

RESPITE CARE FOR CHILDREN WITH INTELLECTUAL DISABILITIES: PERCEPTIONS OF NEED FOR PAIN TRAINING AND PREFERENCES

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Introduction

Pain Among Children with Intellectual Disabilities

- Often inadequately managed (Chen-Lim et al., 2012)
- Assessment and management is difficult (Chen-Lim et al., 2012)
- Caregivers play an important role in assessment & management (Breau et al., 2003)

Respite Caregivers, Pain, and the Children They Support

- Commonly support children with intellectual disabilities (Chan & Sigafos, 2000)
- Pain training is uncommon (Genik et al., in prep.)
- Pain-related beliefs may be inconsistent with current research (Genik et al., in prep.)

Objective

- Gather information about *perceived pain assessment and management training needs* from both *front line and management staff* in organizations which provide *respite care services to children with intellectual disabilities* to *inform development of a pain training program for respite staff*

Participants

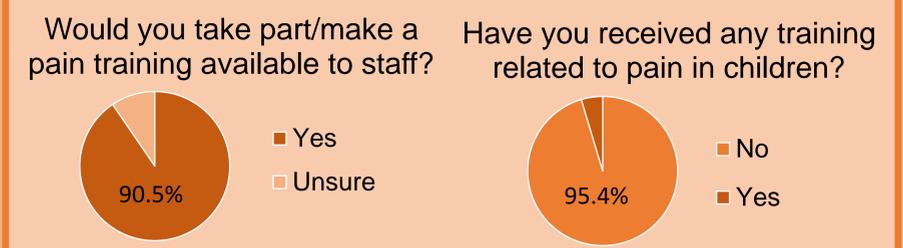
Table 1. Selected participant demographics; C/ID = children with intellectual disabilities

	Full Sample (N = 22)
Age (years)	• M = 37.10 • Range: 20 - 59
Sex	• 3 M; 19 F
Number of years employed with organization supporting C/ID	• M = 9.50 • Range: .58 - 30
Ethnicity	• European/White: 18 (85.7%) • Black/African/Caribbean: 3 (14.3%)
Frequency of Interaction with C/ID	• Occasionally: 1 (4.5%) • Often/ Very Often: 21 (95.5%)

Procedure

- Completed a 15-item questionnaire (part of a larger study)
 - Interest, applicability, importance of pain training (ratings)
 - Training format preferences (rank order and open ended)
 - Preferred topics to include (open ended responses)

Results



Interest, applicability, importance of pain training:

Table 2. PT = pain training; C/ID = children with intellectual disabilities; 10 = "Strongly Agree" (questions 1 – 5); "Extremely Important" (question 6)

Question	Range (0-10)	Mean Rating
1. A PT would be valuable...	• 5 – 10	• 9.18
2. Information provided at a PT would be applicable...	• 5 – 10	• 9.05
3. A PT would be interesting.	• 6 - 10	• 9.50
4. I would encourage other respite workers to take part in a PT.	• 5 - 10	• 9.50
5. I would be interested in learning more about pain in C/ID...	• 6 - 10	• 9.59
6. How important would you rate PT for respite workers?	• 4 - 10	• 8.82

Format Preference	Ideal Length	Ideal Group Size
#1 = In Person	5.20 hours	M: 14.60 Range: 8 - 38
#2 = Hybrid	4.57 hours	
#3 = Online	3.14 hours	

Importance of Handouts (0 – 10)?

- Mean: 8.14
- Range: 2-10

Provide Handouts?

- Yes = 100%

Handout Format?

- Hard Copy: 50%
- Email & Hard Copy: 31.8%

Most Important to Include in Pain Training:

- 78.8% = information was most important
- Assessment Info (30.2%)
- Management Info (18.2%)
- Other Info (30.2%)
- 18.2% = training format was most important (e.g., including interactive activities)

Activities to Include:

- 68.8% wanted interactive activities (e.g., hands on, case studies, group discussion)
- 23.4% wanted passive activities (e.g., watching videos, powerpoint presentations)

Q: Should participants receive a certificate of completion?
A: 100% = YES

Discussion

- Pain training = uncommon for respite workers, but seen as valuable, applicable, interesting, important
- In person training in relatively small groups is valued
 - Small group learning = beneficial (e.g., promotes deep learning; opportunities to ask questions; Jones, 2007)
- Direct information about pain assessment and management is perceived as most important, as are interactive activities
 - Benefits and effectiveness of active learning = well documented in research literature (e.g., Berkhof et al., 2011; Prince, 2004)

Limitations

- Only a small subset of participants from a limited number of organizations
- Some of the specific training preferences indicated may be difficult to incorporate/follow through with (e.g., having parents come in to discuss their experiences with their child's pain)

• ****Next Steps****: Incorporate results with extant research; develop and pilot a pain training program.