

## Improving the oral health of residents with intellectual and developmental disabilities: An oral health strategy and pilot study



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### ARTICLE INFO

#### Article history:

Received 6 May 2014

Received in revised form 17 July 2014

Accepted 21 July 2014

Available online 27 July 2014

#### Keywords:

Oral health

Health disparities

Intellectual and developmental disability

Intervention design

Process and outcome evaluation

### ABSTRACT

This article presents an oral health (OH) strategy and pilot study focusing on individuals with intellectual and/or developmental disabilities (IDD) living in group homes. The strategy consists of four components: (1) planned action in the form of the behavioral contract and caregiver OH action planning; (2) capacity building through didactic and observation learning training; (3) environmental adaptations consisting of additional oral health devices and strategies to create a calm atmosphere; and (4) reinforcement by post-training coaching. A pilot study was conducted consisting of pre- and post-assessment data collected 1 week before and 1 week after implementing a 1-month OH strategy. The study sample comprised 11 group homes with 21 caregivers and 25 residents with IDD from one service organization in a Midwestern city. A process evaluation found high-quality implementation of the OH strategy as measured by dosage, fidelity, and caregiver reactions to implementing the strategy. Using repeated cross-sectional and repeated measures analyses, we found statistically significant positive changes in OH status and oral hygiene practices of residents. Caregiver self-efficacy as a mechanism of change was not adequately evaluated; however, positive change was found in some but not all types of caregiver OH support that were assessed. Lessons learned from implementing the pilot study intervention and evaluation are discussed, as are the next steps in conducting an efficacy study of the OH strategy.

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### 1. Background

It is well known that oral health (OH) problems continue to exist among children and adults across the world (Petersen, Bourgeois, Ogawa, Estupinan-Day, & Ndiaye, 2005; Petersen, 2004). Further, poor OH has been linked to a variety of physical

health problems, including respiratory, cardiovascular, and endocrine disease (Rautemaa, Lauhio, Cullinan, & Seymour, 2007). Notably, OH is impacted by good oral hygiene practices that reduce the development of caries (cavities) (Ashkenazi, Bidoosi, & Levin, 2014) and periodontal (gum) disease (Araujo, Gusmao, Batista, & Cimoos, 2010). Poor OH and dental hygiene are particularly prevalent among vulnerable populations such as individuals with intellectual and developmental disabilities (IDD). These individuals are more likely to have poorer oral hygiene, increased decay, and increased periodontal disease than the general population—a significant health disparity (Anders & Davis, 2010; Girgis, 1985; Glassman & Miller, 2003; Hood, Dean, Cornett, & Boggs, 2001; Lindemann, Zschel-Grob, Opp, Lewis, & Lewis, 2001; Pezzementi & Fisher, 2005; Reid, Chenette, & Macek, 2003).

This study focuses on the OH of individuals with IDD and efforts to improve oral hygiene practices among this population who live in community-based group homes (hereinafter referred to as residents with IDD or residents). Historically, individuals with

**Abbreviations:** CG, caregivers; DMFT, decayed, missing and filled teeth; HLM, hierarchical linear modeling; IRB, Institutional Review Board; IDD, intellectual and developmental disabilities; LARs, legally authorized representatives; PI, multiple principal investigator; NIDCR, National Institute of Dental and Craniofacial Research; NIH, National Institutes of Health; OAG, oral assessment guide; OH, oral health; RCT, randomized controlled trial.

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IDD either lived at home or were placed in large state institutions with fully staffed medical and dental facilities and stable, well-trained workers. However, over the past several decades, efforts to deinstitutionalize these individuals and place them in smaller community residences, commonly referred to as group homes, have been successful. Although the overall quality of life may have been improved for this vulnerable population, their access to dental care and trained caregivers may have become more limited and their OH may have suffered (Stanfield, Scully, Davison, & Porter, 2003). Most individuals with IDD are insured by Medicaid, which many dentists do not accept. In addition, many dentists do not believe they are adequately trained to treat special-needs patients (Dao, Zwetckhenbaum, & Inglehart, 2005; Waldman & Perlman, 2002). Among dentists who do treat individuals with IDD, 99% have identified poor oral hygiene as the single greatest threat to their patient's OH (Hood et al., 2001).

Unfortunately, the OH of this population is compromised by their lack of preventive dental treatment and by their inability to adequately brush and/or floss their own teeth. Thus, the oral hygiene provided or supervised by caregivers is critical to maintaining OH and reducing the need for extensive restoration or extraction of teeth. Providing oral care for individuals with IDD is challenging because they may have physical impairments and may exhibit uncooperative behaviors (Perlman, Friedman, & Tesini, 1991). Caregivers often only clean the anterior teeth, ignoring the posterior teeth and causing the posterior oropharyngeal area to be at risk for colonization with bacteria and infection (Glassman & Miller, 2003; Tesini & Fenton, 1994; Vigild, Brinck, & Christensen, 1993).

There has been limited effort to develop and evaluate promotional strategies to improve the oral hygiene and OH of this vulnerable population living in group homes (Avenali, Guerra, Cipriano, Corridore, & Ottolenghi, 2011; Faulks & Hennequin, 2000; Fickert & Ross, 2012; Glassman & Miller, 2006). Systematic reviews of OH promotion educational interventions conducted with other populations have produced diverse findings, but generally, they

have produced short-term reductions in plaque and gingival bleeding (Watt & Marinho, 2005). What is not known is the relevance of a short-term reduction to the sustained impact on oral health. This void in the literature and practice led to the pilot study of the OH strategy being presented in preparation for a larger randomized controlled trial (RCT). We used the National Institute of Dental and Craniofacial Research (NIDCR) clinical trial planning grant mechanism and the National Institutes of Health (NIH) multiple-principal-investigator (PI) approach to take advantage of the expertise of two PIs – one clinical researcher in dentistry and one social and behavioral scientist. This approach allowed us to develop and pilot test a social science, theoretically based intervention strategy focusing on OH.

## 2. The oral health strategy

### 2.1. Conceptual view

Fig. 1 shows our conceptual framework, which assumes interrelationships between the OH strategy and its proximal, intermediate, and distal outcomes. Moving left to right in the figure, we posit that the OH strategy described in the next subsection will affect caregiver self-efficacy and OH support, which are proximal outcomes. Self-efficacy is an important mechanism of behavioral change in social cognitive theory (Bandura, 2004). We also identified in a qualitative assessment that caregiver OH support (oral hygiene, environmental adaptations, rewards, dietary supervision, and monitoring) may serve as an additional important mechanism of change (Binkley & Johnson, 2013). Further, the PIs posited that impacting these two mechanisms of change would improve oral hygiene practices (intermediate outcomes) of group home residents with IDD and subsequently improve their overall OH (distal outcome).

Possibly, not all OH strategy effects are mediated by caregivers' self-efficacy and OH support. Therefore, we posited direct effects of the intervention on residents' oral hygiene practices and residents'

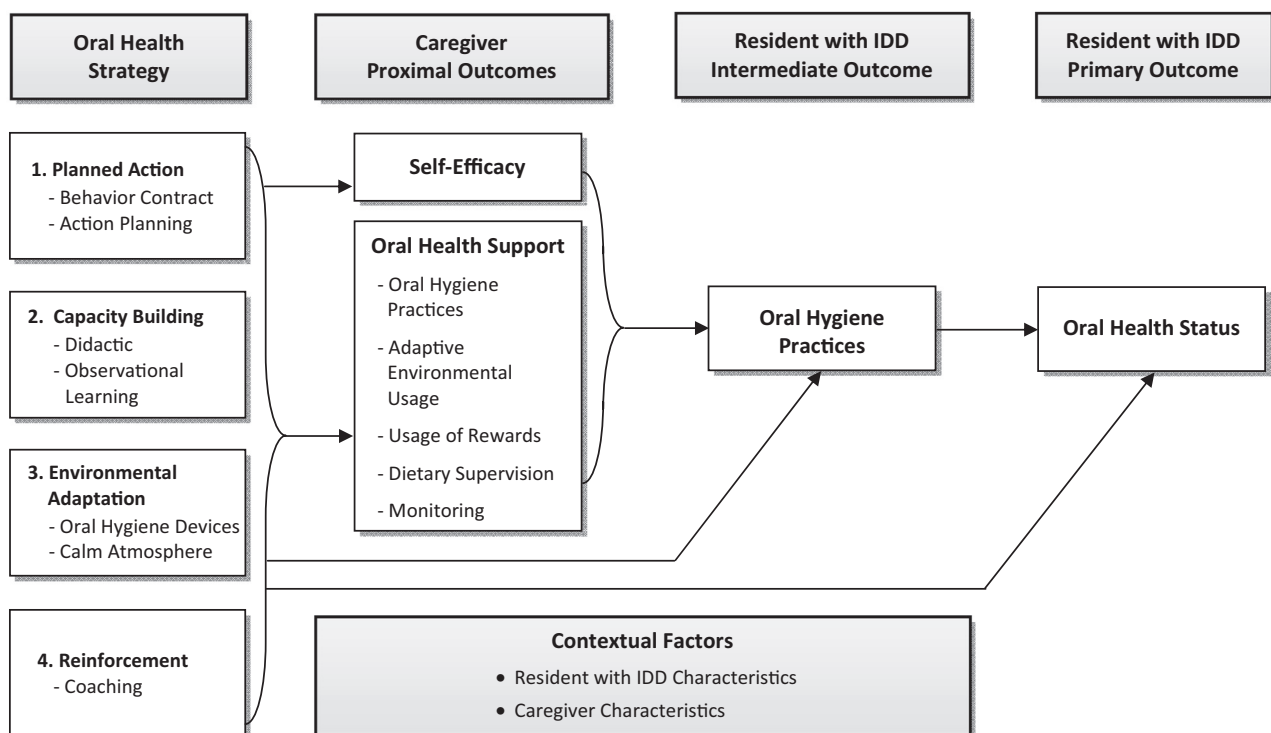


Fig. 1. Conceptual view of an oral health strategy for residents with IDD living in group homes.

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