

## Corrigendum

### Corrigendum to ‘Caring for children with intellectual disabilities part 1: Experience with the population, pain-related beliefs, and care decisions’ [Research in Developmental Disabilities 62 (2017) 197– 208]

Lara M. Genik<sup>a</sup>, C. Meghan McMurtry<sup>a,b,c,d</sup>, Lynn M. Breau<sup>e</sup>

<sup>a</sup> Department of Psychology, University of Guelph, Canada; <sup>b</sup> McMaster Children’s Hospital, Canada; <sup>c</sup> Children’s Health Research Institute, Canada; <sup>d</sup> Department of Pediatrics, Western University, Canada; <sup>e</sup> Glenrose Rehabilitation Hospital, Canada

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Corresponding author: Lara M. Genik  
lgenik@uoguelph.ca

Caring for Children with Intellectual Disabilities Part 1: Experience with the Population, Pain-Related Beliefs, and Care Decisions

Lara M. Genik, C. Meghan McMurtry, and Lynn M. Breau

University of Guelph

Author Note

Lara M. Genik, Department of Psychology, University of Guelph; C. Meghan McMurtry, Department of Psychology, University of Guelph, Clinical Psychologist, Pediatric Chronic Pain Program, McMaster Children's Hospital, Associate Scientist, Children's Health Research Institute, Adjunct Researcher, Department of Pediatrics, Western University; Lynn M. Breau, Glenrose Rehabilitation Hospital, Edmonton, Alberta

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Correspondence concerning this article should be addressed to Lara Genik, Department of Psychology, University of Guelph, Guelph, ON N1G 2W1. Email: [lgenik@uoguelph.ca](mailto:lgenik@uoguelph.ca)

## Abstract

**Some** children with intellectual disabilities (ID): experience pain more frequently than children without ID, express their pain differently, and are incapable of providing self-reports. No research has examined disability and pain-related beliefs of respite workers (RW) and their relations to pain assessment and management decisions for children with ID. **Objectives:** (1) compare disability and pain-related beliefs between RW and a sample with little experience in ID; (2) determine whether individuals' beliefs and personal characteristics are related to pain assessment and management decisions. **Participants:** Fifty-six RW (aged: 18 – 67 years,  $M_{\text{age}} = 33.37$ , 46 female) and 141 emerging adults (aged: 18 – 31 years,  $M_{\text{age}} = 19.67$ , 137 female). **Procedure/Measures:** In an online survey, participants responded to six vignettes depicting pain in children with ID, and completed measures of pain and disability-related beliefs. **Results/Discussion:** Compared to those without experience, RW held more positive disability-related beliefs,  $t(192) = 4.23$ ,  $p < .001$ . Participants' pain-related beliefs (e.g., sensitivity to pain) differed depending on severity of the child's ID and participant group. Participants' pain-related beliefs predicted care decisions. Results provide initial insight into RW pain-related beliefs about children with ID, and a basic understanding of the relations among pain beliefs, personal characteristics and pain-related decisions.

*Keywords:* children, intellectual disability, respite, pain assessment, pain management

### What This Paper Adds?

Pain is prevalent throughout childhood. Children with intellectual disabilities (ID) are particularly at risk because they may: experience pain more frequently than children without ID, express their pain differently, and be incapable of providing pain self-reports. Further, unmanaged pain can impact these children's quality of life (e.g., through decreased ability to use adaptive functioning skills). Despite many of these children receiving respite care, no research has examined disability and pain-related beliefs of respite workers (RW) and their caregiving implications. This novel research is the first to provide insight into RW disability and pain-related beliefs, compare these beliefs to an inexperienced emerging adult population, and investigate the role these factors may play in RW pain-related decision making.

Compared to emerging adults, respite workers held more positive disability-related beliefs; however, respite workers also endorsed inaccurate beliefs including the notion that a larger percentage of children with more severe ID are less sensitive to pain and have a higher emotional reaction to pain. As children's ID severity increased, both participant groups believed that a higher percentage of these children were less able to sense pain, had higher emotional and behavioral reactions to pain, had a decreased ability to communicate their pain, and experienced less pain overall (i.e., prevalence of pain). Some pain-related beliefs predicted participants' care decisions.

Future research directions include the development of educational programming for respite workers to provide them with accurate pain assessment and management-related information and strategies that they can use when supporting children with ID.

## 1. Introduction

For **many** children with intellectual disabilities (ID)<sup>1</sup>, painful experiences **are** more common than in ‘typically developing’ children due to factors such as an increased prevalence of health problems, injuries, and need for medical procedures (Breau & Burkitt, 2009; Dubois, Capdevila, Bringuier & Pry, 2010). Effective pain assessment and management for children with ID is important, not only because relief from pain is a human right, but also because it negatively impacts other areas of their lives such as adaptive functioning (e.g., motor skills, daily living, communication; Breau, Camfield, McGrath, & Finley, 2007; Brennan, Carr, & Cousins, 2007).

Many children with ID cannot provide accurate self-reports of their pain (Stallard, Williams, Lenton, & Velleman, 2001; Dubois et al., 2010). Thus, their pain is commonly assessed and managed by caregivers. Craig’s (2009) Social Communication Model of Pain suggests that there are numerous interpersonal (e.g., situational context, type of relationship between individuals) and intrapersonal (e.g., personal history, level of knowledge) factors which interact and contribute to an individual’s pain experience and expression as well as observers’ assessments of an individual’s pain/decisions of whether to intervene. Differences in how individuals communicate their pain impact responses from others. For example, caregivers may have preconceived ideas about how children should respond to painful experiences; behaviors deviating from this may not be recognized as potential pain indicators, and thus adequate care may not be provided.

To some degree, research has investigated the abilities of professionals and primary caregivers to effectively assess and manage pain in children with ID. **For example, parents**

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<sup>1</sup> For the purpose of this study, children with intellectual disabilities are those children who receive a diagnosis prior to turning 18 years of age and express both lower levels of overall intellectual functioning and limitations in adaptive behavior (e.g., social skills; AAMR, 2002).

generally provide accurate estimates of their children's pain when using structured pain assessment tools (Voepel-Lewis, Malviya, & Tait, 2005), and their reports may be useful to assist professionals in assessment. Further, professionals have expressed difficulty in assessing pain even when one knows a child well (Oberlander & O'donnell, 2001), and research suggests that secondary caregivers with more experience may be better at detecting pain (Shinde & Symons, 2007). The manner in which caregivers' beliefs<sup>2</sup> and attitudes may impact the decisions they make has also been investigated. Breau, Camfield, MacLaren, McGrath, and Finley (2003) found that primary caregivers believed children's pain sensation increased as a function of severity of a child's ID. In their discussion, Breau et al. (2003) suggested that beliefs held by caregivers could impact the level and type of care provided to these children when experiencing pain.

The majority of research regarding pain assessment and management of children with ID has focused on pain in medical settings (Messmer, Nader, & Craig, 2008; Voepel-Lewis et al., 2005; Malviya et al., 2001). Research investigating everyday pain in children with ID is also critical, as this type of pain is highly prevalent, potentially even more common than in typically developing children (Breau et al., 2003; Stallard et al., 2001). When focusing on pain in everyday settings, a critical issue is that children with ID often receive care from non-primary caregivers in order to alleviate some of the stress placed on the family (Shelton & Witt, 2011). Indeed, respite care provides an opportunity for primary caregivers of children with disabilities (including ID) to take a break from the demands of raising a child with special needs (Shelton &

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<sup>2</sup> Note that in other pain-related publications to date, beliefs and attitudes have been regarded as two separate entities without indicating the difference between these terms (e.g., Breau et al., 2003). Throughout the remainder of this paper beliefs and attitudes will be referred to collectively as "beliefs".

Witt, 2011), and is a service that continues to grow for families in need (Chan & Sigafos, 2000). Though previous pain assessment research has focused on both professionals and primary caregivers (e.g., Breau et al., 2003; Voepel-Lewis et al, 2005), no research has examined the beliefs of respite care providers. When children receive support from respite workers, primary caregivers may not be available to assist in identifying when their child is in pain and to what degree. Further, respite workers may hold different beliefs than healthcare providers, close family members, or individuals who do not have experience with children with ID. It is important that research focuses on disability and pain-related beliefs of these respite workers, and how these may impact their assessment and care decisions. Exploring the differences between beliefs of respite workers and others (e.g., those without experience with children with ID), can help us to understand whether beliefs may emerge as a result of direct experience.

## **1.1 Objectives**

**1.1.1 Objective One.** To compare disability and pain-related beliefs between respite workers with direct experience caring for children with ID, and emerging adults with little to no experience with these children. Similar to previous research comparing professionals and students' beliefs towards those with ID (Au & Man, 2006; Slevin & Sines, 1996), it was expected that respite workers would have more positive disability-related beliefs than the emerging adults (hypothesis 1a).

Further, given that previous research has demonstrated parents and healthcare providers have a-priori pain-related beliefs (e.g., Breau et al., 2003), we hypothesized that there would be differences between participant groups and across levels of ID severity in terms of participants' beliefs about children with ID's sensitivity to pain, level of emotional and behavioral reaction, ability to communicate pain, and amount of pain experienced (hypothesis 1b).

**1.1.2 Objective Two.** To determine whether these beliefs or demographic characteristics (e.g., level of education, frequency of interaction with children with ID who are non-verbal) are related to participants' pain assessment and management decisions measured via six situational vignettes. Specifically, it was hypothesized that participants' pain assessment and care decisions would be related to, and could be predicted by, their pain and disability-related beliefs as well as their demographic characteristics. Given that previous research in this area has not investigated these relationships, the research is exploratory and the direction of these relationships was not hypothesized.

## 2. Methods

The data for this article were collected during a larger scale study comprised of two distinct components. The first component is represented in the present article, and examines broad-based disability and pain-related beliefs and care decisions of respite workers in comparison to a sample of emerging adults with limited to no exposure to children with ID. The second component is presented in part two of this publication (submitted concurrently), and describes detailed **qualitative** analyses regarding respite workers' pain assessment and management decisions. There is no data overlap. Ethics approval was obtained from a University's research ethics board.

### 2.1 Participants

Participants consisted of a sample of: 1) respite workers actively providing respite care for children in any setting (e.g., family home, community, group homes), and 2) emerging adults enrolled in an undergraduate University program. All participants were over the age of 18 years, and proficient in the English language.

**2.1.1 Respite Workers.** To recruit respite workers, 77 organizations that provide respite care for children across Ontario were asked by the lead researcher to assist with participant recruitment by circulating study information (and online survey link) via email or flyers to eligible respite workers within their organization. Twenty-seven organizations did not respond or lost contact during the recruitment process. Nineteen organizations indicated that they were unable to assist with recruitment (e.g., did not have time; study not a good match for their services). Thirty-one organizations agreed to assist with participant recruitment, together circulating study information to approximately 965 eligible individuals (50 participants responded; ~5% response rate). Six additional participants were recruited online from an undergraduate University participant pool (described below). A total of 56 respite workers (82.1% female; age range: 18 – 67;  $M_{\text{age}} = 33.37^3$ ) participated in the study. On average, respite workers had been working with children with ID for 4.63 years (range: 0.17 – 30,  $SD = 5.41$ ). For additional information see Table 1.

**2.1.2 Emerging Adults.** A total of 141 emerging adults (97.2% female; age range: 18 – 31;  $M_{\text{age}} = 19.67$ ) recruited from an undergraduate participant pool at a mid-sized University ( $n = 25000$ ) participated. This sample served as a comparison group for the respite workers. For additional information see Table 1.

## 2.2 Study Procedure

All study procedures were conducted online. After reviewing the information about the study and providing informed consent, participants were linked to a voluntary and confidential survey. Participants were asked questions regarding: (1) demographics, (2) six pain vignettes

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<sup>3</sup> An independent samples t-test revealed that the respite worker sample was significantly older than the emerging adult sample,  $t(191) = 11.63, p < .001$ .

(Genik et al., 2015), (3) their pain beliefs (Pain Opinion Questionnaire; Breau et al., 2003) and (4) their general beliefs about individuals with ID (Mental Retardation Attitudes Inventory - Revised; Antonak & Harth, 1994). After completion of the four survey components, all participants could download an informational fact sheet on the study and pain in children with ID who are nonverbal (ID/NV). Participating undergraduate students received compensation in the form of course credit, and respite workers had an opportunity to enter a gift card draw.

## 2.3 Measures

**2.3.1 Demographic Information.** In addition to general demographics (e.g., sex, age), the following demographic questions were used within analyses: level of education, frequency of interaction with children with ID/NV (0 = never, 5 = very often), level of involvement with children with ID/NV (0 = not at all involved, 10 = highly involved), level of involvement with adults with ID (0 = not at all involved, 10 = highly involved), and pain training (yes or no).

**2.3.2 Pain Vignettes: Intensity, Need for Medical and Other Attention.** Participants were asked to read and respond to six situational vignettes (Genik et al., 2015). Each vignette was approximately 80 words in length, and showcased a ten year old child (gender neutral name, sex unspecified) with ID who was either verbal or non-verbal (counterbalanced across participants). Each vignette depicted a different pain-related scenario: unknown source, headache, flu shot, falling down, arthritis, insulin injection.

After reviewing each scenario, participants were first asked to rate the level of pain they believed the child felt from 0 (no pain) to 10 (very high pain intensity). Numeric rating scales have been used to measure children's pain intensity via proxy report (von Baeyer, 2009), and specific forms of these (e.g., individualized numerical rating scale; Solodiuk et al., 2010) have been found to have preliminary evidence for reliability and validity when assessing pain in

children who are nonverbal and have severe ID. Ratings of need for medical and other forms of attention were also measured on a scale from 0 to 10 (0 = no attention necessary, 10 = emergency medical/significant attention necessary) to represent care/management decisions. The initial development and testing of these vignettes with emerging adults suggested these vignettes have face, convergent and divergent validity (Genik et al., 2015).

**2.3.3 Pain Opinion Questionnaire.** Participants also completed the Pain Opinion Questionnaire (POQ); a measure designed to assess the beliefs held by individuals about pain experience and expression in children with ID in comparison to children who do not have ID (Breau et al., 2003). The POQ asks participants to respond to five questions across three levels of ID severity (mild, moderate, severe/profound), with a brief description of functioning provided for each level of ID (Breau et al., 2003). Participants are then asked to estimate what percentage of children with ID would experience each of five pain facets (i.e., sensation, emotional reaction, behavioral reaction, communication and frequency) the same as, less than and more than children without ID (Breau et al., 2003). For example, participants are asked what percentage of children with severe/profound ID they believe experience less pain than children without ID. A psychometric analysis of the POQ found excellent reliability using Streiner and Norman's (1995) formulae (Breau et al., 2003). Given that the percentages have to add up to 100, this scale creates dependency among the data; in order to conduct inferential analyses, only participants' responses for the "less than" question for sensation, communication and amount of pain, and the "more than" question for emotional and behavioral reaction across each level of ID severity were used. The particular questions/responses were chosen because researchers believed that these beliefs in particular could be the most problematic with respect to pain assessment and management.

**2.3.4 Mental Retardation Attitudes Inventory – Revised.** All participants also completed Antonak and Harth’s (1994) Mental Retardation Attitude Inventory – Revised (MRAI-R) which assesses individuals’ attitudes towards those who are mentally challenged. A total of 29 statements are rated on a four point Likert scale (strongly disagree to strongly agree). A total score for each participant was calculated by adding up the number of points given for each response (normally scored items e.g., “We should integrate people who are mentally challenged and who are not mentally challenged in the same neighbourhood.”: strongly disagree = 1 to strongly agree = 4; reverse scored items e.g., “School officials should not place children who are mentally challenged and not mentally challenged in the same classes.”: strongly disagree = 4 to strongly agree = 1; Antonak & Harth, 1994). Scores could range from 50 to 116, with higher scores indicating more positive views (Antonak & Harth, 1994). Adequate split-half reliability and initial support for the inventory’s construct validity have been demonstrated (Antonak & Harth, 1994). Consistent with the MRAI-R’s use by Breau et al. 2003, the terms “mental retardation” and “mentally retarded” were changed to “mental challenge” and “mentally challenged”.

### 3. Results

For the objectives below, a description of analyses used is noted at the beginning of each section.

#### 3.1 Objective 1: Comparison of Disability and Pain-Related Beliefs

**3.1.1 General disability-related beliefs.** As recommended in previous research, individual mean substitution was used to fill missing data for participants missing less than 10% of data (i.e., missing  $\leq 2$  responses) on the MRAI-R scale (Roth, Switzer & Switzer, 1999; Shrive, Stuart, Quan & Ghali, 2006). An independent samples t-test showed that respite workers

held significantly more positive disability-related beliefs ( $M_{MRAI-R\ Score} = 99.22, SD = 11.15, n = 56$ ) than emerging adults with little to no experience working with children with ID/NV ( $M_{MRAI-R\ Score} = 92.09, SD = 10.43, n = 138$ ),  $t(192) = 4.23, p < .001, r = 0.29^4$ , a small effect size (Cohen, 1992).

**3.1.2 Pain – Related beliefs.** A series of mixed 2 (participant group: emerging adult or respite worker) x 3 (ID severity: mild, moderate, severe) ANOVAs were used to compare the percentage of children with ID that respondents reported as being “less” sensitive to pain (i.e., ability to feel pain), having “higher” emotional and behavioral reaction to pain, having “less” ability to communicate pain to others, and experiencing “less” pain (i.e., prevalence of pain) compared to children without ID. Given the structure of the measure, participants with any missing data from this measure were excluded on an analysis by analysis basis. If Mauchly’s test results were violated, Greenhouse-Geisser estimates were used as a correction, unless they were greater than .75, in which case Huynh-Feldt estimates were used (Field, 2013). Unless noted, Levene’s assumption was met. When post-hoc t-tests were conducted, a Bonferroni correction was used based on our desired alpha .05 divided by the number of t-tests in each section ( $n = 3$ ) to correct for type 1 error. Thus, the critical p value for these post-hocs was 0.017.

“Sense Less Pain” A main effect of participant group was found,  $F(1, 184) = 4.63, p = .033$ , such that respite workers ( $M = 19.81, SE = 2.19$ ) believed that a significantly higher percentage of children with ID were less sensitive to pain compared to the emerging adult sample ( $M = 14.33, SE = 1.29$ ). A main effect of ID severity on participants’ reports of the percentage of children with ID believed to sense “less” pain than typically developing children was also found,  $F(1.54, 283.65) = 5.32, p = .010$  (mild ID:  $M = 14.22, SD = 16.83$ ; moderate ID:

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<sup>4</sup> The effect size for t-tests was calculated as suggested by Field (2013) using  $\sqrt{t^2/t^2+df}$ .

$M = 15.47$ ,  $SD = 18.00$ ; severe ID:  $M = 17.56$ ,  $SD = 21.36$ ). However, post-hoc t-tests using the Bonferroni correction did not reveal any significant comparisons. There was no significant interaction effect,  $F(1.54, 283.65) = 2.70$ ,  $p = .083$ . See graph (a) in Figure 1.

“Higher Emotional Reaction” A main effect of participant group was found,  $F(1, 182) = 5.00$ ,  $p = .027$ . Across severity of ID, respite workers ( $M = 36.55$ ,  $SE = 2.96$ ) believed that a significantly smaller percentage of children with ID had higher emotional reactions compared to the emerging adults sample ( $M = 44.25$ ,  $SE = 1.76$ ). A main effect of ID severity on participants’ reports of the percentage of children with ID believed to display “higher” emotional reaction to pain than typically developing children was also found,  $F(1.88, 341.94) = 27.01$ ,  $p < .001$  (mild ID:  $M = 34.30$ ,  $SD = 24.89$ ; moderate ID:  $M = 39.90$ ,  $SD = 23.97$ ; severe ID:  $M = 52.54$ ,  $SD = 28.75$ ). Post-hoc t-tests revealed that there were significant differences between the means for mild ID and moderate ID ratings,  $t(186) = -3.18$ ,  $p = .002$ , mild ID and severe ID ratings,  $t(184) = -8.15$ ,  $p < .001$ , and moderate ID and severe ID ratings,  $t(185) = -6.81$ ,  $p < .001$ . In each of these cases, more severe ID levels resulted in participants believing that a higher percentage of children with ID would have higher emotional reactions. There was no significant interaction between participant group and ID severity,  $F(1.88, 341.94) = 1.77$ ,  $p = .174$ . See graph (b) in Figure 1.

“Higher Behavioral Reaction” There was no main effect of participant group,  $F(1, 183) = 1.80$ ,  $p = .181$ . A main effect of ID severity on participants’ reports of the percentage of children with ID believed to display “higher” behavioral reaction to pain than typically developing children was found,  $F(1.67, 305.93) = 41.42$ ,  $p < .001$  (mild ID:  $M = 34.64$ ,  $SD = 24.85$ ; moderate ID:  $M = 44.83$ ,  $SD = 26.37$ ; severe ID:  $M = 53.85$ ,  $SD = 29.62$ ). Post-hoc t-tests revealed that there were significant differences between the means for mild ID and moderate ID

ratings,  $t(188) = -4.95, p < .001$ , mild ID and severe ID ratings,  $t(184) = -8.67, p < .001$ , and moderate ID and severe ID ratings,  $t(185) = -6.26, p < .001$ . In each of these cases, more severe ID levels resulted in participants believing that a higher percentage of children with ID would have higher behavioral reactions. There was no significant interaction,  $F(1.67, 305.93) = 1.69, p = .192$ . See graph (c) in Figure 1.

“Less Able to Communicate” There was no main effect of participant group,  $F(1, 182) = 1.57, p = .212$ . A main effect of ID severity on participants’ reports of the percentage of children with ID believed to have “less” ability to communicate their pain than typically developing children was found,  $F(1.89, 344.34) = 28.49, p < .001$  (mild ID:  $M = 39.22, SD = 27.62$ ; moderate ID:  $M = 47.81, SD = 27.22$ ; severe ID:  $M = 59.75, SD = 30.75$ ). Post-hoc t-tests revealed that there were significant differences between the means for mild ID and moderate ID ratings,  $t(186) = -4.23, p < .001$ , mild ID and severe ID ratings,  $t(184) = -7.98, p < .001$ , and moderate ID and severe ID ratings,  $t(184) = -5.57, p < .001$ . In each of these cases, more severe ID levels resulted in participants believing that a higher percentage of children with ID would have less ability to communicate their pain. There was no significant interaction  $F(1.89, 344.34) = .718, p = .481$ . See graph (d) in Figure 1.

“Experience Less Pain” There was no main effect of participant group,  $F(1, 182) = 0.09, p = .770$ . A main effect of ID severity on participants’ reports of the percentage of children with ID believed to experience “less” pain than typically developing children was found,  $F(1.94, 353.72) = 4.88, p = .009$  (mild ID:  $M = 9.70, SD = 13.41$ ; moderate ID:  $M = 12.86, SD = 16.30$ ; severe ID:  $M = 13.42, SD = 17.08$ ). Post-hoc t-tests revealed that there were significant differences between the means for mild ID and moderate ID ratings,  $t(187) = -2.54, p = .012$ , and mild ID and severe ID ratings,  $t(184) = -2.88, p = .004$  only. In both of these cases, more severe

ID levels resulted in participants believing that a higher percentage of children with ID would experience less pain. There was no significant interaction,  $F(1.94, 353.72) = .18, p = .831$ . See graph (e) in Figure 1.

### **3.1.3 Participant ratings of pain intensity, need for medical attention, and need for other attention.**

Independent samples t-tests ( $n = 18$ ) with a Bonferroni correction were used to compare ratings from respite workers and ratings from emerging adults leading to a critical p value of 0.002. Only one significant difference was found for need for medical attention in the arthritis vignette: respite workers felt that the child in the vignette's need for medical attention was less urgent than the emerging adults did [as Levene's test of equal variance was violated,  $F(194) = 1.22, p < .05$ , equal variances were not assumed,  $t(135.34) = -4.48, p < .001$ ]. See table 2 for descriptives of participants' ratings of pain intensity, need for medical attention and need for other attention for each of the six vignettes.

## **3.2 Objective 2: Beliefs, Participant Characteristics, Pain Assessment and Care Decisions**

Correlations were used to assess whether, across participant groups (given results explored in 3.1.3), participants' pain assessment and care decisions were related to their pain and disability-related beliefs. All correlations were exploratory in nature and used to inform regression analyses with only correlations significant at  $p < .001$  included. Missing data were excluded from analyses on a case by case basis. First, an investigation of the correlations (Pearson's  $r$  for normally distributed data, Spearman's rho for non-normally distributed) between participant ratings for each *individual* vignette and pain and disability-related was conducted; very few significant correlations existed, effect sizes were small, and only one relation was significant at .001. Thus, the remainder of analyses in this manuscript focuses on responses

*collapsed across vignettes* (i.e., did not differentiate between verbal versus nonverbal manipulations or by pain source); part two of this work (Genik et al., submitted) explores respite workers' assessment and care decisions specific to verbal ability and each pain source in depth.

**3.2.1 Relation between participant demographic information and pain assessment and care decisions.** There were no significant correlations between participant ratings and demographic information (i.e., level of education, frequency of interaction with children with ID/NV, level of involvement with children with ID/NV, level of involvement with adults with ID, and pain training). All  $r$  values ranged from .00 to -.14.

**3.2.2 Relation between participant beliefs and pain assessment and care decisions.** The need for medical and other attention ratings were positively correlated with participants' pain intensity ratings ( $r = .51, p < .001$ , and  $r = .50, p < .001$  respectively; medium effects; Cohen, 1992), and need for medical and other forms of attention were also positively correlated with one another ( $r = .28, p < .001$ ; a small effect; Cohen, 1992). Participants' ratings for need for other attention did not significantly correlate with participants' disability or pain-related beliefs. All  $r_s$  values ranged from .01 to .15. There were no significant correlations between participants' pain or disability-related beliefs and their pain intensity ratings ( $r_s$  values ranged from -.00 to -.12).

Need for medical attention was negatively correlated with disability-related beliefs,  $r_s = -.22, p < .01$  (a small effect; Cohen, 1992). Need for medical attention ratings positively correlated (small effects; Cohen, 1992) with participants' beliefs about the percentage of children with mild ID who are less sensitive to pain,  $r = .27, p < .001$ , have higher emotional ( $r_s = .15, p < .05$ ) and behavioral ( $r_s = .21, p < .01$ ) reactions to pain, and have less pain than typically developing children ( $r = .30, p < .001$ ). These ratings also correlated positively (small effect;

Cohen, 1992) with their beliefs about the percentage of children with moderate ID who are less sensitive to pain than typically developing children,  $r_s = .16, p < .05$  and have less pain than typically developing children,  $r_s = .21, p < .01$ . All other  $r_s$  values ranged from .02 to -.14.

**3.2.3 Predicting individual participants' assessment and care decisions from beliefs and demographic information.** The variables selected for the hierarchical regressions were informed by significant correlations at  $p < .001$  indicated in sections 3.2.1 and 3.2.2. As there were no significant correlations between participants' pain intensity or need for other attention ratings and beliefs or demographic information, regressions were not conducted for these two sets of ratings. Therefore, one regression was conducted to determine whether ratings of perceived need for medical attention could be predicted by pain-related beliefs (specifically POQ ratings for mild ID as specified in section 3.2.1). Missing data were excluded from analyses. All assumptions for this regression were met.

Results from the regression indicated that after controlling for participant group in the first block and pain intensity and need for other attention in the second block, participants' pain-related beliefs (entered into the third block) significantly predicted their ratings for need for medical attention,  $F(5, 161) = 20.73, p < .001$ . While participant group and their rating of need for other attention remained significant individual contributors, the only other significant individual contributor was participants' beliefs about the percentage of children with mild ID who sense less pain than typically developing children which was a positive predictor of need for medical attention,  $t(161) = 2.52, p < .05$  (see Table 3).

#### 4. Discussion

Children with ID commonly experience everyday pain, and it can be difficult for them to provide accurate self-reports of their pain (Stallard et al., 2001; Dubois et al. 2010). This means

that caregivers, whose decisions may be influenced by numerous factors, are relied upon to make pain assessment and management decisions on behalf of children with ID (Breau et al., 2003).

No previous research has examined beliefs of respite workers in everyday settings, nor examined how these may impact care decisions when supporting children with ID.

#### **4.1 Disability and Pain-Related Beliefs**

The first objective of this study was to compare disability and pain-related beliefs of respite workers to those of emerging adults with little to no experience with children with ID. While both participant samples held relatively positive disability-related views (i.e., mean scores for both samples were above 90 on a scale ranging from 29 to 116), respite workers had significantly more positive disability-related beliefs compared to a sample of inexperienced emerging adults. These results are consistent with other research suggesting that professionals hold more positive beliefs towards those with disabilities in comparison to students (Au & Man, 2006), and that nurses who had higher level graduate degrees and had more contact with individuals with learning disabilities<sup>5</sup> held more positive beliefs than registered nurses without higher level graduate experience (Slevin & Sines, 1996). It is unclear, however whether it is more experience that leads to more positive beliefs, or whether people with more positive beliefs may pursue these types of occupations in the first place. Regardless, holding positive beliefs about individuals could contribute to better care overall or attentiveness to their needs.

Similar to parents in Breau et al.'s (2003) study, these results demonstrate that participants held a-priori pain-related beliefs (e.g., aspects of pain experience and expression) about children with ID that varied with severity of ID. Overall, participants in both groups believed that as level of ID severity increased, a larger percentage of children with ID

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<sup>5</sup> In Slevin and Sines (1996), 'learning disabilities' is the term used to describe people with ID.

experienced less pain and were less able to sense pain than children without ID. Further, across ID severity levels, respite workers felt that a higher percentage of children with ID were less sensitive to pain in comparison to the sample of emerging adults. While these beliefs may be linked to respite workers' personal experiences, some are in contrast to other research findings related to **beliefs about pain** and pain in children with ID. **For example, in Breau et al. (2003), parents believed that as severity of children's ID increased, their ability to sense pain relative to those without ID also increased. Perhaps these differences in beliefs reflect differences in roles and experiences with the children for whom they care.** Further, despite past beliefs that children with ID do not experience or are less sensitive to pain, even everyday pain among these children is quite common (Stallard et al., 2001). Another study conducted by Breau et al. (2003) also found that children with intellectual disabilities experience both accidental and non-accidental pain frequently (in some cases, weekly), with children who have the fewest abilities experiencing the most pain. These beliefs and inadequate knowledge about pain assessment and management could limit the level of care that respite workers are able to provide to the children they support.

Results also suggested that as severity of ID increased, participants believed that a larger percentage of children would show higher behavioral and emotional reactions to pain. This could be helpful, as it suggests that participants may be looking for nonverbal pain-related communication. While these beliefs may be accurate for some children, however, research about pain expression among children with ID suggests that these children often have individualized ways of communicating their pain (Breau, Camfield, McGrath, Rosmus, & Finley, 2001). Pain expression may also vary according to a child's verbal ability (Dubois et al, 2010). This means that these children may not necessarily have heightened responses to painful experiences. It is important that caregivers are aware of this. Combined with our other findings that caregivers

believe children with ID are less sensitive but more likely to react to pain, this could increase the vulnerability of these children for under-management of their pain, particularly those who do not have an obvious or typical behavioral or emotional response to pain.

Finally, as severity of ID increased, participants believed that a larger percentage of children with ID were less able to communicate their pain to others. Previous research has also documented the poor communication skills of these children, highlighting struggles with verbalizing and describing their pain to others (Dubois et al., 2010). This finding suggests that these children may not be able to communicate their pain, when really, it may just be that they communicate it differently. This perceived reduction in pain communication as a function of ID severity contrasts with the beliefs described above regarding increased emotional and behavioral reaction to pain. It is possible that these reactions are not viewed as forms of pain expression/communication. Awareness of the challenges and unique cues used by children with ID to communicate may heighten awareness of caregivers' need to watch for other nonverbal communication when assessing pain among these children.

Following a Bonferroni correction, results revealed only one significant difference between respite worker and emerging adult ratings in the context of pain source and verbal ability, such that respite workers believed that the child's need for medical attention was less urgent in comparison to emerging adults in the context of arthritis. In this case, it is possible that respite workers held a better understanding of what a child with a chronic pain condition might need, as not every arthritic flare up would require immediate medical attention.

#### **4.2 Relations between and impact of participant beliefs and demographic information on pain assessment and care decisions**

Participants' ratings of the need for medical and other forms of attention were moderately related to their pain intensity ratings across vignettes, suggesting that pain assessment could play an important role in guiding care. This link is important as researchers may be able to target pain assessment abilities and strategies to determine appropriate pain management strategies in a training program. This could lead to improved care for children with ID. These relations also support the use of vignettes in research with caregivers.

The second objective was to determine whether specific demographics (level of education, frequency of interaction and level of involvement with individuals with ID/NV, and pain training), disability or pain beliefs were related to participants' pain assessment and management decisions. In general, correlational analyses demonstrated only weak relations between the demographic variables, pain and disability-related beliefs and participants' pain assessment and management decisions. This is encouraging, as pain-related decision making should be based on much more than participants' demographic information and beliefs. In contrast, the correlations between participants' pain assessment and management decisions ranged from weak to moderate; as pain assessment should guide pain intervention, these stronger relations are more encouraging. A few weak but surprising positive relations were found between need for medical attention and the belief that children with ID are less sensitive to pain, have higher emotional and behavioral reactions to pain, and experience pain less frequently compared to 'typically developing' children. When interpreting these relations, individuals may decide to seek medical attention to ensure that any potentially painful event is appropriately handled, particularly if they feel that the child is less likely to experience or sense pain. In a similar vein, participants may believe that increased deviation from 'typical' behavior (i.e., higher emotional or behavioral responses) may warrant medical attention as a precaution. Demographic

information was not related to participant ratings. Education level may not have been related as this would not necessarily impact knowledge related to children with ID or pain assessment and management, unless of course the individual was studying in a related field. Level of interaction and involvement with ID/NV was not significantly related to ratings, even though there was a difference between these variables in comparing respite workers and students. It is possible that other relational factors (e.g., how familiar the individual is with the child) impact these decisions.

It is important to further examine the link between positive beliefs and lower ratings for need for medical attention. Is this the case because participants viewed the scenarios as more mild in severity to begin with (i.e., only requiring attention but not medical care), or do these results actually relate to other factors such as disability-related beliefs? For pain-related beliefs, positive correlations were found only between participants' ratings of need for medical attention and some of the percentage ratings for the POQ. Participants' disability-related beliefs significantly (but weakly) predicted their ratings of need for medical attention in response to written vignettes. Thus, participants' disability-related beliefs could impact their pain management-related decision making processes for children with ID. These findings provide further support to intrapersonal factors highlighted in the Social Communication Model of Pain (Craig, 2009). For example, they demonstrate that relations do exist between intrapersonal factors (i.e., beliefs) and individuals' pain-related decisions but that specific contextual factors (e.g., level of pain intensity thought to be experienced) are also important.

It is interesting to consider that results from this study suggest that only certain intrapersonal beliefs (i.e., the percentage of children with mild and moderate ID reported to sense less pain, but not the percentage of children with severe ID reported to sense less pain) appear to be related to and predictive of certain aspects of care decisions. It seems important to further

explore this model in relation to pain in children with ID, as the factors which impact pain assessment and management in this population may differ from other children. These factors have the potential to interfere with the quality of care provided to children, and it is therefore important to further investigate these beliefs in the context of other factors contributing to decisions.

### **4.3 Strengths, Limitations and Future Directions**

A number of strengths, limitations and future directions should be noted. This was the first study to explore the pain-related beliefs of respite workers and compare them to individuals without experience with children with ID. In gaining more knowledge about beliefs and other characteristics of respite workers, potential educational and knowledge-related needs can be better understood. Despite **potential limitations in terms of external validity**, use of vignettes allowed for a high degree of internal validity, ensuring that participants were responding to identical situations. Without this, researchers would not have been able to compare decisions made by participants in the same way, as each situation would have differed. Due to the nature of the study, it could be easily replicated in the future to re-assess needs of respite workers, or to compare responses among different groups of individuals who care for children with ID. The sampling method used to recruit participants allowed the researchers to gain information from respite workers affiliated with respite organizations across the province. This could help minimize some forms of sampling bias. Additionally, in surveying two different populations of individuals - those with and without experience working with the target population - the study was also able to compare responses between groups. This is also the first study to gain a general understanding of the extent to which respite workers are exposed to formal education on pain assessment and management. At present, it appears that respite workers do not typically receive

this type of education, and the extent to which their training is related to children with ID in particular is unclear. In this study, only six participants had pain education. None of this training was specific to children with ID, and was typically acquired through other experiences outside of respite work (e.g., nursing programs).

It is important to note that there were fundamental differences between the samples including recruitment method (one through respite organizations, and the other through a University participant pool), sample size and mean age. Generational factors, such as beliefs about and acceptance of those with disabilities by society, and differing participant experiences may have also influenced some participant responses. Thus, the samples used may not generalize to the general population. The low recruitment response/completion rate for respite workers, which also impacts generalizability, may have resulted in part from the length of the online survey. With respect to study design, this study was cross-sectional and used correlational analyses. Thus, causation (e.g., between pain/disability beliefs and care decisions) cannot be implied. Another limitation of this study involved the MRAI-R, which was created in 1994. Since views towards those with disabilities have changed overtime along with society's attitudes (Drew & Hardman, 2007), some of the MRAI-R items may not adequately assess current disability-related beliefs. Thus, an updated scale measuring the same construct may reveal a different pattern of results. In the future, a more modern or updated scale to measure attitudes towards people who have disabilities could be developed, tested, and utilized. Future research should investigate whether the beliefs and responses of caregivers vary according to different characteristics of children (e.g., age, level of ID, sex). It may also be beneficial to further explore factors contributing to caregiver beliefs about the ability of children with varying levels of ID to

sense pain, such as personal experiences. Given the strength of the correlations and regressions, it is clear that there are other factors related to care decisions beyond those explored in this study.

### **Conclusions**

Results from this novel study outline (a) disability and pain-related beliefs held and (b) insight into the relations between beliefs, personal characteristics and pain-related decisions made by respite workers and those without experience supporting children with ID. While there were some positive findings and potential implications, some participant beliefs (e.g., pain sensation of children with ID) appear contrary to what is known about pain in children with ID in the literature. Further, results suggested that certain beliefs may predict care decisions. Educational initiatives related to pain in children with ID (i.e., general pain knowledge, pain assessment, pain management) could be beneficial for respite workers to improve pain-related knowledge and the quality care provided to the children they support. These children deserve nothing less.

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