



# Measuring happiness in individuals with profound multiple disabilities<sup>☆</sup>



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## ARTICLE INFO

### Article history:

Received 17 April 2015

Received in revised form 26 August 2015

Accepted 13 September 2015

Available online 23 October 2015

### Keywords:

Profound multiple disabilities

Happiness

Applied behavior analysis

## ABSTRACT

This quantitative study assessed whether presentation of preferred items and activities during multiple periods of the day (and over multiple days) increased indices of happiness (over time/sustained) in individuals with PMD. A multiple baseline design across participants was utilized to measure changes in indices of happiness of the participants. Participants were recruited from an adult day activity program specializing in providing assistance to individuals with disabilities. For Mary, baseline indices of happiness were 26.67% of intervals, increasing 6.76% during intervention to 33.43%. For Caleb, baseline indices of happiness were 20.84% of intervals, increasing 6.34% during intervention to 27.18%. For Mark, baseline indices of happiness were 40.00% of intervals, increasing 12.75% during intervention to 52.75%. Overall interobserver agreement was 82.8%, with interobserver agreement observations occurring during 63.04% of the observations. The results of the investigation demonstrated that presenting preferred items and activities increased the indices of happiness compared to baseline rates of indices of happiness. Results may have been more robust if the participants were assessed for overall responsiveness patterns prior to the initiation of measurement of indices of happiness.

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## 1. Introduction

Throughout history, the treatment of individuals with intellectual disabilities (ID) has typically marginalized them from society. Initial efforts to provide support for individuals with ID in the nineteenth century did not have the desired effect of improving care for these individuals (Brown & Radford, 2007). Congregate living situations were developed to provide training and care for the individuals, but became storage facilities providing only minimal custodial care (Nebraska Advocacy Services, 2007). With little oversight in the institutions, the opportunity for caregivers to mistreat their charges increased. Individuals who have ID are victims of abuse at a higher frequency than nondisabled individuals (Beadle-Brown, Mansell, Cambridge, Milne, & Whelton, 2010; Murphy, O'Callaghan, & Clare, 2007).

In an effort to ensure the rights of individuals with disabilities are not violated, the United States Department of Justice Civil Rights Division uses the *Civil Rights of Institutionalized Persons Act* (CRIPA), 42 U.S.C. § 1997a and the *Americans with Disabilities Act* (ADA), 42 U.S.C. § 12132 as well as the U.S. Supreme Court *Olmstead* ruling. With the motivation provided by

<sup>☆</sup> Author note: This article is based on a dissertation submitted by the first author in partial fulfillment for the requirements of a PhD in Psychology from Northcentral University, Prescott Valley, AZ.

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federal statutes and Supreme Court decisions, methods to assist individuals with ID to participate as much as possible in their lives has increased (Gardner & Carran, 2005). The phrase “pursuit of happiness” is well known from the United States Declaration of Independence.

The diagnosis of ID can be seen as descriptive of what an individual is lacking; additional approaches to describe this segment of society would be beneficial to describe what an individual possesses (Dykens, 2006). This research adds to the description of individuals with PMD by the development of a reliable method to *listen* to what the individual prefers. With the legislative and judicial mandates to improve the quality of life for individuals with disabilities, measuring happiness of individuals with PMD is necessary to assist this vulnerable and fragile segment of society.

Happiness can be operationally defined, measured, and increased (Diener, Lucas, & Scollon, 2006; Dillon & Carr, 2007; Wong, 2011). By operationally defining how a person with limited communication abilities (e.g., someone who has PMD) expresses happiness using established research and adding identified preferred items and activities of the person with PMD to an established regular schedule of access to preferred items and activities for that person, it is possible to increase the indices of happiness of the person with PMD.

Petry and Maes (2006) demonstrated that caregivers are significant resources for the identification of indices of mood by individuals with PMD, primarily for identifying idiosyncratic expressions of pleasure and displeasure. This research project also supported the stance that expressions of happiness with individuals who have PMD can be consistently and reliably measured based on similar expression by individuals who do not have disabilities (Green & Reid, 1996; Ivancic, 2004; Petry & Maes, 2006). Regarding the procedure yielding meaningful, useful, and sufficiently differentiated information, the results indicated it is possible to draft individual profiles of expressions of pleasure and displeasure for individuals with PMD.

Individuals with profound multiple disabilities (PMD) have significant deficits in intellectual functioning in addition to physical disabilities and associated medical conditions (Petry, Maes, & Vlaskamp, 2009a, 2009b). In most cases, these individuals have communication deficits making the expression of basic wants and needs very difficult. Communication deficits can be the result of physical disability (lack of muscular control to speak), cognitive disability (unable to form words), or both. A person with PMD may also not have the cognitive skills or motoric capabilities to respond to others' communications. Communication is often a result of idiosyncratic expressions (Dillon & Carr, 2007; Petry & Maes, 2006).

Previous research has demonstrated that presentation of preferred items and activities increases the indices of happiness among individuals with PMD (Dillon & Carr, 2007; Favell, Realon, & Sutton, 1996; Green & Reid, 1996; Ivancic, 2004; Lancioni, Singh, O'Reilly, Oliva, & Basili, 2005). Accessing preferred items and activities has been shown to increase indices of happiness in this population (Dillon & Carr, 2007; Lancioni et al., 2005). Conversely, not being able to access preferred items and activities increases the frequency of problem behaviors (O'Reilly et al., 2009). Given the communication difficulties associated with PMD, there is a need for systematic assessment to measure indices of happiness of individuals with PMD during multiple periods of the day over multiple days. Individuals with PMD have an extremely difficult time accessing preferred items and activities without assistance (Dillon & Carr, 2007; Ivancic, 2004; Lancioni et al., 2005). This study assessed whether repeated presentation of preferred items and activities during multiple periods of the day increased the indices of happiness for individuals with PMD to build on the previous research that demonstrated increasing indices of happiness was possible.

Published research with individuals who have PMD tends to focus on decreasing problem behaviors, increasing functional skills, improving health, and population demographics (Bachmeyer et al., 2009; Bodfish, Harper, Deacon, Deacon, & Symons, 2006; Janicki, 2010). The current research provided a means to address a method to systematically measure indices of happiness communicated by individuals who have PMD. Neglecting this area of knowledge may prevent individuals who have PMD from effective ways to communicate their wishes of how others are to help them as well as perpetuate the impression of individuals who have PMD as merely passive recipients of service rather than active participants. The results of the study provide an empirical method to ascertain emotions of individuals who do not have the ability to describe what they are feeling.

There are potential health benefits for the person's cardiovascular system, muscular-skeletal systems, and general well-being (Brady, 2007; Lancioni et al., 2005; Ryff & Singer, 2004; Seligman, Steen, Park, & Peterson, 2005). Measuring indices of happiness and unhappiness have been shown to be useful for increasing therapeutic activities such as use of walker devices, microswitches, treadmills, and regular classroom activities (Lancioni et al., 2004, 2005, 2007). Therapeutic routines are necessary for the health and well-being of an individual, but are not always pleasant activities.

This study measured indices of happiness in three participants who have PMD during various activities in a structured day program to determine if the presentation of preferred items and activities developed from the Reinforcer Assessment for Individuals with Severe Disabilities (RAISD; Fisher, Piazza, Bowman, & Amari, 1996) resulted in an increase in the indices of happiness compared to baseline. Specifically, this paper expands on previous research (see Dillon & Carr, 2007; Lancioni et al., 2005) by assessing whether providing preferred items and activities during multiple periods of the day increases the indices of happiness among individuals with PMD.

## 2. Method

### 2.1. Participants

This study included three participants who have PMD. The study employed a nonprobability design of purposive sampling. All the participants with PMD attending the day program were solicited (via conservators) over a two-week period

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