



# A model for pain behavior in individuals with intellectual and developmental disabilities

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## ABSTRACT

The dearth of information on the pain experience of individuals with intellectual and developmental disabilities (IDD) calls for a more comprehensive understanding of pain in this population. The Non-Communicating Adults Pain Checklist (NCAPC) is an 18-item behavioral scale that was recently found to be reliable, valid, sensitive and clinically feasible to assess pain levels in adults with IDD. The aim of the present article is to propose and examine a pain model for adults with IDD. The procedure involved videotaping 228 participants (mean age: 38.7 years) before and during an influenza vaccination. The pain model was constructed using previously collected data, by means of confirmatory factor analysis of the sum scores, using the half split procedure. The model was tested on a randomized group of participants ( $N=89$ ) for generalization. The constructed model seems to reflect two categories of pain responses: a basic response consisting of physiological measures and body reaction, and an advanced response consisting of vocal and emotional reactions, as well as facial and protective expressions. The model presented excellent Goodness of Fit Index (0.99) and an acceptable RMSEA value (0.061). We conclude that the current article presents a first-of-its-kind model of pain behavior in adults with IDD.

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## 1. Introduction

Pain evaluation is a challenging task, particularly among populations with intellectual and developmental disabilities (IDD) (Oberlander & Symons, 2006; Richards, Nepomuceno, Riles, & Suer, 1982). Individuals with IDD may have medical conditions that require painful medical procedures (Bodfish, Harper, Deacon, Deacon, & Symons, 2006; Botos, 2006; Malviya et al., 2001). Their inability to report and describe their pain verbally and coherently leaves them improperly treated (Krauss, Gulley, Sciegaj, & Wells, 2003; Malviya et al., 2001). Individuals with IDD have been found to receive less post-surgery analgesics compared to people without IDD (Gauthier, Finley, & McGrath, 1998; Malviya et al., 2001). Therefore there is an urgent need to improve pain management for this population.

The Non-Communicating Children's Pain Checklist-Revised (NCCPC-R) (Breau, Finley, McGrath, & Camfield, 2002) has been found to be a valid scale among children with IDD, showing good psychometric properties and enabling the identification and rating of pain behaviors in different settings and in different pain situations (Breau, Finley, et al., 2002; Breau, McGrath, Camfield, & Finley, 2002). Our assumption that there may be similarities in pain behaviors among adults and

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children with IDD was previously confirmed by using the NCCPC-R to register pain behaviors among adults with IDD (Defrin, Lotan, & Pick, 2006). Yet advanced age, previous pain experiences and a potentially reduced health state may require specific adaptation of the pediatric scale for adults with the same diagnosis (Bodfish et al., 2006). The latter assumption was confirmed during our initial investigation (Defrin et al., 2006), as we found behaviors that were present in the NCCPC-R that did not appear in the adult population and vice versa – pain behaviors that were commonly observed in adults, but not captured by the NCCPC-R. Therefore, an item-by-item investigation was conducted on the 27 items of the NCCPC-R when observing pain behaviors among 228 adults with IDD. We then constructed a new scale, termed the Non-Communicating Adult's Pain Checklist (NCAPC). It was found to have high psychometric properties in adults with all levels of IDD (Lotan, Ljunggren, et al., 2009; Lotan, Moe-Nilssen, Ljunggren, & Strand, 2009).

The importance of constructing a pain behavior model as a means to improve pain management is acknowledged by others (Malviya et al., 2001; Snow et al., 2004). However, when surveying the literature for a model that relates to pain behavior in adults with IDD, no such data was found. The challenge in assessing pain among patients with IDD is our lack of understanding of how pain indicators are related to each other (Snow et al., 2004). Structural equation modeling (SEM) may be used to build a model based on data obtained from examining an adult IDD population with NCAPC. SEM is particularly appropriate for pain, since it accounts for predictive relationships between latent and directly observable variables through structural model specification (Oberlander & Symons, 2006).

Although the NCCPC-R (Breau, Finley, et al., 2002) and the NCAPC scales (Lotan, Ljunggren, et al., 2009; Lotan, Moe-Nilssen, et al., 2009) were constructed to observe pain behaviors in two different populations, by different research teams, in different countries and at different times, they basically consist of the same six subscales (vocal, emotional, facial, body language, protective signs and physiological reactions). Therefore, we hypothesized that the subscales contributing to the scales were acceptable as representing an existing construct with regard to pain behaviors among individuals with IDD.

The aim of the study was to propose a pain model for individuals with IDD by examining the factors involved in the construction of the NCAPC.

## 2. Materials and methods

The study was approved by the Haifa University Research Ethics Committee and by the office of the Medical Director, Division for Mental Retardation, Israeli Ministry of Social Welfare and Social Services, after explaining the aims of the study and its protocol. Informed consent was obtained from the appointed guardians of all IDD participants.

### 2.1. Participants

The present article presents statistical calculations extracted from the data collected during the initial stages of the research project.

The original research population is described in Table 1.

### 2.2. Data collection and construction of the NCAPC

Data collection and inclusion and exclusion criteria were described elsewhere (Lotan, Ljunggren, et al., 2009; v) and was used to construct the NCAPC. The NCAPC is a new scale based on the NCCPC-R scale (Breau, Finley, et al., 2002) for evaluating the pain experience of adults with IDD. The NCCPC-R, was found to have promising psychometric properties, such as: high internal consistency (Alpha = 0.77), sensitivity of each item to pain behaviors ( $p < 0.05$ ) and high sensitivity to pain behaviors of adults with all levels of IDD (SRM = 2.05) (Lotan, Ljunggren, et al., 2009), very high intra- and inter-rater reliability (ICC = 0.94–0.91 correspondingly) (Lotan, Moe-Nilssen, et al., 2009), and sufficient sensitivity to distinguish between pain and non-pain situations and between different pain situations and experiences (Lotan, Moe-Nilssen, Ljunggren, & Strand, 2010). However, the underlying factor structure of the NCAPC has not yet been formerly examined.

#### 2.2.1. Data analysis procedures

As explained within the literature review the NCCPC-R (Breau, Finley, et al., 2002) and the NCAPC scales (Lotan, Ljunggren, et al., 2009; Lotan, Moe-Nilssen, et al., 2009) consist of the same six subscales, and therefore represent an existing construct with regard to pain behaviors among individuals with IDD.

**Table 1**  
Demographic data of all participants with Intellectual Developmental Disabilities (IDD) ( $N = 228$ ).

IDD level	Mild	Moderate	Severe	Profound
Number	22	109	70	27
Age, years: mean (SD) min–max	42.1 (14.9), 26–72	45 (11.9), 21–75	39.4 (12.8), 16–67	34.6(13.7), 15–57
Gender, %: females	45	38	39	48
Ambulation, %: walking/wheelchair user	95/5	76/24	83/17	56/44

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