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Feeling Good About Your Smile: Implementation and Evaluation of an Oral Health Intervention for People With Intellectual Disability

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Abstract

To address the need to improve oral health among people with intellectual disability (ID), the Kansas Disability and Health Program provided workshops to groups of adults with ID as a prevention strategy. *Feeling Good About Your Smile*, a hands-on experience, was delivered by trained Registered Dental Hygienists to 63 adults with ID accompanied by 24 supporting family or attendants in seven workshops. Program evaluation data indicate participants improved their knowledge about how to care for their teeth and mouths. Implications for future research, policy, and practice are discussed.

Key Words: *intellectual disability*; *oral health*; *dental care*

Nearly two decades ago the U.S. Surgeon General's report, *Oral Health in America*, acknowledged the need to improve oral health among people with intellectual disability (ID) (U.S. Department of Health and Human Services [HHS], 2000). The consequences of poor oral health range from pain and difficulty eating to exacerbated chronic health conditions that lead to poor overall health outcomes (Anders & Davis, 2010; Ervin & Dye 2009; Sheiham, 2005). The impacts of poor oral health, in turn, can interfere with meaningful employment, social relationships, leisure activities, civic participation, and inclusion in other aspects of community life (Savage, 2016).

Today, people with ID continue to experience significantly higher rates of poor oral health compared to the U.S. population in general (Anders & Davis, 2010; Campanaro, Huebner, & Davis, 2014; Minihan et al., 2014; Waldron et al., 2017). Limited access to dental care is often cited as an explanation for this health disparity (Prabhu, Nunn, Evans, & Girdler, 2010; Shin & Saeed, 2013). Environmental and social factors that contribute to limited access include lack of insurance coverage, fewer dentists who will work with and are knowledgeable about working with people with ID, and the cost of dental services (Milano, 2017; Prabhu et al., 2010). In fact, many people with ID rely on Medicaid for their health insurance coverage, but the majority of state Medicaid programs do not cover comprehensive dental services for adult beneficiaries (Center for Health Care Strategies [CHCS], 2018). Further, personal characteristics that limit utilization of dental care among people with ID include higher rates of fear or anxiety about seeing a dentist, and complications in care related to other disabilities experienced by the individual (National Institute of Child Health and Human Development [NICHD], 2009; Milano, 2017; Prabhu et al., 2010).

Strategies for improving the underlying reasons for oral health disparities are needed. Many researchers and practitioners call for better dental provider education and training to support and work with people with ID (Milano, 2017; Morad, 2016; Prabhu et al., 2010; Waldman & Perlman, 2006). Others focus on strategies and interventions to change personal behaviors and knowledge (Anders & Davis, 2010; Heger, 2016; Milano, 2017) and the implementation of such interventions in non-traditional, community settings to reach the population where they are (Heger, 2016). Community-based oral health interventions have

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merits and could help to reduce the oral health disparities experienced by people with ID. However, as Anders and Davis (2010) note, "the greatest opportunity to improve oral health for people with ID lies in the development of effective prevention" (p. 115). This article discusses implementation and evaluation of a prevention-focused intervention that presumes competence and empowers adults with ID by providing them facts about oral health and teaching them the skills needed to engage in effective oral care in the community, in locations they already frequent (e.g., community developmental disability organizations [CDDOs] or local Arc chapters).

In the state of Kansas, the Kansas Disability & Health Program (DHP) targeted oral health as part of its state-based program to improve the health of people with mobility limitations and intellectual disability (CDC, 2016). Oral health was selected as one of three target areas based on Kansas Behavioral Risk Factor Surveillance System (BRFSS; Kansas Department of Health & Environment [KDHE], 2015) data indicating significant oral health disparities experienced by Kansans with disabilities. For example, Kansans with disabilities were twice as likely to have no dental insurance compared to those without disabilities (46% versus 23%) (Kansas Department of Health and Environment [KDHE], 2015). They were also nearly three times as likely to need, but not receive, dental care (25% versus 9%) (KDHE, 2015). In fact, Kansans with disabilities reported a significantly lower rate of visiting a dentist in the prior year than those without disabilities (54.3% versus 71.0%) (KDHE, 2015). People with disabilities were almost twice as likely to have permanent teeth removed than those without disabilities (52.7% versus 28.5%) (KDHE, 2014). Further complicating the issue of poor oral health is nutrition and overconsumption of foods high in sugar (Savage, 2016), which can also lead to obesity. A statewide survey of Kansans with disabilities found that 76% of people with ID reported having a body mass index (BMI) that categorized them as overweight or obese as compared to 63% of the state population in general (Hall, Chapman, & Kurth, 2013). The Kansas DHP program chose to initially focus its oral health intervention efforts on adults with ID, given research suggesting that the oral health of people with ID deteriorates quickly in adulthood, with little focus on oral health education outside of school settings (Waldron et al., 2017). Specifically, a preventive strategy intervention, known as *Feeling Good About Your Smile* (Oral Health Kansas [OHK], 2017), designed to improve oral health and by extension health outcomes for adults with ID, was implemented across the state of Kansas with adults with ID. The purpose of this article is to report on the preliminary implementation and evaluation data informing future research and practice on the implementation of oral health interventions in adults with ID.

Method

The Kansas DHP chose to collaborate with OHK in efforts to improve oral health for adults with ID. OHK is a not-for-profit organization in Kansas and was established in 2003 to provide education and advocacy and bring public awareness about oral health issues in Kansas for all people with and without disabilities. OHK's mission includes providing dental health professionals, consumers and the public information about the needs of people with disabilities (OHK, 2019).

Intervention Description

In 2010, Registered Dental Hygienists (RDH) at OHK developed and delivered a curriculum, *Feeling Good About Your Smile (Feeling Good)*, for improving knowledge and behaviors among people with ID who received services and supports from a CDDO. In 2016, an RDH from OHK and the Kansas DHP team worked together to update the *Feeling Good* curriculum to incorporate current oral health practices and best practices for working with and teaching people with ID. The revisions also included addition of a pre/post-test evaluation for participants to complete. The resulting *Feeling Good* intervention was implemented by the Kansas DHP staff as a 90-minute, in-person workshop led by an RDH. The course utilizes hands-on experiments, demonstrations, and plain language to teach people with ID how to best care for their teeth in order to improve and maintain good oral health. Topics covered during the workshop include:

- How sugar and cavity causing bacteria/germs attack teeth and cause cavities,
- How certain foods and drinks can harm teeth more than others,
- How to choose the healthy foods and drinks that are good for teeth, and

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Step-by-step instructions for how to thoroughly brush and care for teeth and gums.

Workshop participants are guided through hands-on experiments to illustrate the concepts listed above. A visual experience replicates how sugar and germs can attack teeth. Each participant places various liquids representing specific foods and drinks onto a "fake tooth," which consists of an antacid tablet (Figure 1). For another activity participants are asked to choose foods and drinks that are good or bad for their teeth and place them in the corresponding good and bad bags. Finally, they rub Plak-Check swabs with yellow sodium fluorescein (a harmless, tasteless liquid that adheres to plaque and germs making them visible under a black light) on their teeth to more easily see the areas of their teeth that have plaque and germs. Then they are instructed how to best brush their teeth to remove the illuminated plaque and germs thoroughly. For many of the participants who have completed the workshop, this activity is their favorite and something they remember later. The instruction itself and activities take approximately 60 minutes to complete leaving 30 minutes for questions and answers, addressing participant concerns individually, and completing the pre- and post-test evaluations (Figure 2).

Brushing and taking care of one's teeth is seen by many, with and without disabilities, as a burden or chore they would rather skip. Likewise, visits to the dentist may be avoided due to anxiety or fear regardless of having a disability. Therefore, we considered it important for *Feeling Good* to include easy-to-understand definitions and plain language explaining why maintaining good oral health behaviors is important and the health and social consequences of not doing so. The materials make the case that one must "feel good," physically and mentally, about their smile.

An important part of the *Feeling Good* intervention is the requirement that people with ID be accompanied to the workshop by a family member, someone the individual employs as a direct support professional (DSP), or a person who provides support from community-based disability organizations or other agencies, if they receive services and supports. We found that by including someone who regularly sees the individual with ID, this person can reinforce or provide reminders of good oral health habits taught during the workshop. In some instances, one supporter for multiple participants attended. We acknowledge that some people with ID may need physical supports to engage in oral health care; however, the focus of this workshop was adults with ID who are able to care for their own mouths and teeth with limited or no physical assistance.

Figure 1. Hands-on experiment illustrating tooth decay.

Intervention Delivery in Kansas

The RDH who developed the *Feeling Good* curriculum conducted workshops and trained two additional RDHs to lead workshops across the state of Kansas. These three RDHs individually conducted *Feeling Good* workshops. The DHP provided them with trainer kits, including materials for conducting the experiments and hands-on learning experiences, such as reusable bowls, squeeze bottles, white antacid tablets, food coloring, baking soda, small mirrors, plastic spoons, paper towels, hand-held lights, Plak-Check swabs, individual flossers, mini trash bins, plastic/wooden food. Items for participants to take-home were also provided and included toothbrushes, toothpaste, reminder magnets, and mirror clings with photos depicting toothbrushing steps that stick to a bathroom mirror or wall. Finally, the kit also contained copies of pre- and post-test forms for participants and instructors submitted these completed evaluation documents to DHP after each workshop they conducted.

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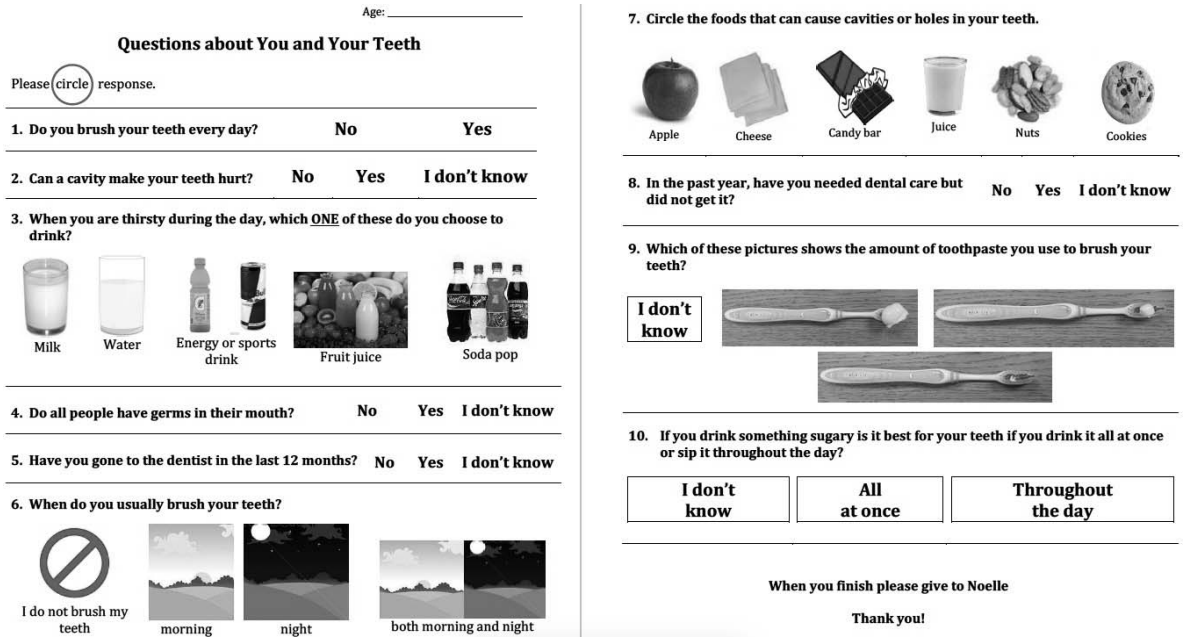

Figure 2. Participant pre- and post-test.

Participant Recruitment

Informational flyers about the opportunity to host a *Feeling Good* workshop were distributed to organizations that support people with disabilities, including Centers for Independent Living (CILs) and CDDOs across Kansas. Interested organizations were asked to provide a physical space to deliver the workshop and assist DHP with outreach and recruitment of participants in their locations. Between March 2016 and October 2018, seven workshops were delivered in urban and rural settings across the state with 87 participants (63 people with ID and 24 support family/staff/attendants/caregivers).

Participant Characteristics

The 63 participants with ID in *Feeling Good About Your Smile* workshops in Kansas ranged in age from 19 to 67 with an average age of 37.9 (see Table 1). Slightly more females participated (55.5%) than males. Participants all had at least some of their permanent teeth, but 19% reported they were missing one or more teeth. A majority of participants, 81.8%, had visited a dentist in the last year, while 40% said they needed dental care of some kind in the past year but did not get it.

Measures

Because the implementation of the *Feeling Good About Your Smile* intervention was part of a non-research focused CDC-funded initiative, data collection was limited to individual-level pre-

Table 1
Workshop Participant Characteristics

Group	*n*	% of *n*
All participants	87	—
Participants with ID	63	72.4
Supporter	24	27.6
Participants with ID	63	—
Female	35	55.5
Male	29	44.5
Mean age (Range)	37.9 years	(19–67)
Missing some teeth	12	19.0
Visited a dentist in the last 12 months*	45	81.8
Needed dental care in the last 12 months but did not get it**	24	40.0

*$n = 55$ due to non-response by participants on this pre-test item.
**$n = 60$ due to non-response by participants on this pre-test item.

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Table 2
Workshop Evaluation Results

Item	Item *n*	Correct response PRE-Workshop	Correct response POST-Workshop
Behaviors			
[Currently/Will] Brush teeth at least once per day	58	82.8%	94.8%
[Currently/Will] Brush teeth both morning and night	60	53.3%	83.3%
Knowledge			
Do all people have germs in their mouth?	63	57.1%	79.4%
Can a cavity make your tooth/teeth hurt?	55	70.9%	80.0%
If you drink something sugary is it best for your teeth to drink it all at once or throughout the day?	47	25.5%	53.2%
Which picture shows the amount of toothpaste you use/will use to brush your teeth?	50	50.0%	76.0%
Which foods can cause cavities or holes in your teeth?	42	28.6%	40.5%
When you are thirsty which ONE do/will you choose to drink? [water]	55	32.7%	47.3%
TOTAL individuals who improved on at least one item between pre and post	63		84.4%

Notes. Varying *n* for items is due to participant non-response on pre-test, post-test or both; "I don't know." option provided for all items and included as not having correct response.

and post-intervention evaluation. The DHP staff developed a pre/post evaluation instrument to determine the effectiveness of the intervention in improving the oral health knowledge and behaviors of participants. The instrument included items directly related to the four intervention objectives: (1) understanding of how and why oral health is important; (2) understanding of how sugar, germs, and acid can attack teeth; (3) knowledge of which foods and drinks are best for health; and (4) how to brush and care for one's teeth. The evaluation instrument (Figure 2) is written in plain language and can be completed by participants on their own, with the assistance of supporters and/or read aloud by the workshop instructor, depending on the needs and preferences of the group. The participants with ID completed evaluation forms at the start of the workshop, prior to any instruction, and completed them again after instruction was completed. Assistance with reading items and writing their responses on the evaluation forms was provided by supporters, as participants needed or requested such assistance. Post-workshop evaluations additionally included four open-ended items asking for participants' feedback about the workshop. The information collected on the evaluation instrument was descriptively analyzed to determine the preliminary impacts of the program on targeted outcomes.

Results

Evaluation Findings

Findings from the pre/post-test responses of the 63 adults with ID on the evaluation instrument were utilized to provide preliminary information on the effectiveness of the intervention in increasing participants' oral health knowledge. The findings are summarized in Table 2. Although participants' knowledge in some areas was satisfactory before participating in *Feeling Good*, the most pronounced areas of improvement were in regard to drinking sugary beverages all at once rather than throughout the day in order to prevent prolonged sugar/acid attack on teeth, and using the correct amount of toothpaste to effectively brush teeth. After the workshop, more participants also reported that they now plan to brush their teeth in the morning and at night (83.3%) than those who reported doing so previously. These findings align with the areas emphasized and repeated in numerous ways throughout the workshop, and they correspond directly to the objectives of the workshop.

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Table 3
Workshop Participant Feedback

Item	Five Most Frequent Participant Responses
What was your favorite part of the Workshop?	The experiment showing how sugar/germs attack teeth Using the light to see germs on my teeth Brushing everything off my teeth after seeing it with the light Learning how to brush back of mouth, tongue, all teeth Getting stuff (toothbrush, toothpaste, mirror clings, magnets)
What did you not like about the Workshop?	Nothing, liked everything Not rinsing after brushing teeth Seeing the germs on my teeth with the light I didn't learn anything I didn't already know or dentist told me Brushing my tongue
What is one thing you learned from the workshop?	Sugar is bad for your teeth It is important to brush teeth twice a day Foods that are good and bad for teeth Bad teeth can make my body sick How I should drink sugary drinks or soda all at once, not all day long (acid attack) and/or drink less soda pop
Would you tell a friend that you liked the Workshop or that it was helpful?	52 of 58 individuals answering this question said Yes, 89.7%

Participant Feedback

As part of the post-test evaluation, participants with ID answered four open-ended questions about their impressions of the workshop. If participants requested or needed assistance writing their responses to these items, it was provided by supporters. In general, participants had positive things to say about the workshop and what they learned. In fact, when asked what part of the *Feeling Good* workshop they did not like, many said they liked all of it and could not report a part they did not like. The majority said they would tell a friend that the workshop was good and worth their time. With respect to what participants learned and liked the most about the workshop, the top five responses for each question are provided in Table 3. The participant feedback supports the findings from the pre/post evaluation of increased oral health knowledge in key areas.

Discussion

The *Feeling Good About Your Smile* program evaluation data from seven workshops with 63 adult Kansans with ID, show improved oral health knowledge for a majority of participants. Expanding the implementation of the *Feeling* Good intervention is planned by another state DHP in the coming year, which will not only increase the number of individuals receiving the intervention, but the same evaluation measure will be utilized, resulting in more data to provide further insight into the effectiveness and impact of the intervention. In order to fully measure the impact of the intervention on participants with ID, further research is needed that includes a follow-up evaluation conducted at a set interval of time after the workshop to examine the maintenance of the impact of the workshop. For the first three workshops, a 3-month follow-up evaluation was attempted, however a majority of the participants were either unable to be reached or did not want to answer the questions. The small number of workshops held to date and the limited number of participants does not allow for rigorous evaluation of the intervention and more workshops and evaluation data need to be collected to fully measure impact and effectiveness. Though not the purpose of the study, it is important to note that more work is needed to examine the generalizability of these findings and the long-term impacts of the workshop on outcomes.

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Additionally, as previously noted by researchers, in order to decrease the oral health disparities experienced by people with ID (and all people with disabilities), interventions must be implemented at both the individual or person-level and systemically. The *Feeling Good* intervention empowers people with ID to improve their own oral health. However, work is needed at the systemic level to improve access to appropriate oral health care to truly decrease oral health disparities. As such, service providers, family members, and advocates should work to assure that Medicaid coverage in their states includes comprehensive dental care and that dental school curricula include instruction on making services accessible to people with disabilities. As noted by Milano (2017), "elimination of this [oral health] disparity and its implications on quality of life should become a public health priority" (p. 115). Indeed, improved access to oral health care is one step in improving inclusion of people with ID in their communities. The impact of combined efforts to provide education to people with ID and to make systemic changes is needed.

References

Anders, P. L., & Davis, E. L. (2010). Oral health of patients with intellectual disabilities: a systematic review. *Special Care in Dentistry*, *30*, 110–117. doi:10.1111/j.1754-4505.2010.00136.x

Campanaro, M., Huebner, C. E., & Davis, B. E. (2014). Facilitators and barriers to twice daily tooth brushing among children with special health care needs. *Special Care in Dentistry*, *34*, 185–192. doi:10.1111/scd.12057

Centers for Disease Control and Prevention (CDC), National Center on Birth Defects and Developmental Disabilities. (2016). *Improving the health of people with mobility limitations and intellectual disabilities through state-based public health programs*. CDC-RFA-DD16-1603. Atlanta: Author.

Center for Health Care Strategies (CHCS). (2018). *Medicaid adult dental benefits: An overview. CHCS Fact Sheet*. Retrieved from www.chcs.org/media/Adult-Oral-Health-Fact-Sheet_051617.pdf.

Ervin, R. B., & Dye, B. A. (2009). The effect of functional dentition on Healthy Eating Index scores and nutrient intakes in a nationally representative sample of older adults. *Journal of Public Health Dentistry*, *69*(4), 207–216. doi:10.1111/j.1752-7325.2009.00124.x

Hall, J. P., Chapman, S. L., & Kurth, N. K. (2013). Poor oral health as an obstacle to employment for Medicaid beneficiaries with disabilities. *Journal of Public Health Dentistry*, *73*(1), 79–82. doi:10.1111/j.1752-7325.2012.00359.x

Heger, N. (2016). Power to the patient. In *The future of oral health: Global challenges, advances, and new technologies* (pp. 20–23). New York: Scientific American Custom Media Group and Colgate.

Kansas Department of Health and Environment. (2014). *Behavioral risk factor surveillance system* (BRFSS). Retrieved from http://www.kdhe.ks.gov/brfss/Questionnaires/quest2014.html

Kansas Department of Health and Environment. (2015). *Behavioral risk factor surveillance system* (BRFSS). Retrieved from http://www.kdhe.ks.gov/brfss/Questionnaires/quest2015.html

Milano, M. (2017). Oral Healthcare for persons with intellectual or developmental disabilities: Why is there a disparity? *Compendium of Continuing Education in Dentistry*, *38*(10), e5–e8.

Morad, R. (2016). Attention on prevention. In *The future of oral health: Global challenges, advances, and new technologies* (pp. 24–28). New York: Scientific American Custom Media Group and Colgate.

Minihan, P. M., Morgan, J. P., Park, A., Yantsides, K. E., Nobles, C. J., Finkelman, M. D., Stark, P. C., Must, A. (2014). At home oral health care for adults with developmental disabilities. *Journal of the American Dental Association, 145*(10), 1018–1025. doi:10.14219/jada.2014.64

National Institute of Child Health and Human Development (NICHD). (2009). *Practical oral care for people with intellectual disability*, NIH Publication No. 09–5194. Bethesda, MD: Author.

Oral Health Kansas (OHK). (2019). *Oral Health Kansas* [website]. http://www.oralhealthkansas.org/AdultsDisabilities.html

Oral Health Kansas (OHK). (2017). *Feeling good about your smile: Intervention to improve oral health for adults with intellectual and developmental disabilities*. Topeka, KS: Author.

Prabhu, N. T., Nunn, J. H., Evans, D. J., & Girdler, N. M. (2010). Access to dental care—parents' and caregivers' views on dental treatment services for people with disabilities.

DOI: 10.1352/2326-6988-7.3.169

Special Care in Dentistry, *30*(2), 35–45. doi:10.1111/j.1754-4505.2009.00127.x

Savage, N. (2016). Crossing the dental divide. In *The future of oral health: Global challenges, advances, and new technologies* (pp. 6–13). New York: Scientific American Custom Media Group and Colgate.

Sheiham, A. (2005). Oral health, general health and quality of life. *Bulletin of the World Health Organization, 83*(9), 644–644.

Shin, C. J., & Saeed, S. (2013). Toothbrushing barriers for people with developmental disabilities: a pilot study. *Special Care in Dentistry*, *33*, 269–274. doi:10.1111/scd.12024

U.S. Department of Health and Human Services (DHHS), 2000. *Oral health in America: A report of the Surgeon General – Executive summary*. Rockville, MD: National Institution of Dental and Craniofacial Research.

Waldman, H. B., & Perlman, S. P. (2006). Mandating education of dental graduates to provide care to individuals with intellectual and developmental disabilities. *Mental Retardation*, *44*(3), 184–188. doi:10.1352/0047-6765(2006)44[184:MEODGT]2.0.CO;2

Waldron, C., Phadraig, C. M., Nunn, J., Comiskey, C., Donnelly-Swift, E., Guerin, S., & Clarke, M. J. (2017). Oral hygiene programmes for people with intellectual disabilities. *Cochrane Database of Systematic Reviews*, *4*(CD012628). doi:10.1002/14651858.CD012628

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