



# Mindful caregiving increases happiness among individuals with profound multiple disabilities

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## Abstract

Happiness is a critical indicator of quality of life in humans. A few studies have measured levels of happiness displayed under different conditions by individuals with profound multiple disabilities. We were interested in determining whether increasing the mindfulness of caregivers would result in increased levels of happiness in adults with these conditions. Using alternating treatments embedded within a multiple baseline across caregivers design, we measured baseline levels of happiness displayed by three adults with profound multiple disabilities when they engaged in leisure activities, each by a different pair of caregivers. Then, we taught mindfulness methods to one of each pair and measured the levels of happiness displayed by the individuals during the 8-weeks training for the caregivers. Finally, we measured the levels of happiness displayed by the three individuals for 16 weeks following the termination of mindfulness training. We found that, regardless of whether the level of happiness was initially observed to be high or low in the presence of a caregiver, it increased markedly when an individual interacted with a caregiver who received training in mindfulness when compared to the control caregiver, who did not receive such training. Our study provides evidence that increasing the mindfulness of a caregiver can produce a substantial increase in the levels of happiness displayed by individuals with profound multiple disabilities.

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## 1. Introduction

Despite advances in the care of individuals with mental retardation, the quality of life remains poor for those with profound multiple disabilities. Quality of life has been variously defined but, at its most basic level, it must have three dimensions: subjective well-being, functioning in daily life, and external resources. While subjective well-being is difficult to assess directly in individuals with profound multiple disabilities, it has been suggested that behavioral indicators of happiness can be used to assess one aspect of their satisfaction with life (Felce & Perry, 1995; Hawkins, 1997; Ross & Oliver, 2003; Yu et al., 2002). For example, happiness in this population has been defined as “any facial expression or vocalization typically considered to be an indicator of happiness among people without disabilities including smiling, laughing, and yelling while smiling” (Green & Reid, 1996, p. 69).

The majority of research on happiness in individuals with profound multiple disabilities has been undertaken in the context of leisure activities. This is appropriate, given that a person’s quality of life can be promoted through meaningful and developmentally age-appropriate leisure and recreation activities. In one of the earliest studies, Realon, Favell, and Phillips (1989) reported increased smiling in a group of individuals with profound multiple disabilities when they were given adapted leisure materials when compared to standard leisure materials typically available in facilities for people with mental retardation. Green and Reid (1996) and Green, Gardner, and Reid (1997) provided empirically validated evidence that happiness can be not only measured in a valid and reliable manner, but also increased by providing items and activities that individuals with profound disabilities prefer. Similar research has provided confirmatory evidence of increased happiness during preferred leisure and other activities (e.g., Favell, Realon, & Sutton, 1996; Green & Reid, 1999; Ivancic, Barrett, Simonow, & Kimberly, 1997; Yu et al., 2002).

In these studies, caregivers provided the individuals with their preferred leisure items and activities to promote enjoyable and meaningful active participation and, thus, increase their level of happiness. Recently, Lancioni and colleagues have reported a series of studies in which individuals with profound multiple disabilities were taught to access reinforcers by operating various microswitches (see Lancioni, Singh, O’Reilly, & Oliva, 2003). Indices of happiness (e.g., smiling, laughing) were measured in three studies where individuals accessed reinforcers through either the use of microswitches (Lancioni, O’Reilly, Singh, Oliva, & Groeneweg, 2002; Lancioni et al., 2003) or physical activities (Lancioni, Singh, O’Reilly, Oliva, & Campodonico, in press). These studies showed that the individuals’ happiness generally increased when they could access reinforcers.

The question arises as to whether caregivers can increase happiness in individuals with profound multiple disabilities by changing their own behavior when engaging with these individuals in one-on-one interactions. Not only would this provide another method of increasing happiness in these individuals but also enable caregivers to increase happiness in these individuals in multiple contexts.

In our studies with treatment team members, we showed that by increasing their own mindfulness, team members functioned better as a team, were more family friendly, and could produce more integrated treatments (Singh et al., 2002a, 2002b, *in press*). Mindfulness can be defined in various ways, such as “knowing your own true nature” but, in the context of these studies, it is defined as a unique method of cultivating awareness of and fully responding to whatever happens in each moment (Gunaratana, 2001). In these studies, we developed specific ways of enhancing the mindfulness of treatment team members so that they could be more mindful of their own attitudes and behaviors in daily life.

Our aim in this study was to assess if caregivers could increase happiness in individuals with profound multiple disabilities without actively focusing on specific contingencies related to their happiness. Specifically, we were interested in empirically assessing the impact of mindfulness training and practice by caregivers on the happiness of the individuals they provide services to.

## **2. Method**

### *2.1. Resident participants*

The resident participants were three adults with complex medical and physical problems and profound mental retardation. Bruce was diagnosed with profound mental retardation due to unknown etiology, with spastic quadriplegia, seizure disorder, profound dysphagia, gastrostomy tube, moderate thoracolumbar scoliosis, moderate flexion deformities, history of esophagitis, and a resection of right proximal femur due to subluxed right hip. Steve was diagnosed with profound mental retardation due to hyperbilirubinemia, choreoathetosis secondary to basal ganglia damage from kernicterus, spastic quadriplegia, iron deficiency anemia, sensorineural hearing loss, and mild dysphagia. Dave was diagnosed with profound mental retardation due to unknown etiology, generalized convulsive epilepsy, spastic quadriplegia, compound myopic astigmatism, hypercholesterolemia, moderate dysphagia due to oral deficit in bolus control and pharyngeal pooling, and chronic non-allergic rhinitis. None of these men had functional speech, but all had some receptive language. They were aged 45, 54 and 55 years, respectively, and all had been in an institution for over 40 years.

### *2.2. Caregiver participants*

The caregiver participants were selected from a pool of day-shift caregivers who worked in four group homes for individuals with medical and physical disabilities and profound mental retardation. Each caregiver was observed during five 10-min observation sessions, interacting one-on-one with each of the residents across the four group homes. The observations were analyzed in terms of the average number of intervals that each resident participant was recorded as displaying behaviors that were indicative of happiness, as defined below.

The caregivers were ranked in terms of producing the highest to the lowest percentage of intervals of happiness across all individuals. The top three (Jane, Penny, and Cyndie) and bottom three (Linda, Kris, and Rachel) were selected to participate in the study, with the following pairings: Jane and Penny (high-high happiness), Cyndie and Linda (high-low happiness), and Kris and Rachel (low-low happiness).

The six caregivers were African American women who worked the day shift during the course of the study. Their average age was 37.5 years, ranging from 28 to 44. They had worked a mean of 12.4 years, ranging from 10 to 14 years, with individuals with medical and physical conditions and profound mental retardation. Each caregiver gave consent to be observed and to be taught the experimental procedures. They were not provided any feedback on the observations that were undertaken by independent observers during the course of the study.

All caregivers at the group homes, including the six participants, were trained in behavior management and skills training procedures and received intensive retraining each year. The agency's quality assurance data showed competency ratings of caregiver performance in behavior management and skills training that ranged from 86 to 100% (mean = 95%) during the month prior to the initiation of baseline observations for this study.

### 2.3. Activities

During the leisure activities sessions, the individuals were provided with a variety of leisure materials, objects and activities. The leisure sessions were designed as periods of low demand for the individuals with the aim of enhancing their enjoyment by having a single staff member interact with and assist them to manipulate their toys and objects and to engage them in preferred activities, such as singing, brushing their hair, and massaging their hands, shoulders and necks. The caregivers provided the three individuals with their preferred objects and activities as determined through a reinforcer preference test (Crawford & Schuster, 1993) to ensure an optimal fit between activity demand/requirement and developmental age/ability.

### 2.4. Definitions, observations and recording procedures

Happiness was defined generically as “any facial expression or vocalization typically considered to be an indicator of happiness among people without disabilities including smiling, laughing, and yelling while smiling” (Green & Reid, 1996, p. 69). However, with the assistance of caregivers familiar with the three individuals and videotapes of their behavior and facial expressions during leisure activities, the definition of happiness was specific to each individual. Across the three individuals, behaviors that were indicative of happiness and a positive affective response included: grinning; eyes opened wide in excitement; open mouth together with furrows high on forehead, eyelids close together, drooling, and happy vocalizations; high-pitched shrieks; clapping or arm waving;

humming or singing; body contortions together with loud, happy vocalizations; and happy growling sounds.

Observational data were collected during the two daily leisure activity sessions scheduled for each individual. Each leisure session was scheduled for 15 min and each observation session, which typically began during the second or third minute of the leisure session, was scheduled for 10 min. Each minute was divided into four 15-s intervals, the first 10-s for observation followed by 5-s for recording. Thus, there were 40 observation intervals per session. An interval was checked for happiness if any of the behaviors indicative of happiness for the individual was observed during that 10-s observation interval, regardless of the duration of the behavior. Data were collected 5 days a week.

### *2.5. Interobserver reliability*

Four staff members not involved with the study group homes were trained to collect the observational data. On any one day, three of them were randomly chosen to serve as primary data collectors and one as the reliability data collector, thus ensuring reliability observations during 33% of all sessions across all participants. An agreement was defined as both observers checking off the same interval as showing that a behavior indicative of happiness for the individual had been observed. Percent interobserver agreement was calculated for each session by dividing the number of agreements by 40 and multiplying by 100. The interobserver reliability ranged from 89 to 100%, with a mean of 93.4% across all observations when two observers were present.

### *2.6. Experimental design and procedure*

We used alternating treatments embedded within a multiple baseline across subjects design. Two caregivers were assigned to interact with an individual participant during leisure activity sessions. Jane and Penny were assigned to Bruce, Cyndie and Linda to Steve, and Kris and Rachel to Dave. The leisure sessions were scheduled twice a day throughout the three phases of the study and lasted about 15 min. Each of the pair of caregivers was randomly alternated between the two daily sessions. Data were collected on the occurrence of indices of happiness exhibited by the individual during  $40 \times 10$ -s observation intervals per session.

#### *2.6.1. Baseline*

The baseline data were collected during 4, 7, and 12 weeks across the three individuals in the presence of each caregiver.

#### *2.6.2. Mindfulness training*

Immediately after the final baseline session with each individual participant, the senior investigator met with a randomly chosen caregiver from each of the three pairs of caregivers for that individual (Jane for Bruce, Cyndie for Steve, and

Kris for Dave) and explained the essence of the study, the nature of the proposed training, and the philosophy of mindfulness. At the end of this interactive session, each caregiver was given a choice of reading one of two books (Hanh, 1991; Kabat-Zinn, 1994) before the second training session that was scheduled 4 weeks

Table 1  
Outline of Mindfulness Training Program

Training sessions	Topics covered
Session I: Pretraining	<ul style="list-style-type: none"> <li>● Review and discussion of quality of life</li> <li>● Happiness as a major indicator of quality of life</li> <li>● Measuring and increasing happiness in individuals with profound multiple disabilities</li> <li>● What is mindfulness?</li> <li>● Mindfulness as a mediator of happiness in others</li> <li>● Reading assignment: <i>Peace is Every Step</i></li> </ul>
Session II: Knowing your mind	<ul style="list-style-type: none"> <li>● Update and discussion from session I</li> <li>● Discussion of mindfulness and mindlessness</li> <li>● Identification of instances of mindfulness and mindlessness when interacting with people at work; outcomes of each type of behavior</li> <li>● Meditation exercise on observing your mind</li> <li>● Instructions on basic meditation techniques for sitting and walking meditation</li> <li>● Discussion: any activity with the mind properly focused can be a meditation</li> </ul>
Session III: Appreciating oneness of everything	<ul style="list-style-type: none"> <li>● Update and discussion from session II</li> <li>● Discussion of diversity, duality, non-duality and oneness</li> <li>● Meditation exercise on emptiness; single pointed meditation on an object</li> <li>● Discussion: developing a disciplined meditation practice; journaling</li> </ul>
Session IV: Being in the present moment	<ul style="list-style-type: none"> <li>● Update and discussion from session III</li> <li>● Discussion: being in the moment in the midst of chaos; applications when working with individuals with profound multiple disabilities</li> <li>● Meditation exercise on being in the present moment</li> <li>● Discussion: living in the silence between thoughts</li> </ul>
Session V: Beginner's mind	<ul style="list-style-type: none"> <li>● Update and discussion from session IV</li> <li>● Discussion: premature cognitive commitment; bounded vs. unbounded reality</li> <li>● Meditation exercise on the beginner's mind</li> <li>● Discussion: responding with our hearts rather than with our minds; doing what is right rather than what is correct</li> </ul>
Session VI: Being the activity	<ul style="list-style-type: none"> <li>● Update and discussion from session V</li> <li>● Discussion: being in the "zone" or having a "peak experience"</li> <li>● Meditation exercise on being the activity</li> <li>● Discussion: putting it all together and practicing mindfulness on a daily basis</li> </ul>
Session VII: Review and wrap-up	<ul style="list-style-type: none"> <li>● Update and discussion from session VI</li> <li>● Review of mindfulness training course and arrangements for individual follow-up and all participants keeping in touch</li> <li>● Discussion: disciplined practice of mindfulness in daily life</li> </ul>

Table 2  
Example of a mindfulness exercise

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Meditation exercise: observing your mind

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1. Sit comfortably, without a meditation posture, preferably with your back straight and feet flat on the floor.
  2. When invited by the bell, simply observe your mind.
  3. When invited by the bell, stop observing your mind and write down your observations. Write down just your observations, without interpretation (i.e., without labels, comparisons, conceptualization, or judgment). Just describe your direct observations of your mind.
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later. For different reasons, all three caregivers chose to read *Peace is Every Step* (Hanh, 1991). Training sessions II–IV were scheduled on Monday, Wednesday, and Friday of the 4th week and sessions V–VII were scheduled on Monday, Wednesday, and Friday of the 8th week. The training sessions and the topics covered are presented in Table 1 and a sample meditation exercise is given in Table 2. Formal training in mindfulness was terminated following the 8th week of the training phase.

The three caregivers who were not given mindfulness training met with the experimenter for the same amount of time as those receiving the mindfulness training (i.e., about an hour each session). They were also given a choice of reading one of two books (Angelou, 1976, 1986). Using the same training schedule as for those being trained in mindfulness, the investigator met with the three caregivers and discussed the book they had read and behavioral methods of skills training appropriate for the individual each caregiver was working with.

During the training phase, the caregivers being trained in mindfulness were encouraged to practice mindfulness while they were engaged in the one-on-one leisure activity sessions with their assigned individual. Apart from that, the procedure was the same as during baseline.

### 2.6.3. Mindfulness practice

During the third phase, the caregivers were given no further formal training but were encouraged to use the methods they had learned, discussed, and practiced during the mindfulness training phase. In all other ways, the procedure was identical to that in the previous phases. The third phase was terminated after each caregiver had completed 16 weeks of one-on-one leisure activity sessions with their assigned individual participants.

## 3. Results

Fig. 1 shows the mean percentage of intervals per week that happiness was observed in each of the three individuals as they interacted with their pair of caregivers during baseline, mindfulness training and mindfulness practice. Bruce displayed a relatively high average percentage of happiness during baseline with both Jane (10.3) and Penny (11.3). During the period of mindfulness training, the

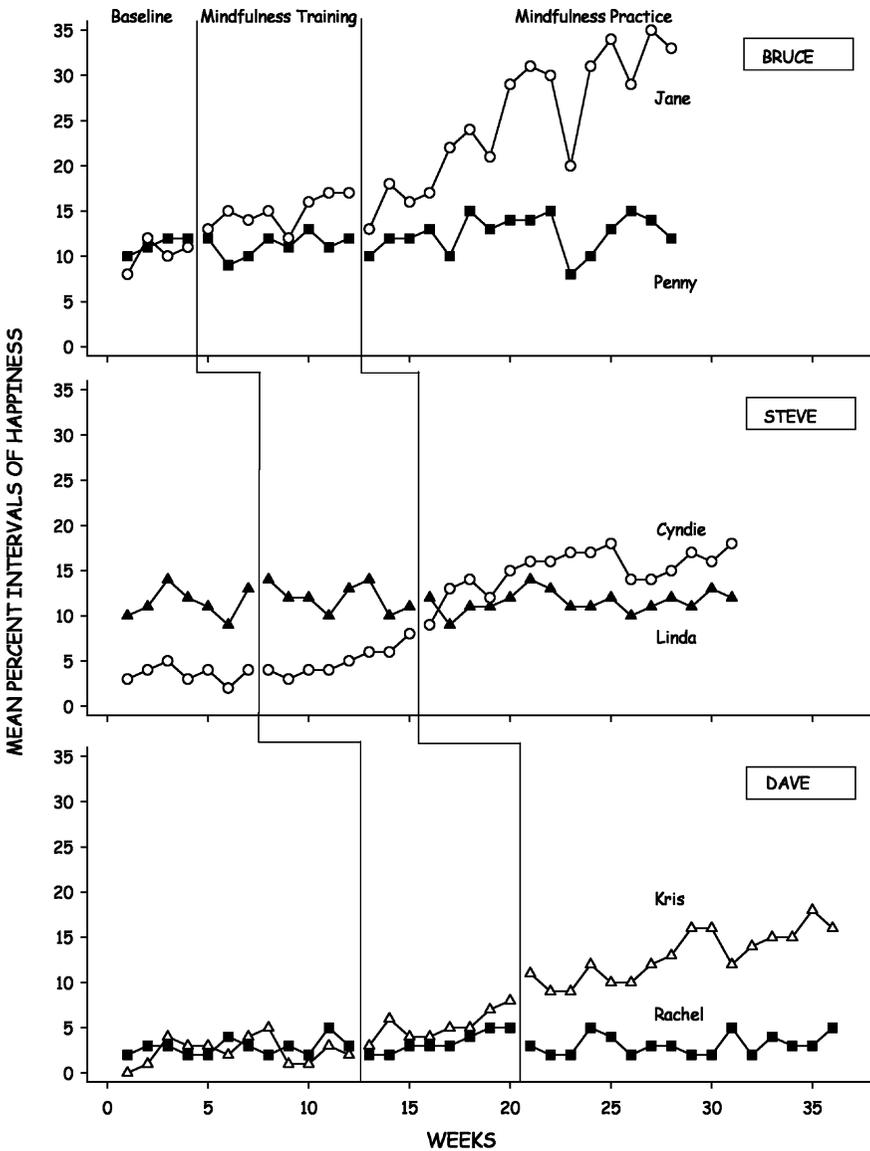


Fig. 1. Mean percent intervals of happiness across the three participants when interacting with trained (Jane, Cyndie, and Kris) and untrained (Penny, Linda, and Rachel) caregivers.

average percentage of happiness remained the same (11.3) with Penny, the untrained caregiver, but increased to 14.9 with Jane, who received mindfulness training. During the following 4-month practice period, it remained almost the same (12.5) with Penny and increased to 25.2 with Jane. This represents an increase in observed happiness, from baseline to the final phase, of about 11% with Penny and 146% with Jane.

With the second pair (Cyndie and Linda), the average percentage of happiness shown by Steve during baseline was low in the presence of Cyndie, who was later given mindfulness training, and relatively high in the presence of Linda, the untrained caregiver. Steve showed an average percent of happiness across the three experimental phases that remained about the same (11.4, 12.0, and 11.6, respectively) in the presence of Linda, but increased (3.6, 5.0, and 15.1, respectively) in the presence of Cyndie. This represents an increase from baseline to the final phase of about 1% with Linda and 322% with Cyndie.

With the third pair (Rachel and Kris), Dave displayed low average levels of happiness with both caregivers during baseline. The average percent intervals of happiness displayed by Dave across the three experimental phases remained about the same (2.8, 3.4, and 3.1, respectively) when interacting with Rachel, the untrained caregiver, but increased (2.4, 5.3, and 13.0, respectively) with Kris, the caregiver given mindfulness training. This represents an increase from baseline to the final phase of about 10% with Rachel and 437% with Kris.

#### 4. Discussion

Our results show very clearly that the levels of happiness of three individuals with profound multiple disabilities were increased substantially during leisure activity sessions. While we were unable to ask these individuals if their enjoyment increased during these sessions, there is strong evidence that specific, observable and measurable behaviors that have traditionally been accepted as indices of happiness and positive affective response increased reliably commensurate with caregiver training. Further, our results are in accord with those from earlier studies that manipulated variables other than staff training to increase indices of happiness in similar samples of individuals with profound multiple disabilities (e.g., Green et al., 1997; Ivancic et al., 1997; Lancioni et al., 2002, 2003).

These results indicate that providing training in mindfulness to caregivers enables them to interact with individuals who have profound multiple disabilities in a manner that increases the individuals' indices of happiness. This was evident regardless of the levels of happiness that they were producing in their one-on-one interactions with the individuals during baseline, before mindfulness training began. We used alternating treatments embedded in a multiple baseline across subjects design to pair caregivers who produced levels of happiness that were either similar during baseline (i.e., both relatively high with Bruce or both low with Dave) or very different levels (i.e., with Steve). This enabled us to also demonstrate that there was virtually no change in the happiness levels of the same individuals throughout the study when they interacted with caregivers who did not receive training in mindfulness.

The data show that levels of happiness in the presence of the caregivers trained in mindfulness increased slowly over time across the three individuals and was still increasing by the end of the study. There were differential effects as well although the number of caregivers trained was too small to form definitive

conclusions. It is possible that if the base rate is low, as with Cyndie and Kris, the increase is more gradual when compared to a higher base rate, as with Jane. However, even with a high base rate, the absolute amount of change over time was not dramatic. This would be expected given that the effects of mindfulness training take time to emerge in overt behavior and social interactions because they result from fundamental changes that take place in the person (Dalai Lama & Cutler, 1998). Indeed, unlike behavioral and other staff training methodologies, where staff's awareness to contingencies is heightened and new behavioral interventions are taught, mindfulness transforms the individual's view of self and others as the basis for behavior change.

This was an initial study about the feasibility of producing behavior change in individuals without actively focusing on specific contingencies that govern their behavior, as is prevalent in the behavioral literature. We are interested in enabling caregivers, parents, therapists, and others involved in providing human services to enhance the quality of life of those they serve by focusing on changing themselves as servers rather than on the behavior of those they serve. In our earlier studies with treatment teams, we found that by engaging in mindfulness practices and didactic education in specific content areas, team members were able to substantially increase their family friendliness (Singh et al., 2002b), better integrate behavioral and psychopharmacological interventions in the treatment of individuals with developmental disabilities (Singh et al., 2002a), and enhance treatment team functioning as evidenced by staff and patient satisfaction ratings and attendance of psychosocial rehabilitation groups (Singh et al., *in press*).

There are many aspects of this approach that need careful and systematic research before being offered as an adjunct or alternative to current empirically validated treatments. For example, we do not know enough about trainer characteristics that impact on the mindfulness practice of the caregivers. This is a very important issue because trainer characteristics have been reported to be critical in outcome research in mindfulness-based therapies (e.g., Segal, Williams, & Teasdale, 2002). Segal et al. have suggested that trainers have to be experienced meditators and to have experienced the states that mindfulness practices produce before they are in a legitimate position to provide training in mindfulness. Thus, we caution therapists not to begin using mindfulness methods without formal training from experienced mindfulness practitioners.

In this study, we did not explore exactly what changes occurred in the caregivers due to mindfulness training that may have acted as a setting event for the expression of increased happiness in the individuals with profound multiple disabilities. Our informal observations suggested that, in their interactions with the individuals, they were more responsive than reactive and they appeared to be non-judgmentally accepting of the behaviors that the individuals displayed. They appeared to be totally involved with the individual during the leisure activity sessions and were more creative, flexible, and adaptable than during baseline. These anecdotal observations need empirical verification in future research.

At present, there is almost no empirical data on the short-term effects of teaching mindfulness practices to caregivers. We know from electrophysiological

studies of long-term meditators, however, that mindfulness results in emotional equanimity and increased compassion, non-judgmental acceptance, loving kindness, and patience (Dalai Lama & Goleman, 2003). Perhaps, what may distinguish mindful caregivers from others is their ability to be more focused on what is occurring in each moment, rather than being affected by any preconceived ideas of an individual's abilities and disabilities. In this way, they interact with each individual as if they are seeing the person with what Suzuki (1970) has called a "beginner's mind."

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