Let’s Talk About Pain: A Randomized Controlled Trial Testing the Effectiveness of a Pain Assessment and Management Training Program for Respite Workers Supporting Children with Developmental Disabilities

by

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Children with intellectual and developmental disabilities (I/DD) commonly experience pain which is often underassessed and mismanaged. Existing work focuses on improving pain-related skills of parents and health care professionals; it is also important to address the needs of others supporting children with I/DD such as respite workers. Let’s Talk About Pain is a training program designed to fill this gap. The goal of this dissertation was to build upon a prior pilot of the program to systematically examine the effectiveness of the Let’s Talk About Pain training. It includes a pre-study and a randomized controlled trial (RCT ClinicalTrials.gov Identifier: NCT03421795) presented in manuscript style. The first manuscript (Chapter Two) presents a multiple-case study which was undertaken to inform feasible follow-up methodology. The second (Chapter Three) presents the RCT protocol. Manuscripts three and four (Chapters Four and Five) present the findings of the RCT in which a sample of 158 respite workers from 14 children’s respite organizations completed either the Let’s Talk About Pain or control training and were evaluated immediately before, after and 4-6 weeks following training. Manuscript three reports on significant increases immediately following training completion and sustained increases at 4-6 week follow-up in participants’ (a) pain-related knowledge and (b) perceptions of the feasibility of and their own confidence and skill in pain assessment and management with
children with I/DD. Although participants from both groups used similar pain assessment and management approaches in practice, manuscript four demonstrates that those receiving pain training also acknowledged additional benefits to pain-related education including heightened awareness of pain and new specific pain-related approaches. Participants positively endorsed the program. The fifth manuscript (Chapter Six) serving as a discussion/commentary is a call for action and highlights the opportunities and challenges associated with conducting community-based research related to pain in children with I/DD. This training may be an effective way to increase respite workers’ pain-related knowledge and perceptions. Future work should explore the application of the training across contexts and its impact on pain-related care for children with I/DD.
Dedication

This thesis is dedicated to the many children and adults with I/DD along with their families who have welcomed me into their lives and allowed me to walk alongside them. Thank you for teaching me invaluable life lessons and for inspiring me to do the work that I do. I would also like to dedicate this work to the respite organizations, executive directors, managers, and front-line respite staff who have shared in my enthusiasm for improving pain assessment and management for children with I/DD, and for taking the time to contribute to this research. This work would simply not be possible without you.
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*In each of these publications, Lara Genik led all aspects of the research conceptualization, data collection, analysis, and written components of the work (including complete first drafts of each manuscript) under supervision of her research advisor, Dr. C. Meghan McMurtry. All other authors participated in components of the work as relevant and reviewed and provided relevant feedback to the various manuscripts.

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Chapter One: Introduction

What is pain?

In 1979, the International Association for the Study of Pain (IASP) formally defined pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (IASP, 2012, Pain terms, para. 1; Bonica, 1979). It was further noted that pain is subjective. This suggests that an individual’s pain experience may vary, and individual reports of pain should be accepted as such (IASP, 2012, Pain terms, para. 2; Bonica, 1979). Viewing pain within a biopsychosocial model highlights the importance of this point given the large number of biological (e.g., genetic predisposition), psychological (e.g., emotions) and social (e.g., who a person is with) factors that can impact an individual’s pain expression and experiences (Hadjistavropoulos et al., 2011). Later added to IASP’s definition of pain was the notion that a lack of verbal communication ability does not prevent an individual from experiencing or requiring relief from pain (IASP, 2012, Pain terms, para. 2; Mersky & Bogduk, 1994).

Pain experiences can be classified a number of ways including: (a) the way pain is produced, (b) the type of tissue involved, (c) the body part involved, or (d) the length of time for which the pain has been present (Gould, 2006; McMurtry, & McGrath, 2018). For the purpose of this paper, pain will be classified based on the length of time for which it has been present using the terms ‘acute’ and ‘chronic’ pain (Gould, 2006). These terms are consistently used within the literature and help to understand different types of pain in a more broad sense (i.e., versus narrowing down to pain in only one body part or tissue type). Specifically, acute pain is known

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1 There have been recent movements in the research literature to update the definition of pain (e.g., Williams & Craig, 2016); however, the definition cited here remains the current definition of pain as per the International Association of the Study of Pain.
to have a rapid onset, often follows an injury, and can vary in intensity and frequency of presentation; it is limited in duration (Gould, 2006; McMurtry & McGrath, 2018). Common examples of acute pain sources include burns, needle procedures, and falls. In contrast, chronic pain occurs for a longer period of time (i.e., greater than three to six months), and can get in the way of ‘normal’ activities (Gould, 2006; Merskey & Bogduk, 1994; McMurtry & McGrath, 2018). Pain may become chronic when it originates from an injury but lasts longer than the predicted injury recovery time, or when it is associated with a chronic condition (e.g., arthritis; Gould, 2006; Merskey & Bogduk, 1994). Both acute and chronic pain can be experienced concurrently (Gould, 2006; Merskey & Bogduk, 1994).

**Pain in ‘Typically Developing’ Children**

Prior to the 1970s, information about pain among children was scarce, and beliefs of caregivers largely impacted their pain assessment and management decisions (Unruh & McGrath, 2013). This approach was problematic, as many individuals made incorrect assumptions about children’s ability to feel pain and their need for pain to be managed (Unruh & McGrath, 2013). Thus, it was not standard practice to provide infants or children with analgesics during or following painful events or procedures (e.g., following surgery; e.g., Anand & Hickey, 1987; Swafford & Allan, 1968).

Countless studies have since demonstrated that pain is common across all ages, and that children experience many types of acute and chronic pain. For example, one study suggested that painful ‘everyday’ incidents (e.g., bumps, cuts) among children between ages three and seven are frequent (i.e., occur approximately once per hour per child), vary in severity, result in visible distress, and impact different body parts (Fearon, McGrath, & Achat, 1996). Another more recent Canadian study found that 2987 out of 3822 surveyed children (78.2%) receiving hospital
care underwent at least one painful medical procedure (e.g., venipuncture) in the 24 hours prior to data collection (Stevens et al., 2011). A recent systematic review suggested chronic pain to be “overwhelmingly prevalent in children and adolescents” (p. 2737), with specific rates varying according to pain location (e.g., median prevalence rate of headaches estimated at 23%; King et al., 2011). A child’s sex (female), age (older), and socioeconomic status (lower) were associated with higher rates of chronic pain prevalence (King et al., 2011). It should therefore be no surprise that pain is recognized as an international problem; the World Health Organization encourages countries to adopt minimum pain management standards (Brennan, Carr, & Cousins, 2007).

Failure to adequately manage pain translates to poor practice in the context of medicine, law, and ethics (Brennan et al., 2007). Thus, pain management can be viewed as a human rights issue (Brennan et al., 2007).

**Pain Assessment and Management.** In order to ensure that pain is adequately managed, pain assessment that is effective and evidence-based is required (McMurtry & McGrath, 2018). A great deal of literature has focused on the development of measures that can be used to this end (McGrath, 2005). To date, over 60 different infant, child and adolescent-related pain assessment measures have been developed, with the focus of these measures centering largely on pain intensity (McGrath, 2005; McMurtry & McGrath, 2018). Pain assessment measures can involve behavioural observation (e.g., Face, Legs, Activity, Cry, Consolability scale; Voepel-Lewis, Shayevitz, & Malviya, 1997), self-report (e.g., Faces Pain Scale – Revised; Hicks, von Baeyer, Spafford, van Korlaar, & Goodenough, 2001), physiological measures (e.g., heart rate), or a mixture of these approaches (McMurtry & McGrath, 2018). Given the subjectivity of pain experience, self-report was initially referred to as the ‘gold standard’ of pain assessment. While convenient and cost-effective, a number of limitations with this approach have been highlighted.
(e.g., pain experience can become oversimplified; it may be problematic when individuals have limited cognitive or communication abilities; it is not always believed; Schiavenato & Craig, 2010; Twycross, Voepel-Lewis, Vincent, Franck, & von Baeyer, 2015; von Baeyer, 2009). As such, it has been suggested that other assessment approaches be used to complement self-report measures, allowing for multi-dimensional assessment (Franck, Greenberg, & Stevens, 2000; von Baeyer, 2009).

While implementing the use of pain management strategies in practice has proved to be, at times, difficult, we continue to learn more about the safety and effectiveness of different strategies (Howard, 2003). Pain management strategies can be divided into four categories: pharmacological, psychological, physical, and process. Pharmacological strategies such as analgesics are commonly used and recommended for children (Berde & Sethna, 2002; Shah et al., 2015). For example, a recent systematic literature review on vaccination-related pain in children suggested that use of topical anesthetics is of particular benefit on its own or combined with other strategies (Shah et al., 2015). Psychological strategies such as distraction, imagery, relaxation therapy, biofeedback, and hypnosis have also been found effective for both acute and chronic pain (e.g., Birnie et al., 2015; Fisher, Law, Dudeney, Palermo, Stewart, & Eccleston, 2018; Uman, Chambers, McGrath, & Kisely, 2008). Further, research supports the use and effectiveness of physical (e.g., positioning; Taddio et al., 2015) and process-related pain management strategies for pain (e.g., education; Pillai-Riddell et al., 2015).

Pain in Children with Developmental Disabilities

Consideration of an individual’s developmental level in the context of pain, assessment, and management, is important; one’s physical and/or cognitive abilities may contribute to variability in experiences and expression of pain (Genik, Constantin, Symons, & McMurtry,
2019; Howard, 2003; Stinson, Kavanagh, Yamada, Gill, & Stevens, 2006). This variability is particularly the case for children with intellectual and developmental disabilities (I/DD), who typically receive a permanent diagnosis (e.g., Down Syndrome, Autism Spectrum Disorder, Intellectual Disability) ranging in severity (e.g., mild, moderate, severe) before age 18 (Developmental Services Ontario, 2014). Individuals with I/DD commonly have trouble learning, and likely require assistance in daily life tasks (Developmental Services Ontario, 2014). Unlike more general research on pain among children, research progress in the area of pain in children with I/DD has remained slow, and there is still much to be learned (Oberlander & Symons, 2006; Genik et al., 2019).

Similar to previous notions and beliefs about pain in children, a number of inaccurate pain-related beliefs have been and are still held about those with I/DD. For example, earlier work shared about widespread beliefs that people with I/DD were not capable of experiencing pain, or that pain could be utilized to teach or facilitate behavioural change (Sobsey, 2006; Genik et al., 2019). More recent work continues to yield similar findings. For example, one recent study demonstrated that participants believed that as the severity of I/DD increased, children with I/DD were less able to sense pain and experienced less pain than children without I/DD (Genik, McMurtry, & Breau, 2017). While a number of conditions related to congenital insensitivity to pain exist, these conditions are extremely rare (Nagasako, Oaklander, & Dworkin, 2003). There is potential for someone with I/DD to also have a syndrome resulting in pain insensitivity, however, this is largely not the case (Nagasako et al., 2003; Sobsey, 2006). In fact, research among children with I/DD does not generally report any accounts of individuals with pain insensitivity or indifference (e.g., Breau, Camfield, McGrath, & Finley, 2003; Nader, Oberlander, Chambers, & Craig, 2004; Valkenburg, Tibboel, & Dijk, 2015).
Although limited data are available, three well-known studies about the prevalence of pain in children with I/DD found relatively consistent and high rates of pain experiences among these children (Breau et al., 2003; Stallard, Williams, & Velleman, 2001; Stallard, Williams, Velleman, Lenton, & McGrath, 2002). For example, researchers in one study reported that over a two week period, approximately 75% of their sample of children with I/DD experienced pain, and this pain occurred on at least five days for 84% of the children (Stallard et al., 2001). In a different sample of children with severe I/DD, greater than one third experienced multiple hours of pain each week (Breau et al., 2003). The amount of pain experienced increased as a function of children’s severity of needs and disability (Breau et al., 2003; Stallard et al., 2001). Further, when compared to pain prevalence in typically developing children (e.g., Perquin et al., 2000), the results from these studies suggest that pain occurs more commonly for children with I/DD. These findings are also consistent with similar work comparing children with and without physical disabilities, whereby children with physical disabilities experience more pain than those without (de la Vega, Groenewald, Bromberg, Beals-Erikson, & Palermo, 2018). The sources of pain for children with I/DD are diverse. For example, pain may occur from organic causes (e.g., infection), non-organic causes (e.g., broad gastrointestinal pain without a clear source), unintentional injuries, and medical procedures (Breau et al., 2003; Bottos & Chambers, 2006; Carter, McArthur, & Cunliffe, 2002). Additionally, children with specific disabilities may be more likely to experience particular types of pain due to comorbidities. For example, common comorbid and painful conditions for those with Down syndrome include congenital health defects and oral health-related diseases (Bottos & Chambers, 2006).

**Pain Assessment and Management in Developmental Disabilities.** Unfortunately, beliefs about pain insensitivity for people with I/DD endure (e.g., Genik, McMurtry, & Breau,
These beliefs can be problematic, and have potential to lead to poor and/or inconsistent practice. For example, one study found that children with I/DD who underwent spinal fusion surgery had their pain assessed less often and received less opioids than children without I/DD (Malviya et al., 2001). A more recent study suggested a lack of intervention consensus and treatment outcomes by physicians for children with severe neurological impairments experiencing pain and irritability of unknown origin (Siden, Carleton, & Oberlander, 2013). It speculated that this type of practice may be explained in part by the fact that physicians often rely on experiences, opinions, and anecdotes in this area due to the lack of evidence-based literature (Siden et al., 2013). In addition to the negative experience of having pain, children with I/DD also experience reduced adaptive functioning abilities when pain is present (Breau, Camfield, McGrath, & Finley, 2007). Indeed, Breau et al. (2007) found the negative impact of pain to be evident in four areas of adaptive functioning: communication (e.g., receptive language), daily living skills (e.g., feeding oneself), socialization (e.g., desire to be with others) and motor skills (e.g., walking). For children with more severe disabilities, the percentage of reduced skills observed is larger (Breau et al., 2007). Pain has also been found to disrupt these children’s sleep, which can lead to further problem behaviour (e.g., aggression; Breau & Camfield, 2011; Didden, Korzilius, van Aperlo, van Overloop, & de Vries, 2002). Thus, beyond pain management representing a human right (Brennan et al., 2007), appropriate treatment of pain has implications for overall quality of life and adaptive functioning. It is thus critical that caregivers have accurate knowledge about pain in children with I/DD and make it a priority to ensure accurate assessment and management.

To complicate things further, however, there are many challenges associated with pain assessment and management for children with I/DD. Parents seem aware of the challenges; many
believe that their children have frequent, ongoing pain, that their children learn to live with pain, that living with this pain likely impacts their children in many ways (Carter, Arnott, Simons, & Bray, 2017; Carter et al., 2002). Significant variability in these children’s complex needs and cognitive and physical abilities (e.g., some can communicate verbally while others cannot) has a marked impact on pain assessment and management (Breau, McGrath, & Zabalia, 2006; Genik et al., 2019). For example, cognitive and/or physical limitations of these children may interfere with their ability to utilize pain assessment tools that have been developed for children who are typically developing (Chen-Lim, Zarnowsky, Green, Shaffer, Holtzer, & Ely, 2011; Dubois, Capdevila, Bringuier, & Pry, 2010; Fanurik, Koh, Schmitz, Harrison & Conrad, 1999; Genik et al., 2019). As such, self-report can pose many challenges and limitations (Schiavenato & Craig, 2010). Adaptations to traditional approaches may help enable more accurate pain self-reports.

Researchers also suggest that children with I/DD may communicate their pain differently than typically developing children, particularly if they are unable to verbalize their pain (Dubois et al., 2010). This, along with other difficulties such as (a) atypical/idiosyncratic behaviours, (b) lack of clarity around which behaviours communicate pain, (c) multiple comorbidities and (d) differing indicators for acute versus chronic pain can complicate the process of behavioural observations for pain assessment (de Knegt et al., 2013). A systematic review on measuring pain in people with intellectual disabilities identified fourteen categories of behavioural pain indicators, with the top four most common categories being motor activity (e.g., not moving), facial activity (e.g., squinting), social-emotional indicators (e.g., social withdrawal or comfort seeking), and nonverbal vocal expression (e.g., sounds of distress; de Knegt et al., 2013). A number of factors such as pain intensity, verbal ability, and developmental age may influence the types of behavioural pain indicators displayed (de Knegt et al., 2013). Thus, it is important for
caregivers to be aware of the wide range of behaviours that these children may use to communicate their pain (Carter et al., 2002; Carter et al., 2017; de Knegt et al., 2013). A number of observational tools specific to pain in children with I/DD have been developed and are recommended in combination with other assessment modalities (Breau & Burkitt, 2009; de Knegt et al., 2013; Dubois et al., 2010; Hadjistavropoulos, von Baeyer, & Craig, 2001; Herr, Coyne, McCaffery, Manworren, & Merkel, 2011). Examples of evidence-based measures that have shown evidence for validity in select contexts include the Non-Communicating Children’s Pain Checklist – Revised (Breau, McGrath, Camfield, & Finley, 2002) and the Pediatric Pain Profile (Hunt et al., 2004).

**Literature Gap: Secondary Caregivers**

Children with I/DD receive care from a range of caregivers beyond their parents who encounter a number of challenges related to pain assessment and management. For example, Quinn, Seibold, and Hayman (2015) describe the challenges (e.g., children’s inability to use typical self-report measures) experienced with pain assessments by nurses and educators in schools, a place where children certainly spend a significant amount of time. Respite care in particular has been identified by families as a necessary support service that is high in demand and tends to positively impact family members of the individual with I/DD (Douma, Dekker, & Koot, 2006; McConkey, Kelly, & Craig, 2011; Robertson et al., 2011). For example, in 2015/2016 alone, the Ontario Provincial Respite Services Network (2016) reported that over 1000 new families created an account, and there were nearly 6000 families actively using the network for services. Since 2008, the number of families registered in the database had grown from approximately 1000 to over 17000 (Provincial Respite Services Network, 2016).

Importantly, this website is only one of many ways families can access respite services in the
community. When receiving respite care, access to a primary caregiver who is knowledgeable about a child’s pain is not always feasible. Further, there may be variability in caregivers (e.g., if in a group home setting for a weekend, the staff may change every few hours). An understanding of respite workers’ beliefs and knowledge about pain assessment and management in children may therefore help identify areas of educational need for respite workers.

Findings from preliminary work suggested that respite workers held more positive general disability-related beliefs than individuals with little to no experience with the population, and recognized that children with more severe I/DD may be less able to communicate their pain compared to typically developing children (Genik, McMurtry, & Breau, 2017a). Importantly, however, some respite workers held inaccurate beliefs regarding pain in children with I/DD (Genik et al., 2017a). For example, compared to a group of inexperienced undergraduate students, respite workers reported that a significantly higher percentage of children with I/DD were less able to feel pain in comparison to children without I/DD (Genik et al., 2017a). As discussed earlier, we know that this belief is inaccurate as almost all children experience pain, with only very rare exceptions. Further, children with I/DD may actually be at higher risk for experiencing pain than typically developing children (Bottos & Chambers, 2006; Genik et al., 2019). Respite workers’ beliefs about pain relate to care decisions, such as whether there is a need for medical and other forms of attention (Genik et al., 2017a), and therefore could impact their corresponding actions. Similarly, while it is encouraging that respite workers have some knowledge of factors to be considered and actions to take when assessing and managing pain in children with I/DD, it is unclear whether they use these approaches (a) in practice and (b) effectively (Genik, McMurtry, & Breau, 2017b).
Targeted training programs developed for other populations have been found to improve pain-related knowledge and other factors such as perceived pain management-related effectiveness (e.g., Dalton et al., 1996; Gagnon, Hadjistavropoulos, & Williams, 2013; Hunter et al., 2008; Zhang et al., 2008). Educational programming specifically about pain in children with I/DD has not been developed or implemented. Indeed, knowing the science of pain is an important necessity to improve pain assessment abilities that many care providers would welcome (Hunt et al., 2002; Carter et al., 2017; Genik et al., 2017a). As such, in a previous study, Genik, McMurtry, Breau, and Lewis (2018) developed the *Let’s Talk About Pain* program, using stakeholder input and extant research literature. This empirically-informed pain assessment and management program designed specifically for respite workers aims to improve these caregivers’ pain-related knowledge and provide them with pain assessment and management strategies that they can use with children who have I/DD. Results from the pre-post pilot study ($n = 50$) demonstrated that after completion of the training program, respite workers’ pain-related knowledge increased significantly (Genik et al., 2018). There were also significant increases in respite workers’ perceptions of (a) the feasibility of, (b) their confidence in, and (c) their skill in pain assessment and management in children with I/DD (Genik et al., 2018). Respite workers who participated in the pilot program positively endorsed the program, and felt that pain was an important topic (Genik et al., 2018).

**Current Dissertation**

While the *Let’s Talk About Pain* program showed promise in improving respite workers’ knowledge about pain and other perceptions, a more rigorous research design such as a randomized controlled trial (RCT) is required to test (a) the program’s impact on respite workers’ pain-related knowledge, and (b) the program’s impact on respite workers’ pain-related
approaches in their practice. Understanding respite workers’ impressions of the program is also important in continuing to develop an effective program. In this way, participants’ knowledge, their practice, and their reaction to the training program are all critical outcome measures. Several models have been used to evaluate training programs, and these are consistent with the first three levels (reaction, learning and behaviour) of a well-known and commonly used training evaluation approach, the Kirkpatrick model (Kirkpatrick, 1996). Indeed, this model has also been used to evaluate training programs directed to staff who support people with developmental disabilities (Smidt, Balandin, Sigafoos, & Reed, 2009).

The goal of this dissertation was to further develop and test the effectiveness\(^2\) of the *Let’s Talk About Pain* training. This remainder of this dissertation includes the following:

- Chapter Two: A multiple-case study gathering stakeholder feedback used to help inform the follow-up methodology of the main randomized controlled trial.
- Chapter Three: A manuscript presenting the full RCT protocol for the *Let’s Talk About Pain* program.
- Chapter Four: A manuscript outlining the quantitative impact of the *Let’s Talk About Pain* program on RCT participants’ (a) pain-related knowledge and (b) perceptions of the feasibility of and their own confidence and skill in pain assessment and management with children with I/DD immediately following and 4-6 weeks after training completion.
- Chapter Five: A manuscript outlining the qualitative impact of the *Let’s Talk About Pain* program on RCT participants’ pain assessment and management approaches in practice, as well as their impressions of the program itself.

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\(^2\) This study will be referred to as a study investigating the training’s effectiveness given that it has an intent-to-treat component (McCoy, 2017).
Chapter Six: A perspectives paper which serves as a call to action and highlights opportunities and challenges in conducting community-based research related to pain in children with I/DD.

These studies are part of a broad research program aimed to improve respite workers’ ability to assess and manage pain in children with I/DD for whom they care.
Chapter Two: Feasible outcome evaluations: A multiple-case study informing follow-up methodology for a randomized controlled trial for children’s respite workers receiving pain-related training

*Note: This chapter is the author version of the following ‘under revision’ manuscript:

Abstract

Objective: Pain is common for children with intellectual and developmental disabilities. It is critical that caregivers have adequate knowledge in this area to assist with pain assessment and management. The Let’s Talk About Pain program has shown promise to provide pain-related knowledge and skills to respite workers; however, more systematic evaluation of the program is needed. The purpose of this multiple-case study was to determine the most feasible follow-up methodology to utilize within a randomized control trial testing Let’s Talk About Pain’s impact on pain-related approaches used in practice. Methods/Design: Four employees in children’s respite organizations completed interviews lasting approximately fifteen minutes and a related questionnaire about feasible follow-up approaches. Results: Based on participant responses, the use of questionnaire and focus group methodology was determined to be the most feasible approach during follow-up to evaluate participants’ pain-related approaches in practice. Conclusions: Special consideration should be made when making methodological-related choices during the study development phase to help ensure study feasibility. This iterative approach with stakeholders may also be helpful in clinical settings, particularly those such as multifaceted organizations supporting individuals with complex needs such as those with I/DD, when designing program evaluations to enhance feasibility and suitability.

Keywords: knowledge translation; study development; children with disabilities; pain education
Introduction

Children with intellectual and developmental disabilities (I/DD) frequently experience pain and are often reliant on caregivers to assist with pain assessment and management [1,2]. It is therefore critical that caregivers of children with I/DD have access to relevant pain-related knowledge and care approaches. Although most work focused on primary caregivers and health providers, children with I/DD often spend time in a variety of settings with other caregivers. Recent work with secondary caregivers including respite workers for children with I/DD, residential support workers of adults with I/DD, and school nurses for children with I/DD has illuminated challenges with pain assessment and management including: inaccurate beliefs [3, 4], limited to no access to specialized pain education [3], lack of knowledge [4, 5], and role confusion with other support staff [5]. Indeed, it seems that a knowledge-to-action gap exists for these caregivers.

Knowledge translation is one way to address this gap and is an important component of the research process [6, 7]. Defined by the Canadian Institutes of Health Research (CIHR), knowledge translation is “a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically sound application of knowledge.” The knowledge-to-action cycle has been used extensively to illustrate knowledge translation [8, 9]. The phases include: identifying the problem; identifying, reviewing, and selecting the knowledge to implement; adapting or customizing the knowledge to the local context; assessing the determinants of knowledge use; selecting, tailoring, implementing and monitoring interventions related to knowledge translation; monitoring knowledge use; evaluating outcomes or impacts of using the knowledge; and determining strategies for ensuring sustained use of knowledge [9]. Phases in the action cycle can occur sequentially or simultaneously and interact with other action phases and/or knowledge creation [9].
Consistent with the knowledge-to-action cycle, we first conducted research with staff in respite organizations supporting children with I/DD to learn more about respite worker’s (RW) pain-related experiences and perceived training needs and preferences [10]. The *Let’s Talk About Pain* program for respite workers supporting children with I/DD was then developed using RW’s responses [10] and extant research literature relevant to the context. RW who completed the initial pilot of *Let’s Talk About Pain* provided favorable endorsements and demonstrated increased pain knowledge and more positive perceptions about pain assessment and management [10]. Following this, the need for systematic evaluation of *Let’s Talk About Pain* using a randomized controlled trial (RCT) was highlighted. Within the RCT, exploration of both short- and longer-term impact on pain-related knowledge and perceptions as well as the training’s impact on pain-related approaches in practice were considered important.

Although certain methods and procedures of the initial pre-post *Let’s Talk About Pain* pilot study [10] could inform the methodology in an RCT of the program, no information was available on the best way to feasibly measure outcomes related to pain assessment and management approaches in practice. A multiple-case study was therefore employed to determine this aspect of the data collection methodology for the RCT. The aim of this paper is to review the multiple-case study conducted with stakeholders. This research was exploratory in nature; hence, there were no a-priori hypotheses. The Consolidated Criteria for Reporting Qualitative Research (COREQ) has been used as a guideline for reporting of this research [11].

**Method**

**Participant Recruitment**

Following research ethics clearance from the institution’s research ethics board, participants were recruited by email until data saturation was reached (i.e., the point where there
were no ‘new’ data being generated by participants). To be eligible, participants had to: (a) be at least 18 years of age, (b) have previously participated in the initial development or pilot study of the Let’s Talk About Pain training and (c) indicated interest in future research involvement [10]. Having participated in earlier phases of this work, participants had experience with the population of interest, the training program being developed, and its goals.

**Procedures**

After providing informed consent, participants completed a demographics questionnaire and a semi-structured phone interview. All interviews were conducted by the first author, a female PhD candidate in clinical psychology with experience in pain and disability research as well as applied experience in respite settings. In addition to the participant and interviewer, a research assistant was present taking field notes during each interview. Field notes were then expanded within 24 hours of each interview. Interviews were based on a series of pre-determined questions and prompts, focusing on participants’ ideas about how researchers could assess RW use of pain assessment and management-related strategies (guide available upon request). All interviews were facilitated by the lead researcher with the accompanying note-taker on speaker phone, were audio-recorded [12] and lasted approximately 15 minutes. Interviews were later transcribed and verified from the audio recordings. Following the interview, participants completed a post-interview questionnaire and were offered a $5 gift card.

**Materials**

**Demographics Questionnaire.** Data gathered included: (a) general demographic information such as age and sex, and (b) information about participants’ employment positions and experience developing protocols, procedures, and staff evaluations in respite settings.
**Post-Interview Questionnaire.** This researcher-generated questionnaire allowed participants to provide additional information about feasible approaches for exploring pain assessment and management strategy use in a respite setting. It was administered after completion of the semi-structured interview. The format of the questions varied (e.g., 0 – 10 point Likert scales; open-ended questions), primarily asking participants to rate the feasibility of and discuss in detail five potential follow-up approaches. For example, participants were asked what makes each approach feasible and what could be challenging. Space was also provided to discuss additional data collection ideas and rank order their data collection preferences.

**Analyses**

**Quantitative analyses.** Frequencies and descriptives were used to analyze closed-ended and rating responses from demographic and post-interview questionnaires (e.g., mean, SD).

**Qualitative analyses.** Inductive qualitative content analysis from an essentialist/realist epistemology [13,14] following the phases outlined by Elo and Kyngäs (preparation, organization, and reporting) was used to analyze open-ended data from the post-interview questionnaire and participant interviews [15]. All data were analyzed concurrently during data collection in order to identify when data became saturated. Although responses to questions were initially analyzed separately, interview analyses were collapsed across questions due to overlap of participant responses. When reviewing the data, the researcher made notes and observations before freely generating initial categories associated with these notes. These initial categories were then broadened, and sub-categories were applied where necessary. Finally, category descriptions were created to represent the different categories. The lead researcher engaged in the entire analysis process manually, and a research assistant also reviewed the process. As recommended in qualitative research, an audit trail in the form of a log was kept in order to document the content analysis and related decision-making processes [16], multiple types of
field notes were cross-checked (i.e., condensed and expanded notes; [17]), and researchers consulted regularly when interpreting the data [16].

**Results**

**Participants**

Participants were two children’s RW and two managers of children’s respite programs ($M_{age}$: 48.75; range $age$: 32 - 63; 4 female) with varying length of employment in respite settings ($M_{yearsemployedinrespite}$: 17.75; range: 3 – 35 years; median: 16.50 years). All participants had experience developing respite related care protocols (e.g., care plans, medication protocols), and three had experience evaluating staff performance in respite settings.

**Participant Results**

Qualitative interview analyses revealed that although participants identified the feasibility of several approaches for collecting data, one single overarching approach was agreed upon by all participants. Specifically, participants highlighted the need for multi-method data collection using observations and/or interviews/focus groups and/or questionnaires. Interviews and focus groups on their own were also commonly suggested. Participants’ ratings of feasibility for various data collection approaches are presented in Table 1. Quantitative ratings on interview/focus group feasibility are not available, as these approaches were not explicitly listed on the post-interview questionnaire. Participants identified three categories of considerations and potential challenges associated with follow-up data collection methods (see Table 2) and had several ideas about when it would be most feasible to collect data. However, two recurring opinions were that: (a) it may be difficult to collect data outside of work hours, and (b) the most feasible approach might vary across individual staff members. Of note, half of participants provided additional suggestions to
collect data during staff meetings (\(M = 9.00; \text{Range: } 8.00 – 10.00\)), and half of participants commented on the potential for online data collection (no feasibility ratings provided).

**Discussion**

Considering the frequency of pain and associated challenges with assessment and management for children with I/DD [1,2], caregivers who support these children require adequate pain-related knowledge and skills. *Let’s Talk About Pain* is a promising approach for translating pain assessment and management information to RW [10] but requires further systematic evaluation through RCT methodology. The current manuscript describes a multiple-case study conducted to inform the RCT methodology. Specifically, the aim of this study was to gather stakeholder feedback regarding feasible approaches for collecting follow-up data from participating respite workers about the impact of the training on pain-related approaches in practice.

**Outcomes and Implications**

Participant responses suggested several potentially feasible data collection approaches including questionnaires, focus groups, interviews and live observations. However, considerations and challenges (a) when collecting data across multiple organizational settings spanning geographical regions and (b) with observation-based methodology were also identified. Results from this multiple-case study therefore indicated that the most feasible approach would be to utilize questionnaire and/or focus group methodology, holding the follow-up meetings during staff meetings or formal work shifts whenever possible. As with any decision, advantages and disadvantages exist. For example, while this methodological approach will allow researchers to collect data at multiple time points and collect both quantitative and qualitative data, there is no direct observation of skill use. Direct observation of skill use was precluded at this time due
to the many participant concerns regarding observation feasibility combined with the researchers’ reflection on what would be feasible if data collection were to span broadly across geographical regions as intended. The approach to decision making and use of the knowledge-to-action framework [9] in this multiple-case study to inform an RCT protocol may also be important to apply in clinical settings when evaluating processes and programs as explored next.

Consistent with literature surrounding knowledge translation and application of the knowledge-to-action framework, it is critical to seek input from stakeholders throughout the process of developing, implementing, and evaluating staff programs within clinical settings [7]. Given the relative scarcity of the research on pain management in children with I/DD, identifying and understanding barriers such as these is important when designing research.

Similar to Genik and colleague’s [10] training development and pilot study, responses from participants in the current multiple-case study provided important information and insight from front line staff and management. Further, information gathered from end users is a critical part of the knowledge-to-action process, related to multiple phases such as identification of barriers to uptake, adapting knowledge to the context and needs of end users, and selecting and tailoring appropriate interventions [7]. While researchers or clinicians may be able to predict some barriers or adaptations required for a given context, end users are likely to have unique insights that can improve the quality of programs and resources being developed for staff in clinical settings. For example, participants in the multiple-case study almost unanimously spoke about the challenge of completing questionnaires outside of work shifts, even if incentives were to be put in place.

The importance of viewing the knowledge-to-action framework as iterative and interactive within not only the action cycle but also the knowledge creation cycle should be
highlighted [7]. Not only is this process relevant for researchers, but it is also likely to represent the trial and error that frequently goes along with development of knowledge translation and implementation initiatives in clinical contexts. The need for an iterative and interactive approach may be particularly important to keep in mind when working with multifaceted organizations working with complex populations such as those with I/DD. For example, throughout the interview and questionnaire data of the multiple-case study, participants often responded with an ‘it depends’ sort of mentality. Their perspective likely reflects acknowledgement of the differences within organization-based programs and between organizations themselves that may influence feasibility and uptake of various programs and evaluation approaches. Indeed, organizations supporting children with I/DD, for example, may host different types of respite programs, support different types of children, and have different types of policies, procedures, and resources available to them which could impact the feasibility of various approaches.

**Strengths, Limitations, and Future Directions**

A major strength of the current study is its utility in proactively exploring potentially feasible data collection approaches and methods during the development of an RCT protocol targeting caregivers of children with I/DD. In approaching protocol development in this way, follow-up methodology to be included in the RCT may be more consistent with what is most feasible for those participating in the research study, particularly within the context of supporting children with I/DD. The use of interview methodology allowed for participants to respond in open-ended ways with more rich and nuanced data, and questionnaires completed by participants then complemented this information provided. Future research may explore the impact that this approach has on the feasibility of research studies examining pain assessment and management.
for children with I/DD. For example, does feedback early on in study protocol development help to improve participants’ completion of various data collection time-points?

Several limitations are also present. Importantly, this study was a multiple-case study with only a small number of participants within a relatively small geographic region. While data saturation appeared to be met, it is still possible that participants spanning a larger geographic area may have had different responses or preferences than those who participated in the study. Future research may consider recruiting participants from a wider geographic domain, or perhaps the full geographic domain in which the RCT will be taking place when developing a study protocol. Additionally, participants in this multiple-case study were not given an opportunity to review the final data collection approaches and methods to be used when measuring the impact of the pain training on participants’ approaches in practice. Providing this final check-in with participants regarding the study protocol could allow for an additional chance to catch any potential challenges or barriers related to a methodological approach.

**Conclusion**

Results from this multiple case study were used to inform aspects of the data collection methodology for a larger randomized controlled trial examining the impact of a pain training on respite workers’ knowledge, perceptions, and pain-related approaches in practice with children with I/DD. Based on study results, a feasible methodological approach was selected and is incorporated into the RCT’s research protocol. Importantly, this approach to the development of study methodology keeps with the knowledge-to-action approach and has important implications for study design as well as the creation and evaluation of clinical programs. Specifically, connecting with stakeholders in the early stages of research and program evaluation can help those in research and clinical settings understand the types of approaches that are most likely to yield the desired information to match research or program evaluation goals. Enhancing the
potential success of research focused on children with I/DD and/or their caregivers is imperative in order to improve the quality of life for these vulnerable and understudied children.
References


11. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research


Table 1

Summary of staff ratings of feasibility for various data collection approaches; 0 to 10 with higher scores reflecting higher feasibility.

<table>
<thead>
<tr>
<th>Data Collection Approach</th>
<th>M</th>
<th>Median</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>● Having a research assistant observe staff during shifts</td>
<td>7.00</td>
<td>7.50</td>
<td>1.41</td>
<td>5-8</td>
</tr>
<tr>
<td>● Having a senior staff member or manager observe staff during shifts</td>
<td>8.50</td>
<td>9.50</td>
<td>2.38</td>
<td>5-10</td>
</tr>
<tr>
<td>● Asking staff to complete a questionnaire at the end of shifts</td>
<td>8.50</td>
<td>9.50</td>
<td>2.38</td>
<td>5-10</td>
</tr>
<tr>
<td>● Incorporating materials into children’s care profiles with routine paperwork</td>
<td>8.50</td>
<td>9.50</td>
<td>2.38</td>
<td>5-10</td>
</tr>
<tr>
<td>● Asking staff to complete questionnaires periodically outside of work hours</td>
<td>4.50</td>
<td>5.00</td>
<td>3.42</td>
<td>0-8</td>
</tr>
</tbody>
</table>
Table 2

*Summary of Participant Identified Considerations and Potential Challenges with Collecting Follow Up Data in a range of Follow Up Formats*

<table>
<thead>
<tr>
<th>Considerations and Potential Challenges</th>
<th>Related Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Documentation requirements</strong></td>
<td></td>
</tr>
<tr>
<td>● May need to provide organizations with police record checks for research assistants if conducting in vivo observations</td>
<td></td>
</tr>
<tr>
<td>● May need consent from more than just research participants (e.g., parents of children receiving respite) if observing</td>
<td></td>
</tr>
<tr>
<td>● May need to consult with Human Resources about other documentation needs (i.e., participants were unsure if other documentation would be needed)</td>
<td></td>
</tr>
<tr>
<td><strong>Logistics</strong></td>
<td></td>
</tr>
<tr>
<td>● Potential need to observe all shifts including overnight shifts to capture variation</td>
<td></td>
</tr>
<tr>
<td>● Time commitment for organizations; staff</td>
<td></td>
</tr>
<tr>
<td>● Coordinating schedules of staff, organizations, research assistants</td>
<td></td>
</tr>
<tr>
<td>● Clientele-based restrictions (e.g., not all parents may consent for their children to be included in observations even if the focus is on staff behavior)</td>
<td></td>
</tr>
<tr>
<td><strong>Staff-specific factors</strong></td>
<td></td>
</tr>
<tr>
<td>● Staff familiarity with each client if observing</td>
<td></td>
</tr>
<tr>
<td>● Staff comfort with data collection approaches (e.g., may feel pressure if managers are observing)</td>
<td></td>
</tr>
<tr>
<td>● Consideration of changes in staff availability (leave of absence, vacation, change in roles, etc.)</td>
<td></td>
</tr>
<tr>
<td>● Staff ability to complete paperwork without training (e.g., are forms user-friendly?)</td>
<td></td>
</tr>
<tr>
<td>● Staff interest in participating in research outside of work hours</td>
<td></td>
</tr>
</tbody>
</table>
Chapter Three: Study protocol for a multi-centre parallel two-group randomized controlled trial evaluating the effectiveness and impact of a pain assessment and management program for respite workers supporting children with disabilities

*Note: This chapter is the author version of the following ‘under review’ manuscript:

Abstract

Objective: Pain is common and complex for children with intellectual and developmental disabilities (I/DD). Secondary caregivers such as respite workers are lacking important pain-related information which can impact care. Here we outline a randomized controlled trial (RCT) protocol testing the effectiveness of a pain training for respite workers supporting children with I/DD. Methods/Design: Organizations enrolled in the RCT were randomly assigned to receive a 3-3.5 hour pain or family-centered care training. Data were collected immediately before, after, and four to six weeks following completion of the training. Outcomes are as follows: pain knowledge (primary), pain assessment and management perceptions (secondary), training evaluations (secondary), and use of pain assessment and management skills (tertiary). Both quantitative and qualitative methodologies are being used including questionnaires, rating scales, a standardized vignette and focus groups. Conclusions: Results from this trial will be used to further understand the impact of the pain training and inform next steps related to implementation. TRIAL REGISTRATION: ClinicalTrials.gov identifier: NCT03421795

Keywords: children, disabilities, pain, education, respite workers
Introduction

Pain is common for children with intellectual and developmental disabilities (I/DD) [1]; limited communication skills and differences in pain expression also make assessment and management challenging [2, 3]. There are short- and long-term consequences of inadequately managed pain in those with I/DD including disrupted sleep and reduced adaptive functioning in communication, daily living skills, socialization and motor skills [4, 5]. There has been progress in assessing pain of children with I/DD using structured behavioral measures such as the Non-Communicating Children’s Pain Checklist – Revised [6] as well as self-report adaptations [e.g., 7]. Some work has also been conducted on pain management for children with I/DD. Existing research has alluded to pharmacological, physical, psychological and process-related management strategies as important and helpful in a disability context [e.g., forms of distraction in a post-operative context: 7; 8].

To date, most work related to pain in children with I/DD has focused on primary caregivers and healthcare providers [e.g., 2, 6, 9]. However, secondary caregivers such as respite workers (RW) also spend considerable time with children with I/DD. Initial research addressing this knowledge gap demonstrated that RW who frequently spend time with these children may hold inaccurate beliefs about pain, and do not typically have access to specialized pain education related to children with I/DD [10]. Recent work in related areas (e.g., residential support workers of adults with I/DD, school nurses for children with I/DD) has illuminated similar challenges including: inaccurate beliefs [11], lack of knowledge [11, 12], and role confusion with other support staff [12]. Access to relevant pain knowledge is critical so caregivers of children with I/DD can provide appropriate care.

Recognizing the knowledge gap in the children’s respite community, Genik, and colleagues [13] conducted a two-phase study which first gathered information about RW’s pain-
related experiences and perceived training needs and preferences. This information was used in tandem with extant literature to develop a relevant, empirically-informed pain assessment and management training, called Let’s Talk About Pain, for RW who support children with I/DD. Pilot study results demonstrated (a) increased pain-related knowledge, (b) increased self-reported perceptions of the feasibility of and participants’ perceived confidence and skill in pain assessment and management (herein ‘pain assessment and management perceptions’), and (c) favorable endorsement of the training by RW [13]. Identified next steps were to systematically evaluate the training’s impact on both knowledge and skill use with a larger, more diverse sample and have a longer-term follow-up.

This paper presents the complete randomized controlled trial (RCT) protocol used to test the effectiveness and impact of Let’s Talk About Pain on RW’s pain-related knowledge, beliefs, and assessment and management approaches when caring for children with I/DD. This paper has been published in advance of the RCT study results to ensure that enough detail regarding the RCT and its development can be available to researchers and clinicians, both of whom could benefit from the information. For example, this information could be important for future RCT implementation, study replication, and application in clinical settings. The Standard Protocol Items: Recommendations for Interventional Trials (SPIRIT) 2013 [14] guideline for the minimum content which should be reported for trial protocols was used to guide protocol content within this manuscript. Additional information not included in the current manuscript is available upon request (e.g., copies of consent forms).

**Trial Status**

This trial is registered with clinicaltrials.gov (identifier: NCT03421795). Data collection was completed in August 2018; analyses are ongoing. Researchers have no conflicts of interest.
**Outcome Measures and Hypotheses**

Participant outcome measures were: (a) pain-related knowledge [primary], (b) pain assessment and management perceptions [secondary], (c) participants’ training endorsements [secondary], and (d) use of evidence-based pain assessment and management strategies [tertiary].

Between-group hypotheses predicted that immediately post and at 4- to 6-week follow-up, participants receiving the pain training would demonstrate significantly higher pain knowledge and pain assessment and management perceptions compared to the control group. It was also predicted that at follow-up participants receiving the pain training would have significantly higher levels of evidence-based pain assessment and management strategy use compared to the control group. Within-group hypotheses for those receiving the pain training predicted significant increases on pain knowledge and pain assessment and management perceptions from pre to post, with maintenance of these gains from post to follow-up. It was also hypothesized that participants would provide favorable endorsements of the training program. Finally, significant increases from pre to follow-up for evidence-based pain assessment and management strategy use were hypothesized. Results from the RCT are to be published in two separate manuscripts: one reviewing the impact of the training on participant knowledge and perceptions, and the other reviewing participants’ training endorsements and its impact on their strategy use in the workplace.

**Design/Methods**

**Study Design and Procedure**

The RCT represents a multi-center parallel two group (pain training, control training) design. Data were collected in person using hard copy questionnaires immediately before and after an initial training, and again at a four to six week follow-up time point using hard copy
questionnaires and focus group methodology (See Figure 1 for procedure). Participating organizations were given information about the general purpose of the study as well as the training topic(s), but were not made explicitly aware of whether they were allocated to the control or intervention condition. Participants were told that the purpose of the study was to learn about the impact that training can have on RW knowledge about caring for children with I/DD. No information was provided to participants about study hypotheses.

**Organization Recruitment**

Ethical approval was secured from the University research ethics board. Participant recruitment occurred in collaboration with children’s respite organizations in Ontario. A researcher-compiled organization database of 95 potentially eligible organizations developed from (a) a list of respite organizations in Ontario from www.respiteservices.com, and (b) online searches for children’s respite services in Ontario was used. These organizations were approached by telephone and/or email. Organizations in closest proximity to the researchers’ home city were contacted first with organizations further away contacted as needed to achieve optimal sample size.

**Randomization**

As organizations agreed to host the program(s) for their RW, the entire organization was randomly assigned to either the control or intervention group. This means that all participating staff from a given organization participated in the same condition. Sequentially numbered, sealed, opaque envelopes (SNOSE) with a 1:1 allocation ratio were created by a research assistant not involved in study recruitment, group allocations, training or data collection processes. Once assigned, primary investigators were no longer blind to the group allocation.

**Participant Recruitment**
Researchers recruited and sought written informed consent from participants at each initial training hosted by participating organizations. Participants had to be proficient in the English language and at least 18 years of age and employed through participating organizations as RW supporting children with I/DD in any setting (e.g., family home, community, group homes) in order to participate. Ineligible staff or those who choose not to participate in the study component could still attend the training(s).

**Sample Size**

G*Power 3 [15] was used to conduct a power analysis based on our previous *Let’s Talk About Pain* training pilot study [13]. Based on the smallest effect size ($d = 0.90$ [effect size $f = 0.45$]; original range of effect sizes $d = 0.90 – 1.71$), a very small sample size (16) was required at power of .95 and alpha of .05 to detect an overall interaction effect of group by time. A much more conservative effect size ($d = 0.25$ [effect size $f = 0.1250$]) was also used to calculate the most stringent estimate at power of .95 and alpha of .05, resulting in a total target sample size of approximately 84 participants per group (168 participants total; [15]). We aimed for our study sample size to fall in the higher end of this range.

**Interventions**

**General Training Characteristics.** Each training occurred in-person with no more than 30 participants, lasting 3 to 3.5 hours with one or two breaks totaling approximately 30 minutes. Training sessions were interactive in nature (e.g., group discussions, case studies) and structured with a Power-Point presentation with notes and provision of relevant resources. A standardized fidelity checklist was used to document key points covered (or not covered in the control group) during the training.
**Let’s Talk About Pain Training.** Previously developed and piloted by Genik and colleagues [13], the training’s content was specific to children with I/DD and focused broadly on providing information on what pain is, pain expression, pain assessment, and pain management specific to a respite context; detailed training outline is available upon request. Let’s Talk About Pain is empirically-informed and covers all relevant aspects of Chapter 43 of the IASP Core Curriculum for Professional Education in Pain [16]. The training was facilitated by the same facilitator throughout the study.

**Control Training.** Participants in the control group completed a training about a family-centered care approach. Specifically, the training provided information about the F-words of childhood disability (function, family, fitness, fun, friends, future; [17]) and how to implement this framework in a respite setting. This translational work is based on the World Health Organization’s (2001) International Classification of Functioning, Disability and Health Framework. The topic is fitting given its relevance to care for children in respite settings and its lack of focus on pain. This training was facilitated by a PhD Candidate from McMaster University (Hamilton, Ontario, Canada).

**Outcome Measures**

**Primary.** Participants’ pain-related knowledge was assessed at pre, post and follow-up using the Questionnaire for Understanding Pain in Individuals with Intellectual Disabilities – Caregiver Version Revised (QUPID-CR), a 39-item true/false and multiple-choice questionnaire. Single points are awarded for each correct response to compute a total score out of 39, and higher scores represent greater levels of knowledge. The QUPID-CR was developed following initial responsivity and item-level analyses of the original QUPID-C [18] completed prior to use.
in this RCT [19]. Like the QUPID-C, the QUPID-CR is based on existing literature and the International Association for the Study of Pain’s (IASP) core curriculum (Chapter 43; [16]).

**Secondary.** Participants provided 6 self-report ratings (Pain Assessment and Management Perceptions) of their perceptions of: 1) the feasibility of \(0 = \text{Not Feasible At All}, 10 = \text{Highly/Extremely Feasible}\), 2) their confidence in \(0 = \text{Not Confident At All}, 10 = \text{Highly/Extremely Confident}\), and 3) their skill in \(0 = \text{Not Skilled At All}, 10 = \text{Highly/Extremely Skilled}\) pain assessment and management for children with I/DD at all three time points. These ratings have shown responsivity to training [13, 18].

Participants also completed a researcher-developed questionnaire at post, rating their level of agreement \(0 = \text{strongly disagree} \) to \(10 = \text{strongly agree}\) with different statements about the training program (e.g., effectiveness of format). Here, participants also provided responses to open-ended questions related to the training program (e.g., what component of the training they thought contributed most to their learning). This questionnaire is based on that which was used in the pilot study for the *Let’s Talk About Pain* training [13].

**Tertiary.** Participants’ use of pain assessment and management skills was assessed using both questionnaire and focus group methodology (see Figure 1). The *Use of Pain Assessment and Management Strategies Questionnaire* is a researcher-generated questionnaire which includes open and closed questions about: (a) participants’ work in a respite setting (e.g., number of shifts/hours per week) and (b) frequency of and types of pain assessment and management strategies used. These questions are intended to explore participants’ use of pain assessment and management strategies within the context of their work environment. This questionnaire also contains a previously developed vignette to explore their use of pain assessment and management strategies in a more standardized way [20]. This vignette has shown divergent and
convergent validity when compared to other pain-related vignettes with different pain sources and background information [20].

The aim of the focus group component was to explore the types of pain assessment and management strategies RW have used on the job more in depth. Each began with a brief introduction of the purpose followed by semi-structured questions about participants’: (1) opinions and knowledge about pain in children with I/DD, and (2) experiences with pain assessment and management in respite settings, specifically in the time period between completion of the training and the follow-up data collection. They were also asked about times when they remembered something from the training and whether they were able or unable to use it; the full focus group guide is available upon request. Audio-recorded focus groups were 30 minutes to one hour in length, with no more than 12 participants per focus group [21]. The number of focus groups was dependent on the number of participants attending each organization’s follow-up data collection. Focus groups were facilitated by the lead researcher with an accompanying research assistant taking field notes [21].

**Participant Compliance and Loss to Follow-up**

Given the single time-point nature of the intervention and previous data from the *Let’s Talk About Pain* pilot study [13], participant compliance was not of great concern. In contrast, the potential to lose participants at the follow-up time point was more unknown. Incentives were used during the initial data collection (pre, post) and follow-up to try to maximize participant retention. Specifically, participants received an entry into a $20 gift card draw (odds of winning: 1 in 25) and refreshments at each visit (i.e., at the pre/post data collection date, and at follow-up), a notebook and pen set at the initial time point, and a certificate along with a $20 honorarium at follow-up.
Analyses

Research assistants double entered the data into an SPSS statistical analysis program which is stored on an encrypted, password protected e-drive. Hard copy data will be stored for seven years after publication of results.

Both intention-to-treat (ITT) and per protocol (PP) analysis approaches will be used to analyze the data related to the study’s primary and secondary outcomes regarding participants’ pain knowledge and pain assessment and management perceptions; ITT will be primary and PP will be complementary [22, 23]. After confirming there are no baseline differences between groups, seven 2 x 3 mixed analysis of variances (ANOVA) will be conducted. If statistical assumptions for these analyses are not met, a more conservative approach using bootstrapping will be considered and conducted if the program allows; SPSS has some limitations in this regard [24]. The dependent variables for the different mixed ANOVAs will be the mean of participants’ pain-related knowledge (primary outcome measure) and pain assessment and management perception rating scores (secondary outcome measures). In all seven analyses, the within-subjects factor will be represented by participants’ scores on the related measure across pre, post and follow-up time periods, and the between-subjects factor will be the condition (pain training or control training). In keeping with the study’s specific hypotheses, follow-up analyses using one-way ANOVAs and paired samples t-tests will be used as needed to further investigate differences in the dependent variables over time within the pain training group if significant group differences are found.

Frequency and descriptive analyses will be used to analyze participant open-ended responses on the Use of Pain Assessment and Management Strategies and training evaluation questionnaire. To describe responses to open ended questions, coding schemes will be developed
from an essentialist/realist perspective using an unconstrained matrix [25,26]. In this scheme, both inductive (i.e., consideration of participant responses) and deductive (i.e., consideration of relevant research literature) approaches will be incorporated as relevant. For example, category names and descriptions will reflect what is known from previous literature as relevant, but new categories will also be developed that may not be consistent with the literature should they arise. First, the primary investigator will become familiarized with the data, and initial categories will be generated and grouped into broader categories with definitions [27]. These schemes will then be reviewed by additional researchers on the team who will: (a) help to ensure that the schemes are representative of the data, and (b) further develop category definitions and examples [27]. Following coding scheme development, two research assistants will be trained on these schemes. Participant responses will then be coded, and inter-rater reliability for coding will be calculated using Cohen’s Kappa. An inductive and essentialist/realist qualitative thematic analysis following the steps outlined by Braun and Clarke [28] will be used to analyze focus group transcript data. Following familiarization with the data, transcriptions will be uploaded to NVivo12 software where meta- and sub-themes will be derived, defined, and refined. How often a topic is raised, the length of time it is discussed, existing research literature, and applied researcher experience in the field will all be considered in developing these themes. Analyses will occur at the semantic level. Intervention and control focus groups will be analyzed separately from one another.

**Discussion**

Pain is often underdiagnosed and treated for children with I/DD, and challenges with verbal communication and behavioral expression can further complicate pain assessment and management [1, 3]. Secondary caregivers such as RW often spend time with children with I/DD
yet are lacking important information about pain [10]. Preliminary work suggests that pain-related education can improve these caregivers’ knowledge and perceptions [17]. These findings are well aligned with similar studies targeting pain assessment strategies for school nurses and residential support workers [29, 30].

It is believed that the current project will provide more information about the impact of the Let’s Talk About Pain training on participants’ knowledge and perceptions both in the short and longer term across organizations. Results from the RCT will also provide preliminary data on the impact this program may have on RW application of skills learned. If found to be effective, this RCT may provide researchers with further direction regarding implementation of the program across respite organizations, and next steps to encourage training uptake and skill application. The described RCT will be an important contribution to the literature on best practices in caring for children with I/DD.
References


11. Beacroft M, Dodd K. Pain in people with learning disabilities in residential settings–the need


Figure 1. Outline of protocol study procedures and methodology to be used for both groups of participants.
Chapter Four: A randomized controlled trial evaluating a pain assessment and management program for respite workers supporting children with disabilities part one:

Pain-related knowledge and perceptions

*Note: This chapter is the author version of the following ‘submitted’ manuscript:

Abstract

**Background:** Pain is common for children with intellectual and developmental disabilities (I/DD), yet specialized education for caregivers is lacking. **Methods:** This parallel group RCT tested the effectiveness of the *Let's Talk About Pain* training on respite workers’ pain-related knowledge and feasibility-confidence-skill ratings using between group (pain vs. control training) and within group (pain training only) analyses. Fourteen children’s respite organizations were randomized using sequentially numbered, opaque, sealed envelopes to receive the pain or a control (family-centered care) training. Researchers were blind until randomization; allocations were not explicitly revealed to organizations and participants. Participants \(n_{\text{intervention}} = 66; n_{\text{control}} = 92\) underwent a 3-3.5 hour training and completed pain-related knowledge measures and feasibility-confidence-skill ratings at pre, post and 4-6 week follow-up. Intention-to-treat \(n_{\text{intervention}} = 65; n_{\text{control}} = 92\) and per protocol \(n_{\text{intervention}} = 26-38, n_{\text{control}} = 40-57\) analyses were conducted. **Results:** Participants receiving the pain training demonstrated (a) significantly higher pain knowledge and feasibility-confidence-skill ratings at post and follow-up versus the control group (large effects) and (b) significant increases in knowledge from pre to post (very large effect). Despite a small decrease in mean scores (medium effect); significant gains in pain-related knowledge and confidence-skill ratings were maintained from post to follow-up. **Conclusions:** Results from this RCT demonstrated improvements in respite workers’ knowledge and perceived feasibility-confidence-skill ratings. This represents a promising step towards enhancing pain-related care provided by respite workers to children with I/DD.
Introduction

Pain is a common experience for children with intellectual and developmental disabilities (I/DD) that negatively affects their adaptive functioning (Breau, Camfield, McGrath, & Finley, 2003; Breau, Camfield, McGrath, & Finley, 2007). Numerous factors, including communication difficulties, cognitive deficits, and unique pain behaviors contribute to challenges with pain assessment and management (Carter, McArthur, & Cunliffe, 2002; Doody & Bailey, 2017). The majority of research to date has focused on developing assessment tools for primary caregivers and health care providers (e.g., Non-Communicating Children’s Pain Checklist; Breau, Camfield, McGrath, & Finley, 2002). There has been limited development of targeted educational programs for key staff in residential and school settings (Mackey & Dodd, 2010; Quinn & Smolinski, 2017). Participants receiving education in these studies have reported: (a) altered attitudes such as better awareness that people with I/DD do not have higher pain thresholds (Mackey & Dodd, 2010); (b) less difficulty assessing pain (Mackey & Dodd, 2010; Quinn & Smolinski, 2017); and (c) intent to change practice standards (Quinn & Smolinski, 2017).

Respite care refers to temporary care of a child with a disability which aims to provide a parent or primary caregiver a break from the demands of caring for their child and their needs (McConkey, Kelly & Craig, 2011). Notably, respite care is identified by families of children with I/DD as a critical, high-in-demand support service (Douma, Dekker, & Koot, 2006; McConkey et al., 2011; Robertson et al., 2011). Yet, many respite workers have not received specialized pain education, and may hold inaccurate pain-related beliefs (Genik, McMurtry, & Breau, 2017; Genik, McMurtry, Breau, Lewis, & Freedman-Kalchman, 2018). Indeed, these workers may have a gap in their knowledge about pain assessment and management for children with I/DD
Genik et al. (2017). Genik et al. (2018) developed the empirically-informed *Let’s Talk About Pain* program to address this gap. Immediately following the training, participating respite workers (*N* = 50) demonstrated significant increases in pain-related knowledge (large effect sizes *r* = 0.81 – 0.88); respite workers also provided higher ratings of the feasibility of pain assessment and management, as well as their confidence and skill in these domains (herein referred to as feasibility-confidence-skill ratings; moderate to large effect sizes *r* = 0.41 – 0.70; Genik et al., 2018). Although promising, this pilot did not include a comparison group or follow-up time point; hence, the present study was designed to address these limitations.

As part of a larger randomized controlled trial (RCT) using a parallel two group design (ClinicalTrials.gov identifier: NCT03421795) with pre, post and four to six week follow-up measures, the objectives of this study were to systematically test the effectiveness of the *Let’s Talk About Pain* program on respite workers’ (a) pain-related knowledge (primary outcome), and (b) feasibility-confidence-skill ratings (secondary outcome) for children with I/DD. We hypothesized that at post and follow-up, respite workers who completed a pain training would demonstrate significantly higher pain-related knowledge scores and feasibility-confidence-skill ratings compared to those receiving the control training. We also expected that participants assigned to the pain training group would demonstrate significant increases from pre to post and maintenance of these gains from post to follow up for all outcomes.

**Method**

Data were collected as part of a multi-center parallel two group (wait-list control) RCT approved by our research ethics board. The RCT consisted of two components. In this manuscript, the quantitative analyses of the impact of the *Let’s Talk About Pain* program on participants’ pain knowledge and perceptions of feasibility, confidence and skill are described.
Part two appears in a separate manuscript (Genik et al., submitted) and focuses on the qualitative analysis of participants’ *Let’s Talk About Pain* training evaluations, and the impact of this training on their use of pain-related strategies. Separate manuscripts for these outcomes allow for adequate discussion and exploration of the results and their implications. The same group of participants are represented in both manuscripts; however, the data in these two publications are distinct except for participant demographics.

Only the methods relevant to the present article are described below. A complete version of the RCT protocol is available (Genik, McMurtry, Barata, Barney, & Lewis, under review). The authors assume full responsibility for consistency between this report and the study protocol, as well as the correctness and completeness of the trial data.

**Participant Recruitment and Randomization**

**Organization Recruitment.** Organization-based recruitment occurred in collaboration with children’s respite organizations in Ontario. Ninety-five organizations were assessed for eligibility (i.e., whether they offered respite services for children with I/DD; see details in Genik et al., under review) and contacted by telephone and/or email. Upon contact, organizations were informed about the research study, which provided the organizations an opportunity to receive one to two free training sessions for respite staff.

After agreeing to host a training session, organizations were randomly assigned to either the pain training intervention condition or the control condition with an opportunity to schedule the pain training after follow-up. Assignments were completed using a permuted block design (total block size: 14; allocation ratio: 1:1). Sequentially numbered, opaque, sealed envelopes were created by a research assistant who was not involved in the randomization process. Organizations were not told to which condition they were allocated, and primary researchers
remained blind until after randomization occurred (for details see Genik et al., under review). Following randomization, organizations were given information about the training and study component to circulate in advance to staff.

**Individual Participant Recruitment.** At the beginning of the initial training date for each organization, the optional study component was discussed in detail with staff. The study purpose was described as examining the impact of training on respite workers’ knowledge about caring for children with I/DD. Eligible staff were proficient in English, at least 18 years of age, and employed at the participating respite organization providing respite to children with I/DD. They could not hold upper management positions or participate more than once in the study if employed in more than one participating organization.

**Training Interventions**

**General Training Characteristics and Training Fidelity.** General training characteristics of both groups were informed by the results of Genik et al.’s (2018) pilot study of the *Let’s Talk About Pain* program. Both the intervention and control training used a standardized Power-Point presentation with notes and included several interactive components (e.g., group discussions, case studies). Participants also received printouts of the slides and relevant resources. The primary investigator conducted all intervention trainings and a different facilitator from an external organization completed the control trainings; both had prior experience facilitating their corresponding trainings and applied experience in the field. Trainings were provided in-person within participating organizations’ spaces. Participants were given the opportunity to ask questions throughout the training, which allowed for some tailoring to the organizations’ interests and needs.
During each training session, a fidelity checklist was completed by a research assistant. The purpose of the checklist was to formally document similarities regarding training length, break length, and group size across conditions, and ensure that key points of information were covered in the intervention training and not covered in the control training. The pain training facilitator also had access to this checklist during each training to help ensure the pertinent information was covered. See Table 1 for a summary of fidelity data. Of note, there was a significant difference (see Table 1) between the length of the intervention and control training, such that the intervention training was on average 18 minutes longer.

**Let’s Talk About Pain Training.** As in the pilot study (Genik et al., 2018), the training aimed to increase knowledge and improve perceptions about pain in children with I/DD. Developed using stakeholder input, information from chapter 43 of the *International Association for the Study of Pain’s* Core Curriculum (Charlton, 2005), and research literature, the training provided education relevant to respite contexts about: what pain is, pain expression, pain assessment, and pain management (Genik et al., 2018). Training materials and a full training outline are available from the corresponding author upon request.

**Control Training.** The training provided to control groups focused on a family-centred care approach intended to improve the quality of life of children with I/DD. Specifically, this training communicated the six ‘F-words’ of childhood disability (function, family, fitness, fun, friends, future; Rosenbaum & Gorter, 2012) and discussed ways to implement these principles into respite programming. This training reflects the World Health Organization’s (2001) International Classification of Functioning, Disability and Health Framework. Thus, like the pain training, the control training was relevant but novel for respite settings.

**Procedures**
**Initial Data Collection.** After providing written informed consent, participants from both the intervention and control groups were asked to complete a series of pre-intervention paper-based questionnaires including: (a) a demographics questionnaire; (b) a pain-related knowledge measure specific to individuals with I/DD; and (c) feasibility-confidence-skill ratings for pain assessment and management. Immediately following consent and pre-intervention questionnaires, participants completed either the intervention or control training session. Immediately following each session, participants were asked to answer post-intervention questionnaires identical to (b) and (c) previously described. All participants received a folder with a copy of the slides, relevant resources, a notepad/pen set, refreshments during the break, and an opportunity to enter a $20 gift card draw (odds of winning: 24 to 1).

**Follow-Up Data Collection.** Approximately four to six weeks following initial data collection, the researchers collected pain knowledge and feasibility-confidence-skill ratings from both groups in person. All follow-up participants received a certificate of completion, another opportunity to enter a $20 gift card draw (odds of winning: 24 to 1), and $20 cash. After follow-up data collection, organizations in the control condition were given the opportunity to complete the Let’s Talk About Pain training program at a time convenient for the organization.

**Measures**

**Organization and Participant Demographics Questionnaires (Pre).** In order to gather information about the host organizations, an organization staff member in an upper leadership position was asked to complete a brief questionnaire about the organization itself. This included questions regarding the type of respite programming that staff are involved in, the types of children staff work with, and staff to child ratios. Individual participants self-reported general
demographic information (e.g., age, gender), information about their experience with children with I/DD, and information about any previous pain-related education completed.

**Questionnaire for Understanding Pain in Individuals with Intellectual Disabilities - Caregiver Version Revised (QUPID-CR; Pre, Post, Follow-Up).** The QUPID-CR was used to assess participants’ knowledge regarding: general pain, pain assessment, and pain management in individuals with DD. The QUPID-CR is a 39-item, empirically-informed true/false and multiple choice questionnaire; one “point” is given for each correct response to compute a total knowledge score out of 39. The QUPID-CR is available from authors upon request. The QUPID-CR is a revised version of the initial QUPID-C, which was responsive to knowledge change in an RCT with undergraduate students; Genik, Pomerleau, McMurtry, & Breau, 2017) and in Genik et al.’s (2018) *Let’s Talk About Pain* pilot study. Revisions to the original QUPID-C consisted of alterations to seven of the original items which performed poorly according to completed item analyses (Genik, Zaretsky, Pomerleau, Freedman-Kalchman, & McMurtry, in preparation). Four new items were also added to the QUPID-CR assessing knowledge regarding pain science and theory (e.g., gate control theory of pain; Genik et al., in preparation). Initial item analyses and responsivity testing for the QUPID-CR support the use of the QUPID-CR (Genik et al., in preparation).

**Feasibility-Confidence-Skill Ratings (Pre, Post, Follow-Up).** Participants provided self-report ratings on 6 items: the feasibility of pain assessment and pain management (0 = *Not Feasible At All*, 10 = *Highly/Extremely Feasible*); their confidence in (pain assessment, pain management (0 = *Not Confident At All*, 10 = *Highly/Extremely Confident*); and their skill in pain assessment and management; (0 = *Not Skilled At All*, 10 = *Highly/Extremely Skilled*) for children with I/DD. Therefore, there were 6 ratings collected at each time point. These ratings showed
responsivity to training in a pilot RCT with undergraduate students (Genik, Pomerleau et al., 2017), and in Genik et al. (2018) pilot study for the *Let’s Talk About Pain* training program.

**Data Collection Summary**

Figure 1 represents a flow diagram of host organization and participant enrollment/allocation, participation, and analysis phases. Individual participant recruitment and data collection occurred across 14 organizations with children’s respite services in southwestern, central, northern and eastern Ontario from May 2017 to August 2018. A total of 158 respite workers’ data were included in the analyses. All participants in the control group (*n* = 92; 100%) and 65/66 participants in the intervention group (95.45%) completed the training intervention in its entirety. The response rate at follow-up included 60.60% (*n* = 40) participants in the intervention group and 67.39% (*n* = 62) participants in the control group. There were no crossovers between groups during the study period as each organization was only randomly assigned to one condition, and all participants were employed in only one participating organization. Five of the seven organizations who were allocated to the control group held the pain training after study completion.

**Statistical Analysis**

**Analysis of Demographic Data**

Frequency and descriptive analyses were used to analyze participants’ demographic data including age, gender, ethnicity, number of years employed in respite settings, experience with children with I/DD, and exposure to pain-related training. When participants left demographic questions blank (e.g., gender, age, frequency of interaction with children with I/DD), they were excluded from those specific analyses only. Demographic data were compared using independent samples t-tests and chi-square analyses to determine whether the groups significantly differed on
Analysis of Primary and Secondary Outcomes

A series of seven 2 (group: treatment, control) x 3 (time: pre, post, follow-up) mixed analyses of variance (ANOVA) were conducted. The dependent variables for the mixed ANOVAs were the participants’ pain-related knowledge scores using the QUPID-CR\(^3\) (primary outcome measure), and feasibility-confidence-skill ratings (secondary outcome measures).

Importantly, there are two common approaches used when conducting analyses for RCT data: 1) intention-to-treat (ITT), which includes all participants who provided data and uses approaches such as imputation to manage missing data (Armijo-Olivo, Warren, & Magee, 2009), and 2) per-protocol (PP) which includes only participants who completed all aspects of the study. Advantages and disadvantages exist with each approach; however, ITT can provide a more conservative estimate of treatment effect, and PP can better reflect treatment differences when participants complete the study protocol (Gupta, 2011). In order to benefit from each of these advantages, ITT was considered the primary analysis approach while PP analyses were considered complementary Armijo-Olivo et al., 2009; Gupta, 2011).

**ITT.** When using ITT, there has been some concern that it may become more about the treatment prescribed as opposed to the treatment received if participants withdraw prior to receiving the intervention (Armijo-Olivo et al., 2009). As such, the one participant who did not complete the full training intervention was excluded from ITT analyses. Missing data analyses were then conducted to determine the nature of all other missing data from the QUPID-CR

\(^3\) Internal reliability of the QUPID-CR was found to range from acceptable to excellent across time points (α pre: 0.73, α post: 0.91, α follow-up: 0.84; George & Mallory, 2003).
questionnaire as well as the feasibility-confidence-skill ratings, and the appropriate imputation method to be applied.

Participants were categorized as missing data on the QUPID-CR if they completed the corresponding time point and had as little as one missing response on the questionnaire. Specifically, the percentage of participants who selected multiple responses, gave unclear responses, or were otherwise missing one or more QUPID-CR question responses at the pre, post, and follow up time periods were 22.60%, 10.96%, and 10.78%, respectively. Of importance, only three participants in the pre period and two in the post period had 4-7 questions considered missing on the QUPID-CR. All other participants with some form of missing data were missing one to three questions. The percentage of participants missing data on at least one of the six feasibility-confidence-skill ratings ranged from 0.64% – and 12.74% across time periods.

Results using Little’s MCAR test to further explore missing QUPID-CR and feasibility-confidence-skill data suggested that data on these measures across time points were considered missing completely at random (p’s range from .121 - .885). The only exception was for the QUPID-CR post data time point, $x^2(540) = 613.52$, $p < .001$. Additional comparison analyses for QUPID-CR post data were therefore conducted between participants with and without missing data, which were non-significant (p’s range from .131 to .939). We can therefore conclude that this QUPID-CR post data is missing at random. To account for the aforementioned patterns, a conservative approach was applied to all QUPID-CR and feasibility-confidence-skill rating data, labelling it as missing at random. This implies that the data were, at a minimum, ‘randomly distributed within one or more subsamples’ (Armijo-Olivo et al., 2009).

4 Additional tables providing a description of the distribution of missing data which was used as a visual inspection of missing data in addition to Little’s MCAR test are found in Appendix M.
Due to the high attrition rate of participants at follow-up, a series of comparison analyses were also conducted specific to participants who did and did not complete follow-up measures. Demographic characteristics (i.e., age, years working with children with I/DD, degree of involvement with children with I/DD, gender), participant condition (i.e., intervention vs. control) and baseline scores (i.e., QUPID-CR, feasibility-confidence-skill ratings) were compared using independent samples t-tests and chi-square tests. There were no significant differences (p’s range from .129 - .963).

When imputing data, SPSS creates several data sets that estimate how the data set may have looked if there were no missing values. In this case, the five final iterations of these data sets are presented. As SPSS does not create and use a pooled estimate for mixed ANOVAs, these analyses were conducted on each of the five final iterations of imputed data, with ranges of values reported. Analyses in which pooled estimates are available (i.e., follow-up one-way ANOVAs and paired samples t-tests) are reported with specific estimates rather than ranges.

PP. Figure 1 indicates the total number of participants per group included in each of the per protocol analyses. A modified PP approach was used for these complementary analyses, such that for participants with missing data on a given item needed for a specific analysis, their data were excluded from the corresponding PP analysis.

Results

Host Organizations and Participants

Table 2 provides demographic information about the participating host organizations. A total of 158 respite workers ($M_{age} = 30.67; SD = 8.62$) consisting of 87.97% women ($n = 139$) and 12.03% men ($n = 19$) participated (83.40% European/White; 5.70% Black/African/Caribbean; 4.50% South and Southeast Asian). Consistent with a-priori power analyses using G*Power 3 (Faul, Erdfelder, Lang, & Buchner, 2007) and effect sizes from Genik
et al.’s (2018) pilot study, this sample size is sufficient to investigate the effectiveness of the *Let’s Talk About Pain* training using mixed ANOVA at power of 0.95 and an alpha of 0.05. All participants provided respite to children with I/DD in at least one of the following settings: in the family home (*n* = 72; 46.15%), in respite workers’ own homes (*n* = 33; 21.15%), in the community (*n* = 119; 76.28%), and at a group home, respite home, residential facility or specialized respite programming (*n* = 130, 83.33%). Seven (4.48%) participants also endorsed providing respite in other settings not listed above such as in hospital or clinical settings. The demographic composition of the intervention and control groups are summarized in Table 3.

There were no significant differences between (a) demographic characteristics of the intervention and control groups (see Table 3), and (b) baseline scores and ratings on outcome measures (see Table 4).

**ITT Analyses**

**Pain Knowledge (Primary Outcome).** Table 4 shows the range of means and standard deviations for ITT analyses for all outcome measures at all time points. ITT analyses using a mixed ANOVA denoted a significant interaction effect of training type (pain training, control training) with time (pre, post, follow-up) for participants’ pain-related knowledge (see Table 5, a large effect). Follow-up analyses using pooled ITT data show support for between-group hypotheses, such that those receiving the pain training had significantly higher pain knowledge scores at post than those receiving the control training Welch’s *F*(1, 845.05) = 392.84, *p* < .001, *ω*² = 0.26 (a large effect; Kirk, 1996) and at follow-up, Welch’s *F*(1, 873.69) = 225.17, *p* < .001, *ω*² = 0.18 (a large effect; Kirk, 1996). Within-groups hypotheses were also partially supported. Those who received the pain training showed significant increases in pain-related knowledge from pre to post, *t*(55) = 8.71, *p* < .001, *d* = 1.08 (a very large effect; Sawilowsky, 2009).
Although there was a significant decrease in knowledge from post to follow-up, $t(112) = 3.62, p < .001, d = .45$ (a medium effect; Cohen, 1988), participant knowledge scores remained significantly higher at follow-up compared to pre, $t(67) = 6.36, p < .001, d = .79$ (a large effect; Cohen, 1988). These results are displayed in Figure 2.

Feasibility, Confidence and Skill Ratings (Secondary Outcomes). Significant interaction effects of training type by time periods were demonstrated for the following ratings: Assessment Confidence, Assessment Skill, Management Confidence, Management Skill (see Tables 4 and 5). Follow up analyses using ITT data demonstrated that all six ratings were significantly higher for participants who completed the pain training compared to the control group at both post and follow up time points (see Table 6). For the within pain group analyses and consistent with pain-related knowledge findings, all six feasibility-confidence-skill ratings increased significantly immediately following the training (post). At follow-up, ratings of confidence and skill for both assessment and management increased significantly from pre to follow-up, but assessment and management feasibility ratings were not significantly different from pre to follow-up (see Table 7 and Figure 3).

PP Analyses

Analyses completed for PP data followed the same results pattern as described above, except for participants’ feasibility ratings. Specifically, there were no significant group by time interaction effects for assessment nor management feasibility ratings when using PP analyses (see Table 5).

Discussion

For children with I/DD, pain is a common experience that is frequently under-recognized and under-managed (Breau et al., 2003; McGuire, Daly, & Smyth, 2010). The mismanagement
of pain in children with I/DD has important implications for their quality of life, sleep, and functioning (Breau et al., 2007; Breau & Camfield, 2011; Tudor, Walsh, Mulder, & Lerner, 2015). It is critical that secondary caregivers, including respite workers, can properly assess and manage pain in children with I/DD. Importantly, respite workers may hold inaccurate beliefs that can influence the care they provide; these workers are also lacking opportunities to receive specialized pain-related training (Genik, McMurtry et al., 2017). Let’s Talk About Pain was developed and successfully piloted with intent to fill this need; however, the pilot study was limited in its lack of comparison group and cross-sectional design (Genik et al., 2018). The current RCT addressed these limitations by providing a more rigorous and longitudinal examination of the effects of Let’s Talk About Pain via data collection over three time points, and utilization of a control group.

Pain Knowledge

As hypothesized, pain-related knowledge of the intervention group increased immediately following the training (very large effect) and was higher than the control group (large effect). The improvement in pain knowledge was observed despite already strong baseline knowledge in both groups. This large increase in knowledge is consistent with Genik et al.’s (2018) Let’s Talk About Pain pilot findings as well as similar outcomes in other pain-related intervention studies (Genik, Pomerleau et al., 2017; Zhang et al., 2008). Increases in pain knowledge demonstrated by the intervention group remained higher than the control group at 4- to-6 week follow-up (large effect) and their own baseline scores, but decreased from an average of approximately 33 points to 31 points out of 39 on the knowledge measure (medium effect). Although this training may be effective in improving knowledge of respite workers, at least some degree of knowledge decay may occur overtime. The decrease in knowledge may suggest factors
such as implementation and on-the-job experiences influence knowledge retention. For example, failure to sufficiently use these new skills and knowledge following training may impact one’s ability to consolidate it; data exploring the training’s impact on strategy use are described in a separate manuscript (see Genik et al., submitted).

Although more training sessions may have potential benefit in maintaining increases in pain-related knowledge, the single-session training format in the current study was chosen based on feedback from stakeholders regarding feasibility (Genik et al., 2018). Organizations may have limited resources for continued training or boosters facilitated by outside personnel. The Train-the-Trainer model is an example of an efficient and effective knowledge dissemination approach that could help to mitigate some of these challenges (e.g., Andersen & Taira, 2018; Marks, Sisirak, & Chang, 2013). For example, creating ‘pain champions’ who could take knowledge and skills back to their organizations to implement these with staff may improve knowledge implementation.

**Feasibility-Confidence-Skill Ratings**

The pattern of results for participants’ self-reported feasibility-confidence-skill ratings at pre, post and follow-up suggest educational programming can alter staff perceptions. Like pain knowledge above, the increases in confidence and skill ratings for assessment and management remained significantly higher than pre-scores. Consistent with previous research (Genik et al., 2018), the patterns of responses between confidence and skill were very similar, suggesting that these constructs may overlap in some way. Unlike confidence and skill ratings, the ratings for feasibility of assessment and management were not significantly higher than pre-scores at follow-up. This makes sense, as one could perceive something as feasible but be lacking in confidence or skill, and vice versa. Further, feasibility may be perceived as outside of one’s
control (e.g., child, family, or organization factors may make aspects of assessment or management less feasible), whereas skill and confidence may be perceived as within a caregiver’s control (e.g., can get more education, practice using skills). Consideration of each of these ratings separately rather than collapsed is therefore important in understanding these self-report constructs.

First, although intervention participants’ ratings of pain assessment and management feasibility improved from pre to post, the effect size was small. These ratings again decreased at follow-up such that there was no difference between pre and follow-up scores. The limited change in feasibility may reflect implementation-related challenges often experienced in organizational contexts, particularly when only front-line staff are included in the trainings. For example, while school nurses struggled to implement new knowledge despite intent in one study related to pain in children with I/DD (Quinn & Smolinski, 2017), 95% of participants in another study believed they could implement new practices in residential care settings for people with I/DD when the training was designed for managers (Mackey & Dodd, 2010). Further, several inherent challenges for people with I/DD may continue to limit the feasibility of pain assessment and management even when caregivers have adequate knowledge and skills.

Second, despite the increase in self-reported confidence following the intervention, confidence ratings of both groups at all time points ranged from 5.95-7.68 (moderate to moderately-high). These ratings may reflect an awareness of the complexities and challenges associated with pain assessment and management in this population; ratings of ‘extreme’ confidence may not actually be ideal. Concerns in other health-care contexts have been raised about being ‘overconfident’ versus ‘appropriately confident’ and its implications for clinical practice, such as a failure to learn from experiences or to consider alternatives Naguib et al.,
2019). Thus, it may be important to consider what ‘appropriate’ confidence might look like in respite settings and how to achieve this.

Finally, participants rated their perceived skill in pain assessment and management. Assuming confidence and skill are related, one may also wish to consider the implications of over- versus appropriate confidence in relation to skill. Indeed, one’s perceptions may not always map onto their actual skill in a domain (Glakchen & Bookbinder, 2001) and this could impact care. For example, it is possible that respite workers may believe they have skill in a strategy but may inappropriately apply it. In operationally defining ‘skill’, one could more objectively compare perceived and actual skill in care settings. This may be a more appropriate way to determine skill and develop an understanding of the ways that one’s skill perceptions may be similar or different from observed skill.

**Strengths and Limitations**

To our knowledge, this was the first RCT to systematically evaluate a specialized pain training program for respite workers of children with I/DD. Designed using extant research literature and the International Association for the Study of Pain’s *Core Curriculum* (Charlton, 2005), data were collected over multiple time points and compared with a group receiving related but distinct training on family-centered care. Recruitment proceeded through multiple children’s respite organizations supporting children with varying needs. The use of CONSORT guidelines, clear reporting and trial registration should allow for replication and implementation of this training. Further, the structure and content of this training may lend itself well to the development of a more manualized training or a train-the-trainer approach that could be shared with key staff within children’s respite organizations.
Although organizations and participants were not explicitly told of the study condition they were assigned to or hypotheses, it is possible that they were able to infer this information based on the provided information. Further, self-report measures were used as a key means of data collection which can lead to bias, and potential overestimation or reporting. For example, those in the pain training condition may have rated their perceived confidence in pain assessment as higher regardless of how they felt after the training (although notably this did not occur for feasibility). A large percentage of participants were lost to follow-up. Despite the presence of missing data across time points, missing data was approached in a very conservative way and missing data on relevant dependent variables was generally below 20% as recommended in the literature (Armijo-Olivo et al., 2009); the exception was the pre time point for the QUPID-CR where 22.6% was missing. These are not uncommon challenges in RCTs and relevant missing data analyses indicated that all missing data appeared to be ‘missing at random’. Further, analyses using ITT and PP methodology were conducted and the results were identical.

**Future Directions and Conclusions**

This study allowed for rigorous examination of *Let’s Talk About Pain*’s impact on respite worker’s pain knowledge and feasibility-confidence-skill ratings. Consistent with Genik et al.’s (2018) pilot study, respite workers’ knowledge and feasibility-confidence-skill ratings significantly increased immediately following completion of a pain training. Pain knowledge and confidence-skill ratings from the intervention group were also significantly higher than the control group at post and follow-up. Respite workers who completed the pain training experienced some knowledge decay at a follow-up time point as early as four to six weeks following training completion. Future work should explore the type of knowledge loss that occurs over time, and its impact on care. Finally, while the program in its current state has been
designed for respite workers, this type of education could also benefit other similar secondary caregivers (e.g., educational assistants), or used as a model for the development of additional training programs to benefit other professions who support children with I/DD (e.g., physical therapists). Research in pain and I/DD populations is scarce, particularly with respect to studies related to knowledge translation and application. These efforts are critical to share knowledge with those who need it to better meet the needs of children with I/DD.
References


European Journal of Pain.


doi:10.1111/j.1468-3156.2010.0061.x


is how we should think! *Child: Care, Health, and Development, 38*(4), 457-463. doi: 10.1111/j.1365-2214.2011.01338.x


Figure 1. CONSORT Flow Diagram
Figure 2. Graph depicting intervention and control group scores on QUPID-CR at pre, post and follow up. *** indicates a significant difference at $p < .001$. 
Figure 3. Graph depicting intervention and control feasibility-confidence-skill ratings at pre, post and follow-up. * indicates significant difference at $p < .05$; ** indicates significant difference at $p < .01$; *** indicates significant difference at $p < .001$
Table 1

**Overview of General Training Characteristics and Fidelity**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Intervention Trainings (n = 7)</th>
<th>Control Trainings (n = 8)</th>
<th>Significant Difference Between Intervention and Control?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Training Length (M_hours ± SD; range)</td>
<td>3.57 ± 0.20; 3.42-3.93</td>
<td>3.27 ± 0.28; 3.00-3.75</td>
<td>Yes; t(13) = 2.40, p &lt; .05</td>
</tr>
<tr>
<td>Total Break Time (M_hours ± SD)</td>
<td>0.52 ± 0.13</td>
<td>0.57 ± 0.12</td>
<td>No; t(13) = -.780, p = .449</td>
</tr>
<tr>
<td>Group Size (M ± SD)</td>
<td>11.00 ± 2.94</td>
<td>13.13 ± 6.33</td>
<td>No; t(13) = -.811, p = .432</td>
</tr>
<tr>
<td>Fidelity (as per checklist)</td>
<td></td>
<td></td>
<td>n/a</td>
</tr>
<tr>
<td>M %</td>
<td>98.77</td>
<td>2.16</td>
<td></td>
</tr>
<tr>
<td>M ± SD</td>
<td>137.29 ± 2.21</td>
<td>3.00 ± 0.00</td>
<td></td>
</tr>
<tr>
<td>Range (max. 139)</td>
<td>133-139²</td>
<td>3-3³</td>
<td></td>
</tr>
</tbody>
</table>

*Notes:*

1 According to the full group size of the training (i.e., research participants + non-research training participants), rather than the number of participants attending the training (i.e., solely research participants).

2 There were only two instances of omission of training content. Specifically, one instance was an omission of the fact that parents do not generally overestimate their children’s pain, and the other instance was an omission of review of a sample script for deep breathing. All other deviations from fidelity were related to time constraints and a need to adapt the case study activities. For example, in some instances, the case studies were discussed as a larger group rather than in smaller groups, or the final case study activity was omitted from the training.

3 As expected, fidelity for the control training against the pain training checklist was very low. No control trainings included any information relevant to pain. All instances of similarity in training content were related to the provision of an introduction of the speaker, an overview of the training, and an icebreaker activity at the beginning of the training.
Table 2

Demographic Data of Participating Organizations, n (%)  

<table>
<thead>
<tr>
<th>Variable</th>
<th>Intervention (n = 7)</th>
<th>Control (n = 7)</th>
<th>Total (n = 14)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of Respite Programming</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In Home/In the Community</td>
<td>2 (28.60)</td>
<td>4 (57.10)</td>
<td>6 (42.86)</td>
</tr>
<tr>
<td>Week Long/Weekend</td>
<td>7 (100.00)</td>
<td>6 (85.70)</td>
<td>13 (92.86)</td>
</tr>
<tr>
<td>Day Long (e.g., P.D. Days)</td>
<td>4 (57.10)</td>
<td>5 (71.40)</td>
<td>9 (64.29)</td>
</tr>
<tr>
<td>Summer Day Camps</td>
<td>5 (71.40)</td>
<td>4 (57.10)</td>
<td>9 (64.29)</td>
</tr>
<tr>
<td>Other (e.g., seasonal programming; after school programming)</td>
<td>3 (42.90)</td>
<td>2 (28.60)</td>
<td>5 (35.71)</td>
</tr>
<tr>
<td><strong>Type of Disability/Needs</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intellectual/Developmental Disability</td>
<td>7 (100.00)</td>
<td>7 (100.00)</td>
<td>14 (100.00)</td>
</tr>
<tr>
<td>Medically Fragile/Technologically Dependent</td>
<td>3 (42.90)</td>
<td>6 (85.70)</td>
<td>9 (64.29)</td>
</tr>
<tr>
<td>Physical Disability</td>
<td>3 (42.90)</td>
<td>5 (71.40)</td>
<td>8 (57.14)</td>
</tr>
<tr>
<td>Co-morbid Conditions</td>
<td>5 (71.40)</td>
<td>7 (100.00)</td>
<td>12 (85.71)</td>
</tr>
<tr>
<td>Brain Injury</td>
<td>3 (42.90)</td>
<td>4 (57.10)</td>
<td>7 (50.00)</td>
</tr>
<tr>
<td>Epilepsy/Seizures</td>
<td>5 (71.40)</td>
<td>6 (85.70)</td>
<td>11 (78.57)</td>
</tr>
<tr>
<td>Other (e.g., mental health)</td>
<td>1 (14.30)</td>
<td>1 (14.30)</td>
<td>2 (14.29)</td>
</tr>
<tr>
<td><strong>Type of Supports Provided</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Skills/Communication</td>
<td>7 (100.00)</td>
<td>7 (100.00)</td>
<td>14 (100.00)</td>
</tr>
<tr>
<td>Personal Care</td>
<td>7 (100.00)</td>
<td>7 (100.00)</td>
<td>14 (100.00)</td>
</tr>
<tr>
<td>Mealtime Assistance</td>
<td>7 (100.00)</td>
<td>7 (100.00)</td>
<td>14 (100.00)</td>
</tr>
<tr>
<td>Behavior Management</td>
<td>6 (85.70)</td>
<td>6 (85.70)</td>
<td>12 (85.71)</td>
</tr>
<tr>
<td>Mobility</td>
<td>3 (42.90)</td>
<td>6 (85.70)</td>
<td>9 (64.29)</td>
</tr>
<tr>
<td>Medical-Related Care</td>
<td>5 (71.40)</td>
<td>4 (57.10)</td>
<td>9 (64.29)</td>
</tr>
<tr>
<td>Other (i.e., recreational supports)</td>
<td>1 (14.30)</td>
<td>0 (0.00)</td>
<td>1 (7.14)</td>
</tr>
</tbody>
</table>

Organization Size$^2$
<table>
<thead>
<tr>
<th></th>
<th>0 (0.00)</th>
<th>2 (28.60)</th>
<th>2 (14.29)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Small</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medium</td>
<td>6 (85.70)</td>
<td>4 (57.10)</td>
<td>10 (71.42)</td>
</tr>
<tr>
<td>Large</td>
<td>1 (14.30)</td>
<td>1 (14.30)</td>
<td>2 (14.29)</td>
</tr>
</tbody>
</table>

**Notes:**
1 Staff to child ratios varied widely from 2:1 to 3:10 across respite programs and between organizations.
2 Organizations were asked to indicate the size of their organization but were not given definitions for these categories. As such, these are subjective categories.
Table 3

**Demographic Characteristics of Participants**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Total ((n = 156-157))</th>
<th>Intervention ((n = 65 - 66))</th>
<th>Control ((n = 89-91))</th>
<th>Significant Difference Between Intervention and Control?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Female, (n (%))</strong></td>
<td>139 (88.50)</td>
<td>58 (87.88)</td>
<td>81 (89.01)</td>
<td>No; (\chi^2(1) = .048, p = .826)</td>
</tr>
<tr>
<td><strong>Age, ((M_{\text{years}} \pm SD))</strong></td>
<td>30.67 years ± 8.62</td>
<td>29.78 ± 7.43</td>
<td>31.30 years ± 9.37</td>
<td>No; (t(154) = 1.08, p = .282)</td>
</tr>
<tr>
<td><strong>Working w/ children I/DD, ((M_{\text{years}} \pm SD))</strong></td>
<td>5.82 years ± 5.15</td>
<td>5.30 years ± 4.68</td>
<td>6.21 years ± 5.47</td>
<td>No; (t(153) = 1.08, p = .282)</td>
</tr>
<tr>
<td><strong>Direct care involvement(^1), ((M \pm SD))</strong></td>
<td>8.85 ± 1.50</td>
<td>8.95 ± 1.29</td>
<td>8.77 ± 1.64</td>
<td>No; (t(153.169) = -.799, p = .426)</td>
</tr>
<tr>
<td><strong>Frequency of interaction(^2), (n (%))</strong></td>
<td></td>
<td></td>
<td></td>
<td>No; (p = .570, \text{Fischer’s Exact Test})</td>
</tr>
<tr>
<td>Occasionally</td>
<td>5 (3.18)</td>
<td>3 (4.55)</td>
<td>2 (2.19)</td>
<td></td>
</tr>
<tr>
<td>Often</td>
<td>18 (11.46)</td>
<td>6 (9.09)</td>
<td>12 (13.19)</td>
<td></td>
</tr>
<tr>
<td>Very Often</td>
<td>134 (85.35)</td>
<td>57 (86.36)</td>
<td>77 (84.62)</td>
<td></td>
</tr>
<tr>
<td><strong>Pain Training(^3)</strong></td>
<td></td>
<td></td>
<td></td>
<td>No; (\chi^2(1) = .058, p = .809)</td>
</tr>
<tr>
<td>Yes</td>
<td>34 (21.79%)</td>
<td>15 (22.73)</td>
<td>19 (21.11)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>122 (78.21%)</td>
<td>51 (77.27)</td>
<td>71 (78.89)</td>
<td></td>
</tr>
</tbody>
</table>

*Notes:*

1. Participants had to select one number on an 11-point scale (0-10). Lower numbers indicated less direct involvement.

2. Represents how frequently participants endorsed interacting with (i.e., direct contact or communication) children who have intellectual/developmental disabilities (never, rarely, occasionally, often, very often). All participant responses were between ‘occasionally - at least monthly’ and ‘very often - multiple times per week’.

3. Of those participants who endorsed previous pain-related training, 23 (67.64%) indicated that their training was provided through formal post-secondary/health related training programs, 6 (17.65%) reported having received in house training with a nurse or health care professional, 4 (11.76) described having received training about pain in a non-specific pain training such as first aid and CPR courses, and 1 (2.94%) participant endorsed previous pain training but did not clarify who or where the training was provided. It was unclear whether these programs included training specific to pain in children with I/DD.
Table 4

*Means and Standard Deviations for ITT Mixed ANOVA Analyses for all Outcome Measures at all Time Points*

<table>
<thead>
<tr>
<th></th>
<th>Intervention</th>
<th>Control</th>
<th>Significant Between Group</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M (SD)</td>
<td>M (SD)</td>
<td>Baseline Difference at Pre?</td>
<td>M (SD)</td>
</tr>
<tr>
<td></td>
<td>Pre</td>
<td>Post</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain Knowledge</td>
<td>27.38-27.89 (4.57-4.92)</td>
<td>26.84-27.40 (4.63-4.98)</td>
<td>No, t(2054) = .688, p = .492</td>
<td>27.06-27.57 (4.63-4.95)</td>
</tr>
<tr>
<td></td>
<td>33.08-33.64 (3.27-4.74)</td>
<td>25.60-26.01 (7.52-7.72)</td>
<td></td>
<td>28.81-29.11 (7.23-7.55)</td>
</tr>
<tr>
<td></td>
<td>31.74-32.22 (4.41-5.09)</td>
<td>25.63-26.03 (6.81-7.36)</td>
<td></td>
<td>28.18-28.43 (6.78-7.01)</td>
</tr>
<tr>
<td>Assessment Feasibility</td>
<td>7.66-7.72 (1.70-1.72)</td>
<td>7.16-7.23 (1.92-1.95)</td>
<td>No, t(19487) = 1.693, p = .090</td>
<td>7.37-7.42 (1.84-1.87)</td>
</tr>
<tr>
<td></td>
<td>8.25-8.31 (1.56-1.58)</td>
<td>7.14-7.16 (1.95-1.95)</td>
<td></td>
<td>7.61-7.64 (1.88-1.88)</td>
</tr>
<tr>
<td></td>
<td>7.25-7.38 (1.52-1.65)</td>
<td>6.71-7.10 (1.55-1.71)</td>
<td></td>
<td>6.93-7.22 (1.56-1.70)</td>
</tr>
<tr>
<td>Assessment Confidence</td>
<td>5.95-5.98 (1.53-1.53)</td>
<td>5.90-6.01 (1.63-1.68)</td>
<td>No, t(1573) = .069, p = .945</td>
<td>5.93-5.99 (1.58-1.61)</td>
</tr>
<tr>
<td></td>
<td>7.65-7.72 (1.38-1.46)</td>
<td>6.29-6.30 (1.72-1.72)</td>
<td></td>
<td>6.86-6.89 (1.73-1.75)</td>
</tr>
<tr>
<td></td>
<td>6.98-7.17 (1.31-1.52)</td>
<td>5.90-6.20 (1.65-1.73)</td>
<td></td>
<td>6.41-6.52 (1.57-1.76)</td>
</tr>
<tr>
<td>Assessment Skill</td>
<td>5.71-5.72 (1.66-1.66)</td>
<td>5.60-5.71 (1.65-1.71)</td>
<td>No, t(2227) = .250, p = .802</td>
<td>5.65-5.71 (1.65-1.68)</td>
</tr>
<tr>
<td></td>
<td>7.45-7.51 (1.37-1.48)</td>
<td>6.15-6.18 (1.83-1.85)</td>
<td></td>
<td>6.69-6.73 (1.78-1.81)</td>
</tr>
<tr>
<td></td>
<td>6.97-7.20 (1.35-1.49)</td>
<td>5.92-6.03 (1.65-1.76)</td>
<td></td>
<td>6.38-6.42 (1.62-1.73)</td>
</tr>
<tr>
<td>Management Feasibility</td>
<td>7.32-7.51 (1.79-1.92)</td>
<td>7.20-7.42 (1.84-2.00)</td>
<td>No, t(147) = .380, p = .704</td>
<td>7.31-7.43 (1.86-1.93)</td>
</tr>
<tr>
<td></td>
<td>8.18-8.32 (1.48-1.64)</td>
<td>7.23-7.39 (1.84-1.89)</td>
<td></td>
<td>7.62-7.76 (1.77-1.84)</td>
</tr>
<tr>
<td></td>
<td>7.52-7.72 (1.50-1.67)</td>
<td>6.83-7.22 (1.61-1.72)</td>
<td></td>
<td>7.14-7.40 (1.59-1.77)</td>
</tr>
<tr>
<td>Management Confidence</td>
<td>5.89-6.08 (1.59-1.71)</td>
<td>6.01-6.13 (1.60-1.85)</td>
<td>No, t(296) = .268, p = .789</td>
<td>6.01-6.10 (1.60-1.75)</td>
</tr>
<tr>
<td></td>
<td>7.57-7.68 (1.29-1.41)</td>
<td>6.34-6.37 (1.72-1.75)</td>
<td></td>
<td>6.86-6.89 (1.69-1.71)</td>
</tr>
<tr>
<td></td>
<td>7.31-7.37 (1.28-1.40)</td>
<td>6.42-6.61 (1.54-1.60)</td>
<td></td>
<td>6.79-6.90 (1.52-1.56)</td>
</tr>
<tr>
<td>Management Skill</td>
<td>5.72-5.85 (1.68-1.72)</td>
<td>5.86-5.91 (1.60-1.78)</td>
<td>No, t(7420) = .384, p = .701</td>
<td>5.80-5.89 (1.63-1.75)</td>
</tr>
<tr>
<td></td>
<td>7.52-7.63 (1.32-1.45)</td>
<td>6.18-6.26 (1.76-1.80)</td>
<td></td>
<td>6.78-6.80 (1.74-1.77)</td>
</tr>
<tr>
<td></td>
<td>7.23-7.37 (1.29-1.40)</td>
<td>6.28-6.40 (1.54-1.66)</td>
<td></td>
<td>6.68-6.77 (1.52-1.61)</td>
</tr>
</tbody>
</table>

*Note:* As pooled estimates of standard deviation values are not available on SPSS, ranges of the means and standard deviations from the five final iterations of the imputation data sets represent descriptive data in this table. Baseline comparisons used data which pooled the five final iterations of data as available through SPSS.
Table 5

F-values, df, p-values, and Effect Sizes for Interaction Effects of Time Period by Group for QUPID-CR Scores and Feasibility-Confidence-Skill Ratings

<table>
<thead>
<tr>
<th></th>
<th>F_{range}</th>
<th>df_{range}</th>
<th>p_{range}</th>
<th>Partial ( \eta^2 )_{range}</th>
</tr>
</thead>
<tbody>
<tr>
<td>ITT Analyses</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>QUPID-CR</td>
<td>29.33-40.97</td>
<td>1.51-1.75, 233.73-271.60</td>
<td>&lt;.001</td>
<td>.16-.21</td>
</tr>
<tr>
<td>Assessment Feasibility</td>
<td>2.56-9.71</td>
<td>1.89-2.00, 292.45-310.00</td>
<td>&lt;.001-.082</td>
<td>.02-.06</td>
</tr>
<tr>
<td>Assessment Confidence</td>
<td>14.00-19.32</td>
<td>1.85-2.00, 287.05-310.00</td>
<td>&lt;.001</td>
<td>.08-.11</td>
</tr>
<tr>
<td>Assessment Skill</td>
<td>13.52-18.27</td>
<td>1.74-2.00, 270.00-310.00</td>
<td>&lt;.001</td>
<td>.08-.11</td>
</tr>
<tr>
<td>Management Feasibility</td>
<td>3.01-6.42</td>
<td>1.92-2.00, 296.78-310.00</td>
<td>&lt;.01-.053</td>
<td>.02-.04</td>
</tr>
<tr>
<td>Management Confidence</td>
<td>14.46-20.38</td>
<td>2.00, 310.00</td>
<td>&lt;.001</td>
<td>.09-.12</td>
</tr>
<tr>
<td>Management Skill</td>
<td>17.84-24.18</td>
<td>1.88-2.00, 291.40-310.00</td>
<td>&lt;.001</td>
<td>.10-.15</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>F</th>
<th>df</th>
<th>P</th>
<th>Partial ( \eta^2 )</th>
</tr>
</thead>
<tbody>
<tr>
<td>PP Analyses</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>QUPID-CR</td>
<td>37.94</td>
<td>2, 128</td>
<td>&lt;.001</td>
<td>.37</td>
</tr>
<tr>
<td>Assessment Feasibility</td>
<td>0.96</td>
<td>2, 186</td>
<td>.384</td>
<td>.01</td>
</tr>
<tr>
<td>Assessment Confidence</td>
<td>12.00</td>
<td>2, 186</td>
<td>&lt;.001</td>
<td>.11</td>
</tr>
<tr>
<td>Assessment Skill</td>
<td>13.68</td>
<td>1.86, 172.85</td>
<td>&lt;.001</td>
<td>.13</td>
</tr>
<tr>
<td>Management Feasibility</td>
<td>2.59</td>
<td>2, 162</td>
<td>.078</td>
<td>.03</td>
</tr>
<tr>
<td>Management Confidence</td>
<td>9.74</td>
<td>2, 162</td>
<td>&lt;.001</td>
<td>.11</td>
</tr>
<tr>
<td>Management Skill</td>
<td>13.22</td>
<td>2, 162</td>
<td>&lt;.001</td>
<td>.14</td>
</tr>
</tbody>
</table>

Note. Partial \( \eta^2 \) magnitudes: 0.01 = small, 0.06 = medium, 0.14 = large. Follow up analyses for QUPID-CR results are described in the text and figures; follow up analyses for the feasibility-confidence-skill ratings are presented in Table 6.
Table 6

*Welch’s F Values, p-values, and Effect Sizes for Follow-Up Analyses of Feasibility-Confidence-Skill Ratings Comparing Participants Who Received Pain vs. Control Training*

<table>
<thead>
<tr>
<th></th>
<th>Welch’s F</th>
<th>Post</th>
<th>ω²</th>
<th>Welch’s F</th>
<th>Follow-Up</th>
<th>p</th>
<th>ω²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessment Feasibility</td>
<td>94.37</td>
<td>&lt;.001</td>
<td>0.08</td>
<td>13.16</td>
<td>&lt;.001</td>
<td>0.01</td>
<td></td>
</tr>
<tr>
<td>Assessment Confidence</td>
<td>183.47</td>
<td>&lt;.001</td>
<td>0.15</td>
<td>842.76</td>
<td>&lt;.001</td>
<td>0.10</td>
<td></td>
</tr>
<tr>
<td>Assessment Skill</td>
<td>156.68</td>
<td>&lt;.001</td>
<td>0.13</td>
<td>854.92</td>
<td>&lt;.001</td>
<td>0.11</td>
<td></td>
</tr>
<tr>
<td>Management Feasibility</td>
<td>81.58</td>
<td>&lt;.001</td>
<td>0.07</td>
<td>817.78</td>
<td>&lt;.001</td>
<td>0.04</td>
<td></td>
</tr>
<tr>
<td>Management Confidence</td>
<td>167.34</td>
<td>&lt;.001</td>
<td>0.14</td>
<td>850.08</td>
<td>&lt;.001</td>
<td>0.08</td>
<td></td>
</tr>
<tr>
<td>Management Skill</td>
<td>182.34</td>
<td>&lt;.001</td>
<td>0.15</td>
<td>854.81</td>
<td>&lt;.001</td>
<td>0.09</td>
<td></td>
</tr>
</tbody>
</table>

*Note.* ω² effect sizes should be interpreted as follows: 0.01 = small effect, 0.06 = medium effect, 0.14 = large effects (Field, 2009; Kirk, 1996)
Table 7

_t_ Values, _p_-values, and Cohen’s _d_ Effect Sizes for Feasibility-Confidence-Skill Ratings Comparing Time Points for Pain Training Participants

<table>
<thead>
<tr>
<th></th>
<th>Pre to Post</th>
<th></th>
<th>Post to Follow-Up</th>
<th></th>
<th>Pre to Follow-Up</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><em>t</em></td>
<td><em>p</em></td>
<td>Cohen’s <em>d</em></td>
<td><em>t</em></td>
<td><em>p</em></td>
<td>Cohen’s <em>d</em></td>
</tr>
<tr>
<td>Assessment Feasibility</td>
<td>2.77</td>
<td>&lt;.01</td>
<td>0.34</td>
<td>5.38</td>
<td>&lt;.001</td>
<td>0.67</td>
</tr>
<tr>
<td>Assessment Confidence</td>
<td>9.38</td>
<td>&lt;.001</td>
<td>1.16</td>
<td>3.22</td>
<td>&lt;.01</td>
<td>0.40</td>
</tr>
<tr>
<td>Assessment Skill</td>
<td>9.87</td>
<td>&lt;.001</td>
<td>1.22</td>
<td>2.24</td>
<td>&lt;.05</td>
<td>0.28</td>
</tr>
<tr>
<td>Management Feasibility</td>
<td>3.15</td>
<td>&lt;.001</td>
<td>0.48</td>
<td>3.15</td>
<td>&lt;.01</td>
<td>0.39</td>
</tr>
<tr>
<td>Management Confidence</td>
<td>8.20</td>
<td>&lt;.001</td>
<td>1.02</td>
<td>1.68</td>
<td>.09</td>
<td>0.21</td>
</tr>
<tr>
<td>Management Skill</td>
<td>8.92</td>
<td>&lt;.001</td>
<td>1.11</td>
<td>1.82</td>
<td>.06</td>
<td>0.23</td>
</tr>
</tbody>
</table>

*Note:* Cohen’s _d_ magnitudes: 0.20 = small, 0.50 = medium, 0.80 = large (Cohen, 1988)
Chapter Five: A randomized controlled trial evaluating a pain training for respite workers supporting children with disabilities part two: Training evaluations and the impact of training on knowledge application

*Note: This chapter is the author version of the following ‘submitted’ manuscript:

Abstract

Background: Previous work suggests that pain training may improve respite workers’ knowledge and self-reported confidence and skill; however, little is known about the impact of pain training on assessment and management approaches in the respite context. Methods: Within a parallel group RCT comparing pain and control training, this paper reports: (1) the pain training’s impact on respite workers’ pain assessment and management approaches, and (2) their training evaluations. Respite workers (n = 158) from fourteen organizations received pain or control training following randomization with sequentially numbered, opaque, sealed envelopes. Researchers were blind until randomization; allocations were not shared explicitly with organizations and participants. Immediately before either training, participants completed a questionnaire about pain assessment and management strategy use, including a standardized vignette. They provided training evaluations immediately after the training. Four-to-six weeks after either training, participants again completed the strategy use questionnaire and a semi-structured focus group. Results: There were no differences in participant’s pain approaches as per the strategy use questionnaire. However, both common and unique approaches between groups emerged from qualitative analyses of the focus group data which are illustrated using a tree metaphor. Both participant groups had similar approaches for developing a ‘knowing’ about pain (roots) and applied similar approaches in practice (making use of their trunk and foliage). Participants receiving the pain training also identified the importance of ‘growing and strengthening’ their pain knowledge ‘tree’ through educational opportunities. Training endorsements were favorable. Conclusions: Findings demonstrate the value of pain training for respite workers and the potential for impact on practice.
Introduction

Pain is common for children with intellectual and developmental disabilities (I/DD) and may occur more frequently compared to those without I/DD (Breau, Camfield, McGrath, & Finley, 2003). The presence of cognitive and communication deficits makes pain assessment and management challenging for these vulnerable children (Carter, McArthur, & Cunliffe, 2002; Doody & Bailey, 2017). These deficits can limit children’s ability to provide self-reports of their pain (Chen-Lim et al., 2012) and caregivers may therefore be relied on to assist with pain assessment and management decisions.

Most research examining pain in children with I/DD has focused on understanding their pain expression and developing pain assessment tools to assist parents and health care providers. However, children with I/DD receive support from other caregivers in the community who would also benefit from pain-related knowledge and tools. For example, many children with I/DD receive respite care: a high in demand, critical support service which provides short-term breaks for parents raising children with disabilities (Douma, Dekker, & Koot, 2006; McConkey, Kelly, & Craig, 2011). Provision of this support to family members results in several positive outcomes including stress reduction, opportunities for rest and relaxation, and a sense of relief (Robertson et al., 2011).

During respite, access to a primary caregiver who can help interpret a child’s pain behavior and make pain-related decisions is not always feasible. Furthermore, respite workers: (a) may hold inaccurate beliefs about pain (Genik, McMurtry, & Breau, 2017), (b) are interested in learning more about pain and related assessment and management strategies (Genik, McMurtry, Breau, Lewis, & Freedman-Kalchman, 2018) and (c) are lacking in specialized pain training opportunities (Genik et al., 2018). Let’s Talk About Pain is an empirically informed
training developed to address this identified need (Genik et al., 2018). Following program completion, respite workers show significant increases in pain-related knowledge and self-reported confidence and skill in pain assessment and management (Genik et al., submitted; Genik et al., 2018). These significant increases are sustained at 4- to 6-week follow-up (Genik et al., submitted).

In addition to summative evaluations such as the outcome of knowledge translation initiatives on participant’s approaches in practice (Carter, Simons, Bray, & Arnott, 2010), formative evaluation such as participant’s training feedback may help inform and improve training content and delivery over time (Newcomer, Hatry, & Wholey, 2015). Thus, these approaches are often considered complementary. As part of a larger randomized controlled trial (ClinicalTrials.gov identifier: NCT03421795; (Genik, McMurtry, Barata, Barney, & Lewis, under review a; Genik et al., submitted), the objectives of this paper were to: (a) examine the Let’s Talk About Pain’s impact on participants’ use of pain-related approaches (summative evaluation) and (b) review participants’ training evaluations (formative evaluation). Participants’ pain assessment and management approaches were measured in three ways: self-reported lists of strategies being used at work (questionnaire), responses to a structured vignette scenario (questionnaire), and discussion of pain-related experiences and approaches at work (semi-structured focus groups). We hypothesized that participants who completed the pain training would report using a greater range of pain assessment and management approaches at work and in response to a structured vignette (a) at follow-up compared to pre-training and (b) compared to those who completed the control training. Focus groups were also used to explore similarities and differences in pain assessment and management approaches of participants in the pain and
control training groups at follow-up (no a priori hypotheses). Finally, we expected that those who completed the *Let’s Talk About Pain* training would provide favourable training evaluations.

**Method**

This work is part of a larger multi-centre two-group parallel RCT. Ethics clearance was received from our research ethics board, including the presentation of direct quotes to support qualitative analyses. Results from this study are explored across two manuscripts to allow for in-depth exploration of the various research objectives. Quantitative analyses related to participants’ (a) pain knowledge (primary outcome) and (b) perceptions of the feasibility of and their own confidence and skill in pain assessment and management (herein referred to as feasibility-confidence-skill ratings; secondary outcomes) are discussed in a separate paper (Genik et al., submitted). The current manuscript (part two) focuses on the impact of the training on participants’ pain assessment and management approaches (tertiary outcome) and participants’ training evaluations (secondary outcome). The full sample of participants represented in both manuscripts are identical; however, data aside from participants’ age, gender and ethnicity are distinct. Only the methods relevant to the current manuscript are described here. The full RCT protocol is presented separately (Genik, McMurtry, Barata, Barney, & Lewis, under review b). The first author accepts full responsibility for the reliability between the methods discussed in the current paper and the published study protocol.

**Recruitment, Randomization and Participants**

*Organization Recruitment.* Ninety-five respite organizations in Ontario, Canada were assessed for eligibility and contacted to discuss the research study/opportunity to receive one or two free training sessions for their respite staff (see details in Genik et al., under review b, and

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5 In our protocol, pain assessment and management approaches were designated as tertiary (vs. secondary) due to the exploratory nature of some hypotheses as well as concerns regarding feasibility in collecting the data.
Figure 1 in Genik et al., submitted). Organizations who agreed to host the training session(s) were randomly assigned to receive the pain (intervention) or control training. This process utilized sequentially numbered, opaque, sealed envelopes following a permuted block design which were created by a research assistant not directly involved in the recruitment and data collection process; the total block size was 14 with a 1:1 allocation ratio. Following randomization, researchers were no longer blinded to condition; organizations were not explicitly told about which condition they were allocated (Genik et al., under review b). After randomization, each organization was provided with training and study information to circulate to staff in advance of the training date.

**Individual Participant Recruitment.** Individual participants at their respective organization were recruited at the beginning of each initial training date. Eligible staff were proficient in the English language, at least 18 years of age, and employed as a respite worker for children with I/DD at the participating organization. Staff in upper management positions were not eligible to participate in the study component.

**Training Interventions**

**General Training Characteristics.** Both trainings were between three and three-and-a-half hours in length with a 30-minute break at the midpoint. Trainings were conducted by consistent facilitators for the duration of the study in person at participating organizations. A standardized Power-Point presentation with notes was utilized for both trainings. Several active learning components including case studies and group discussions were also employed. Throughout each training, participants received slide handouts to take notes as well as relevant hard copy resources. Participants were also able to ask questions as needed throughout the training.
**Let’s Talk About Pain Training.** This training focused on provision of information and strategies related to what pain is, pain assessment, and pain management in children with I/DD (Genik et al., 2018). It was developed using the International Association for the Study of Pain’s *Core Curriculum* (Charlton, 2005), stakeholder input, and extant research literature. The training’s facilitator was the primary investigator, a PhD Candidate with research and applied experience related to pain, children with I/DD, and children’s respite. Training materials and an outline of the training are available upon request to the author.

**Control Training.** This training focused on an introduction to a family-centred care approach called the six ‘F-words’ of childhood disability (function, family, fitness, fun, friends, future; Rosenbaum & Gorter, 2012) and its application in respite settings. The F-Words of Childhood Disability maps onto the World Health Organization’s (2001) International Classification of Functioning, Disability and Health Framework and application of these concepts is intended to improve the quality of life of children with I/DD. The training’s facilitator was a PhD Candidate involved directly in knowledge translation efforts of the F-Words.

**Procedures**

**Pre-Training.** Participants provided informed consent and completed the: (a) demographics questionnaire and (b) questionnaire about their use of pain assessment and management strategies in respite settings.

**Training.** Immediately after completing the pre-training questionnaires, participants completed the pain or control training. During the training, a research assistant completed a fidelity checklist.
**Post-Training.** Immediately after completion of either training program, participants completed a brief training evaluation. A folder with training slides and resources, notepad/pen set, refreshments, and an opportunity to enter a $20 gift card draw were participant incentives.

**Follow-Up.** Four to six weeks following the training, researchers collected follow-up data from those receiving the pain and control training. All participants were again asked to complete the pain assessment and management strategy questionnaire from the pre-training time-point above. Finally, participants completed a 0.5 to one-hour semi-structured focus group with up to 12 other participants from their organization (Mack, Woodsong, MacQueen, Guest, & Namey, 2003). During this focus group, participants shared their opinions about and experiences with pain assessment and management in respite settings. They also discussed their approaches to pain assessment and management on the job and any skills or concepts they remembered or applied from the training. All focus groups were facilitated by the corresponding author; the guide is available upon request. An accompanying research assistant took relevant field notes which were expanded within 24 hours of each focus group (Mack et al., 2003). Focus groups were audio-recorded and later transcribed and verified. A certificate of completion, an additional opportunity to enter a $20 gift card draw, and a $20 cash honorarium were provided as participant incentives for completing the follow-up time point data collection. Organizations who received the control training could complete the *Let’s Talk About Pain* training following completion of follow-up.

**Measures**

**Demographics Questionnaire (pre-training).** Participants provided information about their age, gender, and ethnicity.
Use of Pain Assessment and Management Strategies Questionnaire (pre-training and follow-up). This researcher-generated questionnaire was created based on results from an initial multiple case study with stakeholders aimed at informing feasible follow-up methodology for this RCT (Genik et al., under review a). The questionnaire was used for two purposes. First, it gathered open-ended self-reported data about the types of pain assessment and management strategies being used at work: Please list/describe the strategies you have used when (assessing for pain in/helping manage pain with) a child with an intellectual/developmental disability in respite care in this organization. Second, a previously developed vignette was used to present a standardized and consistent scenario to all participants: “Jordan is a 10-year-old child who receives respite care. Jordan has a developmental disability and is nonverbal. While in respite care, Jordan and his/her respite worker usually go swimming or play at the park. While doing either of these activities, Jordan usually smiles and appears to be very relaxed. Today, after entering a relatively crowded pool, Jordan suddenly exits the water and becomes very restless: lifting his/her hands and holds them to his/her head. Soon after, Jordan begins to scream.” (Genik, McMurtry, & Breau, 2015). After reading the vignette, participants responded to a series of open-ended questions: (a) …please briefly describe the steps you would take to assess whether the child in this scenario is in pain, (b) assuming that the child in this scenario was experiencing pain, please briefly describe the steps you would take to help manage the child’s pain, and (c) please briefly describe any additional follow-up action that you would need to take if you were the respite worker in this scenario. All vignettes in the initial vignette development and evaluation study have shown evidence of convergent and divergent validity (Genik et al., 2015); an ambiguous scenario without a clear pain source was therefore chosen to avoid potential bias towards an assessment or management approach based on the cause of the pain.
Training Evaluation Questionnaire (post-training). Participants provided (a) self-report ratings of their agreement with different statements about the training program (e.g., effectiveness of format; 0 = strongly disagree to 10 = strongly agree), and (b) responses to open-ended questions about the training program (e.g., what component contributed most/least to learning). This questionnaire was researcher-developed and based on the training evaluation used in the Let’s Talk About Pain pilot study (Genik et al., 2018). Participants in both groups were asked to complete the evaluations; however, results will only be presented for the pain training group.

Fidelity Checklist (training). A research assistant present at each training indicated their perceptions regarding the topics that participants were most and least interested in hearing about and what appeared to contribute most to their learning. These were analogous to select open-ended process-based questions from participants’ training evaluations. As part of the larger RCT, detailed fidelity checklists were completed in both the pain and control training groups (Genik et al., submitted); however, results are only presented for the pain training group for the specified questions above.

Participants and Data Collection Summary

A total of fourteen organizations participated in the RCT (Genik et al., submitted). Each organization was randomly assigned to only one condition, and all participants were employed in only one participating organization. Thus, there were no crossovers between groups. Five of seven control training organizations opted to complete the pain training after study completion.

One-hundred and fifty-eight participants took part in the study ($n_{\text{intervention}} = 66; n_{\text{control}} = 92$). At follow-up, the response rate included 60.60% ($n = 40$) pain training participants and 67.39% ($n = 62$) control training participants; see Table 1. All participants who had complete data associated with a given research outcome were included in the corresponding analysis; that
is, participants were only excluded from analyses when they were missing data on the relevant variable or item. For more in-depth details of organization and participant flow regarding other RCT outcomes, see part one (Genik et al., submitted).

**Statistical Analysis**

Demographic data for the pain and control training groups were analyzed using frequency and descriptive analyses (for more detailed demographic information including demographic comparisons between groups, see: Genik et al., submitted). A pragmatic, essentialist/realist approach was used for all qualitative analyses described below.

**Pain Assessment and Management Approaches (Pain and Control Training Groups)**

**Self-Reported Strategies at Work and Vignette Data.** Coding schemes were developed to address 5 open-ended questions from the *Use of Pain Assessment and Management Strategies Questionnaire*. Specifically, two of these questions asked participants to list/describe the strategies they use to help (a) assess and (b) manage pain in children with disabilities when providing respite care. The remaining three questions asked participants to indicate (a) assessment, (b) management, and (c) follow-up approaches they would take in relation to the standardized vignette scenario presented. Coding schemes were developed by the primary researcher (LG) in collaboration with two additional research assistants and their research advisor (CMM) using inductive (i.e., consideration of participant responses) and deductive (i.e., consideration of evidence-based assessment and management approaches to pain; adaptations from vignette coding schemes used in Genik et al., 2015) quantitative content analytic approaches with an unconstrained matrix as per the steps outlined by Elo and Kyngas (2008). See Supplemental Resource 1 for the 3 final coding schemes which focused on assessment, management, or follow-up actions respectively.
Research assistants completing the coding were then trained on each scheme over the course of two to three practice sessions. Practice sessions used contrived data and an initial 5% of randomly selected real data until a minimum of ‘substantial’ interrater reliability was met as represented by a Cohen’s Kappa > 0.60 (Cohen, 1988). All responses from pre-training and follow-up were then double coded, and discrepancies were resolved by consensus with the primary investigator. Across pre and follow-up time points, 90.5% of the codes had substantial to almost perfect interrater reliability (0.61-1.00; Cohen, 1988⁶). Chi-square analyses/Fischer’s exact test were used to compare coded responses between intervention and control groups at pre-training and follow-up, and within groups from pre-training to follow-up (see results below as well as Appendix O). Given the large number of chi-square analyses across codes, a Bonferroni correction was applied to statistically significant results in order to adjust for potential Type I error. Specifically, only values < .001 were considered significant.

**Focus Group Data.** An inductive and essentialist/realist thematic analysis following steps outlined in thematic analysis literature (Braun & Clarke, 2006) was selected to analyze focus group data to capture more rich and detailed accounts of participants’ experiences. These steps included familiarization with the data, developing initial codes, generating initial themes, reviewing themes, defining and refining themes, and compiling the report presented below. Familiarization with the data occurred via review of hard copy transcriptions; subsequently, all other steps were conducted on NVivo12 software. Through this analytic process, a series of meta- or overarching themes and corresponding sub-themes were derived. Frequency (e.g., how often a topic was raised) and topic emphasis (e.g., the length of time a topic was discussed) were

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⁶ Of note, those code categories with lower than substantial reliability were all binary (present/absent) ‘other/unrelated/unspecified’ categories which had sufficient percent agreement values (75% - 97% agreement). Upon further investigation, we believe that these lower Kappa scores are likely a result of imbalances in the crosstab tables of these categories which can lead to paradoxes in binary coding (Feinstein & Cicchetti, 1990).
taken into consideration during theme development. The researchers also considered what is known in the literature about pain assessment and management in children with I/DD, and both the primary investigator and research assistant involved in analyses had applied experience in the field. Data from the focus groups were analyzed holistically at the semantic level, with separate analyses for the intervention versus control groups. Initial analyses were conducted by the primary investigator (LG) with prior experience conducting qualitative analyses and both research and applied experience in the field. These analyses were reviewed, refined, and defined in tandem by another research assistant with applied experience in respite care. The lead researcher’s supervisor (CMM) who is an established pediatric pain researcher and has experience providing training to groups of parents and support workers of children with I/DD was available for consultation as needed throughout, reviewed the final theme configuration, and made suggestions for change as relevant. Theme titles and related metaphors were developed in collaboration with two research assistants and the lead researcher’s supervisor (CMM). De-identified and anonymized quotes from the focus groups have been used in this manuscript to support the themes highlighted in the results section.

**Training Evaluations (Pain Training Group) and Fidelity Checklist (Research Assistants)**

Frequency and descriptive analyses were used. An analogous inductive content analytic approach to that specified above was used for the responses to open-ended questions on the training evaluations which resulted in five different coding schemes described in the results section (Elo & Kyngas, 2008). Two research assistants were trained on the five schemes in one practice session using 5% of randomly selected training evaluation data. As coders met the minimum ‘substantial’ interrater reliability threshold of Cohen’s Kappa > .60, (Cohen, 1988), all remaining responses were then double coded. Interrater reliability measured by Cohen’s Kappa
ranged from 0.70 to 1.00 representing substantial to almost perfect agreement (Cohen, 1988) with one exception. Specifically, one code from the fidelity checklist related to ‘fit to group needs/learning style’ reached only moderate agreement (0.59; Cohen, 1988). Discrepancies were resolved by consensus.

**Results**

**Pain Assessment and Management Approaches (Pain and Control Training Groups; Summative Evaluation)**

**Self-Reported Strategies at Work and Vignette Data.** At the pre-training time point, no significant differences existed between the pain and control training groups for pain assessment, management, or follow-up strategies reported (a) as being used at work or (b) in response to a contrived vignette scenario (all \( p \)'s = .003 – 1.00; all Cramer’s V’s = .01 - .26) or follow-up (all \( p \)'s = .03 – 1.00; all Cramer’s V’s = .00 - .23). There were also no significant changes in the strategies or approaches reported by those regarding (a) or (b) in the pain training group from pre-training to follow-up (all \( p \)'s = .002 – 1.00; all Cramer’s V = .00 - .30).

**Focus Group Data.** After conducting two separate thematic analyses on data from the pain and control training groups, themes were identified both within and across groups. As such, (I) has been used to indicate themes or examples relevant to the pain training group, whereas (C) indicates themes or examples relevant to the control training group. Only themes which directly reflect the qualitative research question about similarities and differences in pain assessment and management approaches are discussed in this manuscript. A tree metaphor will be used to highlight the themes associated with participants’ approaches to pain assessment and management. Of note, these themes are interactive and overlapping as they have potential to influence each other.
Meta-theme #1: Knowing and Growing Your Roots. Like the roots of a tree offering a network of stability, nutrients, and support, this meta-theme encompasses the development of a strong, effective and foundational understanding of pain in the respite context. Broadly, participants spoke about using directly available human resources as a critical approach in developing this foundation. This approach is represented in three core sub-themes or in accordance with the tree metaphor, three types of ‘roots’:

- **Knowing the Child (I, C)**, which represents the need for caregivers to get to know the children for whom they care including their mannerisms, likes/dislikes, baseline behavior and history. This also includes getting to know the child through building rapport.
  
  - *I personally feel like management’s a lot easier based on knowing the client. ‘Cause again if you’re gonna use distraction you’re gonna distract them with what you know they like or is gonna work….So I think the management really has to go based on knowing the client.* (I)
  
  - *I think once you start knowing the child you are able to see when there is maybe discomfort in the child, just behavioral change or instead of smiling they become very quiet or they’re acting out or…but that only comes with knowing the child better.* (C)

- **Consideration of Personal Factors and First-Hand Experiences (I, C)**, which represents the need for caregivers to take their own ideas, beliefs and experiences on the job and elsewhere into consideration.
  
  - *All of your experience, you kind of put it together and patch work something that you can use - that makes sense for you and for the people that you work with.*” (I)
  
  - *I guess more or less we look at our own personal experiences of us, how we would feel if we were sick…* (C)

- **Collaborating and Communicating with Others (I, C)**, which represents the need for caregivers to gain knowledge through collaboration and communication with others, particularly parents and peers.
...I’ve only worked here for 2 years, so a lot of the time if it’s a client I’ve only seen once, I have no idea what I’m assessing in terms of pain assessment, because I haven’t worked with that individual…so a lot of times I have to rely on more senior staff to be like, ‘what do you usually see’, and ‘how do they usually exhibit it?’ (I)

The caregivers give us a lot of information too, and sometimes when we question something we can call them and they will give us feedback - try this or do that or see if this helps…and then you keep that in mind for the next time. (C)

Respite workers in both the pain and control training groups discussed how these approaches contribute to a better understanding of and ability to manage situations at hand as well as feeling more confident in care-based decisions. However, a handful of responses also spoke about how these approaches may have limitations or lead to ‘weaker roots’. For example, primary caregivers and respite providers may share different opinions or experiences with a child: We were communicating with the parents…and the parent was not concerned at all… (I), and So what they might do for pain management would be very different too ‘cause we are limited to what we have and what the parents have told us. (C).

**Meta-theme #2: Using Your Trunk and Foliage.** Tree trunks, branches, and foliage serve many purposes in helping a tree to function and could be likened in this context to skill application. For example, ‘nutrients’ or key information from the roots need to travel through the trunk to the branches/leaves for use in the environment. Once applied, such key information can be shared (e.g., passing on seeds) to others around. This meta-theme therefore encompasses the approaches that respite workers were aware of and their application to care for children with I/DD experiencing pain. A wide range of pain assessment and management approaches were discussed across organizations and individual participants; however, two core assessment and three core management sub-themes were identified in participants’ experiences assessing and managing pain in children with I/DD:
• Pain Assessment – Informal Behavioral Observation (I, C), which refers to observations of children’s behavior without completion of formal checklists or behavioral measures specific to pain.

  o *I think the most typical way that everybody uses is just like, that there’s a significant, or even sometimes a subtle change in their [the child’s] behavior. Something that they’re doing that’s not typical for them. It’s a pretty good indicator that there’s something going on in their world.* (I)

  o *I usually just [can] tell that there’s something not quite right, like their whole aura and demeanor is not right. Like someone who’s more happy can all of a sudden just be really quiet…* (C)

• Pain Assessment – Informal Self-Report (I, C), which refers to asking the child whether they are in pain without using any formal self-report measures (e.g., body diagram, pain scale). This can encompass verbal and non-verbal forms of self-report.

  o *I think that it’s important to look for that self-report regardless of the individual that you are working with umm because ultimately what we’re seeing isn’t necessarily what may be going on. So even the slightest form of self-report [can] kind of change a diagnosis or a thought process.* (I)

  o *For a lot of them, like, if you notice something different, you can ask them like, ‘do you have a headache?’ Sometimes they can answer you yes or no.* (C)

• Pain Management – Pharmacological Strategies (I, C), which refers to use of any form of approved oral or topical over the counter or prescribed medication to alleviate pain.

  o *…they have like pre-prescribed MAR [medication administration record] sheets, so if they need something you can give it to them and sign off on it.* (I)

  o *We administered his PRN [as needed; standing order], like for a headache, and within half an hour he just, he was fine.* (C)

• Pain Management – Physical Strategies (I, C), which refers to use of any physical approach (e.g., massage, stretching, water therapy, hugs) to alleviate pain.

  o *And a lot of our kids do have that in their care plans where, you know they’re not comfortable at all in their [wheel]chair so they spend, you know maybe 9 hours*
out of that 12 hour shift...like on a bean bag or on the mats. (I)

- Sometimes a nice hot bath can be like...with the jets even can help soothe some muscles... (C)

- Pain Management – Psychological Strategies (I) which refers to pain management approaches that may target psychological distress and/or muscle relaxation to alleviate pain.
  
  - It depends on what kind of pain. Sometimes I’m so good at using distraction with the kids when it comes to pain. Yeah, because they might...hit their toenail or hand or something. So instead of saying, “Oh, how are you,” I can just go and hit the table that they hit you know, [and say to the table] “Stop it! Don’t do this!” “Hehehe.” They start laughing, you know, help distract them... (I)

  - Usually it’s like breathe. Deep breaths. Take deep breaths with me. (I)

As with different trees, some may have more branches or foliage than others. For example, the pain training group demonstrated this with their additional theme for psychological pain management. Unlike the control training group, pain training participants frequently discussed using a wide range of psychological strategies throughout all focus groups, with particular emphasis on distraction. They made direct reference to having learned many of these strategies as a result of the Let’s Talk About Pain training. Additionally, the pain training group spoke of adapting and individualizing pain assessment and management approaches. These branches and their leaves may be perceived as stronger because the strategies and knowledge can be more flexibly and creatively applied. For example:

- I think just how to modify it to our kids. Because everything that’s out there is for children that can talk or can identify that, so just the modification to the individual. I think that’s what we learned from that [the Let’s Talk About Pain program]. (I)

- It was good too to see the different assessment tools and like how we can modify them to work more for the population that we work with, and the clients that we work with and how easy it [is] to actually do them. Like we came up with solutions to that in just a couple of minutes so... (I)
The accessibility and feasibility of the approaches themselves were central in almost all discussions of pain assessment and management in the pain and control training groups, often framed as important considerations as well as barriers. For example, regarding more formal, individualized behavioral assessment measures: *There’s a lot of great ideas and people get really excited about it but then when you’re actually looking at the logistics of how to do it, it’s daunting to be honest.* (I). Further, regarding pharmacological pain management approaches: *It’s not like if you were in the hospital, where you could contact a doctor…but, there’s usually PRNs that we can use…* (C).

**Meta-theme #3: Growing and Strengthening Your Tree.** While roots, trunks, and foliage are important, trees cannot remain alive and functional without continued access to resources such as sunlight and water. Without these resources, trees will fail to grow and thrive, and new trees may not be able to grow at all. Adequate resources can also allow for the foundational network of roots to grow. Similar to trees, we have continual professional development needs that must be met for any position we hold.

This third and final meta-theme relates to the value of pain-specific education in a respite context, which can be likened to the sunlight and water trees need to grow. All pain training groups referenced the ‘*Let’s Talk About Pain*’ training and the impact of this training. For example: “*...that training literally changed the way that I thought about pain...*”. They were keen to suggest the relevance of the training to other caregivers of children with I/DD (e.g., educational assistants) or the remaining staff base of their organization. For example: “*I think this training is really important and I think it’s really important for not just respite workers...there are adults that interact with these kids on a more daily basis than we do that don’t have this information like teachers and caregivers and doctors...it’s really something that...*
could be expanded and beneficial to the general population”. Three core sub-themes specific to this meta-theme were identified for the pain training group:

- Knowledge Development, Validation, and Confidence (I), which refers to knowledge consolidation and expansion and improved confidence that can result when new information is provided or skills already being applied are confirmed as useful.
  
  - *I feel like I’m more confident in what I know, like in terms of like strategies and stuff when I’m trying to assess a child’s pain.* (I)
  
  - *So I think it was kind of nice to have that reassurance that we are on the right track with that [pain management], that there is research behind what we are doing even though we didn’t know that it was necessarily there.* (I)

- Improved Awareness of Pain and Nuanced Perspectives (I), which refers to the increased awareness and altered outlooks on pain in children with I/DD, such as recognizing that behavior may serve to communicate a need, or an awareness of how common pain is in this population. Participants may also report that they are more likely to consider pain as a potential explanation for behavior rather than overlook that possibility.
  
  - *I guess just “don’t just think [maladaptive] behaviors, think pain!” I think that’s the first thing because we are so trained in behavior training...so to really get out of that “this is only [negative] behavior” mindset is, I think, the first step...* (I)
  
  - *I would say that probably before [the training], you don’t necessarily check for pain without an obvious kind of physical mark, or, you saw the situation happen kind of thing...but they could be experiencing other things, like different chronic pain or headaches, which is hard to just see, so I feel like maybe more checking for that more usually than just the obvious pain.* (I)

- New, Specific Strategies and Approaches (I), which refers specifically to novel and/or tailored methods (e.g., different language to use) gained as a result of educational initiatives. Participants here refer to having new approaches which they may not have been aware of for pain assessment or management prior to the training.
So I think as far as respite workers, we definitely have a bit more of - like - more tools in our tool box type thing on how to assess for pain...and just addressing those needs so they feel like their pain is listened to... (I)

Yeah actually the breathing one - so I tried it with my one client… (I)

In contrast to the pain training group, the control training group had a theme of missed pain opportunities, such that these participants frequently recounted times when pain may have been dismissed as attention-seeking or missed entirely. This also speaks to a need for ‘growing or strengthening your tree’. For example:

Well, sometimes...saying you’re in pain is just a behavior...just to get attention. (C)

...he broke his toe and they didn’t even know his toe was broken because he would just walk on it completely fine and stuff like that and he wouldn’t tell anyone... (C)

Pain Training Evaluations (Pain Training Group) and Process Questions (Pain Training Group and Research Assistants; Formative Evaluation)

Participants rated the importance of pain training for respite workers as very high ($M = 9.55$; range = 7-10; 0-10; 10 = Extremely Important). Overall, they provided positive endorsements of the training (range of means: 9.22-9.63; 0-10 Likert scale; 10 = Strongly Agree; see Table 2). In response to open-ended questions, those who wanted to learn more about pain in children with I/DD highlighted three broad training topics of interest: general pain-related information ($n = 9/52, 17.3\%$), pain management ($n = 9/52, 17.3\%$), and pain assessment ($n = 8/52, 15.4\%$). Half of participants [26/52 (50.0\%)] believed the training content was sufficient. Similarly, a slight majority did not want to change anything about the Let’s Talk About Pain training ($n = 27, 51.9\%$). When changes were suggested, they varied from format/delivery ($n = 7, 13.5\%$), length ($n = 6, 11.5\%$), aspects of the training content ($n = 5, 9.6\%$), ‘other’ ($n = 5, 9.6\%$), and group size ($n = 2, 3.8\%$). See Table 3 for a summary of pain training participant and
research assistant responses to multiple-choice and open-ended process-based training evaluation questions. There was consensus that participants were most interested in learning pain assessment and management-related information and least interested in general pain-related information; pain assessment and management were also rated by participants as the most important things they learned. The presentation/speaker was rated as contributing most to participants’ learning, followed by large group discussions. Small group discussions and videos were rated as contributing least to participants’ learning. Varied explanations were proposed as to why these factors contributed the most or least to learning.

**Discussion**

Pain assessment and management for children with I/DD is challenging, and their pain is often underdiagnosed and undertreated (e.g., Malviya, Voepel-Lewis, Burke, Merkel, & Tait, 2006; McGuire, Daly, & Smyth, 2010). Caregivers must be adequately equipped to monitor and address pain. *Let’s Talk About Pain* appears efficacious in improving pain-related knowledge and feasibility-confidence-skill perceptions of respite workers immediately post-training with gains generally maintained at follow-up (Genik et al., submitted; Genik et al., 2018). This manuscript describes the impact of the training on pain assessment and management approaches used in practice (summative evaluations) and participants’ perspectives on and feedback for the training (formative evaluations).

**Pain Assessment and Management Strategy Use**

Pain assessment and management strategy use was measured with self-reported lists of strategies used at work (questionnaire), responses to open-ended questions about a structured vignette scenario (questionnaire), and discussion of pain-related experiences and approaches at work (semi-structured focus groups). Unexpectedly, there were no differences between groups...
on pain-related assessment, management, or follow-up reported by participants (a) as being used
at work or (b) in response to the vignette; furthermore, there were no differences within the pain
training group over time. Although this could raise questions about the training’s effectiveness
regarding pain-related approaches in practice, triangulating this result with the demonstrated
increase in knowledge post-training (Genik et al., submitted) and the focus group data (discussed
next) suggests another explanation. Specifically, the lack of differences may be due to the
methodology used. Open-ended questions and vignettes (Genik et al., 2015) may be efficient
ways to gather information about caregivers’ approaches to pain in children with I/DD but may
not elicit the same depth as an interview or focus group. In listing their approaches, participants
did not elaborate on the implementation details (the “how”). For example, participants may have
reported asking the child if they were in pain, but it was unclear what language they would use,
or whether they would use specific assessment tools.

Focus groups addressed these challenges by gathering more in-depth information about
participants’ experiences and approaches. Similar themes in both groups emerged regarding two
of the meta-themes. ‘Knowing and Growing Your Roots’ represented the approaches being used
to develop a foundational understanding of a child’s pain in a respite context: knowing the child,
consideration of personal factors and first-hand experiences, and communication and
collaboration. ‘Using Your Trunk and Foliage’ highlighted the pain assessment (i.e., informal
behavioral observations; informal self-report) and management approaches (e.g.,
pharmacological, physical) applied in respite settings. These themes are consistent with: (a)
extant research with parents and other professionals discussing development and acquisition of
pain knowledge (Carter et al., 2016; Hunt, Mastroymannopoulou, Goldman, & Seers, 2003) and
(b) evidence-based assessment and management strategies (e.g., Taddio et al., 2015). The
similarities of these themes across participant groups and caregiver types in extant literature may demonstrate the need for more universal approaches to challenges associated with pain in children with I/DD (e.g., Carter et al., 2016). For example, one common challenge reported was knowing the child being cared for and accurate interpretation of their behaviors. This uncertainty cannot be entirely alleviated (Brashers, 2001; Breau et al., 2003; Hall, 2002); yet, educational programming may help to build tolerance of uncertainty around the need to ‘know’ (Carter et al., 2016).

Pain training provided benefit beyond knowledge acquisition. Unlike the other meta-themes, ‘Growing and Strengthening Your Tree’ was unique to the pain training group. These individuals provided reports of knowledge development, confidence, validation, new perspectives/awareness of pain, and new specific strategies; they attributed this growth to their participation in Let’s Talk About Pain. Both groups of participants had relatively strong baseline knowledge and an intuitive understanding of how to approach issues related to pain, which may help to explain the similarities in questionnaire responses discussed above; yet, those in the pain training differed in more nuanced but critical ways. For example, unique to the pain-training group in meta-theme two ‘Using Your Trunk and Foliage’ were discussions about psychological management approaches, particularly the use of distraction. Pain training participants also spoke about adaptation and individualization of strategies. Both these topics were discussed in-depth during the training, so it is possible that participants in the intervention group internalized some of these teachings and/or were given vocabulary to describe skills they were previously using. Pain training participants placed great emphasis on the training’s importance, which speaks to the educational need in these settings and training relevance.

Training Evaluations
Consistent with the pilot (Genik et al., 2018), participants provided favourable ratings of the *Let’s Talk About Pain* training. These evaluations combined with findings of increased knowledge and feasibility-confidence-skill perceptions (Genik et al., submitted) support the training’s relevance for a broad range of children’s respite workers. Participants’ primary interests in learning about pain assessment and management were also consistent with data gathered during training development (Genik et al., 2018). Participants indicated that they were least interested in hearing about general pain-related information. However, understanding how to assess and manage pain likely requires foundational pain-related knowledge, just as sunlight on its own is not enough for a tree to grow. Parents and health care professionals supporting children with severe to profound impairments have reported similar viewpoints, suggesting that knowing the science of pain is critical for optimal pain assessment and management (Hunt et al., 2003).

The preference for active learning was less obvious in the current training endorsements compared to during the training’s development (Genik et al., 2018). Participants reported that the presentation/speaker was the most important contributor to learning whereas a more active component of small group discussions was reported as least important. Although active learning is efficacious in educational literature (e.g., interprofessional education: Hammick, Freeth, Koppen, Reeves, & Barr, 2007), a balance of passive and active learning styles may be beneficial to meet a range of learning styles. Beyond what learning approaches are being used, consideration of how they are implemented is important to ensure audience-relevant content and interactive activities (Braun & Clarke, 2006). Here, factors contributing least to learning were most commonly seen as not fitting with the group’s learning needs. Respite organizations can vary substantially in their programming; this suggests that a train-the-trainer approach and/or
more tailored, interactive activities may increase relevance to different support services. For example, case scenarios could be designed to represent a wide range of children with varied needs and the most appropriate ones could be used in each training rather than using standardized vignettes.

Strengths, Limitations, and Future Directions

To our knowledge, this was the first RCT to explore the impact of a specialized pain training for respite workers supporting children with I/DD on their approaches to pain assessment and management in practice. The follow-up methodology and approaches were developed based on stakeholder feedback (Genik et al., under review a), enabling application in varied respite organizations, regardless of organization-specific policies and staff constraints. A balance of descriptive quantitative and qualitative feedback about the training and its impact enabled a nuanced understanding of the training’s outcomes. We present novel, rich data on how trained and untrained respite workers assess and manage pain in children with I/DD; a close inspection yielded critical insights following pain training which can guide future research efforts and knowledge translation.

However, using self-report approaches as a primary means of data collection can lead to bias and potential overestimation or reporting as self-reported and actual responses to a given situation are may differ. Although the vignette allowed exploration of participant responses to a standardized scenario, it was not real. Further, although researchers were able to probe further about participants’ responses in pain-related scenarios during focus groups, these were time limited and not all participants may have been fully forthcoming or comfortable sharing in this context. Future research should consider feasible approaches to incorporate observational or
other forms of data collection to better understand participants’ approaches to pain in the respite context (e.g., ‘case-study’ methodology may lend itself better to this observational approach).

As study participants were not given an opportunity to review the themes generated from their focus group data, it is unclear whether they would fully agree with the themes and outcomes. Given the difficulties with response rate at follow-up, important perspectives may have been lost. It is impossible to know whether those absent from the focus groups had different experiences than those attending. Although many strategies for participant retention were used (e.g., gift card draws, honorariums), future work should also consider more flexible data collection approaches (e.g., phone interviews, questionnaires for those who cannot attend focus groups).

Conclusions

The current study described the impact of the *Let’s Talk About Pain* training on pain assessment and management strategy use in practice (summative evaluations), as well as participants’ perspectives of and feedback on the training (formative evaluations). Both groups had similar approaches for developing a ‘knowing’ about pain (roots) and applied similar strategies (making use of their trunk and foliage). However, an additional theme for the pain training group was identified which related to ‘growing and strengthening’ their pain knowledge ‘tree’. These participants seemed to have a broader knowledge(strategy base, more confidence in themselves, and a greater awareness of pain. Consistent with the pilot (Genik et al., 2018), participants provided very positive endorsements of the training program. *Let’s Talk About Pain* may be an effective and positively regarded strategy to provide respite workers with pain-related knowledge and approaches that are relevant to a respite setting, ultimately increasing caregivers’ awareness of, sensitivity to, and ability to address pain in children with I/DD.
References


Feinstein, A.R., & Cicchetti, D.V. (1990). High agreement but low kappa: I. The problems of
two paradoxes. *Journal of Clinical Epidemiology, 43*(6), 543-549.

Feasible outcome evaluations: A multiple-case study informing follow-up methodology
for a randomized controlled trial for children’s respite workers receiving pain-related
training. Under review with the journal of *Paediatric and Neonatal Pain*

Study protocol for a multi-centre parallel two-group randomized controlled trial
evaluating the effectiveness and impact of a pain assessment and management program
for respite workers supporting children with disabilities. Under review with the journal of
*Paediatric and Neonatal Pain*


Table 1

Demographic Characteristics of Participants

<table>
<thead>
<tr>
<th>Variable</th>
<th>Total (n = 152-157)</th>
<th>Intervention (n = 64 - 66)</th>
<th>Control (n = 88-91)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female, n (%)</td>
<td>139 (88.5)</td>
<td>58 (87.9)</td>
<td>81 (89.0)</td>
</tr>
<tr>
<td>Age, (M years ± SD)</td>
<td>30.67 years ± 8.62</td>
<td>29.78 ± 7.43</td>
<td>31.30 years ± 9.37</td>
</tr>
<tr>
<td>Ethnicity, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>European/White</td>
<td>131 (83.4)</td>
<td>48 (72.7)</td>
<td>83 (91.2)</td>
</tr>
<tr>
<td>Black/African/Caribbean</td>
<td>9 (5.7)</td>
<td>7 (10.6)</td>
<td>2 (2.2)</td>
</tr>
<tr>
<td>South and Southeast Asian</td>
<td>7 (4.5)</td>
<td>6 (9.1)</td>
<td>1 (1.1)</td>
</tr>
<tr>
<td>Aboriginal/First Nations/</td>
<td>2 (1.3)</td>
<td>0 (0.0)</td>
<td>2 (2.2)</td>
</tr>
<tr>
<td>Metis</td>
<td>8 (5.1)</td>
<td>5 (7.6)</td>
<td>3 (3.3)</td>
</tr>
</tbody>
</table>

Notes:
1 Other ethnicity includes: Arab, Latin American, and selection of multiple ethnicities for a given participant.
### Table 2

**Participant evaluation of various aspects of the pain training [0 (strongly disagree) - 10 (strongly agree)].**

| Intervention Group Mean (SD; range) |  
|-----------------------------------|---
| 1. The training content was valuable. | 9.29 (1.05; 6-10) |
| 2. The information provided at this training is applicable to my work. | 9.38 (1.07; 6-10) |
| 3. The format of the training was effective/well-suited to the material. | 9.37 (1.07; 5-10) |
| 4. The size of the group present for the training was ideal. | 9.57 (0.83; 7-10) |
| 5. The group discussions were useful in further understanding the topic. | 9.39 (0.89; 7-10) |
| 6. The topic was interesting. | 9.56 (0.76; 7-10) |
| 7. I would encourage other respite workers to take part in a training workshop like this. | 9.56 (0.88; 7-10) |
| 8. I would be interested in learning more about this topic. | 9.40 (1.09; 5-10) |
| 9. I plan to incorporate what I have learned into my work. | 9.63 (0.77; 7-10) |
| 10. I believe my pain-related training needs were met in completing this training program. | 9.22 (1.28; 4-10) |

*Note: Sample size: 60-63. The median and mode for all questions was 10.*
Table 3

**Process Evaluation Questions for the Let’s Talk About Pain Training Program [n, (%)]**

<table>
<thead>
<tr>
<th>Process Evaluation Question</th>
<th>Response Type</th>
<th>Participant Responses (n = 62-66)</th>
<th>Research Assistant Responses (n = 7)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Topic Most Interested in Learning</td>
<td>Multiple-Choice</td>
<td></td>
<td></td>
</tr>
<tr>
<td>● General Pain-Related Information</td>
<td></td>
<td>10 (15.2)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>● Pain Assessment Information</td>
<td></td>
<td>33 (50.0)</td>
<td>5 (71.4)</td>
</tr>
<tr>
<td>● Pain Management Information</td>
<td></td>
<td>25 (37.9)</td>
<td>2 (28.6)</td>
</tr>
<tr>
<td>● Other</td>
<td></td>
<td>1 (1.5)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Topic Least Interested in Learning</td>
<td>Multiple-Choice</td>
<td></td>
<td></td>
</tr>
<tr>
<td>● General Pain-Related Information</td>
<td></td>
<td>32 (48.5)</td>
<td>3 (42.9)</td>
</tr>
<tr>
<td>● Pain Assessment Information</td>
<td></td>
<td>3 (4.5)</td>
<td>1 (14.2)</td>
</tr>
<tr>
<td>● Pain Management Information</td>
<td></td>
<td>3 (4.5)</td>
<td>3 (42.9)</td>
</tr>
<tr>
<td>● Nothing (All Interesting)</td>
<td></td>
<td>16 (24.2)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>● Other</td>
<td></td>
<td>5 (7.6)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Most Important Thing Learned</td>
<td>Open-Ended</td>
<td></td>
<td></td>
</tr>
<tr>
<td>● General Pain-Related Information</td>
<td></td>
<td>7 (10.6)</td>
<td>n/a</td>
</tr>
<tr>
<td>● Pain Assessment Information</td>
<td></td>
<td>34 (51.5)</td>
<td></td>
</tr>
<tr>
<td>● Pain Management Information</td>
<td></td>
<td>27 (40.9)</td>
<td></td>
</tr>
<tr>
<td>● Other</td>
<td></td>
<td>0 (0)</td>
<td></td>
</tr>
<tr>
<td>Factor Contributing Most to Learning</td>
<td>Multiple-Choice</td>
<td></td>
<td></td>
</tr>
<tr>
<td>● Presentation/Speaker</td>
<td></td>
<td>38 (57.6)</td>
<td>6 (85.7)</td>
</tr>
<tr>
<td>● Small Group Discussions/Activities</td>
<td></td>
<td>11 (16.7)</td>
<td>0 (0)</td>
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<tr>
<td>● Large Group Discussions/Activities</td>
<td></td>
<td>18 (27.3)</td>
<td>1 (14.3)</td>
</tr>
<tr>
<td>● Sharing with the Larger Group</td>
<td></td>
<td>10 (15.2)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>● Videos</td>
<td></td>
<td>8 (12.1)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>● Other</td>
<td></td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Why Factor Contributed Most to Learning</td>
<td>Open-Ended</td>
<td></td>
<td></td>
</tr>
<tr>
<td>● Effective Information Provision</td>
<td></td>
<td>8 (12.1)</td>
<td>2 (28.6)</td>
</tr>
<tr>
<td>● Fit to Group – Passive</td>
<td></td>
<td>10 (15.2)</td>
<td>2 (28.6)</td>
</tr>
<tr>
<td>● Fit to Group – Active</td>
<td></td>
<td>12 (18.2)</td>
<td>2 (28.6)</td>
</tr>
<tr>
<td>● Presenter Personal Quality</td>
<td></td>
<td>10 (15.2)</td>
<td>2 (28.6)</td>
</tr>
<tr>
<td>● Peer Support</td>
<td></td>
<td>13 (19.7)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>● Other</td>
<td></td>
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### Factor Contributing Least to Learning

<table>
<thead>
<tr>
<th>Factor</th>
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<tbody>
<tr>
<td>Presentation/Speaker</td>
<td>4 (6.5)</td>
</tr>
<tr>
<td>Small Group Discussions/Activities</td>
<td>22 (35.5)</td>
</tr>
<tr>
<td>Large Group Discussions/Activities</td>
<td>6 (9.7)</td>
</tr>
<tr>
<td>Sharing with the Larger Group</td>
<td>3 (4.8)</td>
</tr>
<tr>
<td>Videos</td>
<td>13 (21.0)</td>
</tr>
<tr>
<td>None/Nothing</td>
<td>11 (17.7)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (3.2)</td>
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</tbody>
</table>

### Why Factor Contributed Least to Learning

<table>
<thead>
<tr>
<th>Reason</th>
<th>Open-Ended</th>
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<tbody>
<tr>
<td>Lack of Effective Information Provision</td>
<td>8 (12.1)</td>
</tr>
<tr>
<td>Lack of Fit – Passive</td>
<td>4 (6.1)</td>
</tr>
<tr>
<td>Lack of Fit – Active</td>
<td>11 (16.7)</td>
</tr>
<tr>
<td>Difficulty Sustaining Attention</td>
<td>2 (3.0)</td>
</tr>
<tr>
<td>Time Too Short/Too Long</td>
<td>1 (1.5)</td>
</tr>
<tr>
<td>None/Nothing</td>
<td>6 (9.1)</td>
</tr>
<tr>
<td>Other</td>
<td>5 (7.6)</td>
</tr>
</tbody>
</table>

**Notes:**

1. Some participants selected more than one response option for a given question, so the values may not add up to the number of participants responding to a given question.
2. Following each training and as part of a fidelity checklist, an accompanying research assistant indicated responses to these questions based on their observations of the training.
3. (Lack of) Fit to group – passive refers to a passive learning approach that contributed most or least to participants’ learning and involves looking or listening to information provided within the workshop; (Lack of) Fit to group – active refers to an active learning approach that contributed most or least to participants’ learning which focused on active use of information through applied or hands on activities during the workshop.
Chapter Six: Pain Training for Caregivers of Children with Intellectual and Developmental Disabilities: Reflections and Considerations on Knowledge Translation and Education Efforts

*Note: This chapter is the author version of the following ‘submitted’ manuscript:

Pain management is a human right (Brennan et al., 2007). However, despite (a) the frequency with which children with intellectual and developmental disabilities (IDD) experience pain (Breau et al., 2003) and (b) the negative short and long-term impacts of pain on their functioning and development (Breau et al., 2007), those with I/DD continue to suffer from unidentified and undertreated pain (e.g., de Knegt et al., 2013; Malviya et al., 2001). Imagine the frustration and fear children with IDD must feel when experiencing pain and struggling to effectively communicate their needs to others. Similarly, consider the dedicated and loving caregivers who, despite their best efforts, may feel as though they are falling short when it comes to knowing when a child is in pain or what to do about it. There is no question that these children have complex needs and are vulnerable. If anything, this vulnerability should justify and drive research in this field. Yet, only a small body of pain research in IDD populations exists, and it has been slow to progress, lagging well behind other areas of childhood pain. Beyond knowledge generation, one might also wonder what good any knowledge is if not shared with those who need it, such as caregivers of children with IDD.

*Let’s Talk About Pain* is an example of a training which was designed to educate respite workers about pain and introduce practical evidence-based assessment and management approaches (Genik et al., 2018; Genik et al., submitted a). Respite workers are important caregivers to target in knowledge translation, as they provide support to children with IDD while parents take necessary short-term breaks from the demands of raising children with special needs. While providing this care, parents are unlikely to be present and it is therefore understood that respite workers may therefore need to make difficult decisions about a child’s pain in the absence of their parents from time to time. Following training completion within a randomized controlled trial, respite workers’ pain-related knowledge increased as did their ratings of their
perceptions of the feasibility of and their own confidence and skill in pain assessment and management (Genik et al., submitted a). In the process of planning, conducting, and publishing this work, we grappled with many decisions including what knowledge to share, how to effectively impact our target audience, and how to build a program that would be sustainable. The current paper shares reflections on these issues from our experience. It also serves as a call to action for further research and knowledge translation in this area.

**On Knowledge Translation in Slow-Moving, Complex Fields**

When thinking about knowledge translation and education provision, one might wonder about the ‘right time’ to share information. When do we know enough to share what we know? When are we confident enough in our findings? When do benefits of more broadly sharing preliminary findings outweigh the costs of waiting for more conclusive support? Indeed, there is a degree of uncertainty and complexity that comes with caring for children with IDD (Carter et al., 2002), and the need for individualized approaches with these children were commonly discussed by participants in *Let’s Talk About Pain* (Genik et al., submitted b). Anecdotally and per their focus group responses, these care providers seemed evidently aware that there is no ‘magic bullet’ and appeared appreciative of attempts to join them in the trenches and work together with the tools we do have to support children in the best ways possible (Genik et al., submitted b). There is value in sharing knowledge despite not knowing all the answers, and in helping stakeholders to become critical users of information. There will always be more questions to be asked and there may not always be an easy or straightforward answer; however, it is important to share what we do know and the limitations of this knowledge with the people who need it in a more timely way.
On Ensuring Audience Impact for a Heterogenous Population

Structure is important when completing systematic program evaluation; yet, a program that is too structured is unlikely to be effective across settings and needs when implemented more broadly. In the context of IDD, both the needs and abilities of children and the respite programs from which these children receive support are varied. For example, respite organizations with staff participating in Let’s Talk About Pain varied in their staff to child ratios (e.g., 2:1, 1:2, 1:10), program locations (e.g., group home, community, family home), staff educational backgrounds (e.g., personal support worker training, nursing, high school education), children’s needs (e.g., medically fragile, behavioral support, personal care), and children’s diagnoses (e.g., autism spectrum disorder, global developmental delay, cerebral palsy) to name a few. Let’s Talk About Pain included several features to ensure relevance for a heterogeneous population. For instance, interactive group activities during training sessions allowed staff to critically review evidence-based measures, determine which fit best within their specific programs, and discuss how to adapt approaches to their program context. Thus, training focused on core information must be balanced with tailored content as meaningful application of knowledge is enhanced by in depth exploration of key issues and interests of the organization.

On Building a Sustainable Program

Collaboration and research partnerships are imperative for researchers and program developers; however, they are insufficient for the successful implementation of a program or research project, and certainly do not guarantee sustainability. Further, what may work in a research study may not be feasible when thinking about formal, long-term adoption of a program. In addition to research-specific considerations, organizational structures are ever-
changing, and many factors influence sustainability. In the case of respite organizations, these factors may include the economic culture, time of year, policies and procedures, and logistical barriers. These factors may also interact. For example, although it worked to have an external facilitator provide *Let’s Talk About Pain* in the context of the research study, it is not feasible that such a program could ‘live on’ with only one primary facilitator; given the economic culture, many organizations would not be able to host staff trainings on a regular basis if there are fees. Finding ways to balance stakeholder preferences (e.g., in person trainings; Genik et al., submitted) with more realistic approaches (e.g., train-the-trainer approach) may be fruitful for next steps in more broadly implementing the program in a sustainable way.

**Closing Remarks**

As we continue to generate knowledge and develop approaches for sharing information, we are continually called to adapt our approaches to suit those working on the front lines. In our experience working with pain in children with IDD, the delays in both knowledge generation and translation related to pain in children with IDD is unacceptable. This is a call to action. We need to work together to move forward in a coordinated and helpful way. We need to think carefully about the goal of knowledge sharing, and the most effective ways to reach our audiences. The proactive consideration of these factors by researchers and stakeholders in program development has the potential to streamline the development of trainings, inform their design, and improve their impact in the field of pain and childhood disability. Knowledge is only potential power. As researchers, it is our responsibility to ensure it is harnessed and used for the greater good of children with IDD and their families.
References


References (Chapter One)


Appendices

Appendix A: Pre-Study One - Demographics Questionnaire

Demographics Questionnaire

**Reminder:** You may refuse participation, choose to withdraw at any time before the end of your phone/skype session, and are not obligated to provide responses for every question**

1. What is your age (in years)? ____________
2. Please indicate your gender: ____________
3. Please indicate your ethnicity (check all that apply):
   - Aboriginal/First Nations/Metis
   - White/European
   - Black/African/Caribbean
   - Southeast Asian (e.g., Chinese, Japanese, Korean, Vietnamese, Cambodian, Filipino, etc.)
   - Arab (Saudi Arabian, Palestinian, Iraqi, etc.)
   - South Asian (East Indian, Sri Lankan, etc.)
   - Latin American (Costa Rican, Guatemalan, Brazilian, Columbian, etc.)
   - West Asian (Iranian, Afghani, etc.)
   - Other (please specify): __________________________________________
4. Which of the following describes your HIGHEST level of education?
   - Some high school
   - Completed high school
   - Some college/university
   - Apprenticeship training and trades
   - Completed college/university
   - Some graduate education
   - Completed graduate education
   - Professional degrees
4. How many years have you been working in an organization providing support to children with intellectual disabilities?

______________________________________

5. What best describes your current position at your present employer (choose one)?

☐ Respite Worker/Inclusion Facilitator/Direct Support Professional/Support Worker for children with intellectual disabilities

☐ Manager who oversees a respite program for children with intellectual disabilities

6. Do you have any experience developing protocols/procedures to be utilized in respite settings?

☐ Yes
  ☐ Please describe the types of protocols/procedures you have developed for respite settings:
    _______________________________________________________

☐ No

7. Do you have experience evaluating staff performance in a respite setting?

☐ Yes
  ☐ Please describe the types of evaluations that you have participated in (what were you evaluating and how did you evaluate it): _________________________________

☐ No

8. On a scale of 0 – 10 (0 = Not Important At All; 10 = Extremely Important), how important do you think it is for respite workers to use new knowledge and skills in the workplace after completing professional development/additional trainings (please circle)?

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<thead>
<tr>
<th>0</th>
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<th>10</th>
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<tbody>
<tr>
<td>Not Important At All</td>
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<td></td>
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<td>Extremely Important</td>
</tr>
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</table>
## Appendix B: Pre-Study One - Interview Questions

### Interview Questions

<table>
<thead>
<tr>
<th>Question:</th>
<th>Potential Question-Specific Probes:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>INTRODUCTION TO INTERVIEW</strong></td>
<td></td>
</tr>
<tr>
<td>The researcher will spend about 3-5 minutes orienting the participant to the purpose of the research. The researcher can answer any questions from the participant at this point as well to ensure that they understand. The researcher should cover the following items:</td>
<td></td>
</tr>
<tr>
<td>● You (or staff from your organization) previously participated in a research study related to the development of a pain training program designed to increase workers’ knowledge specific to pain assessment and management in children with intellectual disabilities.</td>
<td></td>
</tr>
<tr>
<td>● Results from phase two, the pilot pain training program, demonstrated that participants’ knowledge improved, as did their perceptions of the feasibility of, and their own confidence and skill in pain assessment and management.</td>
<td></td>
</tr>
<tr>
<td>● Our next step as researchers is to further evaluate the program and to determine whether respite workers then use the knowledge and skills they have acquired when supporting children with CI.</td>
<td></td>
</tr>
<tr>
<td>● The questions I will be asking are related to how we could best find out about how/whether respite workers are using their new pain-related knowledge at work.</td>
<td></td>
</tr>
<tr>
<td><strong>Estimated Time Spent:</strong></td>
<td></td>
</tr>
<tr>
<td>● Based on a 30 minute interview: 3-5 minutes</td>
<td></td>
</tr>
<tr>
<td><strong>MAIN QUESTIONS</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Estimated Time Spent:</strong></td>
<td></td>
</tr>
<tr>
<td>● Based on a 30 minute interview: 22-25 minutes</td>
<td></td>
</tr>
<tr>
<td>1) What do you think is the best way to gather this information from respite workers (e.g., observation, completion of additional questionnaires/checklists)?</td>
<td>Can you tell me a bit more about that? What do you think about _____ as an approach? Why do you think that _____ would be better than ____? What do you think would be most feasible for staff? Is this any different than what might be most feasible for management?</td>
</tr>
<tr>
<td>2) Following a pain training workshop, how often do you think respite workers would have the opportunity to use new skills related to pain assessment (e.g., observing behaviour) and management (e.g., using distraction) in their work setting?</td>
<td>Do you think they would have the opportunity to use these skills at least once per shift? More often? Less often?</td>
</tr>
<tr>
<td>3) What factors are important to consider when deciding how to track respite workers’</td>
<td>Would these considerations be different depending on how we try to track this? Would</td>
</tr>
<tr>
<td>Question</td>
<td>Response</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------</td>
</tr>
<tr>
<td>use of new pain assessment and management skills?</td>
<td>we need parent consent? Would we need to coordinate ahead of time with respite organizations?</td>
</tr>
<tr>
<td>4) What types of challenges (organization-related and staff-related) do you think we might encounter when trying to track the use of these skills in respite settings?</td>
<td>Would specific data collection approaches be more or less challenging? What might help us to overcome some of those challenges?</td>
</tr>
<tr>
<td>5) Do you think it would be better to follow-up with staff regarding use of their skills during or outside of work hours?</td>
<td>Why do you think ________ would be better?</td>
</tr>
<tr>
<td>6) Let’s return to our original question: Has your opinion regarding the best way to gather this information changed at all?</td>
<td>Why or why not?</td>
</tr>
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</table>

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

**Estimated Time Spent:**
- Based on a 30 minute interview: 2-3 minutes

6) Can you think of anything else that might be useful for us to know when deciding how we will assess/track respite worker’s use of pain assessment and management strategies?
Appendix C: Pre-Study One - Post-Interview Questionnaire

Post-Interview Questionnaire

**Reminder:** You may refuse participation, choose to withdraw at any time before the end of your phone/skype session, and are not obligated to provide responses for every question**

1. Following completion of a pain training program, I believe it is very important for respite workers to apply evidence-based pain assessment and management-related skills in their work (please circle your response).

   0 1 2 3 4 5 6 7 8 9 10

   Strongly Disagree   Moderately Agree   Strongly Agree

2. Below are a number of possible approaches a researcher may use to track the use of new pain assessment and management skills used by respite workers following completion of a pain training workshop. Please respond to the questions related to each approach.

   (a) Having a research assistant come to the organization/group home/respite program and observe staff during shifts periodically.

   ☐ How feasible is this approach?

   0 1 2 3 4 5 6 7 8 9 10

   Not Feasible   Moderately Feasible   Extremely Feasible

   ☐ What makes this approach feasible? _____________________________

   ☐ What would be challenging about this approach? _____________________________

   ☐ Would additional permission be required from parents in order to have a research assistant observe in the respite programs (no identifying information of children)?

   ☐ Yes (please specify what would be needed)

   ________________________________________________________________

   ________________________________________________________________

   ________________________________________________________________
(b) Having a senior staff member or management observe staff during shifts periodically.

☐ How feasible is this approach?

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<tbody>
<tr>
<td>Not Feasible At All</td>
<td>Moderately Feasible</td>
<td>Extremely Feasible</td>
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☐ What makes this approach feasible? ________________________________

☐ What would be challenging about this approach? ____________________________

☐ Would additional permission be required from parents in order to have a research assistant review the observations made by senior staff/management in respite programs (no identifying information of children)?

☐ Yes (please specify what would be needed)

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

☐ No

☐ Don’t know

(e) Asking staff to complete a questionnaire at the end of each shift periodically.

☐ How feasible is this approach?

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<tr>
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<td>Moderately Feasible</td>
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☐ What makes this approach feasible? ________________________________

☐ What would be challenging about this approach? ____________________________
If this approach were used, what is a reasonable length of time to spend completing the questionnaires?

________________________________________________________________________

(d) Incorporating materials (e.g., documenting pain assessment) into children’s care profiles that are completed for each individual child with other routine paperwork.

How feasible is this approach?

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<td>Not Feasible At All</td>
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What makes this approach feasible? ________________________________

What would be challenging about this approach? ________________________________

If this approach were used, what is a reasonable length of time to spend completing the paperwork?

________________________________________________________________________

Would additional permission be required from parents for research assistants to review this paperwork, even if identifying information were removed prior to sending to the research assistants?

☐ Yes (please specify what would be needed)

________________________________________________________________________

________________________________________________________________________

☐ No
☐ Don’t know

(e) Asking respite workers to complete some questionnaires periodically outside of the work hours.

How feasible is this approach?

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<td>Not Feasible At All</td>
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</table>
What makes this approach feasible? ________________________________

What would be challenging about this approach? ________________________________

If this approach were used, how long should the questionnaires reasonably take them to complete?

________________________________________

(f) Other (please describe in detail): ________________________________

How feasible is this approach?

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<tr>
<td>Not Feasible At All</td>
<td>Moderately Feasible</td>
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</table>

What makes this approach feasible? ________________________________

What would be challenging about this approach? ________________________________

3. Please rank order your preference in the type of format researchers could use to track whether respite workers are using new pain assessment and management-related skills when supporting children with ID (i.e., 1 = most preferred, 6 = least preferred)?

_____ Observation by research assistants

_____ Observation by senior staff/management

_____ Filling out questionnaire at end of shifts

_____ Filling out paperwork required for each child’s profile at the end of a shift

_____ Filling out paperwork outside of work hours

_____ Hybrid

** Please describe what a feasible hybrid would look like to you (e.g., observation combined with questionnaire):

________________________________________

4. Do you have any other suggestions regarding how we could gather this information from respite workers in organizations?

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

**Reminder: This is the final point at which you are able to withdraw your data from the study.**
Appendix D: RCT - Focus Group Questions

A research assistant will first spend a few minutes orienting participants to the purpose of this focus group, which is ultimately to learn more about the types of pain assessment and management strategies they use with the children they care for in respite settings. This time will also be spent reminding participants about confidentiality, assigning nick names, etc. Researchers will remind participants throughout this procedure not to use specific/actual names when they provide/discuss examples.

Estimated Time Spent:
Focus Group (based on a 60 minute focus group): 5 minutes

<table>
<thead>
<tr>
<th>Question:</th>
<th>Potential Question-Specific Probes:</th>
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<tbody>
<tr>
<td>OPINIONS AND KNOWLEDGE ABOUT PAIN IN CHILDREN WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES (ice breaker but also gets at some general beliefs and knowledge of both experimental and control groups)</td>
<td></td>
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</table>

Estimated Time Spent:
- Focus Group (based on a 60 minute focus group): 10 minutes

1) What are your thoughts on pain in children with intellectual and developmental disabilities?

2) How much do you think you know about pain in children with intellectual and developmental disabilities compared to the ‘average respite worker’?

RW EXPERIENCES WITH PAIN ASSESSMENT AND MANAGEMENT IN RESPITE SETTINGS

A research assistant will indicate that they will now be asked some questions about their experiences with pain assessment and management in respite settings. They will be told that if they have not assessed or managed pain of a child in respite in the last month, they can speak about how they would approach a similar situation or base their responses on the experiences described by others in the room.

Estimated Time Spent:
- Focus Group (based on a 60 minute focus group): 40 minutes

3) Thinking about the last month, tell me about some experiences where you have had to assess and/or manage the pain of a child in respite care when it went well.

<table>
<thead>
<tr>
<th>Question:</th>
<th>Potential Question-Specific Probes:</th>
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</thead>
<tbody>
<tr>
<td>1) What are your thoughts on pain in children with intellectual and developmental disabilities?</td>
<td>How have you come to thinking about pain in that way? Do you think the training has had an impact in how you think about pain? How so/Why or why not?</td>
</tr>
<tr>
<td>2) How much do you think you know about pain in children with intellectual and developmental disabilities compared to the ‘average respite worker’?</td>
<td>Why do you think you have (more, less, the same) knowledge? What sorts of things do you think they (would/wouldn’t) know? Do you think the training had an impact on how much you know about this topic? How so/why or why not?</td>
</tr>
<tr>
<td>3) Thinking about the last month, tell me about some experiences where you have had to assess and/or manage the pain of a child in respite care when it went well.</td>
<td>Can you tell me more about that? How confident/skilled/knowledgeable did you feel in the situation? Did you respond differently than you might have before this training or study? How so? How easy/hard was it for you to use assessment and management skills in</td>
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<td>Question</td>
<td>Follow-up</td>
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<td>4) Thinking about the last month, tell me about some experiences where</td>
<td>Can you tell me more about that? How confident/skilled/knowledgeable did</td>
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<td>you have had to assess and/or manage the pain of a child in respite</td>
<td>you feel in the situation? Did you respond differently than you might</td>
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<td>care when it did not go well.</td>
<td>have before this training or study? How so? How easy/hard was it for you</td>
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<td></td>
<td>to use assessment and management skills in your work with children with</td>
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<td></td>
<td>intellectual and developmental disabilities?</td>
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<td>5) What types of pain assessment strategies have you been able to use</td>
<td>How did you go about this? Are there any strategies you know about but</td>
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<td>in the last month?</td>
<td>have not used? How did you decide to use the strategies you chose? Is</td>
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<td>there a strategy you find most/least useful? What barriers or challenges</td>
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<td></td>
<td>have you encountered to using any pain assessment strategies in your work</td>
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<td></td>
<td>over the past month? Can you describe them?</td>
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<tr>
<td>6) What types of pain management strategies have you been able to use</td>
<td>How did you go about this? Are there any strategies you know about but</td>
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<td>in the last month?</td>
<td>have not used? How did you decide to use the strategies you chose? Is</td>
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<td>there a strategy you find most useful? What barriers or challenges have</td>
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<td></td>
<td>you encountered to using any pain management strategies in your work</td>
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<td></td>
<td>over the past month? Can you describe them?</td>
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<tr>
<td>7) Can you think of a time when you specifically remembered something</td>
<td>Tell me more about that? Why do you think that is?</td>
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<tr>
<td>from the training and were able to put it into use in practice?</td>
<td></td>
</tr>
<tr>
<td>8) Can you think of a time when you specifically remembered something</td>
<td>Tell me more about that? Why do you think that is?</td>
</tr>
<tr>
<td>from the training but were not able to put it into use in practice?</td>
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</table>

**CLOSING QUESTION**

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

| 9) What else would you like to share with us about your experiences     |                                                                 |
| related to pain in children with intellectual and developmental         |                                                                 |
| disabilities?                                                           |                                                                 |
Appendix E: RCT - Demographics Questionnaire

Participant ID#: __________________________

A. GENERAL DEMOGRAPHIC INFORMATION

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

2. Please indicate your gender: ______________

3. Please indicate your ethnicity:
   - ☐ Aboriginal/First Nations/Metis
   - ☐ White/European
   - ☐ Black/African/Caribbean
   - ☐ Southeast Asian (e.g., Chinese, Japanese, Korean, Vietnamese, Cambodian, Filipino, etc.)
   - ☐ Arab (Saudi Arabian, Palestinian, Iraqi, etc.)
   - ☐ South Asian (East Indian, Sri Lankan, etc.)
   - ☐ Latin American (Costa Rican, Guatemalan, Brazilian, Columbian, etc.)
   - ☐ West Asian (Iranian, Afghani, etc.)
   - ☐ Other (please specify): __________________________________________

4. How many years have you been working in an organization providing respite care to children with developmental disabilities?

____________________________________

5. How many years have you been employed providing respite support to children with developmental disabilities with this current organization?

____________________________________

B. EXPERIENCE WITH CHILDREN WHO HAVE DEVELOPMENTAL DISABILITIES

6. About how frequently do you interact with (i.e., direct contact or communication with a child with a developmental disability) children who have developmental 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)

7. a) Thinking of children who have developmental 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.

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<thead>
<tr>
<th>Not At All Involved</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5 Moderately Involved</th>
<th>6</th>
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<th>9</th>
<th>10 Highly Involved</th>
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</table>

7.b) Please indicate the type(s) of setting(s) in which you have provided any type of support (e.g., personal care, behaviour management, mealtime assistance) to children who have developmental disabilities. Check all that apply.

- In the family home.
- In your own home.
- In the community.
- At a group home.
- Other (please specify): ____________________________________________

C. PAIN EDUCATION INFORMATION

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

- Yes (if YES see 8 b, c, and d)
- No

8. b) If you responded YES to 8. a), please name and describe the type of pain training you received:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
8. c) If you responded YES to 8. 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):

____________________________________

☐ No (please specify who provided the training): _________________________________

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

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<tr>
<td>Not Important At All</td>
<td>Somewhat Important</td>
<td>Extremely Important</td>
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Appendix F: Organization Specifics Questionnaire

**Organization Specifics Questionnaire**

1. Please briefly describe the types of respite programming available to children with developmental disabilities that staff involved in this training are involved with (e.g., weekend respite, day respite, summer day camps):

______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

2. Please briefly describe the types of children who receive services in this/these respite program(s) (e.g., children’s abilities, diagnoses, etc.):

______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

3. What are the typical staff to child ratios in this program?

______________________________________________________________________________
______________________________________________________________________________

4. Please list the types of support that children in these respite programs receive from respite workers (e.g., social support, personal care):

______________________________________________________________________________
______________________________________________________________________________

5. Which geographic location does your organization serve?

______________________________________________________________________________
Appendix G: RCT - Feasibility, Confidence and Skill Ratings

Participant ID#: ______________________________

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

**ASSESSMENT:**

1) ASSESSING WHETHER A CHILD WITH A DEVELOPMENTAL DISABILITY IS IN PAIN IS...

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<tbody>
<tr>
<td>Not Feasible At All</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>Moderately Feasible</td>
<td>6</td>
<td>7</td>
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<td>9</td>
<td>Highly/Extremely Feasible</td>
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2) I AM ___________________________ IN ASSESSING WHETHER A CHILD WITH A DEVELOPMENTAL DISABILITY IS IN PAIN...

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<tr>
<td>Not Confident At All</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>Moderately Confident</td>
<td>6</td>
<td>7</td>
<td>8</td>
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<td>Highly/Extremely Confident</td>
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3) I AM ___________________________ IN ASSESSING WHETHER A CHILD WITH A DEVELOPMENTAL DISABILITY IS IN PAIN...

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<tr>
<td>Not Skilled At All</td>
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<td>Moderately Skilled</td>
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<td>Highly/Extremely Skilled</td>
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**TREATMENT:**

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

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<tbody>
<tr>
<td>Not Feasible At All</td>
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<td>2</td>
<td>3</td>
<td>4</td>
<td>Moderately Feasible</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>Highly/Extremely Feasible</td>
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</table>

5) I AM ___________________________ IN HELPING A CHILD WITH A DEVELOPMENTAL DISABILITY TO MANAGE THEIR PAIN...

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<th>10</th>
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</thead>
</table>
6) I AM ________________________ IN HELPING A CHILD WITH A DEVELOPMENTAL DISABILITY TO MANAGE THEIR PAIN...

<table>
<thead>
<tr>
<th>0</th>
<th>Not Skilled At All</th>
<th>1</th>
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<th>3</th>
<th>4</th>
<th>5</th>
<th>Moderately Skilled</th>
<th>6</th>
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<th>9</th>
<th>10</th>
<th>Highly/Extremely Skilled</th>
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Appendix H: RCT - QUPID-CR

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) You should only use one pain management strategy at a time.
   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 to 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) Pain is 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) Don’t Know
21) An individual’s level of physical disability…
   a) Accurately reflects his/her level of intellectual disability
   b) May or may not accurately reflect his/her level of intellectual disability
   c) Is positively related to their level of intellectual disability
   d) Don’t Know

22) Pain may be more common among individuals with intellectual disabilities for the following reasons:
   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 expresses pain:
   a) The environment in which the individual grew up
   b) The individual’s temperament
   c) The social context
   d) B and C
   e) All of the above
   f) 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 would be most useful for an individual who:
   a) Just fell down and is crying
   b) Has a sore stomach
   c) Just fell down and is trying to hit you
   d) Has lower levels of cognitive functioning
   e) All of the above
   f) 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 immediately following the fall.
   a) 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) None of the above
   f) 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 should:
   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) All of the above
   e) None of the above
   f) Don’t Know
Appendix I: RCT - Training Evaluation Questionnaire

Training Evaluation 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>0 Strongly Disagree</th>
<th>1</th>
<th>2</th>
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<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>
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<tbody>
<tr>
<td>1. The training content was valuable.</td>
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<td>2. The information provided at this training is applicable to my work.</td>
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<td>3. The training format was effective/well suited to the material.</td>
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<td>4. The group size was ideal.</td>
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<td>5. The group discussions were useful in further understanding the topic.</td>
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<td>6. The topic was interesting.</td>
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<td>7. I would encourage other respite workers to take part in a training like this.</td>
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<td>8. I would be interested in learning more about this topic.</td>
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<tr>
<td>9. I plan to incorporate what I have learned into my work.</td>
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<tr>
<td>10. My training needs on this particular topic were met in completing this training.</td>
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</tbody>
</table>

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

| 0 Not Important At All | 1 | 2 | 3 | 4 | 5 Somewhat Important | 6 | 7 | 8 | 9 | 10 Extremely Important |
12. What topic during the training were you MOST interested in hearing about (please select ONE)?

☐ General pain-related knowledge
☐ Pain assessment information
☐ Pain management information
☐ Other (please specify): ________________________________

13. What topic during the training were you LEAST interested in hearing about (please select ONE)?

☐ General pain-related knowledge
☐ Pain assessment information
☐ Pain management information
☐ Other (please specify): ________________________________

14. What was the most important thing you learned at this training (please select ONE)?
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

15. What component of the training contributed MOST to your learning (please select ONE)?

☐ Powerpoint presentation/speaker
☐ Small group discussions/activities
☐ Large group discussions/activities
☐ Sharing with the larger group
☐ Videos
☐ Other (please specify): ________________________________

**Please indicate why you believe this component contributed most to your learning:
______________________________________________________________________________
______________________________________________________________________________

16. What component of the training contributed LEAST to your learning (please select ONE)?
☐ Powerpoint presentation/speaker
☐ Small group discussions/activities
☐ Large group discussions/activities
☐ Sharing with the larger group
☐ Videos
☐ Other (please specify): ____________________________________________

**Please indicate why you believe this component contributed most to your learning:
_________________________________________________________________________________________________________________
_________________________________________________________________________________________________________________
_________________________________________________________________________________________________________________

17. Was there anything you wanted to hear more about?
_________________________________________________________________________________________________________________
_________________________________________________________________________________________________________________
_________________________________________________________________________________________________________________

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

19. Additional comments/suggestions. Is there anything else that you would like to tell us that we haven’t asked about?
_________________________________________________________________________________________________________________
_________________________________________________________________________________________________________________
Appendix J: RCT - Use of Pain Assessment and Management Strategies Questionnaire

Participant ID#: __________________________

Please respond to the following questions based on your work as a respite worker in THIS organization only.

1) On average, about how many shifts per week do you work as a respite worker in THIS ORGANIZATION?

☐ Less than one shift per week
☐ One to two shifts per week
☐ Three to four shifts per week
☐ Five to six shifts per week
☐ Seven or more shifts per week

2) On average, about how long are your shifts as a respite worker in THIS ORGANIZATION?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

3) On average, about how often do you engage in pain assessment with a child with a developmental disability in respite care in THIS ORGANIZATION?

☐ Never (I have never assessed pain with a child who has an intellectual/developmental disability in respite care)
☐ Rarely (I assess pain...less than once per month)
☐ Occasionally (I assess pain...on a monthly basis)
☐ Often (I assess pain...about once a week)
☐ Very Often (I assess pain...multiple times a week)

4) Please list/describe the strategies you have used when assessing for pain in a child with an intellectual/developmental disability in respite care in THIS ORGANIZATION:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
5) About how often do you engage in pain management with a child with an intellectual/developmental disability in respite care in THIS ORGANIZATION?

☐ Never (I have never managed pain with a child who has an intellectual/developmental disability in respite care)

☐ Rarely (I manage pain...less than once per month)

☐ Occasionally (I manage pain...on a monthly basis)

☐ Often (I manage pain...about once a week)

☐ Very Often (I manage pain...multiple times a week)

6) Please list/describe the strategies you have used when helping manage pain with a child with an intellectual/developmental disability in respite care in THIS ORGANIZATION:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

7) Please read the following scenario and respond to the accompanying questions. There are no “right” or “wrong” answers. We just want to know your honest opinion.

*Jordan is a 10-year-old child who receives respite care. Jordan has a developmental disability and is nonverbal. While in respite care, Jordan and his/her respite worker usually go swimming or play at the park. While doing either of these activities, Jordan usually smiles and appears to be very relaxed. Today, after entering a relatively crowded pool, Jordan suddenly exits the water and becomes very restless: lifting his/her hands and holds them to his/her head. Soon after, Jordan begins to scream.*

(a) Based on your initial impression of the scenario described above, do you believe this child experienced pain?

☐ Yes

☐ No

☐ Maybe

(b) Please list three factors you considered when coming to your conclusion in (a) about the presence or absence of pain in this specific scenario:
1. ________________________________________________________________
2. ________________________________________________________________
3. ________________________________________________________________

(c) Regardless of your responses in (a) and (b), please briefly describe the steps you would take to assess whether the child in this scenario is in pain.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

(d) Assuming that the child in this scenario was experiencing pain, please briefly describe the steps you would take to help manage the child’s pain.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

(e) Please briefly describe any additional follow-up action that you would need to take if you were the respite worker in this scenario.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
Appendix K: RCT - Training Fidelity Checklist

Training Fidelity Checklist

Research Assistant Name Completing Form: __________________________

Name of Facilitator: ______________________________

Training Date: _________________

Participating Organization Code: _________________

Time Training Started: _________________

Time Training Ended: _________________

Break Provided? ☐ Yes (Time Started: __________ ; Time Ended: __________)  ☐ No (Why Not? ____________________________________________)

Group Size: _____________________

<table>
<thead>
<tr>
<th>General Pain-Related Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Material Covered? (✓ or X)</td>
</tr>
<tr>
<td>Information to be Covered</td>
</tr>
<tr>
<td>☐ Brief introduction of the presenter</td>
</tr>
<tr>
<td>☐ Brief overview of training objectives</td>
</tr>
<tr>
<td>☐ Brief icebreaker activity (asking individuals to share what they hope to learn from the training)</td>
</tr>
<tr>
<td>☐ What is pain? – read definition and break it down more in depth. Elaboration about:</td>
</tr>
<tr>
<td>☐ Unpleasant sensory experience</td>
</tr>
<tr>
<td>☐ Sensory or emotional experience</td>
</tr>
<tr>
<td>☐ Actual or potential tissue damage</td>
</tr>
</tbody>
</table>

7 This is a template fidelity checklist designed specifically for the pain training. A parallel form fidelity checklist will also be developed for the control training. As discussed in the methods, a number of factors will be similar between the two trainings (e.g., group size, training length, general format).
- Or described in terms of such damage
- Says NOTHING about cognitive skills being required to experience pain, but clearly skills are important in expression and understanding
- Pain is complex

- Lorimer Moseley video clip
  - Check with participants for any questions/comments about the video

- Acute Pain (material on slide covered IN ADDITION TO information below)
  - Examples – bumps, bruises, needle procedures, burns, fractures
  - Pain diminishes steadily over time
  - A warning that something is wrong

- Chronic Pain (material on slide covered IN ADDITION TO information below)
  - May be a sign of ongoing tissue damage or disease (e.g., juvenile arthritis) OR there may not be anything physical going on, but body is still sending pain signals to the brain
  - Like a false alarm

- What is Pain – inability to communicate verbally…(material on slide covered IN ADDITION TO information below)
  - Importance of nonverbal communication
  - Sounds like common sense but many challenges with this in the past (e.g., babies) and even still in present some resistance

- Historically… (material on slide covered IN ADDITION TO information below)
  - As a result, pain in DD not as well assessed or managed, and in the past was even ignored
<table>
<thead>
<tr>
<th>Topic</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Was even used as a teaching tool in the past – obviously we know today this is unacceptable</td>
<td></td>
</tr>
<tr>
<td>Still problem – study about spinal fusion surgery</td>
<td></td>
</tr>
<tr>
<td>We Know Today… (material on slide covered IN ADDITION TO information below)</td>
<td></td>
</tr>
<tr>
<td>Give examples of the different types of pain experienced</td>
<td></td>
</tr>
<tr>
<td>Pain may be comorbid (e.g., DS, CP, ASD)</td>
<td></td>
</tr>
<tr>
<td>Don’t necessarily tolerate pain better than adults</td>
<td></td>
</tr>
<tr>
<td>Examples of areas of adaptive functioning impacted</td>
<td></td>
</tr>
<tr>
<td>Untreated pain prolongs recovery</td>
<td></td>
</tr>
<tr>
<td>Short and long term effects are evident</td>
<td></td>
</tr>
<tr>
<td>Pain is Always Subjective (material on slide covered IN ADDITION TO information below)</td>
<td></td>
</tr>
<tr>
<td>Cannot be directly observed by others; instead use overt cues</td>
<td></td>
</tr>
<tr>
<td>No test that tells you if a person is in pain or not</td>
<td></td>
</tr>
<tr>
<td>Multidimensional nature of pain</td>
<td></td>
</tr>
<tr>
<td>Biopsychosocial Model of Pain (material on slide covered IN ADDITION TO information below)</td>
<td></td>
</tr>
<tr>
<td>Integrates factors related to health</td>
<td></td>
</tr>
<tr>
<td>All factors here influence on and can be influenced by pain experience, expression, health behaviours</td>
<td></td>
</tr>
<tr>
<td>Many factors come into play for the same injury for difference people</td>
<td></td>
</tr>
<tr>
<td>E.g. tearing ligaments (ask for participation in the example)</td>
<td></td>
</tr>
<tr>
<td>Environment, cultural background, parent behavior, neurological factors, medical conditions, medications</td>
<td></td>
</tr>
<tr>
<td>Pain Desensitization/Hyper/Hyposensitivity (material on slide covered IN ADDITION TO information below)</td>
<td></td>
</tr>
</tbody>
</table>
No real reason to believe that children with DD in particular are indifferent to pain
Many studies have shown people with DD have normal pain perception
Disrupted expression doesn’t mean less or insensitive to pain – may just process more slowly or express differently
With repeated exposure could become hypersensitive, hyposensitive or no change in sensitivity
Presence of self-injury does not necessarily mean that a person is insensitive or indifferent to pain

Pain Assessment and Management (material on slide covered IN ADDITION TO information below)
Opportunity for the group to share what they think may contribute to assessment and management decisions
Give a concrete example of EACH area on the slide (training experience, relationship with child, previous experiences, pain opinions, disability related attitudes)

### Pain Assessment-Related Information

<table>
<thead>
<tr>
<th>Material Covered? (✔️ or X)</th>
<th>Information to be Covered</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Why is assessment important/why should we care? (material on slide covered IN ADDITION TO information below)</td>
<td>☐ Elicit ideas from participants</td>
</tr>
<tr>
<td>☐ Assessment: Why is it Important? (material on slide covered IN ADDITION TO information below)</td>
<td>☐ Reiterate that pain has negative short and long term impacts</td>
</tr>
<tr>
<td>☐ Assessment: (material on slide covered IN ADDITION TO information below)</td>
<td>☐ Pain assessment is difficult – lots of challenges</td>
</tr>
</tbody>
</table>
- May have multiple impairments that can affect motor, cognitive, language, social/emotional capabilities to communicate pain

- Pair & Share/Group Discussion *may be a pair and share and then a large group activity OR just a large group activity
  - Discuss at least one example with the large group

- Assessment: How? (material on slide covered IN ADDITION TO information below)
  - Inappropriate methods can lead to underestimation of pain
  - Limited communication abilities – should be assessing on a regular basis
  - Whenever a child is able they should contribute (but will need to adapt)

- Self-Report Activity (material on slide covered IN ADDITION TO information below)
  - When able to should contribute
  - Think about: stage of cognitive development, physical VS cognitive disability, adaptations
  - Give each group a different measure and a chance to discuss it in the group addressing the questions on the slide
  - Each group to speak about the outcome of their discussion

- Reports from Others: Expanded (material on slide covered IN ADDITION TO information below)
  - Provide and review caregiver pain resource
  - Mention pediatric pain profile
  - Parents do not generally exaggerate their child’s pain

- Behavioural Observations (material on slide covered IN ADDITION TO information below)
- Do not always communicate it in the same way as typically developing (less likely to cry)
- Can sleep when in pain, do not necessarily breathe faster
- Core set of behavioural cues to look for but remember can be idiosyncratic/atypical (potential for underrecognition/misinterpretation) – need to consider wide range
- Expression and experience do not mirror each other
- Observation assumes that child expresses pain in a reasonably consistent way
- Caregivers are an important resource

- How do children communicate their pain? (material on slide covered IN ADDITION TO information below)
  - Give opportunity for participants to share their ideas
  - Even children who communicate verbally may also demonstrate some of the examples on the slide
  - Not always one behavior – could be multiple
  - Give real life example
  - Sometimes may express through problem behaviours
  - Less likely to cry/help seek
  - Pay attention to facial expression and a wide range of behaviours

- Behavioural Observations Activity (material on slide covered IN ADDITION TO information below)
  - Groups should all have a different behavioural observation measure and spend time discussing questions on the slide
  - Groups each take time discussing their behavioural observation measure in front of the group (in response to the questions)

- Helpful Assessment Tips (material on slide covered IN ADDITION TO information below)
|   | Learn as much as you can from caregivers (ask about specific types of pain, pain expression, triggers, changes in behavior)  
|   | Learn about child/observe (consider a wide range of things, cognitive ability, neurological factors)  
|   | Within individual differences (verbally expand here – what does this mean)  
|   | If capable self-report (note that even yes or no is self report, highlight different ways to obtain e.g., ESL, pecs)  
|   | Re-assess periodically  
|   | Keep calm and keep trying (material on slide covered IN ADDITION TO information below)  
|   | Assessment is difficult! Sometimes need to use trial and error  
|   | Watch brief video to reiterate difficulty and trying different things (if no time for video provide a verbal example about this)  
|   | Case Studies activity for assessment (material on slide covered IN ADDITION TO information below)  
|   | Group time to discuss their case  
|   | Opportunity to share with larger group  

### Pain Management-Related Information

<table>
<thead>
<tr>
<th>Material Covered? (✔ or X)</th>
<th>Information to be Covered</th>
</tr>
</thead>
</table>
|                           | Taking Action (material on slide covered IN ADDITION TO information below)  
|                           | Speak briefly about deciding when to take action, note that this may vary from child to child  
|                           | Pair & Share/Group Discussion *may be a pair and share and then a large group activity OR just a large group activity  
<p>|                           | Discuss at least one example with the large group |</p>
<table>
<thead>
<tr>
<th>Topic</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain Management</td>
<td>Has lagged behind in research; strategies used will vary widely for each child; want to know how other caregivers typically approach it for a given child; want to match intervention approaches to needs and abilities of child.</td>
</tr>
<tr>
<td>Pharmacological</td>
<td>Important to follow instructions – meds given to the child if not previously ok’d could have negative side effects with other medications or not help with pain management.</td>
</tr>
<tr>
<td>Physical</td>
<td></td>
</tr>
<tr>
<td>Psychological: Deep Breathing</td>
<td>Sample script out loud.</td>
</tr>
<tr>
<td>Psychological: Imagery</td>
<td>Go through small part of imagery script or summarize what one might look like; many imagery scripts available online; can also make up your own specific to the child’s interests; child can also help create; might be more appropriate for some types of pain more than others (e.g., headache/sore stomach vs. falling).</td>
</tr>
<tr>
<td>Psychological: Progressive Muscle Relaxation</td>
<td>Relaxation can be very effective for reducing children’s pain.</td>
</tr>
</tbody>
</table>
| | • Lots of different ways to adapt – with visualization or with props (e.g., stress ball)
| | • Share some of a sample script or summarize how it would look
| | • Psychological: Distraction (material on slide covered IN ADDITION TO information below)
| | | • Very effective
| | | • Talk about example scenario and using smartphone as a distraction
| | | • Show sample video of example of distraction in medical procedure *note being distracted easily doesn’t mean you aren’t still in pain*
| | • Other tips (material on slide covered IN ADDITION TO information below)
| | • Process (material on slide covered IN ADDITION TO information below)
| | • Picking and Choosing Pain Management Strategies (material on slide covered IN ADDITION TO information below)
| | | • Provide examples of when certain types of management strategies may be better than others
| | • Creating a Pain Management Menu (material on slide covered IN ADDITION TO information below)
| | | • Idea of having some standard management strategies in place
| | • Case Studies for Management (material on slide covered IN ADDITION TO information below)
| | | • Group time to discuss their case
| | | • Opportunity to share with larger group |
In your opinion, how engaged was the group overall with the training and materials?

| 0 Not Engaged At All | 1 | 2 | 3 | 4 | 5 Moderately Engaged | 6 | 7 | 8 | 9 | 10 Extremely Engaged |
|----------------------|--|--|--|--|--|----|--|--|--|--|-------------------|

In your opinion, what topic during the training were participants MOST interested in hearing about (please select ONE)?

- General pain-related knowledge
- Pain assessment information
- Pain management information
- Other (please specify): _____________________________________________

In your opinion, what topic during the training were participants LEAST interested in hearing about (please select ONE)?

- General pain-related knowledge
- Pain assessment information
- Pain management information
- Other (please specify): _____________________________________________

In your opinion, what component of the training contributed MOST to participants’ learning (please select ONE)?

- Powerpoint presentation/speaker
- Small group discussions/activities
- Large group discussions/activities
- Sharing with the larger group
- Videos
- Other (please specify): _____________________________________________

**Please indicate why you believe this component contributed most to participants’ learning:
___________________________________________________________________________
___________________________________________________________________________

In your opinion, what component of the training contributed LEAST to participants’ learning (please select ONE)?

- Powerpoint presentation/speaker
☐ Small group discussions/activities
☐ Large group discussions/activities
☐ Sharing with the larger group
☐ Videos
☐ Other (please specify): _____________________________________________

**Please indicate why you believe this component contributed most to participants’ learning:
______________________________________________________________________________
______________________________________________________________________________
Appendix L: RCT - Training Outline (extracted directly from Lara Genik’s MA Thesis)

*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.

יקים 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

יקים 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
Appendix M: Additional Tables Descriptively Depicting Missing Data

Table 1

*Participants Missing Data in the QUPID-CR.*

<table>
<thead>
<tr>
<th>Data Collection Time Point</th>
<th>No Missing Data</th>
<th>n Participants 1-3 Questions Missing</th>
<th>4-7 Questions Missing</th>
<th>Total Questions Missing Responses</th>
<th>n Types of Missing Data</th>
<th>Selected Multiple Options</th>
<th>Selection Unclear</th>
<th>Left Blank</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre (n = 146)</td>
<td>111</td>
<td>30</td>
<td>3</td>
<td>63</td>
<td>46</td>
<td>2</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>Post (n = 155)</td>
<td>136</td>
<td>15</td>
<td>2</td>
<td>28</td>
<td>22</td>
<td>0</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Follow Up (n = 102)</td>
<td>91</td>
<td>11</td>
<td>0</td>
<td>13</td>
<td>8</td>
<td>1</td>
<td>4</td>
<td></td>
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</tbody>
</table>

*Note:* 1The number of participants considered for the Pre time point in this table includes all participants who completed the pre data collection time point with the exception of 11 participants who were given the wrong QUPID-CR questionnaire. One participant did not complete the pre-data collection time period. 2The number of participants considered above for the post time point in this table includes all participants who completed the post data collection time point with the exception of one participant who left post-data collection early, and two participants who did not complete post data collection measures. 3The number of participants considered for the follow up time point in this table includes all participants who completed the follow up data collection time point. A total of 56 participants did not complete follow up data collection measures.
Table 2

Participant Missing Data QUPID-CR per Question

<table>
<thead>
<tr>
<th>Question</th>
<th>Pre Multiple</th>
<th>Pre Unclear</th>
<th>Pre Blank</th>
<th>Post Multiple</th>
<th>Post Unclear</th>
<th>Post Blank</th>
<th>Total</th>
<th>Follow-up Multiple</th>
<th>Follow-up Unclear</th>
<th>Follow-up Blank</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>--</td>
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Table 3

**Missing Data for Pain and Assessment and Management Perception Ratings Across Time Points: Number of Participants and Number of Missing Responses Per Participant.**

<table>
<thead>
<tr>
<th>Data Collection Time Point</th>
<th>Did Not Participate in Data Collection Time Point</th>
<th>n Participants</th>
<th>n Missing Responses per participant</th>
</tr>
</thead>
<tbody>
<tr>
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<td>1-3</td>
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<tr>
<td>Pre</td>
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<td>Post</td>
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<td>144</td>
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<tr>
<td>Follow-Up</td>
<td>56</td>
<td>95</td>
<td>6</td>
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</tbody>
</table>

*Note:* In all cases, participants were either missing three ratings or all six ratings. As such, it appears that participants either: missed the questionnaire, skipped it (due to fatigue) or missed the back page of the questionnaire, as the questionnaire was double-sided. Nevertheless, there was no pattern to the missing data and these are still interpreted as random occurrences within the data set.
Table 4

Number of Missing Pain and Assessment and Management Perception Ratings Responses for Participants who Completed Each Corresponding Time Point.

<table>
<thead>
<tr>
<th>Question</th>
<th>Pre (n = 157)</th>
<th>Post (n = 156)</th>
<th>Follow-Up (n = 102)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessment – Feasibility, n (%)</td>
<td>5 (3.18)</td>
<td>1 (0.64)</td>
<td>3 (2.94)</td>
</tr>
<tr>
<td>Assessment – Confidence, n (%)</td>
<td>5 (3.18)</td>
<td>1 (0.64)</td>
<td>3 (2.94)</td>
</tr>
<tr>
<td>Assessment – Skill, n (%)</td>
<td>5 (3.18)</td>
<td>1 (0.64)</td>
<td>3 (2.94)</td>
</tr>
<tr>
<td>Treatment – Feasibility, n (%)</td>
<td>20 (12.73)</td>
<td>12 (7.69)</td>
<td>6 (5.88)</td>
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<tr>
<td>Treatment – Confidence, n (%)</td>
<td>20 (12.73)</td>
<td>12 (7.69)</td>
<td>6 (5.88)</td>
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<tr>
<td>Treatment – Skill, n (%)</td>
<td>20 (12.73)</td>
<td>12 (7.69)</td>
<td>6 (5.88)</td>
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Note: One participant did not complete pre-measures, two participants did not complete post measures, and 56 participants did not complete follow-up measures.
Appendix N: Coding Schemes for Quantitative Content Analysis

**Supplemental Resource 1 – Coding Schemes for Quantitative Content Analysis**

**Coding Scheme for Pain Assessment-Related Questions**

QUESTION: Please list/describe the strategies you have used when assessing for pain in a child with an intellectual/developmental disability in respite care in THIS ORGANIZATION

QUESTION: Regardless of your responses in (a) and (b), please briefly describe the steps you would take to assess whether the child in this scenario is in pain.

**DIRECTIONS:**

- Code for the presence/absence of EACH strategy. There is an individual code for each strategy listed below, and you select Yes or No depending on whether the participant has endorsed each one.
- Code responses based on the explicit content only
- For example, if a participant states: “look for changes in facial expressions and behaviour, ask them if they are in pain and see if they are holding their head”, then Self-Report: Verbal Questions and Behavioural Observations: Informal would be coded ‘yes’ as present, and all others as ‘no’ (not present)

<table>
<thead>
<tr>
<th>Code</th>
<th>General Category</th>
<th>Type of Strategy</th>
<th>Definition</th>
<th>Examples</th>
</tr>
</thead>
</table>
| 1    | Self-Report      | Scale or structured activity | Response mentions use of a self-report scale or more structured assessment activity. | ● Numerical scale  
|      |                  |                  |            | ● Adapted scale  
|      |                  |                  |            | ● Colour your pain |
| 2    | Verbal Questions |                  | Response mentions asking questions verbally to ask the child if they are in pain. | ● Does it hurt?  
|      |                  |                  |            | ● Do you have a booboo? |
| 3 | Nonverbal questions/visuals | Response mentions use of nonverbal communication and/or visuals to ask the child if they are in pain. | • Sign language  
• PECS  
• Pointing to body parts |
| 4 | Behavioural Observations | Formal scale or structured measure | Response mentions use of a formal and structured behavioural observation scale when assessing a child’s pain.  
• Behavioural checklist  
• NCCPC  
• FLACCR |
| 5 | Informal | Response mentions use of informal behavioural observations (either verbal or nonverbal) to determine whether a child is in pain. | • Change in emotion  
• Facial expressions  
• Body language  
• Screaming  
• Crying  
• Saying they are in pain |
| 6 | Physical Inspection | Response mentions visual or physical inspections of the child’s body for physical injury. | • Looking for bumps, bruises, etc.  
• Physical signs of injury |
| 7 | Information from Other Source | Review of History/Documentation | Response mentions review of previously provided documentation or information about the child and/or the child’s pain. | • Review records  
• Bowel movement record forms |
| 8 | Asking Others | Response mentions reaching out to speak with others directly about the child to assess their pain. | • Call parents  
• Consult with other staff members |
| 9 | Environmental Assessment | Consideration of Environment | Response mentions consideration of the surrounding environment | • Is it noisy? |
and whether there are potential sources of injury or pain present.  

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</table>
| 10 | Intuition | “Gut”, “Intuition”, “Guessing” | Is there something the person could have injured themselves on?  
|   |   |   |   |
|   |   |   | Sometimes you need to guess  
|   |   |   | Use my intuition  
|   |   |   | Follow my gut  

Response mentions needing to guess about the presence or absence of pain, or make individual own judgements via intuition, a gut feeling, etc.

| 11 | Other | Assessment Strategy Unclear | Figure out what is wrong  
|   |   |   | Find out if they are in pain  
|   |   |   | Assess the level of severity  

Suggestion of use of a specific assessment strategy is clear, however the type of strategy used is unclear. For example, cannot decipher whether strategy would involve self-report, behavioural observations, gaining information from another information source etc.

| 12 | Management Strategy | Provide medication  
|   |   | Follow up with pharmacy  
|   |   | Change the environment  
|   |   | Take him away from the crowded area and see if behaviour changes  

Response refers to a strategy that is considered to be a management strategy rather than an assessment strategy, OR seems to be using management (e.g., changing scenario) to see whether it changes behaviour.

| 13 | Unclear/Unrelated | I have cared for a child in pain.  

Response is either unclear as to the meaning or unrelated.
to strategies one use when assessing pain. Cannot effectively code into another given category without adding additional interpretation of the response.

| 999  | No Response | Missing Field | No response provided to the question |
### Coding Scheme for Pain Management-Related Questions

**QUESTION:** Please list/describe the strategies you have used when helping manage pain with a child with an intellectual/developmental disability in respite care in THIS ORGANIZATION.

**QUESTION:** Assuming that the child in this scenario was experiencing pain, please briefly describe the steps you would take to help manage the child’s pain.

**DIRECTIONS:**

- Code for the presence/absence of EACH strategy. There is an individual code for each strategy listed below, and you select Yes or No depending on whether the participant has endorsed each one.
- Code responses *explicitly* only.
- For example, if a participant states: “use ice, distract them, play a game”, then Physical Pain and Distress management and Psychological Pain and Distress Management: Distraction would be coded ‘yes’ as present, and all others as ‘no’ (not present).

<table>
<thead>
<tr>
<th>Code</th>
<th>General Category</th>
<th>Specific Type of Strategy</th>
<th>Definition</th>
<th>Examples</th>
</tr>
</thead>
</table>
| 1    | Pharmacological Pain and Distress Management | Pharmacological | Suggestion of using a form of medication (over the counter or prescribed) to help manage pain the child may be experiencing. Also include suggestions of investigating whether pharmacological pain management protocols exist for the child. | ● Give tylenol  
● See if medication can be given  
● See if there is a PRN medication  
● Use an ointment |
| 2    | Physical Pain and Distress Management | Physical | Suggestion of using a pain management strategy that involves physical touch or application of something (non-pharmacological). | ● Physical comfort  
● Hugging  
● Use soothing touch (e.g., depending on child’s comfort with touch) |
| 3 | Psychological Pain and Distress Management | Distraction | Suggestion of using a pain management strategy that is psychological in nature, defined as a strategy that might target the child’s mind/cognitions about the event, emotional response etc. This could involve strategies using language, physical presence (but not physical touch), distraction, etc. This might include the use of objects (e.g., therapeutic toy as a distraction). If reference is made to physical contact the strategy would NOT fall under this category. | Distraction  
- Provide the child with something they like to calm them down  
- Redirection |
| 4 | Progressive Muscle Relaxation | Progressive muscle relaxation; systematic tensing and relaxing of muscles to target pain/distress. | Progressive muscle relaxation  
- Tensing and relaxing muscles |
| 5 | Storytelling and/or Imagery | Suggestion of using imagery or storytelling (NOT reading a book) to target pain/distress. May describe this as a detailed story using all of the senses or have other related ways to describe this. | Telling them a detailed story  
- Using imagery  
- Visualization |
| 6 | Deep Breathing | Suggestion of using breathing to target pain/distress. May or may not refer to this as deep breathing | Deep breathing  
- Belly breathing |
or a specific type of breathing. May just comment ‘breathing’.

<table>
<thead>
<tr>
<th>7</th>
<th>Other</th>
<th>Suggestion of using another psychological pain and distress management strategy that does not fall into any of the four sub-categories above.</th>
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<tbody>
<tr>
<td>8</td>
<td>Modification of Other Factors</td>
<td>Explicitly states active physical modification of the setting or situation in order to address the issue (may not be explicitly related to pain management)</td>
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<tr>
<td>9</td>
<td>Other</td>
<td>Suggestion of use of a specific management strategy is clear, however the type of strategy used is unclear. For example, cannot decipher whether strategy would involve physical or psychological strategies or the strategy appears to involve more general behaviour management rather than what might help decrease the pain intensity.</td>
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<thead>
<tr>
<th>10</th>
<th>Assessment Strategy</th>
<th>Response refers to a strategy that is considered to be an assessment strategy rather than a management strategy.</th>
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</table>
|    |                     | • Make a plan of action together  
• Provide comfort  
• Provide a reward  
• Get medical attention  
• Give food/water |   |
|    |                     | • Ask them if they are in pain  
• Locate source of pain |   |
| 11 | Information from Other Source | Response refers to asking someone else for input (e.g., parents, other staff, medical professionals) or seeking input from information about the child on file. |   |
|    |                     | • Call the parents  
• Call 911  
• Take them to a clinic  
• Review child’s all about me form |   |
| 12 | Completing documentation | Response refers to documentation of the incident for other staff, parents, and/or organizational policies. |   |
|    |                     | • Complete incident report  
• Document  
• Make notes for other staff |   |
<p>| 13 | Unclear/Unrelated | Response is either unclear as to the meaning or unrelated to strategies one uses when managing pain. Cannot effectively code into another given category without adding additional interpretation of the response. |   |
|    |                     | • Help them |   |</p>
<table>
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<tr>
<th>999</th>
<th>No response</th>
<th>Missing Field</th>
<th>This code indicates that a participant left this field blank in the survey.</th>
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</thead>
</table>
**Coding Scheme for Pain-Related Follow-Up Question**

**QUESTION:** Please briefly describe any additional follow-up action that you would need to take if you were the respite worker in this scenario.

**DIRECTIONS:**

- Code for the presence/absence of EACH strategy. There is an individual code for each strategy listed below, and you select Yes or No depending on whether the participant has endorsed each one.
- Code responses explicitly only
- For example, if a participant states: “ask how they are feeling, complete incident report, tell other staff members”, then Child-Focused: Reassess, Reporting-Documentation and Reporting-Inform Caregiver/Others of the Event would be coded ‘yes’ as present, and all others as ‘no’ (not present)

<table>
<thead>
<tr>
<th>Code</th>
<th>General Category</th>
<th>Type of Action</th>
<th>Definition</th>
<th>Examples</th>
</tr>
</thead>
</table>
| 1    | Child-Focused   | Re-assess/Continued Assessment and Monitoring | Suggest assessment, re-assessment or continued monitoring of pain or injuries and/or effectiveness of management approaches provided. | ● Monitor child  
• Check if behaviour is back to normal  
• Ask how they are feeling  
• See if there is a change in behaviour after administering PRN  
| 2    | Continued management of pain and distress | Suggest continued pain management using any of the 4 P’s (pharmacological, psychological, physical, process/environment), or | ● Continue to distract  
• Provide ice as needed  
• Manage pain appropriately |
<table>
<thead>
<tr>
<th>Step</th>
<th>Category</th>
<th>Information from Other Source</th>
<th>General Mention of Continued Pain Management</th>
<th>Actions</th>
</tr>
</thead>
</table>
| 3    | Information from Other Source         | Information from Other Source| Explicitly suggests seeking supports or care based suggestions from external care providers (e.g., hospital, clinic, parents) and/or previous documentation. | - Call 911  
- Take them to the clinic  
- Talk to the physician  
- Find out if parents have had similar difficulties before and what usually works  
- Check medical information/charts |
| 4    | Reporting                             | Documentation                | Suggest the need to document the occurrence through logs, incident reports, etc. | - Complete an incident report  
- Document in file  
- Document |
| 5    | Inform Caregiver/Others of the Event  | Inform Caregiver/Others of the Event | Suggest the need to inform another caregiver of the child or staff member within the organization about what has occurred. | - Inform guardians after  
- Call the parents  
- Communicate with other staff members |
| 6    | Future Planning                       | Future Planning              | Suggest the need to reflect on or think about a plan should the event occur in the future; may also suggest the need to try something specific in the future. Any future-oriented responses should fall into this category. | - Come up with a plan in case this happens again  
- Reflect on what happened  
- Create a protocol |
|   | Other | Follow-Up Unclear/Unspecified | Acknowledgement of the need to follow-up/continue with care without explicit identification of what kind of follow up would be used. | Continue with care depending on what was found  
• Take further action after knowing what the problem is  
• Follow-up |
|---|---|---|---|---|
| 7 | Unclear/Unrelated | Response is either unclear as to the meaning or unrelated to follow up actions. Cannot effectively code into another given category without adding additional interpretation of the response, OR may refer to a strategy that is not considered relevant to follow up. | Don’t know  
• It depends |
| 8 | Missing Field | This code indicates that a participant left this field blank in the survey. | N/A |
Appendix O: Additional Information about Chi-Square Analyses Conducted in Chapter Five

Of note, quantitative analyses for this study (Chapter Four) were conducted using both intent-to-treat and per protocol approaches. Despite the difficulties encountered with response rate at follow-up, chi-square analyses investigating participant’s self-reported strategies at work and in a vignette scenario in Chapter Five were conducted once with all participants regardless of whether they completed follow-up (intent-to-treat), and a second time with only participants who completed both the pre-training and follow-up time points (per protocol). This allowed results to be viewed from both analytic protocol perspectives. As with results from quantitative analyses in Chapter Four, the pattern of results between these groups were compared and found to be virtually identical. Based on these analogous results, analyses which included all participants regardless of whether they completed follow-up are reported in Chapter Five (intent-to-treat).