workers gave higher average ratings compared to those in management positions. Descriptively, participants’ interests in and perceived benefits of learning more about pain in children with ID was a continued topic of discussion throughout the focus groups and interviews.

*Format.* Quantitatively, participants preferred an in person pain training program; online training workshops were less preferred (see Table 5). Descriptively, participants indicated that an online resource could have value for long-term reference or for “dry” material. Participants reported an ideal group size for a pain training program as ranging from eight to 38 participants ($M = 14.60$, Median: 12). On average, participants indicated that 5.20 hours for a pain training program was desirable, however the ideal length varied between respite staff and management (see Table 5). The need for consideration of feasibility (e.g., booking staff time) and funding training programs were expressed by management.

During the focus groups and interviews, participants identified three categories of ‘key ingredients’ for a successful training program. First, participants communicated the need to consider general aspects of a training program, such as the training format (e.g., use in person format) and the presenter (e.g., someone with new ideas who is engaging). Second, participants expressed the importance for those providing the training to address the needs and wants of those attending the training. For example, they wanted the trainer to clearly communicate the purpose
of the training and ensure its relevancy for their work. The final ‘key ingredient’ category involved incorporating a variety of learning activities. While 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 in a training program, their discussion centered on interactive activities. Quantitatively, 68.8% of participants highlighted interactive activities compared to only 23.4% of participants who indicated that passive activities would be beneficial to include. All participants indicated that they would like to receive a certificate of completion as well as handouts to reference. Out of the 21 questionnaire responses regarding handout format, hard copies (52.4%) or provision of both hard copies and electronic copies (33.3%) were most preferred.

**Content.** Participants believed that pain assessment and management knowledge go “hand in hand”, and due to child individuality, it is ideal to have as many different strategies and as much information as possible. Providing information and tools/strategies were seen as most useful for the following categories: (a) general pain knowledge (e.g., basic pain-related information, specific information related to a subtype of children), (b) pain assessment (e.g., how caregivers can assess pain, how to help a child communicate his/her pain), and (c) pain management (e.g., how and when to use pharmacological, physical and psychological strategies).

Participants spent considerable time discussing types of simple and adaptable tools that would be particularly helpful, including step by step tools/protocols/decision trees and individual child profiles highlighting pain-related information. While participants reported that all strategies and information were important, they also described some strategies as being less useful depending on the setting (e.g., in respite settings, pharmacological strategies can only be used for children who have a medication approved for use by physicians and parents) or if the strategies
have already been indirectly addressed in other types of training (e.g., some physical strategies may be provided in first aid). They also indicated highly variable levels of comfort in using different types of pain management strategies; their comfort seemed to be linked to a number of 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 a pain training workshop, 78.8% of participant responses were related to provision of information and tools about pain assessment and management (assessment specific information provision and tools: 30.3%; management specific information provision and tools: 18.2%; information provision and tools - other: 30.3%). The remaining 18.2% of responses suggested that an aspect of the training format itself was most important, and 3.0% of responses were unclear. There were only 9 responses provided regarding the least valuable thing to include in a pain training workshop. Of those responses, 33.3% indicated that everything in a pain training is important (i.e., there is nothing that would be considered ‘least important’), 33.3% indicated aspects of the training format which would be least important (e.g., talks being too boring), and 33.3% indicated an aspect of information provision that would be least useful (e.g., providing information about strategies that organizations are unable to use).

**Desired Goals and Outcomes.** A content analysis highlighted two broad categories of participants’ desired goals and outcomes. First, participants wanted more organization support or “buy in” related to the importance of pain training for respite workers, and also an ability to utilize strategies and skills learned while working for the organization (e.g., incorporation of pain information into child profiles). Second, participants would like respite staff to gain increased
confidence, skill and/or knowledge related to pain in general, pain assessment, or pain
management.

**Barriers and Facilitators for Knowledge Use.** Three categories of barriers which could
limit the ability of respite staff to use information from the pain training program in their
workplace settings included: (a) the organization itself (e.g., policies and procedures, staff
training philosophies, the nature of the respite programming), (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 served by the organization (e.g., child’s ability to
communicate, communication between various child caregivers).

Participants suggested that to facilitate use of information, those creating a pain training
program should consider how they present the information to staff. For example, they suggested
making sure that participants are not overloaded with information, and keeping the information
broad and adaptable, as well as simple to use and remember (e.g., creating mnemonics).

**Discussion**

Pain is common among children with ID (Breau et al., 2003). Respite care as a service for
children with ID and their families continues to grow (Chan & Sigafos, 2000), yet formal pain-
related training designed specifically for these caregivers has not yet been created. The aim of
this study was to gather information about pain assessment and management experiences as well
as perceived pain-related training needs and preferences directly from employees within
organizations that provide respite care services to children with ID. This information is intended
to be used to develop a pain training program for these caregivers in Phase Two.
Participant Experiences with Pain Among Children with ID

The extant literature suggests children with ID may experience pain more commonly than children without ID (Breau et al., 2003). Overall, participants expressed considerable variability in how commonly they thought that children with ID in respite care experience pain (e.g., not common versus very common). However, participants also suggested that pain may occur more than they are aware of at times, suggesting 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., Sobsey, 2006; Malviya et al., 2001; Carter, MacArthur, & Dunliff, 2002).

Similar to Breau et al.’s (2003) findings, participants described pain related to unintentional injury and pain without a “visible cause” (e.g., stomach aches) as the most common. Given that they also described pain without a “visible cause” as the most difficult to assess, respite workers would benefit from additional knowledge and instruction on this issue. As highlighted throughout the literature related to pain in children with ID (e.g., Breau et al., 2009; Chen-Lim et al., 2012), participants described pain assessment for children with ID as being challenging in general due to a variety of factors including the child’s verbal and cognitive abilities. Understanding pain assessment and its complexities is critical in order to provide accurate pain assessment and monitor pain management efforts (Malviya, Voepel-Lewis, Merkel, & Tait, 2005; Valkenburg, van Dijk, de Klein, van den Anker, & Tibboel, 2010). It is therefore important to ensure that respite workers are given this information. Participants expressed some concerns regarding pharmacological strategies with the children for whom they care. Specifically, they were unsure about potential medication-related side effects, as well as the
potential for pain medications to interact with other medications that a child may already be taking regularly. These concerns are consistent with the research literature (e.g., Taddio & Oberlander, 2006). Participants also described sometimes simply “not knowing what to do” - a logical reaction given that they have not been exposed to formal training related to pain in this specific population of children.

Despite the challenges highlighted throughout focus groups and interviews, participants were able to identify some important and empirically sound assessment strategies such as using behavioural observation, learning about a child’s history, and seeking reports from others more familiar with the child (Herr, Coyne, McCaffery, Manworren, & Merkel, 2011). However, the specifics are unclear (e.g., do they know what particular behaviours to watch for?). While participants were able to name some techniques that would be related to psychological (e.g., talking to the child), pharmacological (e.g., provide pain medication) and physical (e.g., use ice) pain management approaches, it was noted that respite workers may not always recognize when they use these strategies, or their purpose. Participants’ knowledge of different strategies combined with a potential lack of understanding suggests that these caregivers are, at a minimum, applying a management strategy that may or may not be appropriate and, at best, taking a comprehensive approach as has been recommended in the literature (Oberlander, 2001). They were also somewhat limited in the diversity of strategies they reported (e.g., giving medication, using ice, talking to the child). Having a broader repertoire of strategies may help respite workers to be more effective in managing pain in the children they support.

Throughout the focus groups and interviews, participants also discussed a number of topics such as children with ID's pain tolerance and subjective experience and expression with sensory stimuli. While it is clear that these should be of concern and are relevant to respite
workers, the empirical literature on these topics is limited. For example, while research evidence has quite strongly opposed the notion of pain insensitivity among those with ID, it is still unclear whether these children have attenuated, different, or even slower reactions to pain (e.g., Bottos & Chambers, 2006; Van Dijk, Valkenberg, Boerlage, Tibboel, & Veerkamp, 2009). It is important that respite workers are given up to date and accurate information about these topics, so that they are well-informed and better able to both assess and manage pain to the best of their abilities. A lack of knowledge regarding these phenomena among children with ID may limit the quality of care that caregivers are able to provide.

**Pain-Related Knowledge and Skills**

Participants’ beliefs in the feasibility of and their confidence and skill in pain assessment and management were generally moderate to high. Feasibility ratings at both pre and post time points (mean range: 7.77 - 8.88) were encouraging. Believing that pain assessment and management are feasible in this population of children may increase individuals’ perceptions regarding the value of participating in a training program. Given the lack of pain training for these caregivers, the mean ratings for confidence and skill were perhaps somewhat inflated although the range was large. It is possible that participants were responding in a socially desirable way to some degree. It will be important to further explore whether participants’ perceptions of these areas change after having received pain-related training, as they may further play a role in caregivers’ likelihood of using their knowledge in practice.

Participants’ opinions regarding pain-related knowledge of respite workers were quite variable. While all participants agreed that there was no formal pain training program 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. While experience may very well give respite
workers strategies and ideas, it is unclear whether this experience could also have negative effects (e.g., learning inappropriate assessment or management strategies).

Despite the variability in the perceived baseline of pain-related knowledge of respite workers, the concept of a pain training program was very well received. Participants were highly interested in and saw great value for respite workers to have access to this type of information. While 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.

Preferences for Delivery and Content of Pain Training Workshop

Participants expressed a number of preferences and ideas related to the development of a pain training program. Participants preferred an in person training format and were able to identify a number of empirically supported reasons why this format would be best. For example, participants’ endorsement of a group based training format with other staff from the same organization is in line with research suggesting that groups will be able to perform a skill or task better if they learn about it together (e.g., Moreland & Myaskovsky, 2000). In addition, respite workers highlighted a number of interactive activities related to case studies, role plays and hands on experiences. The effectiveness of active learning has been empirically demonstrated (e.g., teaching communication skills to physicians; e.g., Prince, 2004; Berkhof, van Rijssen, Schellart, Anema, & van der Beek, 2011).

A consideration raised by management was the feasibility of running an in person training workshop. For example, it may be difficult to find a time when all staff are available and funds may be limited. Management’s thoughts around feasibility may explain differences in preferences compared to respite workers. For example, management seemed to prefer a shorter
training program; an online training option, or a video that they could share at staff meetings was also viewed more favorably by management than the front line workers. Consideration of these preferences in addition to feasibility are important when developing a training workshop for staff employed in a respite organization setting.

Participants seemed to have an understanding that all aspects of pain assessment and management are linked, as they expressed wanting to know about both pain in general, as well as more specific information about pain assessment and management. Desired outcomes were identified at the organization (e.g., organization support for use of strategies learned in the training) and staff (i.e., increased skill and confidence) level. Given the number of barriers that participants believed could limit their ability to apply the new knowledge (e.g., policies and procedures within organizations, individual comfort level in using strategies, children’s communication abilities), participants believed that a broad and adaptable training may best facilitate their ability to use new knowledge. It is important to develop programming that meets the needs of its stakeholders by addressing the topic at an accessible and feasible level for its audience to facilitate later application. This approach is similar to participatory or action based research, which involves the co-construction of research by including stakeholders in the research development process and has been found to be a valuable component of the research process, increasing its value (Jagosh et al., 2012, Viswanathan et al., 2004). Given the results from this phase of the research study, it seems as though an ideal pain training program designed for respite workers would involve a half-day, in person program with a relatively small group of trainees. The training would cover pain in general as well as pain assessment and management strategies, and would incorporate a variety of learning activities, with an emphasis on interactive learning. Participants had opportunities to learn about strategies and tools that could be used to
help them with pain assessment and management.

**Strengths and Limitations and Other Considerations**

This research study gathered opinions about pain in children with ID, their perceived pain training needs, and training preferences directly from respite workers and management in children’s respite care organizations. The research study incorporated qualitative and quantitative methodology to inform the creation of a pain training program designed for children’s respite care staff. The study also involved three different organizations as well as both front line respite worker staff and management in order to gain perspectives from individuals with differing experiences, opinions and perspectives. Pre-determined interview and focus group questions and probes ensured consistency across interviews and focus groups. Use of focus groups also allowed respite workers to collaborate and build off of each other’s ideas. A number of strategies as highlighted in established qualitative methodology (e.g., Morse et al., 2002; Thyer, 2009) were also used throughout the analyses to maximize validity and reliability (e.g., choosing an appropriate sample and ensuring the data was saturated before ceasing data collection, applying theory to analyses where possible, keeping an audit trail for qualitative analyses, using Cohen’s Kappa for quantitative-based coding).

Despite the number of strengths listed above, there are some limitations to consider. First, the focus groups and interviews were time-limited, so participants may not have had time to cover topics as thoroughly as they wished. The researchers were also unable to verify themes and content categories with participants. Participants may have felt some pressure to present their ideas in a socially desirable way. This study only included a very small sample of respite workers. Their ideas and experiences may not directly map on to other respite workers and organizations, particularly those outside of South Western Ontario. Finally, it is important to
consider that the lead researcher of the project is not only a pain researcher but also has a plethora of first-hand experience 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.

Conclusions and Future Directions

This research study allowed insight into respite workers’ experiences related to pain when supporting children with ID in respite settings. It enabled researchers to gain a better understanding of perceived need for pain training programs among this unique group of caregivers, and their preferences for training-specific details (e.g., format, content). While respite workers seem to be quite aware of the challenges associated with pain assessment and management, the current study could not confirm the depth of their knowledge. Currently there is no formal pain training program designed for respite caregivers who support children with ID. The creation and pilot testing of this type of pain training program was completed in Phase Two. Ensuring that respite workers have access to accurate information specific to pain in children with ID is critical in order to improve the pain-related care of these children.

Phase Two

Objectives

The 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., International Association for the Study of Pain Core Curriculum for Professional Education in Pain; Charlton, 2005) to create an empirically-informed pain assessment and management training program for respite workers, and (b) conduct a small pilot study with respite workers investigating the initial effectiveness of the pain training program using both pre-post outcome measures as well as
participants’ endorsement/opinion of the program. It was hypothesized that the following participant characteristics would increase pursuant to participation in the training program: (a) overall level of pain assessment and management knowledge; (b) self-rated perception of pain assessment and management feasibility in children with ID (c) self-rated levels of confidence in assessing and managing pain in children with ID, and (d) self-rated levels of perceived skill in assessing and managing pain in children with ID. It was expected that participants’ endorsement/opinion of the program would be favourable.

Methods

Participant Recruitment

As in Phase One, the primary method for recruiting participants for Phase Two involved the help of various organizations providing respite care for families in Southwestern Ontario. Two organizations were approached by telephone and/or email. After being provided with relevant information about the opportunity from the lead researcher (LG), both organizations agreed to host a free pilot pain training program for respite workers who would also be eligible to take part in Phase Two. Eligible participants had to: (a) be over the age of 18 years, (b) be proficient in the English language, and (c) currently providing respite care to children with intellectual disabilities under age 18. They also could not have participated in Phase One. Organizations sent out study information letters and consent forms ahead of time for review by eligible respite workers who would be attending the pain training. On the day of the training program, the lead researcher (LG) reviewed the study information and consent forms with all potential participants. Participating in the research study was optional (i.e., individuals could attend the training but not participate in the research study).

Participants
All participants present at both training pilot programs decided to take part in the study component. Participants consisted of a sample of 50 individuals ($M_{age}$: 33.20; range$_{age}$: 20 - 59; 46 female) from two different respite organizations in Southwestern Ontario. A total of 26 individuals participated in the first pain training pilot program ($M_{age}$: 39.70; range$_{age}$: 27 - 59; 24 female) and 24 individuals participated in the second pain training pilot program ($M_{age}$: 26.63; range$_{age}$: 20 - 42; 22 female). All participants had, at a minimum, completed high school, and 98% of the sample had at least some form of post-secondary education (e.g., college, university, trades, graduate school). Additional demographic information regarding participants can be found in Table 6. At the time of participation, all participants were actively providing respite care to children with ID, and held position titles such as Registered Practical Nurse, Respite Instructor, Residential Care Staff, and Community Living Staff.

According to guidelines on the sample size required in pilot studies (Hertzog, 2008), this sample size was sufficient for: (a) a pilot study aiming to investigate the effectiveness of an intervention (could detect a large effect at power of .80 and alpha of .05; Cohen, 1992) and (b) providing an effect size estimate for future intervention trials.

**Procedures**

Following provision of information about the study, eligible and interested participants provided informed consent. Participants were first asked to complete: (a) a demographics questionnaire, (b) two pain-related knowledge measures specific to children with ID, and (c) ratings of perceived levels of feasibility of, as well as confidence and skill in assessing and managing pain in children with ID. Individuals then participated in a 3.5 hour interactive pain training program. In addition, a 30 minute refreshment break was provided about halfway through the program. Following the pain training program, participants were asked to complete
post-measures for (b) and (c) described above, as well as an evaluation of the pain training program. All participants received an informational fact sheet about pain in children who have ID, the resources provided at the pain training, and an opportunity to enter a $15 gift card draw (odds of winning: 1 in 10).

Materials

A complete copy of each of these materials can be viewed in the Appendices.

Demographics Questionnaire (Pre-Training Intervention). The data gathered from participants in Phase Two was very similar to that which was gathered in Phase One (see Appendix A).

Pain Knowledge Questionnaire (Pre and Post Intervention). There are no well validated measures for assessing pain knowledge in respite workers, or pain knowledge specific to children who have ID. Thus, the researchers used two pain knowledge questionnaires to assess participants’ knowledge about pain in children with ID: an adapted published measure and a researcher developed measure. Both of these 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 (Pomerleau, Genik, McMurtry, & Breau, in prep.).

(a) The adapted pain knowledge questionnaire was based on Twycross and Williams’ (2013) Pediatric Pain Knowledge and Attitudes Questionnaire Revised (PPKAQ-R). Herein, this questionnaire will be referred to as the Adapted PPKAQ. In a sample of nursing students, Twycross and Williams (2013) found that the measure had acceptable internal consistency for five subscales (i.e., attitudes towards pain in children; physiology of pain; non-pharmacological methods of pain relief; pharmacological treatment of pain; sociology and psychology of pain), with all
Cronbach Alpha coefficients ranging from .70 to .82. Acceptable test-retest reliability was also found; all Spearman correlations for the subscales were greater than or equal to .70. Further analyses of participant responses from test-retest analyses revealed three items that were problematic in reliability analyses of individual items (Twycross & Williams, 2013).

In order to suit the purpose of the present study, the questionnaire was substantially adapted, with removal of the three items identified as problematic in individual item reliability analyses from the initial validation study (Twycross & Williams, 2013), as well as a large number of items not relevant to respite workers ($n = 49/71$ items; e.g., those related to post-operative analgesic drugs). Remaining relevant items were adapted as needed (e.g., to relate better to an everyday setting and one involving people with ID; see Appendix F). Eight questions specifically related to children with ID were created by the researchers and added to the questionnaire. Thus, there were 26 items on the final adapted questionnaire (see Appendix F). As in the original measure, participants responded on a 5-point Likert scale ranging from agree to disagree. In order to capture change in knowledge and attitudes, each item earned up to 5 points (for example, if the answer was “agree”, participants would earn 5 points for the correct answer, and 1 point for the least correct answer, disagree).

Given that the present study utilized an adapted version of the measure, only the total score was calculated; the individual subscales were not calculated or analyzed.

(b) The Pain Knowledge Test for Carers of Individuals with Intellectual Disabilities (PKT-CID) is a researcher generated 35 item true/false and multiple choice questionnaire (see Appendix G). It is designed to assess caregivers’ knowledge about
pain in individuals with ID. It was developed using Chapter 43 of the International Association for the Study of Pain’s (IASP) core curriculum (Pain Issues in Individuals with Limited Ability to Communicate Due to Cognitive Impairment) in tandem with existing research in the field. The questionnaire assesses both general pain-related knowledge, as well as comprehension of specific pain assessment and management issues. This questionnaire is scored by providing the respondent with one “point” for every correct response (maximum 35 points).

**Measures of Feasibility, Confidence and Skill (Pre and Post Intervention).** Aside from being administered twice (pre and post-training), these questions were identical to those in Phase One (see Appendix B).

**Pain Training Evaluation Questionnaire (Post Intervention).** This researcher-developed questionnaire included ten questions about aspects of the training (e.g., training format) for participants to rate ($0 = \textit{strongly disagree}$ to $10 = \textit{strongly agree}$). These questions were presented on a $0 – 10$ point scale to allow for increased variability in response. The questionnaire also included open-ended questions which asked participants for more specific answers about what they liked or did not like about the training and how it could be improved in the future (see Appendix H).

**Pain Training Pilot Program**

Participants completed a training program about pain in children with ID that was approximately 3.5 hours in length, plus one half hour break. The format and content emphasized in the workshop 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 from previous delivery of two similar pain training
workshops designed for respite care workers in day camp settings, four similar pain training workshops for a different research study, and direct experience as a respite caregiver. The training consisted of an interactive, in person training workshop with a focus on what pain is, pain expression in children with ID, how to assess pain in this population, and pain management strategies that can be used in respite settings. In an attempt to meet participating organizations’ needs and the large amount of interest in the training program, the pilot groups were larger than participants’ median group size preferences from Phase One. However, the sample size of both pilot groups fell in the overall range of responses regarding ideal group size. The same researcher (LG) facilitated both pilot training programs, and used a Power-Point presentation with notes in order to provide consistent information across sessions. Interactive activities included group tasks and discussions (e.g., case studies, reviewing pain assessment tools and working together to adapt the tools for children with particular needs and abilities), watching and discussing videos. During the training, participants received empirically supported resources and materials that could be used with or adapted for some of the children they support [e.g., the Faces Pain Scale - Revised, a self-report tool that measures pain intensity; Hicks et al., 2001; Non-Communicating Children’s Pain Checklist - Postoperative Version; Breau et al., 2002); and a link to the Pediatric Pain Profile, a behaviour rating scale designed to help with pain assessment in children with severe disabilities; Hunt et al., 2004]. See Appendix I for a detailed outline of the content within the training program.

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, but not analyses for which all their data were available. This approach was chosen to best represent the data for the pain
knowledge measures, given that they were targeting multifaceted aspects of pain-related knowledge.

Given that this was a pilot study, the nature of the missing data were further explored. On a few occasions for the demographics as well as feasibility, confidence and skills ratings, participants seemed to skip the back side of some pages, as they were presented double-sided. Both pain knowledge measures had missing data from a number of participants at both pre and post time points (PKTCID Pre: 9; PKTCID Post: 10; adapted PPKAQ Pre: 7; adapted PPKAQ Post: 9). The pre and post sets of questionnaires had similar numbers of participants with missing responses, and about half of the participants with missing data at the pre-training time point also had missing data in the corresponding post measure. Participants ranged from missing only one response on a given questionnaire to skipping entire questionnaires (median for missing items for each questionnaire: PKTCID Pre: 3; PKTCID Post: 2; adapted PPKAQ Pre: 2; adapted PPKAQ Post: 1). At the question level, no question on either measure was missing more than four responses out of the 50 participants. The items on the second half of the PKT-CID seemed to be most commonly missing, while items missing from the adapted PPKAQ seemed to be more randomly distributed. Given that the PKT-CID involved more reading and critical thinking through the use of true/false and multiple choice questions, it is possible that those participants with more missing items towards the end of the given questionnaire were demonstrating fatigue. Anecdotally, some participants spoke with the lead researcher (LG) about the length of the questionnaires, and feeling fatigued towards the end of each data collection period. It appears that one of three factors may have most likely led to missing data: (a) some items may have been accidentally missed (e.g., overlooking a question), (b) some items may have been intentionally skipped (e.g., due to fatigue, as a number of participants indicated how long the questionnaires
were), and (c) some participants may have opted not to complete some of the questionnaires at all.

**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 (Field, 2005). Although the training was structured in nature, the two groups were compared for significant differences in demographics (e.g., age) using independent samples t-tests. Participant age ($M_{agePilot1}$: 39.70; $M_{agePilot2}$: 26.63; $t$ (36.88) = 6.12, $p < .001$), the number of 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 their level of direct involvement in the care of children with ID ($M_{directcontactPilot1}$: 9.88; $M_{directcontactPilot2}$: 8.48; $t$ (23.33) = 3.62, $p < .01$) were significantly different between groups. Given these demographic differences, analyses of the outcome measures (knowledge, feasibility, confidence, skill; described below) were conducted and reported for the entire sample ($n = 50$; main analysis) as well as by group (exploratory analyses) below.

**Effect of Training**

**Pain Knowledge.** After total scores were calculated for both the adapted PPKAQ and the PKT-CID, 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 (Field, 2005). As the current study was exploratory 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.** Given the lack of information about psychometric properties of the feasibility, confidence and skill ratings, descriptive statistics (e.g., ranges) for these ratings and their inter-relationships were examined. Given 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. As recommended for small sample sizes by Field (2005), variables with z score values above 2.58 were considered non-normal. Spearman’s correlation coefficient was used for variables with z scores above this threshold; Pearson’s correlation coefficient was used for those that had z scores below this threshold. In order to examine pre-post ratings of perceived feasibility of, confidence in, and skill in assessing and managing pain in children with ID (hypotheses b, c, and d), paired samples t-tests were used, following the same guidelines as described above for the two knowledge measures.

**Training Program Evaluations**

Finally, data from the training program evaluations (i.e., participants’ ratings on various aspects of the pain training program) were analyzed using frequency and descriptive analyses.

**Results**

**General Observations of Pain Training Pilot Program Group Dynamics**

When conducting both pain training pilot programs, the lead researcher (L.G.) observed that both groups were clearly well invested and passionate about their work with the children for whom they care, and were interested in learning more about pain in these children. However, there were some general differences in the group dynamics. For example, one of the training
pilot programs engaged in more off-topic discussions and questions compared to the other, and, on occasion, the lead researcher (L.G.) had to remind the participants to stay on task, or to pay attention. This was particularly the case during and directly following group activities. They were also much more critical of the information provided to them in the training. While this group still seemed to see the training as important, as a whole, they seemed less receptive and interested in the material.

Knowledge Measures

On average, participants’ scores on both knowledge measures were significantly higher following completion of the pain training pilot program than their scores before completion of the training, adapted PPKAQ: \( t(37) = -11.71, p < .001 \); PKT-CID: \( t(37) = -8.32, p < .001 \). These analyses yielded large effects of \( r = .88 \) and \( .81 \) respectively (see Table 7 for descriptives). These results also held for both Pilot One, adapted PPKAQ: \( t(17) = -8.50, p < .001, r = .90 \); PKT-CID: \( t(19) = -5.54, p < .001, r = .79 \), and for Pilot Two, adapted PPKAQ: \( t(19) = -7.96, p < .001, r = .88 \); PKT-CID: \( t(17) = -6.14, p < .001, r = .83 \), when the groups were examined separately,

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

Although feasibility ratings often did not correlate significantly with other variables, positive correlations existed between many of these ratings, with significant correlational coefficients ranging from \(.519\) to \(.844\), at \( p < .001 \) (see Table 8). More specifically, the strongest correlations were seen 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. There were some significant positive correlations between participants’ ratings for feasibility, confidence and skill between their assessment and treatment
ratings. Ratings of feasibility, confidence and skill at the pre time period were not significantly correlated with participants’ ratings at the post time period.

Descriptive statistics for these ratings appear in Table 9. Overall, participants’ beliefs about the feasibility of, and their own perceived confidence and skill in assessing pain in children with ID increased significantly following the pain training program [feasibility: $t(47) = -3.06, p < .01$; confidence: $t(48) = -6.81, p < .001$; skill: $t(48) = -4.80, p < .001$]. Similarly, participants’ beliefs about the feasibility of, and their own perceived confidence and skill in managing pain in children with ID also increased significantly following the pain training program [feasibility: $t(45) = -3.97, p < .001$; confidence: $t(46) = -4.99, p < .001$; skill: $t(46) = -5.34, p < .001$]. All of these analyses yielded large effects ($r = .51 - .70$), with the exception of the assessment feasibility ratings, which was a medium effect ($r = .41$; Cohen, 1992).

In comparison to the second pilot training group, the first pilot training group gave a number of significantly higher ratings at both pre and post time points (see Table 10 for results statistics). Despite this, significant increases in all ratings across time remained even when examining both groups individually, with the exception of the first pilot training’s assessment feasibility ratings, $t(24) = -1.73, p = 0.96$ (see Table 11 for additional statistics).

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

Overall, participants positively endorsed aspects of the pain training pilot program such as its value and format. Interestingly, while rated favourably in both groups, many of these ratings did vary significantly between groups, such that the first pilot training group had higher ratings compared to the second pilot training group. See Table 12 for descriptives.
Discussion

As explored in Phase One, respite workers view pain training as important and have many ideas regarding desired content and formatting. Previous research has found that pain training programs can improve pain knowledge for those entering or currently working in health-related fields (e.g., Hunter et al., 2008). The aims of Phase Two were to use results from Phase One along with extant research and guidelines to develop a pain training program for respite workers, and to evaluate its initial effectiveness by conducting a small pilot study.

Participants’ Pain Knowledge

As hypothesized and consistent with related research (e.g., Gagnon et al., 2013; Hunter et al., 2008; Zhang et al., 2008), participants’ pain knowledge on both measures increased significantly following completion of the pain training program. Notably, even though participants from the first pilot program had more experience than those in the second pilot program, both groups demonstrated a significant increase in knowledge. These findings suggest that a pain training program could be an effective and appropriate method of providing respite caregivers who have varying levels of experience with the information they need to better assess and manage pain in children with ID. What remains unclear, however, is whether this increase in knowledge will translate into practice, or further, whether the knowledge will be sustained over time. It is important to note that even immediately following the pain training program, no one received a perfect score on the PKT-CID, and only one participant received a perfect score on the adapted PPKAQ. In future research, an error analysis on the knowledge measure(s) may be beneficial. From there, researchers could investigate why participants were responding incorrectly to specific questions. For example, is there a problem with the question itself that
makes it difficult to understand, or is there a gap in participants’ knowledge that needs to be more clearly addressed within a training program?

**Participants’ Ratings of the Feasibility of, and Their Confidence and Skill in Pain Assessment and Management for Children with ID**

Overall, the inter-relationships between participants’ ratings of feasibility of and their own confidence and skill in pain assessment and management for children with ID made intuitive sense. For example, participants’ perceptions of the feasibility of pain assessment and management was uncorrelated with the majority of other variables at both pre and post time periods. This is logical as simply because something is feasible, it does not necessarily mean that an individual will be confident or skilled in that area. Further, participants may not have control over institutional factors that could impact feasibility of pain assessment and management. In turn, this could also impact participants’ feasibility ratings. Confidence and skill ratings however, were often significantly positively correlated, suggesting that those with higher skill also believe themselves to be more confident in pain assessment and management. Further, the correlations between participants’ ratings of aspects of assessment and treatment could also suggest that individuals’ confidence and perceived skill in both assessment and treatment may be, in general, quite similar to each other.

As hypothesized, participants’ ratings of feasibility of and their own confidence and skill in pain assessment and management for children with ID increased significantly following training. Again, this finding is consistent with similar research, such as Dalton et al.’s (1998) study in which factors other than knowledge (i.e., perceived credibility and effectiveness) improved following a pain training program. Improved feasibility ratings suggest that the workshop increased participants' perceptions that it is possible to assess and manage pain in this
population. This is a positive finding, as participants may be more likely to engage in these activities if they feel they are feasible. Notably, however, when examining the training groups separately, one group’s ratings of assessment feasibility did not increase significantly following the training. However, the initial assessment feasibility ratings of these participants were quite high initially which may have been related to unique participant characteristics (e.g., having more or different pain-related training experiences than pilot 2), or perhaps unique experiences or characteristics of the children with whom they work. The null result may simply reflect a ceiling effect.

The improved ratings of feasibility, confidence and skill of the full sample following the pain training may also suggest that further exposure, education and discussion about the issue of pain in children with ID can improve caregivers’ perceptions of these three areas. However, it is important to remember that the skill ratings are only participants’ perceptions. Similar research reviewing 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 (Glajchen & Bookbinder, 2001). The extent to which participants’ ratings accurately reflect their actual skills in pain assessment and management is unknown.

**Participants’ Training Program Evaluations**

Finally, participants’ evaluations of the pain training program (e.g., content, format) were highly favourable, ranging from mean ratings of 8.61 to 9.15 out of 10. Combined with the use of international guidelines, the positive evaluation suggests that the researchers did an adequate job of ensuring that the training included appropriate and empirically based information that also met the needs and preferences of respite workers. Participants also indicated that they planned to
incorporate what they learned into their work \([M = 9.01\) (out of 10)]. It would be important to further investigate how and what respite workers incorporate into their work with children with ID.

While both training groups rated the program favourably, their ratings differed significantly from each other. In other research related to training programs, it has been suggested that a number of factors including the number of years in the specific job, and participants’ satisfaction with the employment program itself may impact training such as their likelihood to use the information (e.g., Lim & Morris, 2006). Thus, it is possible that differing demographics (e.g., age), experiences, and dynamics of a group may determine their response to the training material and format, as well as their likelihood to apply the new knowledge in their work. In the present study, participants from the two pilot training groups not only differed in demographics (i.e., age, number of years working in a children’s respite organization, degree of direct involvement in care of children with ID), their experiences (e.g., working with children with differing types of needs; working in different types of respite programming), and but also in their group dynamics and response to the training (e.g., level of distraction/off topic discussions throughout the training). It is important to remember, however, these differences in dynamics did not seem to affect the benefits of the training, as both groups demonstrated an increase in knowledge and other ratings.

Nevertheless, participant and group-based factors are important to consider in future research, as they could have implications for engagement with the material and success of the training. For example, a group that engages in more off-task behaviours or discussion may not be as focused and therefore more likely to miss some of the material being covered. Similarly, organizations who support children with more complex needs or who are considered non-
communicative would likely have differing needs and interests related to pain assessment and management than a respite organization who provides recreational support to children that are ambulatory and have some verbal and communicative abilities. These differences between groups may lead staff to focus on or resonate with one particular aspect of the training compared to another.

**Strengths and Limitations**

This was the first study to develop and conduct preliminary testing on a pain training program tailored to secondary caregivers who support children with ID outside of health care settings. This pilot study allowed the researchers to explore the feasibility and initial effectiveness of the pain training program and identify challenges to be addressed prior to conducting a larger scale study (e.g., missing data - see limitations). Given the adequate sample size, information from this pilot study can be used for a power analysis in planning a large-scale intervention study (Hertzog, 2008). The program was carefully constructed based on extant research literature and pre-identified needs and preferences gathered directly from respite staff and management in children’s respite organizations, which helped to ensure the program’s credibility and relevance to its audience. Two different organizations offering different types of respite care participated, allowing the researchers to gain a sense of the suitability of the pain training program for workers within organizations who engage in different types of respite programming and support children with differing needs and abilities.

There are also a number of limitations to consider. This was a pilot study which did not include a control group nor long term/follow up assessment of participants’ knowledge. It also did not examine actual behaviour. However, participants indicated that they were likely to use the knowledge in their work with children with ID. This study involved only a small sample of
respite workers. This means that the results are limited in scope and may not generalize to other respite workers in the field. Social desirability was not examined, and so it is possible that some of the self-report measures about feasibility of and perceived confidence and skill in pain assessment and management were inflated. A large number of participants skipped or missed questions in both the PPKAQ and PKT-CID knowledge measures at pre and/or post data collection. In the future, it will be important to reduce the amount of missing data. For example, it seemed as though much of the missing data may have been related to a combination of accidentally missing questions, intentionally skipping items, and opting to skip some questionnaires during the data collection time periods. In the future, participants may be provided with stronger encouragement to select an “I don’t know” option if they do not know an answer, and to review their questionnaires for completion prior to submitting to researchers. Further, the length of the questionnaires could be shortened to address participant fatigue, and single sided pages could be used so that participants are less likely to accidentally miss a page. Finally, it may also be important to consider group dynamics and the potential impact of this on group data collection processes (e.g., amount of missing data).

**Future Directions and Conclusions**

This research study involved the development of a pain training program directed towards respite workers who care for children with ID. Results suggested that completion of the pain training program can increase pain-related knowledge of these caregivers, as well as their perceptions of the feasibility of, and their own confidence and skill in pain assessment and management in children with ID. Further, various aspects of the training program’s content and format were rated favourably by those who participated. Research should be conducted identify the mechanisms of change responsible for the success of the intervention in order to create and
tailor the intervention. Future research should continue to evaluate this training program using larger, diverse samples in a randomized control trial. It should also explore knowledge translation pathways to ensure this knowledge is disseminated to respite workers and other secondary caregivers who support children with ID. 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.
References


Genik, L.M., McMurtry, C.M., & Breau, L. (in preparation(a)). Caring for children with cognitive impairments part 1: Experience with the population, pain-related beliefs, and care decisions.


knowledge, attitude, and self-esteem of volunteer providers. *American Journal of Alzheimer's Disease and Other Dementias, 18*(6), 375-382.


Table 1

Phase one: Additional participant demographics and characteristics.

<table>
<thead>
<tr>
<th></th>
<th>Management (Interviews) n = 4 - 5</th>
<th>Respite Workers (Focus Groups) n = 16 - 17</th>
<th>Full Sample n = 21 - 22</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnicity (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>European/White</td>
<td>4 (100%)</td>
<td>14 (82.4%)</td>
<td>18 (81.8%)</td>
</tr>
<tr>
<td>Black/African/Caribbean</td>
<td>0 (0%)</td>
<td>3 (17.6%)</td>
<td>3 (13.6%)</td>
</tr>
<tr>
<td>Number of years employed with organization related to respite care for children with ID (years)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean years</td>
<td>11</td>
<td>9.1</td>
<td>9.5</td>
</tr>
<tr>
<td>Median</td>
<td>7.0</td>
<td>7.0</td>
<td>7.0</td>
</tr>
<tr>
<td>Range</td>
<td>4 - 30</td>
<td>0.6 - 20</td>
<td>0.6 - 30</td>
</tr>
<tr>
<td>Frequency of interaction with children with ID (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occasionally</td>
<td>1 (20%)</td>
<td>0 (0%)</td>
<td>1 (4.5%)</td>
</tr>
<tr>
<td>Often/Very Often</td>
<td>4 (80%)</td>
<td>17 (100%)</td>
<td>95.5%</td>
</tr>
<tr>
<td>Degree of direct involvement in care of children with ID (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean Rating</td>
<td>8.40</td>
<td>9.56</td>
<td>9.29</td>
</tr>
<tr>
<td>0 - 3</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>4 - 6</td>
<td>1 (20%)</td>
<td>0 (0%)</td>
<td>1 (4.8%)</td>
</tr>
<tr>
<td>7 - 10</td>
<td>4 (80%)</td>
<td>16 (100%)</td>
<td>20 (95.2%)</td>
</tr>
</tbody>
</table>

Note: Participants rated their frequency of interaction with children with ID on a five point Likert scale ranging from ‘Never’ to ‘Very Often’. Participants rated their degree of direct involvement in care of children with ID on a scale of 0 (Not At All Involved) to 10 (Highly Involved). Valid percent was used in the case of missing data.
Table 2

Phase one: Coding for pain training specifics questionnaire - coded questions and their cohen’s kappa reliability values for practice and final coding.

<table>
<thead>
<tr>
<th>Question</th>
<th>Practice Coding: Cohen’s Kappa</th>
<th>Final Coding: Cohen’s Kappa</th>
</tr>
</thead>
<tbody>
<tr>
<td>• What types of activities would be beneficial to include (e.g., case studies, group discussions, etc.)?</td>
<td>1.00</td>
<td>0.75</td>
</tr>
<tr>
<td>• Should handouts and resources be provided to participants? If so, in what format should they be provided (e.g., hard copy, via email, etc.)?</td>
<td>1.00</td>
<td>0.93</td>
</tr>
<tr>
<td>• What would be the most important thing to include in a pain training workshop?</td>
<td>0.75</td>
<td>0.82</td>
</tr>
<tr>
<td>• What would be the least important thing to include in a pain training workshop?</td>
<td>0.77</td>
<td>0.79</td>
</tr>
</tbody>
</table>

Note: Qualitative descriptions of Cohen’s Kappa values according to Landis & Koch (1977): < 0: no agreement; 0–0.20: slight agreement; 0.21–0.40: fair agreement; 0.41–0.60: moderate agreement; 0.61–0.80: substantial agreement; 0.81–1: almost perfect agreement.
Table 3

Phase one: Mean and standard deviation of perceived feasibility, confidence and skill in pain assessment and management for children with ID (0 – 10)

<table>
<thead>
<tr>
<th></th>
<th>Management (Interviews)</th>
<th>Respite Workers (Focus Groups)</th>
<th>Full Sample N = 22</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain Assessment</td>
<td>N = 5</td>
<td>N = 17</td>
<td></td>
</tr>
<tr>
<td>• Feasibility (Range: 3 - 10)</td>
<td>7.80 (1.48)</td>
<td>8.06 (2.22)</td>
<td>8.00 (2.05)</td>
</tr>
<tr>
<td>• Confidence (Range: 2 - 10)</td>
<td>5.80 (1.92)</td>
<td>6.24 (2.41)</td>
<td>6.14 (2.27)</td>
</tr>
<tr>
<td>• Perceived skill (Range: 2 - 10)</td>
<td>5.20 (2.59)</td>
<td>6.29 (2.42)</td>
<td>6.05 (2.44)</td>
</tr>
<tr>
<td>Pain Management</td>
<td>N = 5</td>
<td>N = 17</td>
<td></td>
</tr>
<tr>
<td>• Feasibility (Range: 5 - 10)</td>
<td>7.20 (0.84)</td>
<td>7.35 (1.90)</td>
<td>7.32 (1.70)</td>
</tr>
<tr>
<td>• Confidence (Range: 4 - 10)</td>
<td>6.40 (1.34)</td>
<td>6.60 (2.17)</td>
<td>6.55 (1.96)</td>
</tr>
<tr>
<td>• Perceived skill (Range: 2 - 10)</td>
<td>5.60 (2.30)</td>
<td>6.40 (2.13)</td>
<td>6.20 (2.14)</td>
</tr>
</tbody>
</table>

Note: 0 = Not Feasible At All, 10 = Highly Feasible; 0 = Not Confident At All, 10 = The Most Confident Possible; 0 Not Skilled At All, 10 = The Most Skilled Possible
Table 4

Phase one: Participant ratings of general interest in and perceived value of a pain training program.

<table>
<thead>
<tr>
<th></th>
<th>Management (Interviews)</th>
<th>Respite Workers (Focus Groups)</th>
<th>Full Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(N = 5)</td>
<td>(N = 17)</td>
<td>(N = 22)</td>
</tr>
<tr>
<td>1. A PTW for respite workers would be valuable.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(\text{Mean (SD)})</td>
<td>7.80 (2.28)</td>
<td>9.59 (1.23)</td>
<td>9.18 (1.65)</td>
</tr>
<tr>
<td>(\text{Range})</td>
<td>5 - 10</td>
<td>5 – 10</td>
<td>5 - 10</td>
</tr>
<tr>
<td>2. Information from a PTW would be applicable to my work</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(\text{Mean (SD)})</td>
<td>7.20 (2.28)</td>
<td>9.59 (1.23)</td>
<td>9.05 (1.76)</td>
</tr>
<tr>
<td>(\text{Range})</td>
<td>5 - 10</td>
<td>5 - 10</td>
<td>5 - 10</td>
</tr>
<tr>
<td>3. A PTW would be interesting</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(\text{Mean (SD)})</td>
<td>8.80 (1.79)</td>
<td>9.71 (0.77)</td>
<td>9.50 (1.10)</td>
</tr>
<tr>
<td>(\text{Range})</td>
<td>6 - 10</td>
<td>7 - 10</td>
<td>6 - 10</td>
</tr>
<tr>
<td>4. I would encourage other respite workers to participate in a PTW</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(\text{Mean (SD)})</td>
<td>9.00 (2.24)</td>
<td>9.65 (1.22)</td>
<td>9.50 (1.47)</td>
</tr>
<tr>
<td>(\text{Range})</td>
<td>5 - 10</td>
<td>5 - 10</td>
<td>5 - 10</td>
</tr>
<tr>
<td>5. I am interested in learning about pain in C/ID</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(\text{Mean (SD)})</td>
<td>9.40 (1.34)</td>
<td>9.65 (1.00)</td>
<td>9.59 (1.05)</td>
</tr>
<tr>
<td>(\text{Range})</td>
<td>7 - 10</td>
<td>6 - 10</td>
<td>6 - 10</td>
</tr>
<tr>
<td>6. Importance of a PTW for respite workers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(\text{Mean (SD)})</td>
<td>7.40 (1.95)</td>
<td>9.24 (1.56)</td>
<td>8.82 (1.79)</td>
</tr>
<tr>
<td>(\text{Range})</td>
<td>5 - 10</td>
<td>4 - 10</td>
<td>4 - 10</td>
</tr>
</tbody>
</table>

Note: PTW = Pain Training Workshop; C/ID = children with intellectual disabilities; 10 = “Strongly Agree” (questions 1 to 5); 10 = “Extremely Important” (question 6)
Table 5

*Phase one: Participants’ format preferences for a pain training program.*

<table>
<thead>
<tr>
<th></th>
<th>Management (Interviews; N = 5)</th>
<th>Respite Workers (Focus Groups; N = 17)</th>
<th>Full Sample (Interviews and Focus Groups Combined; N = 22)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Most Preferred Format</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• In Person</td>
<td>3 (60%)</td>
<td>11 (68.8%)</td>
<td>14 (66.7%)</td>
</tr>
<tr>
<td>• Online</td>
<td>0 (0%)</td>
<td>1 (6.3%)</td>
<td>1 (4.8%)</td>
</tr>
<tr>
<td>• Hybrid</td>
<td>2 (40%)</td>
<td>4 (25%)</td>
<td>6 (28.6%)</td>
</tr>
<tr>
<td><strong>Least Preferred Format</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• In Person</td>
<td>1 (20%)</td>
<td>1 (7.1%)</td>
<td>2 (10.5%)</td>
</tr>
<tr>
<td>• Online</td>
<td>3 (60%)</td>
<td>11 (78.6%)</td>
<td>14 (73.7%)</td>
</tr>
<tr>
<td>• Hybrid</td>
<td>1 (20%)</td>
<td>2 (14.3%)</td>
<td>3 (15.8%)</td>
</tr>
<tr>
<td><strong>Mean Preferred Workshop Length</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• In Person</td>
<td>3.95</td>
<td>5.64</td>
<td>5.20 hours</td>
</tr>
<tr>
<td>• Online</td>
<td>2.00</td>
<td>3.58</td>
<td>3.14 hours</td>
</tr>
<tr>
<td>• Hybrid</td>
<td>4.88</td>
<td>4.48</td>
<td>4.57 hours</td>
</tr>
<tr>
<td><strong>Ideal Workshop Group Size</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Mean</td>
<td>17.50</td>
<td>13.63</td>
<td>14.60</td>
</tr>
<tr>
<td>• Range</td>
<td>10 - 30</td>
<td>8 - 38</td>
<td>8 - 38</td>
</tr>
<tr>
<td><strong>Provision of Handouts/Certificate</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Yes</td>
<td>5 (100%)</td>
<td>17 (100%)</td>
<td>22 (100%)</td>
</tr>
</tbody>
</table>

*Note: When missing data was present, the valid percentages were calculated and used; a star (*) is placed before the category name where this is relevant.*
Table 6

Phase two: Additional participant demographics and characteristics from the pain training pilot program.

<table>
<thead>
<tr>
<th></th>
<th>Pain Training Pilot #1 (n = 24 - 26)</th>
<th>Pain Training Pilot #2 (n = 23 - 24)</th>
<th>Full Sample (n = 48 - 50)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnicity (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>European/White</td>
<td>14 (53.8%)</td>
<td>7 (29.2%)</td>
<td>21 (42%)</td>
</tr>
<tr>
<td>Black/African/Caribbean</td>
<td>8 (30.8%)</td>
<td>8 (33.3%)</td>
<td>16 (32%)</td>
</tr>
<tr>
<td>South/West/Southeast Asian</td>
<td>0 (0%)</td>
<td>7 (29.2%)</td>
<td>7 (14%)</td>
</tr>
<tr>
<td>Latin American</td>
<td>2 (7.7%)</td>
<td>0 (0%)</td>
<td>2 (4%)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (7.7%)</td>
<td>2 (8.3%)</td>
<td>4 (8%)</td>
</tr>
<tr>
<td>Number of years employed with organization related to respite care for children with ID (years) *</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meanyears</td>
<td>11.7</td>
<td>4.6</td>
<td>8.3</td>
</tr>
<tr>
<td>Medianyears</td>
<td>8.5</td>
<td>3.0</td>
<td>6.3</td>
</tr>
<tr>
<td>Range</td>
<td>1 - 41</td>
<td>1 - 14</td>
<td>1 - 41</td>
</tr>
<tr>
<td>Frequency of interaction with children with ID (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occasionally</td>
<td>2 (7.7%)</td>
<td>1 (4.3%)</td>
<td>3 (6.3%)</td>
</tr>
<tr>
<td>Often/Very Often</td>
<td>23 (88.5%)</td>
<td>22 (95.6%)</td>
<td>45 (93.8%)</td>
</tr>
<tr>
<td>Degree of direct involvement in care of children with ID (%) *</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean Rating</td>
<td>9.88</td>
<td>8.48</td>
<td>9.21</td>
</tr>
<tr>
<td>0 - 3</td>
<td>0 (0%)</td>
<td>1 (4.3%)</td>
<td>1 (2.1%)</td>
</tr>
<tr>
<td>4 - 6</td>
<td>0 (0%)</td>
<td>1 (4.3%)</td>
<td>1 (2.1%)</td>
</tr>
<tr>
<td>7 - 10</td>
<td>25 (100%)</td>
<td>21 (91.3%)</td>
<td>46 (95.8%)</td>
</tr>
<tr>
<td>Number of participants who had participated in training related to pain in children (%) *</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>8 (30.8%)</td>
<td>1 (4.2%)</td>
<td>9 (18%)</td>
</tr>
<tr>
<td>No</td>
<td>18 (69.2%)</td>
<td>23 (95.8%)</td>
<td>41 (92%)</td>
</tr>
</tbody>
</table>

Note: Participants rated their frequency of interaction with children with ID on a five point Likert scale ranging from ‘0 - Never’ to ‘4 - Very Often’. Participants rated their degree of direct involvement in care of children with ID on a scale of 0 (Not At All Involved) to 10 (Highly Involved). Valid percent was used in the case of missing data. An asterisk indicates that the variable was significantly different between pilot groups.
Eight of the nine participants who had participated in training related to pain in children did so via nursing-related educational programming. Previous pain training received is not necessarily specific to children with ID.
## Table 7

*Phase two: Mean and standard deviation of participants’ scores at pre and post time points for the adapted PPKAQ and the PKT-CID.*

<table>
<thead>
<tr>
<th></th>
<th>Pain Training Pilot #1 (n = 26)</th>
<th>Pain Training Pilot #2 (n = 24)</th>
<th>Full Sample (n = 50)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Adapted PPKAQ - Pre - Mean (SD; n)</strong></td>
<td>102.79 (8.76; 19)</td>
<td>97.67 (9.46; 24)</td>
<td>99.93 (9.41; 43)</td>
</tr>
<tr>
<td><strong>Adapted PPKAQ - Post - Mean (SD; n)</strong></td>
<td>117.29 (9.16; 21)</td>
<td>110.65 (9.65; 20)</td>
<td>114.04 (9.87; 41)</td>
</tr>
<tr>
<td><strong>PKT-CID - Pre - Mean (SD; n)</strong></td>
<td>23.10 (4.67; 21)</td>
<td>19.20 (6.09; 20)</td>
<td>21.20 (5.69; 41)</td>
</tr>
<tr>
<td><strong>PKT-CID - Post - Mean (SD; n)</strong></td>
<td>28.09 (3.12; 22)</td>
<td>25.17 (4.69; 18)</td>
<td>26.78 (4.12; 40)</td>
</tr>
</tbody>
</table>

*Note: Maximum score for adapted PPKAQ: 135; Maximum score for PKT-CID: 35*
### Table 8

*Phase two: Correlational analyses for participant ratings of feasibility, confidence and skill in pain assessment and management for children with ID.*

<table>
<thead>
<tr>
<th>Rating</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7^</th>
<th>8</th>
<th>9</th>
<th>10^</th>
<th>11</th>
<th>12</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Assessment - Feasibility (Pre)</td>
<td>--</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Assessment - Confidence (Pre)</td>
<td>.273</td>
<td>--</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Assessment - Skill (Pre)</td>
<td>.369</td>
<td>.611**</td>
<td>--</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Treatment - Feasibility (Pre)</td>
<td>.389</td>
<td>.564**</td>
<td>.306</td>
<td>--</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Treatment - Confidence (Pre)</td>
<td>.302</td>
<td>.806**</td>
<td>.581**</td>
<td>.582**</td>
<td>--</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Treatment - Skill (Pre)</td>
<td>.341</td>
<td>.768**</td>
<td>.585**</td>
<td>.602**</td>
<td>.844**</td>
<td>--</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Assessment - Feasibility (Post)^</td>
<td>.271</td>
<td>.329</td>
<td>.388</td>
<td>.280</td>
<td>.348</td>
<td>.192</td>
<td>--</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Assessment - Confidence (Post)</td>
<td>.268</td>
<td>.339</td>
<td>.316</td>
<td>.230</td>
<td>.387</td>
<td>.352</td>
<td>.536**</td>
<td>--</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Assessment - Skill (Post)</td>
<td>.191</td>
<td>.191</td>
<td>.272</td>
<td>.100</td>
<td>.269</td>
<td>.213</td>
<td>.348</td>
<td>.816**</td>
<td>--</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Treatment - Feasibility (Post)^</td>
<td>.128</td>
<td>.277</td>
<td>.236</td>
<td>.394</td>
<td>.328</td>
<td>.222</td>
<td>.583**</td>
<td>.616**</td>
<td>.454</td>
<td>--</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Treatment - Confidence (Post)</td>
<td>-.008</td>
<td>.439</td>
<td>.098</td>
<td>.401</td>
<td>.395</td>
<td>.316</td>
<td>.411</td>
<td>.554**</td>
<td>.457</td>
<td>.711**</td>
<td>--</td>
<td></td>
</tr>
<tr>
<td>12. Treatment - Skill (Post)</td>
<td>-.069</td>
<td>.332</td>
<td>.150</td>
<td>.196</td>
<td>.280</td>
<td>.216</td>
<td>.256</td>
<td>.511**</td>
<td>.519**</td>
<td>.523**</td>
<td>.742**</td>
<td>--</td>
</tr>
</tbody>
</table>

*Note.* Ratings with a ^ sign indicates that the distribution was non-normal, and that Spearman’s correlation coefficient was used. ** indicates $p < .001$. 
Table 9

Phase two: Descriptives of participant ratings of feasibility of, confidence in, and skill in pain assessment and management for children with ID.

<table>
<thead>
<tr>
<th></th>
<th>Pain Training Pilot #1 (n = 24 - 26)</th>
<th>Pain Training Pilot #2 (n = 23 - 24)</th>
<th>Full Sample (n = 47 - 50)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>Pre-Ratings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Assessment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>o Feasibility</td>
<td>8.40 (1.68)</td>
<td>7.61 (2.02)</td>
<td>8.02 (1.87)</td>
</tr>
<tr>
<td>o Confidence</td>
<td>7.08 (1.55)</td>
<td>5.54 (2.02)</td>
<td>6.33 (1.94)</td>
</tr>
<tr>
<td>o Skill</td>
<td>7.08 (1.78)</td>
<td>6.17 (2.08)</td>
<td>6.63 (1.97)</td>
</tr>
<tr>
<td>• Management</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>o Feasibility</td>
<td>8.46 (1.14)</td>
<td>7.04 (2.12)</td>
<td>7.77 (1.82)</td>
</tr>
<tr>
<td>o Confidence</td>
<td>7.87 (1.54)</td>
<td>6.33 (1.44)</td>
<td>7.10 (1.67)</td>
</tr>
<tr>
<td>o Skill</td>
<td>7.54 (1.38)</td>
<td>6.38 (1.41)</td>
<td>6.96 (1.50)</td>
</tr>
<tr>
<td>Post-Ratings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Assessment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>o Feasibility</td>
<td>9.04 (1.43)</td>
<td>8.71 (1.23)</td>
<td>8.88 (1.34)</td>
</tr>
<tr>
<td>o Confidence</td>
<td>8.50 (1.42)</td>
<td>8.00 (1.25)</td>
<td>8.26 (1.35)</td>
</tr>
<tr>
<td>o Skill</td>
<td>8.27 (1.56)</td>
<td>7.92 (1.25)</td>
<td>8.10 (1.42)</td>
</tr>
<tr>
<td>• Management</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>o Feasibility</td>
<td>9.27 (1.31)</td>
<td>8.30 (1.40)</td>
<td>8.82 (1.42)</td>
</tr>
<tr>
<td>o Confidence</td>
<td>8.88 (1.28)</td>
<td>7.78 (1.35)</td>
<td>8.37 (1.42)</td>
</tr>
<tr>
<td>o Skill</td>
<td>8.62 (1.13)</td>
<td>7.91 (1.13)</td>
<td>8.29 (1.17)</td>
</tr>
</tbody>
</table>

Note: All ratings were from 0 - 10 (highly/extremely feasible, confident, skilled). As skewness analyses indicated that the post ratings of assessment feasibility and treatment feasibility were significantly non-normal, the medians for these variables were also calculated: 9 and 10, respectively.
Table 10

Phase two: Independent t-test results comparing participant ratings of assessment and treatment feasibility, confidence and skill between groups at pre and post data collection time periods.

<table>
<thead>
<tr>
<th></th>
<th>t</th>
<th>df</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre: Assessment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Feasibility</td>
<td>1.48</td>
<td>46</td>
<td>.146</td>
</tr>
<tr>
<td>• Confidence</td>
<td>2.99</td>
<td>47</td>
<td>.004**</td>
</tr>
<tr>
<td>• Skill</td>
<td>1.66</td>
<td>47</td>
<td>.104</td>
</tr>
<tr>
<td>Pre: Treatment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Feasibility</td>
<td>2.83</td>
<td>33.44</td>
<td>.008**</td>
</tr>
<tr>
<td>• Confidence</td>
<td>3.59</td>
<td>46</td>
<td>.001**</td>
</tr>
<tr>
<td>• Skill</td>
<td>2.90</td>
<td>46</td>
<td>.006**</td>
</tr>
<tr>
<td>Post: Assessment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Feasibility</td>
<td>0.87</td>
<td>48</td>
<td>.388</td>
</tr>
<tr>
<td>• Confidence</td>
<td>1.32</td>
<td>48</td>
<td>.194</td>
</tr>
<tr>
<td>• Skill</td>
<td>0.88</td>
<td>48</td>
<td>.385</td>
</tr>
<tr>
<td>Post: Treatment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Feasibility</td>
<td>2.49</td>
<td>47</td>
<td>.016*</td>
</tr>
<tr>
<td>• Confidence</td>
<td>2.94</td>
<td>47</td>
<td>.005**</td>
</tr>
<tr>
<td>• Skill</td>
<td>2.17</td>
<td>47</td>
<td>.035*</td>
</tr>
</tbody>
</table>

Note: * = p < .05; ** = p < .01
Table 11

Phase two: Paired samples t-test results comparing participant ratings of assessment and treatment feasibility, confidence and skill at pre and post data collection time periods within training pilot program groups.

<table>
<thead>
<tr>
<th></th>
<th>t</th>
<th>df</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Training Pilot 1: Assessment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feasibility</td>
<td>-1.73</td>
<td>24</td>
<td>.096</td>
</tr>
<tr>
<td>Confidence</td>
<td>-5.28</td>
<td>24</td>
<td>.000***</td>
</tr>
<tr>
<td>Skill</td>
<td>-3.71</td>
<td>24</td>
<td>.001**</td>
</tr>
<tr>
<td><strong>Training Pilot 1: Treatment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feasibility</td>
<td>-2.19</td>
<td>23</td>
<td>.039*</td>
</tr>
<tr>
<td>Confidence</td>
<td>-2.99</td>
<td>23</td>
<td>.007**</td>
</tr>
<tr>
<td>Skill</td>
<td>-3.29</td>
<td>23</td>
<td>.003**</td>
</tr>
<tr>
<td><strong>Training Pilot 2: Assessment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feasibility</td>
<td>-2.53</td>
<td>22</td>
<td>.019*</td>
</tr>
<tr>
<td>Confidence</td>
<td>-5.11</td>
<td>23</td>
<td>.000***</td>
</tr>
<tr>
<td>Skill</td>
<td>-3.37</td>
<td>23</td>
<td>.003**</td>
</tr>
<tr>
<td><strong>Training Pilot 2: Treatment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feasibility</td>
<td>-3.40</td>
<td>21</td>
<td>.003**</td>
</tr>
<tr>
<td>Confidence</td>
<td>-4.05</td>
<td>22</td>
<td>.001**</td>
</tr>
<tr>
<td>Skill</td>
<td>-4.29</td>
<td>22</td>
<td>.000***</td>
</tr>
</tbody>
</table>

Note: * = $p < .05$; ** = $p < .01$; *** = $p < .001$
## Table 12

**Phase two: Participant evaluation of numerous aspects of the pain training pilot program [0 (strongly disagree) - 10 (strongly agree)].**

<table>
<thead>
<tr>
<th></th>
<th>Pain Training Pilot #1 (n = 23)</th>
<th>Pain Training Pilot #2 (n = 23)</th>
<th>Full Sample (n = 46)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The training content was valuable.*</td>
<td>Mean (SD)</td>
<td>9.17 (1.64)</td>
<td>8.04 (1.72)</td>
</tr>
<tr>
<td></td>
<td>Range</td>
<td>4 - 10</td>
<td>5 – 10</td>
</tr>
<tr>
<td>2. The information provided at this training is applicable to my work.**</td>
<td>Mean (SD)</td>
<td>9.78 (0.60)</td>
<td>8.52 (1.56)</td>
</tr>
<tr>
<td></td>
<td>Range</td>
<td>8 - 10</td>
<td>5 - 10</td>
</tr>
<tr>
<td>3. The format of the training was effective/well suited to the material.**</td>
<td>Mean (SD)</td>
<td>9.61 (0.84)</td>
<td>8.09 (1.78)</td>
</tr>
<tr>
<td></td>
<td>Range</td>
<td>7 - 10</td>
<td>5 - 10</td>
</tr>
<tr>
<td>4. The size of the group present for the training was ideal.</td>
<td>Mean (SD)</td>
<td>9.13 (1.52)</td>
<td>8.78 (1.54)</td>
</tr>
<tr>
<td></td>
<td>Range</td>
<td>5 - 10</td>
<td>5 - 10</td>
</tr>
<tr>
<td>5. The group discussions were useful in further understanding the topic. *</td>
<td>Mean (SD)</td>
<td>9.52 (1.20)</td>
<td>8.35 (1.82)</td>
</tr>
<tr>
<td></td>
<td>Range</td>
<td>5 - 10</td>
<td>4 - 10</td>
</tr>
<tr>
<td>6. The topic was interesting. ***</td>
<td>Mean (SD)</td>
<td>9.83 (0.65)</td>
<td>8.09 (1.76)</td>
</tr>
<tr>
<td></td>
<td>Range</td>
<td>7 - 10</td>
<td>5 - 10</td>
</tr>
<tr>
<td>7. I would encourage other RW to take part in a training workshop like this.**</td>
<td>Mean (SD)</td>
<td>9.65 (1.19)</td>
<td>8.39 (1.23)</td>
</tr>
<tr>
<td></td>
<td>Range</td>
<td>5 - 10</td>
<td>7 - 10</td>
</tr>
<tr>
<td>8. I would be interested in learning more about this topic.</td>
<td>Mean (SD)</td>
<td>9.52 (1.16)</td>
<td>7.83 (1.67)</td>
</tr>
<tr>
<td></td>
<td>Range</td>
<td>5 - 10</td>
<td>5 - 10</td>
</tr>
</tbody>
</table>
9. I plan to incorporate what I have learned into my work. ***
   - **Mean (SD)**   - 9.30 (2.29)   - 8.83 (1.30)   - 9.07 (1.86)
   - **Range**       - 0 - 10       - 6 - 10       - 0 - 10

10. I believe my pain-related training needs were met in completing this training program. **
    - **Mean (SD)**   - 9.35 (1.19)   - 8.13 (1.52)   - 8.74 (1.48)
    - **Range**       - 5 - 10       - 5 - 10       - 5 - 10

*Note: RW = Respite Workers; Across the full sample, the mode for all questions was 10, and the median for all questions ranged from 9 to 10. Significant differences in ratings between the two pilot groups are denoted as follows: * p < .05; ** p < .01; *** p < .001*
Figure 1. Phase one and two of the completed study with a summary of methodology used.
Appendix A: Demographics Questionnaire (for Phase One and Two)

**NOTE: In Phase Two, questions 5, 6, 9, 10, 12, 14d and 15 were eliminated from the demographics questionnaire.**

Participant ID#:____________________________________

A. GENERAL DEMOGRAPHIC INFORMATION

1. What is your age (in years)? ______________

2. Please indicate your gender:
   - [ ] Male
   - [ ] Female
   - [ ] Other

3. Please indicate your ethnicity:
   - [ ] African-Canadian
   - [ ] Asian-Canadian
   - [ ] Euro-Canadian/White
   - [ ] First Nations
   - [ ] Indo-Canadian
   - [ ] Other (please specify):_________________________________________

4. How many years have you been working in an organization providing support to children with intellectual disabilities? ______________

5. Please list the types of positions you have held within organizations providing support to children with intellectual disabilities (e.g., respite worker, inclusion facilitator, manager of respite services).

   _______________________________________________________
   _______________________________________________________
   _______________________________________________________
   _______________________________________________________

6. How many years have you been employed with this current organization? ______________
7. What is the name of the current position you hold with your current employer?

______________________________________________________________________________

B. EXPERIENCE WITH CHILDREN WHO HAVE ID IN ANY CONTEXT

**For the purpose of this questionnaire, an intellectual disability begins before the child turns 18 years of age. It presents itself through limitations in various areas of an individual’s adaptive behaviour (e.g., personal hygiene, social skills) and also in his or her level of intellectual functioning (AAIDD, 2002).**

8. In relation to this question, the word interact will refer to any form of direct contact or communication you have with a child who has an intellectual disability. This would NOT include simply seeing a child with an intellectual disability near you. About how frequently do you interact with children who have intellectual disabilities?

☐ Never (I have never interacted with a child who has an intellectual disability)
☐ Rarely (I interact with...about once a year)
☐ Occasionally (I interact with...on a monthly basis)
☐ Often (I interact with...about once a week)
☐ Very Often (I interact with...multiple times a week)

9. Please provide the approximate number of children you have interacted with (see definition in question 8) in all contexts who have intellectual disabilities:

In the last 6 months: __________

In the last year: ____________

In the last 5 years: __________

In your entire life: __________

10. Have you ever (throughout your entire life) provided any type of support (e.g., personal care, behaviour management, mealtime assistance) to a child who had an intellectual disability?

☐ Yes
☐ No

11. a) Thinking of children who have intellectual disabilities, please rate your degree of direct involvement in their care in ensuring their needs are adequately met. Please consider all involvement (both past and present) and circle the most appropriate response.
11.b) Please indicate the types of settings in which you have provided any type of support (e.g., personal care, behaviour management, mealtime assistance) to children who have intellectual disabilities. Check all that apply.

- In the family home.
- In your own home.
- In the community.
- At a group home.
- Other (please specify): __________________________________________
- Not Applicable

C. RESPITE WORK AND PAIN EDUCATION INFORMATION

12. a) For the purpose of this questionnaire, respite care will be defined as a form of short-term, temporary relief provided to parents or guardians who are caring for a child who has an intellectual disability. Respite care can take place in a variety of settings including the family home, the community, and group home settings. In addition to providing a break for the family, respite is designed to provide a positive experience for the child, often providing them with opportunities to be more involved in the community.

Considering the definition of respite care above, have you ever been employed as a respite worker, providing this type of support to a family with a child who has an intellectual disability?

- Yes
- No
- Unsure

12. a) Have you been employed as a respite worker at any point in your career?

- Yes
- No

12. b) Are you employed as a respite worker currently?

- Yes - for how long? ____________________________________________
No - how long were you a respite worker? _____________________

13.) Please indicate any training or certifications relevant to respite care that you possess.

*Please check all that apply:*

- SafeGuards Respite Services Training Course
- SafeGuards – Other (please specify): _________________________________
- Non-Violent Crisis Intervention Training (NVCI)
- CPR
- First Aid
- AED (Automatic External Defibrillation)
- Understanding and Managing Aggressive Behaviours (UMAB)
- Applied Behaviour Analysis/Intensive Behavioural Intervention related training (please specify):___________________________________________________
- Other (please specify):________________________________________
- None

14. a) Have you received any training related to pain in children (e.g., assessment of pain, management of pain)?

- Yes (if YES see 14 b, c, and d)
- No  (if NO see 14 d)

14. b) If you responded YES to 14. a), please name and describe the type of pain training you received:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

14. c) If you responded YES to 14. a), was this training provided to you through an organization that provides respite care to children/families?

- Yes, in a respite context (please specify who provided the training):
14. d) If a pain training program was available for respite workers, would you choose to partake/would you make this training available for your respite worker staff?

☐ Yes  
☐ No  
☐ Unsure

15. Do you have any experience providing training programming to individuals (i.e., you have led or co-led a training program such as NVCI/First Aid etc. to a group of people)? If so, specify the audience and the type of training.

☐ Yes:

   ○ Specify audience to whom the training was provided: ______________________

   ○ Specify Type of Training(s): _________________________

☐ No

16. On a scale of 0 – 10 (0 = Not Important At All; 10 = Extremely Important), how important would you rate pain training programs for respite workers (please circle)?

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
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<th>10</th>
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</thead>
<tbody>
<tr>
<td>Not Important At All</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Somewhat Important</td>
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<td></td>
<td></td>
<td></td>
<td>Extremely Important</td>
</tr>
</tbody>
</table>
Appendix B: Feasibility, Confidence, and Skill Ratings (for Phase One and Two)

Participant ID#: ________________________________

For each question, please circle how YOU feel about the following items.

**ASSESSMENT:**

1) KNOWING/ASSESSING WHETHER A CHILD WITH AN INTELLECTUAL DISABILITY IS IN PAIN IS...

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<tr>
<th>0</th>
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<th>8</th>
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<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not Feasible At All</td>
<td>Moderately Feasible</td>
<td>Highly/Extremely Feasible</td>
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</table>

2) I AM __________________________ IN KNOWING/ASSESSING WHETHER A CHILD WITH AN INTELLECTUAL DISABILITY IS IN PAIN...

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
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<th>4</th>
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<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not Confident At All</td>
<td>Moderately Confident</td>
<td>Highly/Extremely Confident</td>
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</table>

3) I AM __________________________ IN KNOWING/ASSESSING WHETHER A CHILD WITH AN INTELLECTUAL ABILITY IS IN PAIN...

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<thead>
<tr>
<th>0</th>
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<th>2</th>
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<th>4</th>
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<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not Skilled At All</td>
<td>Moderately Skilled</td>
<td>Highly/Extremely Skilled</td>
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</table>

**TREATMENT:**

4) HELPING MANAGE PAIN IN A CHILD WITH AN INTELLECTUAL DISABILITY IS...

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<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not Feasible At All</td>
<td>Moderately Feasible</td>
<td>Highly/Extremely Feasible</td>
<td></td>
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</tbody>
</table>

5) I AM __________________________ IN HELPING A CHILD WITH AN INTELLECTUAL DISABILITY TO MANAGE THEIR PAIN...

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
</table>
3) I AM ___________________________ IN HELPING A CHILD WITH AN INTELLECTUAL DISABILITY TO MANAGE THEIR PAIN…

<table>
<thead>
<tr>
<th>Not Confident At All</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5 Moderately Skilled</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10 Highly/Extremely Skilled</th>
</tr>
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</tr>
</tbody>
</table>
Appendix C: Interview and Focus Group Questions (Phase One)

**Interview/Focus Group Questions**

<table>
<thead>
<tr>
<th>Question:</th>
<th>Potential Question-Specific Probes:</th>
<th>Analysis Type</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>GENERAL ORGANIZATION/RESPITE WORKER INFORMATION</strong> (can be used to break the ice but also to gain a sense about the types of supports provided and programs offered within the organizations the training would be directed towards)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Estimated Time Spent:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Interview (based on a 60 minute interview): 5 minutes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Focus Group (based on a 90 minute focus group): 10 minutes</td>
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</tr>
</tbody>
</table>

1) Tell us a bit about the types of programming offered and the role of respite workers in these. Can you tell me more about that? How involved are the respite workers in care of the children? How long are the children in the care of respite workers for this program? What is the ratio of respite provider to children? How long are the children in the care of respite providers? How frequently? Do most respite workers work with only one child, or many? Is there a lot/little turnover in terms of clients? Do you offer respite in more than one setting for the same child? | Descriptive |

2) When beginning to work here, what types of training do respite providers generally receive, and where does this usually take place? Do they receive any continued education/training throughout employment? Is there any requirement for continued training? What happens if a worker identifies a training need? | Descriptive |

**GENERAL PAIN QUESTIONS/PERCEIVED PAIN KNOWLEDGE OF RESPITE WORKERS**

| **Estimated Time Spent:** |
| • Interview (based on a 60 minute interview): 27 minutes |
| • Focus Group (based on a 90 minute focus group): 45 minutes |

3) How common would you say that painful incidents occur with the children during respite care (e.g., falling, insulin shots, etc.)? Which do you think is the most common? Which is the most difficult to assess? To manage? What factors have you found to | Thematic Analysis |
stomach aches, chronic pain, etc.) make pain assessment/management the most difficult?

4) As care providers for children with ID, what sorts of challenges have you experienced/heard about regarding pain assessment or management (L. to briefly define) with these children that could be addressed in a pain training program? Can you tell me more about that? What sorts of things were tried/strategies were used? Can you remember reviewing any incident reports that stood out to you? What makes it hard for you to tell whether a child is in pain?

5) How much knowledge do you think the average RW would have regarding pain assessment and management strategies and how to deal with these types of situations in a respite context? What sorts of things do you think they would already know? Where do you think they have learned the knowledge that they already have (e.g., word of mouth, advice from others)?

6) What sorts of things do you think would be helpful to include in a pain training program that would help RW to better support the children they care for and feel more confident in the care they provide? What sort of pain assessment information? What types of pain management information?

7) There are lots of different types of pain management strategies -- three broad categories include pharmacological (e.g., giving Tylenol), psychological (e.g., using distraction) and physical (e.g., physical comfort, providing ice) - could you see value in learning about all three of these? Which would be most useful in a respite setting? Which would be least useful? How comfortable do you think a typical RW would be in using each management strategy?

## Thematic Analysis

## Content Analysis

---

**GENERAL TRAINING DEVELOPMENT AND FORMAT OF PAIN TRAINING-RELATED QUESTIONS**

**Estimated Time Spent:**
- Interview (based on a 60 minute interview): 25 minutes
- Focus Group (based on a 90 minute focus group): 30 minutes

<table>
<thead>
<tr>
<th>8) From your experience, what are some key ingredients for a strong training program or seminar - one that would be both enjoyable and educational for respite workers?</th>
<th>Can you tell me more about that? How did that work in a large group/small group? What do you think made that strategy so effective? What are your thoughts on providing take-home tools/handouts at training programs? What about interactive training activities (e.g., role playing, open discussion)?</th>
<th>Content Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>9) What sorts of goals/outcomes would you like to see after participating in/having your staff participate in a pain training program?</td>
<td>What types of barriers could you foresee in using the information in respite settings? What might facilitate the use of the material?</td>
<td>Content Analysis</td>
</tr>
<tr>
<td>10) What parts of a pain training program might be most useful to respite staff? What parts do you think would be useful or most used?</td>
<td></td>
<td>Content Analysis</td>
</tr>
<tr>
<td>11) Has anyone heard about a pain training program specifically designed for those who provide respite care to children? Adults?</td>
<td>Is pain assessment and management ever included in any of the current training programs? Could any of these programs potentially have overlap with a pain training program? How are these training programs similar/different from each other?</td>
<td>Descriptive</td>
</tr>
<tr>
<td>12) What type of format do you think could be more effective for this form of pain training? (In person, online, hybrid?) Which do you think RW would be more likely to complete? Which would be most feasible for organizations?</td>
<td>Can you tell me a bit more about that? Why do you think that ____ would be better than ____? What are some advantages and disadvantages of these?</td>
<td>Descriptive</td>
</tr>
</tbody>
</table>

**If there is time at the end of the interview or focus groups, the researchers will have on hand a printed copy of the slides for the pain training and some of the activities and ideas regarding what to include. The participants will have an opportunity to give their feedback regarding these**

**CLOSING QUESTION/ADDRESS MATERIAL THAT WAS NOT COVERED**

**Estimated Time Spent:**
- Interview (based on a 60 minute interview): 3 minutes
- Focus Group (based on a 90 minute focus group): 5 minutes

<table>
<thead>
<tr>
<th>Question</th>
<th>Description</th>
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<tbody>
<tr>
<td>13) Can you think of anything else that might be useful for us to know about when developing this training program?</td>
<td>Descriptive</td>
</tr>
</tbody>
</table>
## Appendix D: Pain Training Specifics Questionnaire (Phase One)
### Pain Training Specifics Questionnaire

Participant ID#: __________________________

Please rate your level of agreement with the following statements by placing an “X” in the appropriate box:

<table>
<thead>
<tr>
<th>Statement</th>
<th>0 Strongly Disagree</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5 Moderately Agree</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10 Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. A pain training program for support workers would be valuable for teaching pain assessment and management.</td>
<td></td>
<td></td>
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<tr>
<td>2. Information provided at a pain training program would be applicable to my work.</td>
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<tr>
<td>3. A pain training program would be interesting.</td>
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<tr>
<td>4. I would encourage other support workers to take part in a pain training program.</td>
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<tr>
<td>5. I would be interested in learning more about pain in children with intellectual disabilities</td>
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</tr>
<tr>
<td>6. On a scale of 0 – 10, how important would you rate pain training programs for respite workers?</td>
<td>0 Not At All Important</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5 Moderately Important</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>Extremely Important</td>
</tr>
</tbody>
</table>

1. Please rank order your preference in the type of format for a pain training program for respite workers (i.e., 1 = most preferred, 3 = least preferred)?

   - _____ In person training workshop
   - _____ Online Pain Training Program (e.g., interactive modules)
   - _____ Hybrid (i.e., part completed online, part completed in person)

   a. How long do you think the pain training should be if in person? _____ hours
b. How long do you think the pain training should be if completed online? ___ hours

c. How long do you think the pain training should be if a hybrid? _______ hours

2. If completed in person, what is an ideal group size for the pain training program?

_________________________________________________________________________

3. What types of activities would be beneficial to include (e.g., case studies, group discussions, etc.)?

_________________________________________________________________________

_________________________________________________________________________

_________________________________________________________________________

_________________________________________________________________________

_________________________________________________________________________

_________________________________________________________________________

4. Should handouts and resources be provided to participants? If so, in what format should they be provided (e.g., hard copy, via email, etc.).

☐ Yes (please specify)

_________________________________________________________________________

_________________________________________________________________________

_________________________________________________________________________

☐ No

5. On a scale of 0 – 10 (0 = Not important at all, 10 = Extremely important), please circle how important would the provision of handouts and resources to you be in a training workshop?

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<tr>
<th>0</th>
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<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not Important At All</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>Moderately Important</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
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</tbody>
</table>

82
6. What would be the most important thing to include in a pain training program?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

7. What would be the least important thing to include in a pain training program?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

8. Should participants receive a certificate of completion after participating in a pain training program?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

9. Do you have any other suggestions regarding topics to be covered or formatting for a pain training program for respite workers?

  ➔ Pain Assessment:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

  ➔ Pain Management:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

  ➔ Pain Training Format:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
10. On a scale of 0 to 10 (0 = not helpful at all; 10 = the most helpful possible), please circle how helpful did YOU find THIS INTERVIEW/FOCUS GROUP was in:

a) Sharing your thoughts and experiences with pain in children who have intellectual disabilities:

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<tr>
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<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not Helpful At All</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>Moderately Helpful</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>Highly/Extremely Helpful</td>
</tr>
</tbody>
</table>

b) Discussing important aspects of training programs that should be included in a future pain training program for respite caregivers:

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<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
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<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not Helpful At All</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>Moderately Helpful</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>Highly/Extremely Helpful</td>
</tr>
</tbody>
</table>

11. Is there anything else that you would like to tell us that we haven’t asked about?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
Appendix E: Coding Categories for Quantitative Content Analysis (Phase One)

3. What types of activities would be beneficial to include (e.g., case studies, group discussions, etc.)?

<table>
<thead>
<tr>
<th>Type</th>
<th>Definition</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Passive - Multimedia</td>
<td>Participant mentions an activity that involves more passive learning (i.e., one way receipt of information) about the topic. This may or may not involve some form of multimedia/visual</td>
<td>-Videos</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Pictures</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Powerpoint</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Someone there to speak</td>
</tr>
<tr>
<td>Interactive – Case Based or Other Hands On Activity</td>
<td>Participant mentions an activity that is interactive in nature that reflects a discussion based activity (e.g., case studies) or involves “hands on” participation.</td>
<td>-Role play</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Case studies</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Hands on</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Make and take</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Group discussion</td>
</tr>
<tr>
<td>Other/Unclear/Unrelated</td>
<td>Participant’s comment is unclear, unrelated to the question or does not fit in any of the above three categories.</td>
<td>-Variety</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Statistics</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Information sharing</td>
</tr>
</tbody>
</table>

4. Should handouts and resources be provided to participants? If so, in what format should they be provided (e.g., hard copy, via email, etc.).

<table>
<thead>
<tr>
<th>Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hard Copy</td>
</tr>
<tr>
<td>Email</td>
</tr>
<tr>
<td>Both</td>
</tr>
<tr>
<td>Other/Unrelated/Unclear</td>
</tr>
</tbody>
</table>

6. What would be the most important thing to include in a pain training workshop?

<table>
<thead>
<tr>
<th>Type</th>
<th>Definition</th>
<th>Examples</th>
</tr>
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<td></td>
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</tr>
<tr>
<td>Information Provision/Tools - Assessment</td>
<td>Participant suggests that it would be most important to provide information about a topic related to pain assessment.</td>
<td>- How to tell if a child is in pain through their behaviours</td>
</tr>
<tr>
<td>Information Provision/Tools – Management</td>
<td>Participant suggests that it would be most important to provide information about a topic related to pain management or intervention.</td>
<td>- Up to date management strategies that can work</td>
</tr>
<tr>
<td>Information Provision/Tools - Other</td>
<td>Participant suggests that it would be most important to provide information about a topic related to pain, but the suggestion refers to factors outside of pain assessment and management OR too broad to code as Information Provision/Tools – Assessment or Information Provision/Tools – Management</td>
<td>- Strategies</td>
</tr>
<tr>
<td>Training Format – Related</td>
<td>Participant indicates that an aspect of the training or attribute of the presenter would be most important.</td>
<td>- Interesting and engaging speakers</td>
</tr>
<tr>
<td>Other/Unclear/Unrelated</td>
<td>Participant’s comment is unclear, unrelated to the question or does not fit in any of the above three categories.</td>
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</table>

7. What would be the least important thing to include in a pain training workshop?
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<tr>
<th>Type</th>
<th>Definition</th>
<th>Examples</th>
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<tbody>
<tr>
<td>Everything is important</td>
<td>Participant indicates that everything would be important to include OR that “nothing is not important”</td>
<td>- Everything is important</td>
</tr>
<tr>
<td>Information Provision/Tools - Pain Assessment/Management</td>
<td>Participant suggests that it would be most important to provide information about a topic related to pain assessment or management.</td>
<td>- Details about how the medication actually works</td>
</tr>
<tr>
<td>Information Provision/Tools - Other</td>
<td>Participant suggests that it would be least important to provide information about a topic that is not directly related to pain.</td>
<td>- Talking too much about a child’s specific diagnosis</td>
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<tr>
<td>Training Format – Related</td>
<td>Participant indicates that an aspect of the training or attribute of the presenter would be most important.</td>
<td>- Reading off the slides</td>
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<tr>
<td>Other/Unclear/Unrelated</td>
<td>Participant’s comment is unclear, unrelated to the question or does not fit in any of the above three categories.</td>
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## Appendix F: Adapted PPKAQ (Phase Two)

* = from Twycross & Williams, 2013

- = adapted from Twycross & Williams, 2013 *(italicized text indicates the original question from Twycross & Williams, 2013)*

^ = new researcher-developed question

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<th>Participant ID#: ____________________________</th>
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Indicate whether you agree or disagree with the following statements:

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<tr>
<th></th>
<th>Agree</th>
<th>Agree to some extent</th>
<th>Neither Agree Nor Disagree</th>
<th>Disagree to some extent</th>
<th>Disagree</th>
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</thead>
<tbody>
<tr>
<td>*1. Children tolerate pain better than adults do.</td>
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<td>*2. A child who is crying and says they are experiencing pain is likely to be in pain.</td>
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<td>-3. When a child is able to, they should be asked to rate/report their own pain intensity (note that this may include nonverbal communication methods). <em>(When a child can talk, they should be asked to rate their own pain intensity)</em></td>
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<td>^4. Children who have intellectual disabilities are indifferent to pain.</td>
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<td>*5. Parents exaggerate their children’s pain.</td>
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<td>-6. Untreated pain prolongs recovery from injuries. <em>(Untreated pain prolongs recovery)</em></td>
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<td>*7. Acute (i.e., short term) pain is a warning that something is wrong.</td>
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<td>^8. There is a test that determines if a child is in pain.</td>
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<td>^9. Pain should be used as a teaching tool for people with intellectual disabilities.</td>
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<td>^10. A child will always breathe faster if they are in pain.</td>
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<td>11. Massage can be an effective method of relieving pain in children.</td>
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<td>12. Children who have intellectual disabilities always communicate their pain the same way as children who are considered typically developing.</td>
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<td>13. Rocking a young child in one’s arms can help reduce pain. (Rocking a child in one’s arms reduces pain.)</td>
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<td>14. Relaxation strategies (e.g., imagery) are not effective in reducing a child’s pain.</td>
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<td>15. A good way to reduce pain in children is to distract them from the pain.</td>
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<td>16. The environment in which children grow up has a major influence on the way they express pain.</td>
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<td>17. Children who have intellectual disabilities experience less pain than children who do not have intellectual disabilities.</td>
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<td>18. A child’s cultural background affects the way they experience pain.</td>
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<td>19. The way that children express pain is affected by their temperament.</td>
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<td>20. Changes in a child’s behaviour can be used to assess their pain.</td>
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<td>21. A child who can be easily distracted is unlikely to actually be in pain.</td>
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<td>22. Pain in children does not usually cause mood changes. (Chronic pain in children does not usually cause mood changes.)</td>
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<td>23. When assessing a child’s pain it is important to first ascertain their stage of cognitive development.</td>
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<tr>
<td>24. The way that children experience pain is influenced by their parents’ behaviour.</td>
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<td>25. It can be challenging to assess pain in children with intellectual disabilities who can’t talk.</td>
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<td>26. Children can sleep even if they are in pain.</td>
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</table>
Appendix G: Pain Knowledge Test for Carers of Individuals with Intellectual Disabilities (PKT-CID; Phase Two)

INSTRUCTIONS:

Please respond to the following questions to the best of your ability. If you simply do not know the answer (or do not have a good guess), you may select the “Don’t Know” option.

**Part A: True/False**

1) It is best to only use one pain management strategy at a time rather than multiple strategies at once.
   a) True
   b) False
   c) Don’t Know

2) Pain is common among individuals with intellectual disabilities – and, in some cases, – even more common than in individuals without intellectual disabilities.
   a) True
   b) False
   c) Don’t Know

3) Due to major impairments, individuals with intellectual disabilities do not experience everyday pain that individuals without intellectual disabilities experience (e.g., headaches, toothaches, ear-aches).
   a) True
   b) False
   c) Don’t Know

4) In the past, some people believed that individuals with intellectual disabilities did not feel pain. Consequently, these individuals may not have received appropriate pain-related care.
   a) True
   b) False
   c) Don’t Know

5) Difficulties in an individual’s ability to communicate may decrease his/her likelihood of receiving adequate pain management.
   a) True
   b) False
   c) Don’t Know

6) Neurological factors, medical conditions and medications for these conditions are unrelated to an individual’s pain experience, processing, and expression.
   a) True
   b) False
   c) Don’t Know
7) Being exposed to painful stimuli repeatedly can lead to someone becoming more sensitive to pain.
   a) True
   b) False
   c) Don’t Know

8) A person who engages in self-injury is insensitive or indifferent to pain.
   a) True
   b) False
   c) Don’t Know

9) Generally, individuals with severe intellectual disabilities can provide self-reports of their own pain.
   a) True
   b) False
   c) Don’t Know

10) Some individuals with intellectual disabilities may be able contribute to their own pain assessment if you adapt the methods used (e.g., asking yes/no, showing pictures).
    a) True
    b) False
    c) Don’t Know

11) In some cases, a pain medication (e.g., anti-inflammatory, muscle relaxant) may be prescribed by qualified health care professionals to be regularly administered to an individual with an intellectual disability.
    a) True
    b) False
    c) Don’t Know

12) Most individuals with intellectual disabilities are capable of verbally communicating their pain to others, so caregivers don’t usually need to help with assessing their pain.
    a) True
    b) False
    c) Don’t Know

13) Research demonstrating successful pain management strategies for individuals with intellectual disabilities has lagged behind research with ‘typically developing’ populations.
    a) True
    b) False
    c) Don’t Know

14) Secondary caregivers (e.g., respite providers) should administer pain medication to individuals they care for even if the primary caregivers have not previously approved or requested this.
    a) True
b) False  
c) Don’t Know

15) Given advances in research, pain is now rarely underestimated or undertreated in individuals with intellectual disabilities.  
a) True  
b) False  
c) Don’t Know

16) Paying attention to facial expressions and a wide range of behaviours shown by an individual with an intellectual disability can be useful in helping to determine whether pain is present.  
a) True  
b) False  
c) Don’t Know

17) If individuals with intellectual disabilities can be distracted, they are not in severe pain.  
a) True  
b) False  
c) Don’t Know

18) Individuals with intellectual disabilities will not sleep if they are in pain.  
a) True  
b) False  
c) Don’t Know

19) Individuals with intellectual disabilities should be encouraged to endure as much pain as possible before using medication or other pain management strategies.  
a) True  
b) False  
c) Don’t Know

**Part B: Multiple Choice**

20) Some individuals can experience a true insensitivity to pain. This occurs…  
a) In a large percentage of the population  
b) In only some parts of the world  
c) Very rarely  
d) In individuals who have a genetic syndrome involving intellectual disability  
e) B and C  
f) Don’t Know

21) An individual’s level of physical disability…  
a) Accurately reflects his/her level of intellectual disability  
b) Can sometimes accurately reflect his/her level of intellectual disability  
c) Does NOT accurately reflect his/her level of intellectual disability  
d) None of the above
e) Don’t Know

22) Pain may be more common among individuals with intellectual disabilities for the following reason(s):
   a) Increased number of health problems
   b) Higher need for medical procedures
   c) Increased likelihood of accidental or intentional injury
   d) All of the above
   e) Pain is not more common in individuals with intellectual disabilities
   f) Don’t Know

23) Which of the following is NOT typically impacted by pain in individuals with intellectual disabilities?
   a) Communication skills
   b) Daily life skills
   c) Social skills
   d) Participation in regular activities
   e) All of the above (i.e., none are impacted)
   f) None of the above (i.e., all may be impacted)
   g) Don’t Know

24) Using inappropriate pain assessment/measurement tools with individuals with intellectual disabilities could most likely lead to…
   a) Underestimation of pain
   b) Overestimation of pain
   c) Appropriate estimation of pain
   d) All of the above
   e) None of the above
   f) Don’t Know

25) For individuals who are limited in their ability to communicate, pain should be assessed…
   a) On a regular basis
   b) Only when the individual is crying
   c) Only when the individual’s behaviour changes
   d) Occasionally - they are not likely to have pain on a regular basis
   e) Don’t Know

26) The following factor(s) can impact how an individual with an intellectual disability responds to pain:
   a) Environment and social context
   b) Emotions
   c) Their response to painful medical procedures
   d) A and B
   e) All of the above
   f) None of the above
g) Don’t Know

27) An individual’s ability to communicate pain effectively may be limited by factors such as:
   a) Level of intellectual functioning
   b) Physical limitations (e.g., can’t use fingers to point)
   c) Deficits specific to a given disability (e.g., not engaging in social behaviours)
   d) All of the above
   e) None of the above
   f) Don’t Know

28) When employing pain assessment or management strategies, you should…
   a) Use strategies that will most accurately match the individual’s mental age and abilities
   b) Use strategies that you have found useful for most other individuals
   c) Use strategies matched to the individual’s age in years (chronological age)
   d) All of the above
   e) None of the above
   f) Don’t Know

29) Imagery or visualization might be best used for an individual who:
   a) Just fell down and is crying
   b) Has a headache
   c) Has chronic pain
   d) B and C
   e) All of the above
   f) None of the above
   g) Don’t Know

30) When working with individuals with intellectual disabilities, you might also do the following when helping them engage in progressive muscle relaxation:
   a) Get a group of children to do this all at once
   b) Incorporate tactile stimuli (e.g., instead of making tight fists, squeezing a ball as hard as they can)
   c) Give them an instruction booklet to read about how to engage in progressive muscle relaxation
   d) All of the above
   e) None of the above
   f) Don’t Know

31) You are working with an individual who has an intellectual disability. He or she can communicate verbally but often reverses pronouns and speaks in an idiosyncratic manner. While on a walk the individual says to you “Why does your head hurt?”. Given what you know about the individual’s communication style…
   a) You should check in with the individual and try to assess whether he/she is in pain.
   b) You can dismiss the comment since he/she is not showing any physical signs of being in pain.
c) You should consider your past experiences with the individual and beliefs you may have about the individual’s pain behaviours

d) All of the above.

e) A and C

f) Don’t Know

32) You are caring for an individual who has a moderate intellectual disability, and very limited verbal abilities. In addition, the individual has a physical disability that does not allow use of his/her hands. To assess his/her pain you should (choose the best option):

a) Ask the individual to report his/her pain using traditional pain assessment tools

b) Rely only on behaviour you observe, ignoring other situational information

c) Adapt a pain assessment measure in a way that will allow the individual to provide you with some form of self-report

d) Ask another individual who can communicate verbally to rate the individual’s pain

e) All of the above would be equally effective

f) None of the above

g) Don’t Know

33) An individual you are caring for falls down while running at the park. The individual begins to cry, but you cannot see a physical injury. Assuming that this is not a serious injury, select the best action(s) to take.

a) Immediately call the caregivers

b) Speak to the individual in a soothing voice

c) Distract the individual with a favourite toy or activity

d) B and C

e) All of the above

f) None of the above

g) Don’t Know

34) While caring for an individual who has a severe intellectual disability and is nonverbal, he/she begins to act “out of the ordinary”, hitting his/her head and screaming sporadically. You have been told the individual does this when he/she doesn’t get his/her way, but you think the individual could have a headache. You are supporting this individual in a “weekend away” program at a group home, and have not met the caregivers. There is no action plan for pain in the individual’s profile. The best action would probably be to:

a) Give the individual pain medication to potentially alleviate the headache.

b) Call the caregivers to ask about past behaviour patterns

c) Ask the individual to give a pain rating on a scale of 0 to 10

d) Ignore the behaviour in case it is manipulative, and see if it goes away.

e) Any of the above would be adequate responses

f) None of the above

g) Don’t Know

35) You are about to begin providing care to an individual with a mild intellectual disability, but have not yet worked with the caregivers. When gathering information about the individual’s pain behaviours you might:
a) Ask the individual and his/her caregivers about pain behaviours and pain history
b) Be aware of your own previous experiences, beliefs and attitudes towards pain
c) Work with the caregivers to develop a pain assessment and management plan for you
to follow while the individual is in your care
d) B and C
e) All of the above
f) None of the above
g) Don’t Know
Appendix H: Pain Training Evaluation Form (Phase Two)

Pain in Children with Intellectual Disabilities – INSERT PAIN TRAINING DATE HERE

Participant ID#: ____________________________

Please rate your level of agreement with the following statements by placing an “X” in the appropriate box:

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<tr>
<td></td>
<td>Strongly Disagree</td>
<td>1</td>
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<td>5</td>
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<td>7</td>
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<td>Strongly Agree</td>
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<tr>
<td>1.</td>
<td>The training content was valuable.</td>
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<td>2.</td>
<td>The information provided at this training is applicable to my work.</td>
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<td>3.</td>
<td>The format of the training was effective/well suited to the material.</td>
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<td>4.</td>
<td>The size of the group present for training was ideal.</td>
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<td>5.</td>
<td>The group discussions were useful in further understanding the topic.</td>
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<td>6.</td>
<td>The topic was interesting.</td>
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<td>7.</td>
<td>I would encourage other respite workers to take part in a training workshop like this.</td>
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<td>8.</td>
<td>I would be interested in learning more about this topic.</td>
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<td>9.</td>
<td>I plan to incorporate what I have learned into my work.</td>
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<td>10.</td>
<td>I believe my pain-related training needs were met in completing this training program.</td>
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11. What was the most valuable piece of the training for you?

__________________________________________________________________________
12. What was the least valuable piece of the training?

__________________________________________________________________________

__________________________________________________________________________

13. Was there anything you wanted to hear more about?

__________________________________________________________________________

__________________________________________________________________________

14. If you could change one thing about this workshop, what would it be?

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________

15. Additional comments/suggestions. Is there anything else that you would like to tell us that we haven’t asked about?

__________________________________________________________________________

__________________________________________________________________________

__________________________________________________________________________
Appendix I: Pain Training Pilot - Training Program Outline (Phase Two)

*Note: This was an interactive presentation, and participants were encouraged to ask questions throughout the training in addition to participating in the interactive activities. A copy of the PowerPoint is also available upon email request to the lead researcher, L.G, at lgenik@uoguelph.ca.*

10:00 am - 12:00 pm: This first block of the training program included an introduction to what pain is as well as information about pain assessment.

➔ 10:00 am - 10:45 am: What is Pain?
- review what pain is (and watch the first five minutes of Lorimer Moseley’s TedX Talk “Why Things Hurt”: https://www.youtube.com/watch?v=gwd-wLdIHjs)
- types of pain (e.g., acute, chronic)
- IASP definition of pain and its relevance to those with ID
- review historical beliefs about pain in those with ID and what we know today
- biopsychosocial model of pain
- brief discussion about pain desensitization/hyper/hyposensitivity
- factors impacting caregiver’s decisions regarding pain in children with ID

➔ 10:45 am - 12:00 pm: Pain Assessment
- why is pain assessment important/why should we care (and group discussion)
- pair and share discussion about previous experiences working with children with ID in pain
- pain assessment strategies - in-depth discussions about self-report, reports from others and behavioural observations, in addition to the following activities:
  - group activity and discussion critiquing and adapting types of self-report measures (i.e., pieces of hurt tool, numeric rating scale, colour your pain, faces pain scale-revised, informal pain assessment strategies), so that they might be used for higher functioning children with ID, children with physical limitations, etc.
  - review a researcher-generated caregiver pain resource designed for encouraging communication between caregivers of children with ID; also provide participants with a link to the Pediatric Pain Profile which is available free online.
  - group activity and discussion critiquing types of behavioural observation measures (i.e., Faces, Legs, Activity, Cry, Consolability - Revised Scale, Infant Behavioural Pain Scale, Non-Communicating Children’s Pain Scale - Post-Operative Version) and how these could be used in a respite care setting
• reminder of the difficulty in assessing pain in children with ID. Watch a video where a father tries to understand why his child with ASD is upset (ends up being constipation): https://www.youtube.com/watch?v=rvC5gzmwq_8

12:00 pm - 12:30 pm: Lunch Break

12:30 pm - 2:00 pm: This second block of the training program included a review and final activity related to pain assessment and also discussed pain management.

→ 12:30 - 12:45: Review and Final Activity for Pain Assessment
  • review helpful assessment tips (i.e., summary of all material discussed)
  • participants split into groups and given a vignette scenario, they then presented their ideas regarding how they would best assess the child’s pain to the larger group

→ 12:45 pm - 2:00 pm: Pain Management
  • deciding to take action
  • pair and share related to participants’ experiences trying to manage pain for a child with ID
  • discuss four types of pain management - pharmacological, physical, psychological, process and give some examples of each; suggestions regarding how to adapt management strategies for children with ID (e.g., demonstrating skills, using tactile stimuli such as a stress ball to facilitate progressive muscle relaxation); watch a video with example of distraction in needle procedure: https://www.youtube.com/watch?v=MOOxpT9q2mo
  • considerations when choosing which strategies to use (e.g., age, developmental level, physical abilities); benefits of using multiple strategies at once
  • group activity creating a “pain management menu” with a list of strategies that could work for the children (or a specific child) that they care for
  • groups go back to case studies previously reviewed and discuss management strategies that would be most appropriate given the type of pain, situation and child