Intellectual and Developmental Disabilities

Preliminary results of an interdisciplinary program improving dental care access for adults with intellectual/developmental disabilities

--Manuscript Draft--

Manuscript Number:	IDD-D-21-00025R3
Article Type:	Research
Keywords:	oral health; behavior therapy; dental exam; graduated exposure; adults with intellectual and developmental disabilities
Corresponding Author:	John Berens, MD Baylor College of Medicine Houston, TX UNITED STATES
First Author:	John C Berens, MD
Order of Authors:	John C Berens, MD
	Loukia Tsami, MA
	Dorothea C Lerman, PhD
	Marissa Matteucci, BA
	David F Fray, DDS
	Ben F Warner, DDS, MD
	Laura A Keehan, BS
	Kristen A Staggers, MS
	Cynthia Peacock, MD
Manuscript Region of Origin:	UNITED STATES
Abstract:	Adults with intellectual/developmental disabilities (AIDD) experience significant oral health disparities, partially due to perceived behavioral issues. This paper describes the preliminary outcomes of a developing interdisciplinary (dental, medical, behavioral) program involving a behavioral intervention for AIDD previously receiving preventative dental care with sedation, general anesthesia, or protective stabilization (SAS). After a baseline assessment, a board-certified behavior analyst® implemented increasingly complex behavioral interventions during simulated dental visits. Prior to COVID-19 pandemic-related restrictions, there were 32 active participants; 15 (46.9%) successfully completed a focused, real dental exam with simple behavioral interventions and 17 (53.1%) remain in treatment. These preliminary results suggest that many AIDD previously receiving SAS may participate in a preventative dental exam with minimal behavioral supports, if given the opportunity.

training dentists/dental students with these procedures, and we have included this information in the manuscript.

Preliminary results of an interdisciplinary behavioral program to improve access to preventative dental care for adults with intellectual/developmental disabilities

TITLE: Preliminary results of an interdisciplinary behavioral program to improve access to preventative dental care for adults with intellectual/developmental disabilities

Abstract

Adults with intellectual/developmental disabilities (AIDD) experience significant oral health disparities, partially due to perceived behavioral issues. This paper describes the preliminary outcomes of a developing interdisciplinary (dental, medical, behavioral) program involving a behavioral intervention for AIDD previously receiving preventative dental care with sedation, general anesthesia, or protective stabilization (SAS). After a baseline assessment, a board-certified behavior analyst® implemented increasingly complex behavioral interventions during simulated dental visits. Prior to COVID-19 pandemic-related restrictions, there were 32 active participants; 15 (46.9%) successfully completed a focused, real dental exam with simple behavioral interventions and 17 (53.1%) remain in treatment. These preliminary results suggest that many AIDD previously receiving SAS may participate in a preventative dental exam with minimal behavioral supports, if given the opportunity.

Keywords: oral health; behavior therapy; dental exam; graduated exposure; adults with intellectual and developmental disabilities

Preliminary results of an interdisciplinary behavioral program to improve access to preventative dental care for adults with intellectual/developmental disabilities

Adults with intellectual and developmental disabilities (AIDD) have a higher incidence of poor oral health, dental caries, and tooth loss, and they receive less dental treatment than those without IDD (Anders & Davis, 2010; Kancherla et al., 2013; Koritsas & Iacono, 2011; Morgan et al., 2012; for reviews, see Ward et al., 2019; Wilson et al., 2018; Zhou et al., 2017). Oral health is an essential component of general health and quality of life (Nazir et al., 2019), and poor oral health has been associated with an increased risk of diabetes, cardiovascular diseases, and stroke (U.S. Department of Health and Human Services, 2000). More immediately, oral pain or discomfort can impact nutrition and quality of life and potentially lead to unintended behavioral changes. These behaviors combined with the historically limited training most general dentists receive in caring for AIDD may result in utilization of more invasive measures to achieve dental care.

Uncooperative behavior during dental exams is at least partly responsible for oral health problems in those with IDD (Duker et al., 2017; Gabre et al., 1999; Morgan et al., 2012) and is one of the most common reasons that dentists report for excluding individuals with special health needs from their practice (Derbi et al., 2016). Failing to follow necessary instructions (e.g., open the mouth) and engaging in problem behavior (e.g., aggression, crying) are significant barriers to preventative care and treatment. The physical and sensory stimuli associated with dental exams may evoke emotional responses (e.g., fear) and escape behavior (e.g., noncompliance) that compete with cooperation (Altabet, 2002; Cumuella et al., 2000). Some individuals with disabilities in motor or receptive language skills also may have challenges following dentists' instructions.

Some dentists who treat AIDD use sedation, general anesthesia, or protective stabilization (SAS) as the standard of care during preventative dental exams (Boynes et al., 2010; Connick et al., 2000a; Dougherty, 2009). Surveys indicate these methods are used in the United States and other countries due to actual or expected low levels of cooperation (e.g., Chang, et al., 2014; Hulland & Sigal, 2000; Lim & Borromeo, 2017, 2019; Prabhu et al., 2008; Savanheimo et al., 2012). Dentists likely rely on these methods because 1) they have not received adequate training on alternative interventions to improve compliance; 2) they assume that these alternative interventions will be ineffective for individuals with more severe disabilities; and/or 3) non-adherence may become expected due to prior unsuccessful attempts at dental care without SAS (Casamassimo et al., 2004; Connick et al., 2000b). As a result, dentists continue to use SAS despite calls to restrict these methods to individuals not responding to behavioral interventions (e.g., Lim & Borromeo, 2019).

Use of SAS is associated with undesirable side effects and may increase the risk of physical harm to the patient. Dental professionals have reported complications from general anesthesia (e.g., nausea, vomiting, and airway obstruction) in as many as 24% of individuals with special needs (Boynes et al., 2010). Likewise, nearly 16% of individuals with IDD receiving dental procedures with sedation may encounter side effects including nausea, vomiting, and hyperexcitability (Collado et al., 2013). Both individuals and staff have experienced physical injury in facilities that employ therapeutic holds to manage problematic behavior (see Reed et al., 2013 for a review). Not only does SAS carry some level of physical risk, but they may also be an additional barrier to regular dental care if the individual's caregivers are opposed to their use (e.g. concern for stabilization-related trauma and post-treatment anxiety) or cannot afford the additional cost of care, particularly hospital-based dentistry and anesthesia (Duker et al., 2017).

Although few studies have assessed the reasons for uncooperative behavior during dental exams, most behavioral interventions for this problem are based on a presumption that problem behavior is maintained by escape or avoidance of aversive stimuli associated with dental exams. A growing literature has demonstrated the effectiveness of behavioral interventions for increasing cooperative behavior or decreasing physiologic measures of fear in individuals with IDD during dental exams (Kupzyk & Allen, 2019; Lyons, 2009). These interventions vary in terms of complexity, ease of implementation, necessity for supplementary (adjunctive) therapy, compatibility with routine dental procedures, and evidence of effectiveness.

Systematic desensitization, or graduated exposure (GE), is one type of behavioral intervention with an extensive amount of empirical support for promoting compliance during dental exams (e.g., Altabet, 2002; Carter et al., 2018; Cuvo et al., 2004; Luscre & Center, 1996; Nelson et al., 2000; Szalwinski et al., 2019). This approach gradually exposes the individual to the instructions and stimuli associated with dental exams, typically by breaking down the dental procedure into a sequence of steps (e.g., sit in the chair, permit application of a bib). In behavior analysis, this is sometimes called a "task analysis." Behavioral therapists gradually increase the amount, duration, or intensities of the steps and associated stimuli (e.g., sound of the dental equipment) while coaching the participant to engage in relaxation responses. Research on GE with individuals with IDD typically focus on gradual exposure to the dental exam steps while excluding elements of traditional systematic desensitization (e.g., relaxation training). In most studies, therapists provided reinforcement for compliance or tolerance to the current steps and prevented the individual from escaping the exam unless they complied with the steps (i.e., combining GE with escape extinction). Although research findings suggest GE can be highly effective, most studies did not assess participants' compliance during actual dental exams.

Several limitations make GE less desirable as a first-line strategy. Successful treatment typically requires numerous therapy sessions due to the gradual introduction of steps and because sessions may be more effective when implemented more frequently, e.g., multiple sessions per week (Szalwinski et al., 2019). Individuals with more severe disabilities may be less likely to benefit from this intervention (e.g., Nelson et al., 2017). GE also is relatively complex compared to other interventions, so it may take more training or experience to implement these strategies over simpler ones. Nevertheless, the increased time and potential costs still must be weighed against the strategy's potential effectiveness and the costs of SAS.

A number of studies have examined relatively less intensive approaches for promoting dental exam compliance, such as providing patients with continuous access to preferred auditory and visual stimuli like movies or music (Fakhruddin & Batawi, 2017; Isong et al., 2014; Suresh & George, 2019). Often called "distraction," this approach may promote cooperation by reducing the averseness of the dental exam. It has been associated with reductions in physiological measures of fear or anxiety (i.e., heart rate) and improved scores on behavior or anxiety rating scales for some participants during dental exams. A related intervention, "sensory adapted environment," focuses on modifying sensory stimuli in the dental treatment room (e.g. darkening the room or placing weighted wraps or aprons on participants; Cermak et al., 2015; Kim et al., 2019; Potter et al., 2018). However, results suggest that these modifications have weak and inconsistent effects on behavioral measures of cooperation for individuals with IDD. Furthermore, no studies evaluating the effectiveness of either method reported the number of exam steps completed by the practitioner.

Other procedures intended to promote compliance, such as video models, visual schedules, "tell-show-do" (describing and demonstrating each step of the dental procedure), and

frequent short breaks from dental procedures, have produced inconsistent results when studied in isolation (e.g., Mah & Tsang, 2016; Schindel et al., 2011) or have only been evaluated with young, typically developing children (e.g. Allen & Wallace, 2013). However, when implemented as part of complex intervention packages (e.g., Maguire et al., 1996; Orellana et al., 2014), participants with IDD have demonstrated improvement in the number of dental steps completed, regardless of cognitive level.

In sum, research has demonstrated that behavioral interventions can improve the cooperation of individuals with IDD during dental exams, which supports calls for restricting routine use of SAS to patients who do not respond to these interventions (e.g., Lim & Borromeo, 2017, 2019). However, behavioral interventions with the most empirical support, such as GE or approaches combining multiple procedures, tend to be the most complex and intensive. The cost, time, and expertise needed to implement these interventions make them less ideal for dentists to adopt as the first-line standard of care to address uncooperative behavior during exams. Other less intensive interventions (e.g. frequent breaks, Allen & Wallace, 2013), have not been evaluated in adults with IDD. Research also indicates that none of these interventions, either alone or in combination, will be effective for every patient. These findings highlight the need for additional research exploring less intensive approaches that dentists could implement with minimal training and thus be more widely and immediately applicable.

In this manuscript, we report the preliminary outcomes of a developing program that employs an interdisciplinary team (behavior therapist, dentist, and physician) and a hierarchical approach to the selection and evaluation of behavioral interventions for AIDD who have a history of receiving SAS during routine dental exams. As a first step in program development, we evaluated the efficacy of relatively simple interventions during mock dental exam performed

by a behavioral therapist before exposing the patients to an actual exam with a dentist. The primary aim of this study was to determine whether patients who had previously relied on SAS could complete a dental exam with minimal behavioral support. Secondary aims were to assess the feasibility and acceptability of these behavioral interventions in oral health care and to identify any factors that might predict the need for behavioral intervention prior to completing a dental exam without SAS. While the program is still in progress, this manuscript describes the preliminary results and experiences that have potential real-world significance.

Method

Participants and Setting

Study participants were identified by routine screening questions directed to the support person and, if appropriate, to the AIDD, during a medical visit at an academic primary care clinic serving AIDD (Berens & Peacock, 2015). Individuals were invited to participate if they were previously unable to receive routine preventative dental care without the use of 1) protective stabilization (restraint), defined as any restriction of the limbs or face beyond gentle redirection (e.g., for an individual with uncontrolled limb movements); 2) intravenous ("conscious") sedation, defined as any type of intravenous medication used to decrease level of consciousness and performed in the office setting; or 3) general anesthesia, a deeper form of sedation requiring respiratory support and typically occurring in a hospital or operating room. In some cases, dentists had recommended these measures due to an unsuccessful routine dental exam, but the individual had not actually experienced SAS at the time of study enrollment. Participants with limited English proficiency were excluded from the study.

A total of 37 patients were recruited, of which 5 withdrew shortly after enrollment (see Figure 1 for a process map of recruitment and procedural overview). The majority (N=23, 71.9%) were male with a median age of 23 (range 19-36 years) and represented a diverse sample

across race/ethnicity and primary medical diagnosis, coinciding with the larger clinic population (Berens & Peacock, 2015). All participants had an intellectual disability of varying degree, and 23 (71.9%) individuals had guardianship in place. Table 2 summarizes additional demographic information including medical insurance coverage, basic medical information, functional ability, and caregiver-reported problem behavior for participants. Caregivers described a wide range of home dental hygiene practices, but the majority of participants had at least some assistance from a caregiver in brushing their teeth. Table 3 shows information on participants' dental history including prior use of SAS and caregiver expectations for compliance and problem behavior; these instruments were created for this study and can be found in full in Table 4.

All study activities took place within the medical primary care setting in a procedure room that included a reclining exam table, overhead light, and a procedure tray containing the necessary dental equipment: electric toothbrush, flosser, scaler, mirror, suction, oral irrigation device, bib, and bite block. The investigatory team was comprised of 1) board certified behavior analysts®, who conducted mock exams using a variety of behavioral interventions, 2) dentists, who conducted the actual preventative dental exam (two of whom had prior experience caring for AIDD), and 3) physicians, who helped coordinate the interdisciplinary team, recruit participants, and provide logistical support. The entire team was involved in ongoing program development and evaluation.

Ethics

Prior to project activities, investigators obtained consent from the participant or their guardian or next of kin if the participant did not have capacity. The majority of participants did not have capacity, as would be expected given the proportion with guardianship in place. Assent was built into program procedures as described below; the program was also described to

individuals in a developmentally appropriate manner at the time of consent and assent was obtained verbally whenever possible. Participants' caregivers were invited to be present during all procedures if desired. The study obtained institutional review board approval from the primary study site, affiliated dental school, and affiliated behavioral analysis program.

Measures

An investigator collected demographic information through electronic health record review and information regarding a participant's dental background, including the need for SAS, through caregiver report. Investigators assessed caregiver-reported expectations of a participant's compliance and problem behavior during dental visits using a series of original questions on a 6-point scale (see Table 4). After the initial visit, the research team administered the Vineland Adaptive Behavior Scale and Aberrant Behavior Checklist by telephone (Sparrow et al., 2005; Aman et al., 1985).

With the input of dental professionals, a routine dental exam was broken down into component steps in a task analysis (see Table 1), which was the framework to measure the percentage of steps completed by participants throughout the study. A board certified behavior analyst® ("therapist") always performed a mock exam (e.g., touched the teeth with the floss pick but did not actually floss). All exams were video recorded using Zoom™, a HIPAA-compliant videoconferencing software, for later analysis. Investigators viewed the videotaped sessions and recorded whether each step in the task analysis was attempted and completed. An attempted step was defined as the therapist providing the corresponding antecedent (presentation and description of the tool used, and if applicable, the instruction to complete the step) before the patient engaged in problem behavior or was non-compliant (i.e., refused or was unable to complete the step). For example, the therapist held the toothbrush and described that she was

going to clean the participant's teeth and then provided the instruction "open your mouth". A completed step was defined as the therapist providing the relevant antecedent and the patient complying with or tolerating the step. For example, after the therapist provided the instruction "open your mouth," the patient opened his/her mouth and held it open for at least 15 s while the therapist examined the teeth. The percentage of completed steps was calculated by dividing the total number of completed steps by the total number of potential steps. Any steps that a participant could not physically perform (e.g., sitting on the exam table for participants in wheelchairs) were omitted from the calculation.

Two observers collected data independently for a convenience sample involving 42% of the sessions for the purpose of measuring inter-observer agreement (IOA) of completed steps; discrepancies were noted but not resolved. IOA was calculated by dividing the number of agreements by the number of agreements plus disagreements of applicable steps and converted to a percentage. Mean IOA was 96% (range 83% to 100%). In addition to the video recording of the dental exam, dentists reported the steps that they were able to complete during their actual dental exam and completed Frankl's behavior rating scale (Frankl et al., 1962), one of the most commonly used behavior rating scales in pediatric dentistry (Riba et al., 2017). With the Frankl behavior rating scale, the dentist uses a 4-point scale (definitely positive, positive, negative, and definitely negative) to rate the patient's attitude and cooperation during an exam. Investigators collected information regarding the dental procedures performed and the time spent during the encounter. Upon successful completion of a dental exam, each participant's caregiver completed a survey reporting their views on the acceptability of program procedures, their potential to affect future change, and how the outcome matched their expectations (see Table 5).

An investigator collected data on the procedural integrity of the therapist and the dentists for 50% of the participants. Mean procedural integrity for the behavior therapist was 88% (range, 79 - 98%) during baseline and 82% (range, 75 - 96%) during intervention sessions. Mean procedural integrity for the dentists was 63% (range, 45 - 78%) during the dental exam. Mean IOA for procedural integrity was 96% (range, 91 - 100%) during baseline, 97% (range, 93 - 100%) during intervention, and 96% (range, 90 - 100%) during the dental exam.

Conditions

Overview

The therapist began with an assessment using techniques that dentists commonly employ with pediatric or anxious patients (i.e., tell-show-do, frequent brief breaks, praise for cooperation; e.g., Allen & Wallace, 2013) but that have not yet been well-established as efficacious for AIDD. Participants who completed at least 90% of mock dental exam steps during this initial ("baseline") assessment then received an exam from a dentist. For the remaining patients, the behavior therapist systematically introduced additional intervention components, starting with the least intensive procedure (continuous access to preferred stimuli) and, as needed, progressing to more intensive procedures (contingent reinforcement, graduated exposure), until the participant completed at least 90% of mock exam steps. The participant then received a real exam from a dentist, in coordination with the therapist, as the final measure of program success.

In all conditions, the encounter began with the therapist (mock exam) or dentist (true exam) making a welcoming statement and providing a couple of compliments to the participant. The therapist or dentist then presented each step in the task analysis while implementing the following procedures: 1) Described each step (e.g. "I'm going to look at your teeth now"),

prompted the participant to touch the object involved in the step as applicable (e.g. the mirror), and then delivered an instruction ("open your mouth") prior to attempting each step ("tell-show-do"); 2) Delivered enthusiastic praise contingent on each completed step; and 3) Provided 15-s breaks after 15 s of continuous dental work by placing all dental tools on the tray and turning off all equipment. The intent of these procedures was to reduce the aversiveness of the dental exam by making the steps more predictable (i.e., "tell-show-do"), providing positive reinforcement for cooperative behavior (i.e., praise for compliance), and scheduling frequent breaks from the exam (Allen & Wallace, 2013). To avoid escalations in problem behavior, the therapist or dentist provided a 10 to 15-s break contingent on noncompliance. The uncompleted step was then reattempted with verbal instruction if applicable (e.g. placing the bib on did not require participant intervention so no instruction was provided) for a maximum of three times, moving to the next step regardless of completion of the prior step. The participant was never restrained or prevented from leaving the room. If the participant refused to remain in the room or engaged in severe problem behavior, the session was immediately terminated. If the participant refused to sit in the dental chair, the dentist or therapist attempted the steps in alternate positions as feasible (e.g. seated in a regular chair).

Baseline

During a single appointment, the therapist first used the interventions described above to perform a baseline assessment of participants' completion of the task analysis steps. The therapist referred the participant for an actual dental exam if the individual completed at least 90% of the steps. If the participant completed less than 90% of the steps, the participant received additional behavioral intervention.

Additional Interventions

The therapist implemented the interventions described above but also included additional procedures. The therapist began with the simplest interventions and progressed to more intensive interventions each time a given method failed to increase the percentage of steps completed by at least 25% in one session. The approach was individualized when necessary; for example, for an individual displaying aggressive behavior, not all strategies would be safe or appropriate to attempt. The frequency of intervention sessions depended on family availability. Sessions lasting 15-45 min typically occurred every 2 to 3 weeks, but larger intervals were common.

Noncontingent Reinforcement (NCR). Prior to the first intervention session, the therapist identified from one to three of the participant's preferred item(s) by interviewing the caregiver using the Reinforcer Assessment for Individuals with Severe Disabilities (Fisher et al., 1996) and then conducted a preference assessment. The format of the assessment was individualized by the participant and included paired choice (Fisher et al., 1992) and multiple-stimulus-without-replacement (DeLeon et al., 1996) formats. During NCR sessions, the therapist implemented the baseline procedures previously described and provided the participant with continuous access to the preferred item(s) (e.g., movies played on a tablet, holding a toy) while introducing each step in the task analysis. The therapist ensured that the participant could continue to access the item (e.g., could view the movie) throughout the entirety of the exam. If unsuccessful in increasing the percentage of steps completed, the therapist also increased the duration of the noncontingent breaks from 15 s to 30 s.

Contingent Reinforcement and Gradual Exposure. If unsuccessful with the procedures described above, the therapist then added contingent reinforcement followed by graduated exposure. No participants requiring these interventions have completed the program at the time of this manuscript, so procedural details will be described in a later publication.

Dental Exam

Participants were referred for a dental exam with one of three different dentists after completing at least 90% of the task analysis during a mock exam performed by the therapist. Prior to the dental exam, the therapist created a written summary of the interventions required to achieve the 90% benchmark and reviewed it with the dentist in person. The therapist was present during the dental exam and assisted the dentist in following the established protocol. A successful dental exam (the primary outcome measure) was defined as a participant completing at least 90% of the applicable steps and scoring a 4 (highest) rating on Frankl's behavior rating scale (Frankl et al., 1962). There were two exceptions where a participant was determined to have a successful dental exam with completion of less than 90% of applicable steps because the dentist omitted one or more steps; in both cases over 90% of the attempted steps were completed and the dentists reported the highest rating on Frankl's scale. If unsuccessful, he or she was referred for additional behavioral intervention or a repeat dental exam.

Statistical Analysis

Data were collected using REDCap electronic data capture tools hosted at the first author's institution (Harris et al., 2009). Patient demographic and clinical characteristics were summarized using median with minimum and maximum values, or frequency with percentage. Independent logistic regressions were used to test the association between participant factors and having a successful 1st or 2nd dental visit and only requiring baseline or NCR. Factors found to be significant at the $p<0.05$ level were considered for inclusion in a multiple logistic regression.

Results

Primary Aim (Determine Whether Patients Who Had Previously Relied on SAS Could Complete a Dental Exam With Minimal Behavioral Support)

All 32 active participants completed the baseline assessment (see Figure 1 for overview). Of these, 20 participants (62.5%) completed at least 90% of the task analysis steps during baseline and just 12 (37.5%) required additional behavioral intervention. Of the 20 participants who did not require additional intervention, 17 attempted a first true dental exam, and 12 (70.6%) successfully completed it. The remaining five (29.4%) were not successful and were awaiting a second attempt. Three (15%) were waiting for their first dental exam.

Of the 12 participants who required additional behavioral intervention, six (50%) reached the 90% threshold on the task analysis steps and six (50%) were still receiving behavioral intervention. Of the six who completed the behavioral intervention, four had attempted a first true dental exam. Two (50%) successfully completed it on their first attempt and one (25%) completed it on their second attempt; one participant (25%) was waiting for their third attempt. Two (16.7%) were waiting for their first true dental exam. All three participants who had successfully completed a true dental exam only required NCR, receiving an average of 2.3 additional behavioral sessions beyond the baseline. Those still receiving intervention have all together received a total of 10 therapy sessions with an average of a 6% increase of task analysis steps completed per session.

Figure 2 displays a summary of the strongest behavioral intervention required prior to successful completion of the dental exam, or for those still in treatment, at the time of manuscript preparation. Of the total 15 participants who successfully completed a true dental exam, all (100%) required just baseline or NCR procedures. However, no participant factors were associated with a successful dental exam on the first or second attempt and only requiring baseline or NCR. Although not significant at the $p<0.05$ level, patients who previously required anesthesia for dental exam tended to be less likely to successfully complete the dental exam

within the second attempt and only require baseline with or without NCR (OR 0.15; 95% CI: 0.02, 1.37; p=0.093).

Secondary Aim (Assess the Feasibility and Acceptability of These Behavioral Interventions in Oral Health Care)

All 15 successful dental exams were completed in less than 45 min; 11 of the visits were completed in less than 30 min. Caregivers for 13 of the 15 participants (86.7%) who successfully finished the dental exam completed a follow up survey about their experiences. Table 5 summarizes these results; a large majority found the experience acceptable and the procedures likely effective during future dental visits.

Discussion

These preliminary results suggest that many AIDD currently receiving SAS may be able to participate in routine dental care with relatively simple behavioral interventions. At the time that data collection was halted due to COVID-19 pandemic-related restrictions, nearly half of the active participants had successfully completed the dental exam, all of whom needed little intervention. Those still receiving behavioral treatment had a wider range of interventions, but just two individuals have required the most intensive behavioral treatments thus far. While previously published literature has demonstrated efficacy in typically developing children (Allen & Wallace, 2013), the initial, less complex interventions were not expected to be effective for so many adult participants with IDD. Achieving success with the baseline procedures (tell-show-do, contingent praise, frequent breaks) or with NCR is especially noteworthy as these strategies could theoretically be utilized in a real-world dental setting with minimal training or financial investment. In other words, while a therapist initially tested these procedures in this program, it is possible that some participants would be successful starting with a dentist utilizing these

strategies. Real-world feasibility is further supported by the visit times and the fact that preferred items used for NCR were typically brought from home, or in the case of audio/video stimuli, accessed using widely available streaming platforms. Additionally, the majority of caregivers reported favorable acceptability ratings for dental and behavioral procedures that they expect will improve future attempts at dental care. It is worth highlighting that caregivers, too, seem to under-predict what the individuals were capable of doing. The reason for this finding is unclear, but it is possible that years of SAS utilization made it seem unlikely for an individual to possess the skills needed to engage in their own care.

Implications for Practice and Research

As opposed to recruiting individuals with demonstrated behavioral difficulties, inclusion in this study was contingent on SAS being used previously (or in a few cases, recommended) as the primary means of receiving preventative dental care. This approach allows us to address a very practical question: Do AIDD actually need SAS to get preventative dental care? The results thus far suggest that often they may not, though it is too early to determine if this is related to the specific intervention or can be best attributed to over-utilization of SAS. Either way, the difficulty lies in predetermining which individuals will continue to need SAS and, for those who do not, the strength of the behavioral intervention required. At this time, no predictive factors have been identified, but this will be reassessed as more individuals participate in the program. Developing predictive models would enable practitioners to identify the least intrusive, most effective approach to address dental noncompliance in AIDD.

The primary reason for publishing these preliminary findings is because of the potentially significant implications. If a substantial proportion of AIDD who currently receive SAS can participate in routine dental care with relatively simple behavioral interventions, then a large

number of individuals may be receiving SAS unnecessarily. In-office sedation and general anesthesia carry additional risks and can result in less frequent preventative care, which was reflected in the majority of participants identifying a dentist, yet only 21.9% reported having a routine dental exam in the prior 6 months. This is not to say that SAS does not have a role in dentistry, particularly when more invasive or urgent procedures are required, but it does suggest that the ongoing need for SAS in preventative care should be reassessed for adults (and possibly adolescents) with IDD. While the optimal timing for reassessment is unknown, the age of the participants in this study suggests it should occur at the latest upon transitioning to adult dentistry.

Many dentists are reluctant to treat individuals with IDD in a typical office setting and may perceive that SAS is necessary for a successful visit (Casamassimo et al., 2004). While dentists receive training on techniques such as voice control, non-verbal communication, tell-show-do, positive reinforcement, and distraction, most dental education does not include direct exposure to persons with IDD and lacks additional training that may be necessary to successfully care for some AIDD, such as GE and contingent escape (Lyons, 2009). There are also significant financial barriers when caring for AIDD, many of whom may require additional and/or extended visits and behavioral interventions to accomplish preventative care. AIDD more commonly have Medicaid insurance (96.9% of participants had Medicaid and 34.4% had private insurance), yet nationwide only 38.6% of general dentists accept Medicaid (American Dental Association Health Policy Institute, 2017). Enhanced or alternative reimbursement strategies is a crucial factor in expanding access to care and incentivizing dental professionals to treat AIDD, acquire skills to address problem behavior, and collaborate with interdisciplinary teams that include behavioral therapists and physicians. Decreasing reliance on SAS is congruent with the statues of

the Americans with Disabilities Act (1990) and the US Supreme Olmstead Decision (1999) that view all persons with disabilities as capable of growth who should receive services in the "most integrated community setting".

Limitations

There are several noteworthy limitations to this study. The follow up interval was brief, so the long-term maintenance of the response is unknown. It is also unknown if the study was adequately powered so different results may be seen with increasing participant numbers. Study participation was based on caregiver report of SAS use for routine dental care and verifying documentation was typically not available, so there may be an element of recall bias in the recruitment. All activities took place in the participants' medical primary care office, and it is unknown if the same response would be seen in an unfamiliar dental environment that would add additional sensory cues that weren't present in the study location. Two of the dentists who performed the exams had extensive experience caring for AIDD, and procedural integrity for the dental team was fairly low for some exams. This finding was typically due to the dentist omitting the tell-show-do procedure. Further research is needed to understand this observation and whether it has practical significance; an additional study investigating a training program for dentists is underway.

Additionally, social validity and program evaluation were only collected for participants who completed the procedures, so overall acceptability may be less positive for those who did not complete them. The generalizability and replicability of these results must be assessed in a more typical dental environment and with additional participants. Recruitment is ongoing and the research team is identifying community partners who can address these issues and also test the

efficacy of this approach in obtaining radiographs, which was not possible in the current study setting.

Future Directions

It will be crucial to test the durability of the observed response with dental professionals who are not experienced in caring for AIDD: Will similar rates of individuals demonstrate success if dentists are trained in the baseline and NCR interventions? Will it be practical for dentists to follow a written behavior plan created by a therapist? Given the relatively simple interventions often required, we expect these procedures to translate well to a real-world setting, although it is possible that the collaborating dental provider may need to have some level of training or comfort in caring for AIDD. We have identified a community dentist (also with experience treating AIDD) who will see participants who have successfully completed the real dental exam. We have shared our program experiences through interdisciplinary educational efforts, but there remains a great need to meaningfully incorporate these skills into undergraduate and graduate dental and medical education (Holder et al., 2009). Greater exposure to these methods in training may make it more likely for dentists to utilize behavioral strategies before SAS. Changes in the Standards set by the Council on Dental Accreditation of the American Dental Association will help ensure opportunities to care for individuals with disabilities during dental training, but it is unknown if these experiences will emphasize behavioral supports or change rates of SAS utilization. Creation of graduate-level fellowship programs may also train dentists in more advanced behavioral techniques, preparing them to treat individuals with more severe behavior challenges.

Conclusions

Improving access to timely, quality preventative dental care will reduce the oral health disparities faced by AIDD. Preliminary study results not only augment the literature demonstrating the effectiveness of behavioral interventions in improving dental exam compliance, but also call into question the reliance on SAS in completing preventative dental care. Moving forward, future research is needed to evaluate the generalizability and strength of these findings and to identify factors that predict the response to behavioral intervention and the required "dose". In the meantime, healthcare professionals may consider giving AIDD a chance to attempt routine, preventative dental exams with the use of behavioral supports regardless of the interventions previously utilized.

References

Allen, K. D. & Wallace, D. P. (2013). Effectiveness of using non-contingent escape for general behavior management in a pediatric dental clinic. *Journal of Applied Behavior Analysis*, *46*(4), 723-737.

Altabet, S. C. (2002). Decreasing dental resistance among individuals with severe and profound mental retardation. *Journal of Developmental and Physical Disabilities*, *14*(3), 297-305. https://doi.org/10.1023/a:1016032623478.

Aman, M. G., Singh, N. N., Stewart, A. W., & Field, C. J. (1985). The aberrant behavior checklist: a behavior rating scale for the assessment of treatment effects. *American Journal of Mental Deficiency*, *89*(5), 485–491.

American Dental Association Health Policy Institute, 2017 June. *Methodology for developing the American Dental Association office database*. http://www.ada.org/~/media/ADA/Science%20and%20Research/HPI/Files/HPIOfficeDatabaseMethods.pdf

Anders, P. L. & Davis, E. L. (2010). Oral health of patients with intellectual disabilities: a systematic review. *Special care in dentistry*, *30*(3), 110-117. https://doi.org/10.1111/j.1754-4505.2010.00136.x.

Berens, J. C., & Peacock, C. (2015). Implementation of an academic adult primary care clinic for adolescents and young adults with complex, chronic childhood conditions. *Journal of Pediatric Rehabilitation Medicine, 8*, 3-12. https://doi.org/10.3233/PRM-150313.

Boynes, S. G., Moore, P. A., Lewis, C. L., Zovko, J., & Close, J. M. (2010). Complications associated with anesthesia administration for dental treatment in a special needs

clinic. *Special Care in Dentistry*, *30*(1), 3-7. https://doi.org/10.1111/j.1754-4505.2009.00114.x.

Carter, L., Harper, J. M., & Luiselli, J. K. (2019). Dental desensitization for students with autism spectrum disorder through graduated exposure, reinforcement, and reinforcement-fading. *Journal of Developmental and Physical Disabilities*, *31*(2), 161-170. https://doi.org/10.1007/s10882-018-9635-8.

Casamassimo, P. S., Seale, N. S., & Ruehs, K. (2004). General dentists' perceptions of educational and treatment issues affecting access to care for children with special health care needs. *Journal of Dental Education*, *68*(1), 23-28. https://doi.org/10.1002/j.0022-0337.2004.68.1.tb03730.x.

Cermak, S. A., Duker, L. I. S., Williams, M. E., Dawson, M. E., Lane, C. J., & Polido, J. C. (2015). Sensory adapted dental environments to enhance oral care for children with autism spectrum disorders: a randomized controlled pilot study. *Journal of Autism and Developmental Disorders*, *45*(9), 2876-2888. https://doi.org/10.1007/s10803-015-2450-5.

Chang, J., Patton, L. L., & Kim, H. Y. (2014). Impact of dental treatment under general anesthesia on the oral health- related quality of life of adolescents and adults with special needs. *European Journal of Oral Sciences*, *122*(6), 363-371. https://doi.org/10.1111/eos.12150.

Collado, V., Faulks, D., Nicolas, E., & Hennequin, M. (2013). Conscious sedation procedures using intravenous midazolam for dental care in patients with different cognitive profiles: a prospective study of effectiveness and safety. *PLoS One*, *8*(8), e71240. https://doi.org/10.1371/journal.pone.0071240.

Connick, C., Palat, M., & Pugliese, S. (2000a). The appropriate use of physical restraint: considerations. *Journal of Dentistry for Children*, *67*(4), 256-262.

Connick, C., Pugliese, S., Willette, J., & Palat, M. (2000b). Desensitization: strengths and limitations of its use in dentistry for the patient with severe and profound mental retardation. *Journal of Dentistry for Children*, *67*(4), 250-255.

Cumella, S., Ransford, N., Lyons, J., and Burnham, H. (2000). Needs for oral care among people with intellectual disability not in contact with community dental services. *Journal of Intellectual Disabilities Research, 44*(1), 45–52

Cuvo, A. J., Godard, A., Huckfeldt, R., & DeMattei, R. (2010). Training children with autism spectrum disorders to be compliant with an oral assessment. *Research in Autism Spectrum Disorders*, *4*(4), 681-696. https://doi.org/10.1016/j.rasd.2010.01.007.

DeLeon, I. G., & Iwata, B. A. (1996). Evaluation of a multiple- stimulus presentation format for assessing reinforcer preferences. *Journal of Applied Behavior Analysis*, *29*(4), 519-533. https://doi.org/10.1901/jaba.1996.29-519.

Derbi, H. A., & Borromeo, G. L. (2016). The perception of special needs dentistry amongst general dentists within Western Australia, Australia. *Journal of Gerontology & Geriatric Research*, *5*(4), 2-10. https://doi.org/10.4172/2167-7182.1000322.

Dougherty, N. (2009). The dental patient with special needs: a review of indications for treatment under general anesthesia. *Special Care in Dentistry*, *29*(1), 17-20. https://doi.org/10.1111/j.1754-4505.2008.00057.x.

Duker, L. I. S., Henwood, B. F., Bluthenthal, R. N., Juhlin, E., Polido, J. C., & Cermak, S. A. (2017). Parents' perceptions of dental care challenges in male children with autism

spectrum disorder: An initial qualitative exploration. *Research in Autism Spectrum Disorders, 39,* 63-72. https://doi.org/10.1016/j.rasd.2017.03.002.

Fakhruddin, K. S., & El Batawi, H. Y. (2017). Effectiveness of audiovisual distraction in behavior modification during dental caries assessment and sealant placement in children with autism spectrum disorder. *Dental Research Journal, 14*(3), 177-182. https://doi.org/10.4103/1735-3327.208768.

Fisher, W., Piazza, C. C., Bowman, L. G., Hagopian, L. P., Owens, J. C., & Slevin, I. (1992). A comparison of two approaches for identifying reinforcers for persons with severe and profound disabilities. *Journal of Applied Behavior Analysis, 25*(2), 491-498. https://doi.org/10.1901/jaba.1992.25-491.

Fisher, W. W., Piazza, C. C., Bowman, L. G., & Amari, A. (1996). Integrating caregiver report with a systematic choice assessment to enhance reinforcer identification. *American Journal on Mental Retardation, 101*(1), 15–25.

Frankl, S. N. Shiere, F. R., & Fogels, H. R. (1962). Should the parent remain with the child in the dental operatory? *Journal of Dentistry for Children, 29*, 150-163.

Gabre, P., Martinsson, T., & Gahnberg, L. (1999). Incidence of, and reasons for, tooth mortality among mentally retarded adults during a 10-year period. *Acta Odontologica Scandinavica*, *57*(1), 55-61. https://doi.org/10.1080/000163599429110.

Harris P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N., Conde, J. G. (2009). Research electronic data capture (REDCap) – A metadata-driven methodology and workflow process for providing translational research informatics support, *Journal of Biomedical Information, 42*(2), 377-81.

Holder, M., Waldman, H. B., & Hood, H. (2009). Preparing Professionals to Provide Care to Individuals with Disabilities. *International Journal of Oral Science,* 1(2), 66-71.

Hulland, S., & Sigal, M. J. (2000). Hospital- based dental care for persons with disabilities: a study of patient selection criteria. *Special Care in Dentistry*, *20*(4), 131-138. https://doi.org/10.1111/j.1754-4505.2000.tb01149.x.

Isong, I. A., Rao, S. R., Holifield, C., Iannuzzi, D., Hanson, E., Ware, J., & Nelson, L. P. (2014). Addressing dental fear in children with autism spectrum disorders: a randomized controlled pilot study using electronic screen media. *Clinical Pediatrics*, *53*(3), 230-237. https://doi.org/10.1177/0009922813517169.

Kancherla, V., Braun, K. V. N., & Yeargin-Allsopp, M. (2013). Dental care among young adults with intellectual disability. *Research in Developmental Disabilities*, *34*(5), 1630-1641. https://doi.org/10.1016/j.ridd.2013.02.006

Kim, G., Carrico, C., Ivey, C., & Wunsch, P. B. (2019). Impact of sensory adapted dental environment on children with developmental disabilities. *Special Care in Dentistry*, *39*(2), 180-187. https://doi.org/10.1111/scd.12360.

Koritsas, S., & Iacono, T. (2011). Secondary conditions in people with developmental disability. *American Journal of Intellectual and Developmental Disabilities*, *116*(1), 36-47. https://doi.org/10.1352/1944-7558-116.1.36.

Kupzyk, S., & Allen, K. D. (2019). A review of strategies to increase comfort and compliance with medical/dental routines in persons with intellectual and developmental disabilities. *Journal of Developmental and Physical Disabilities*, *31*(2), 231-249. https://doi.org/10.1007/s10882-018-09656-y.

Lim, M. A. W. T., & Borromeo, G. L. (2017). The use of general anesthesia to facilitate dental treatment in adult patients with special needs. *Journal of Dental Anesthesia and Pain Medicine*, *17*(2), 91-103. https://doi.org/10.17245/jdapm.2017.17.2.91.

Lim, M. A. T., & Borromeo, G. L. (2019). Oral health of patients with special needs requiring treatment under general anaesthesia. *Journal of Intellectual & Developmental Disability*, *44*(3), 315-320. https://doi.org/10.3109/13668250.2018.1477409.

Luscre, D. M., & Center, D. B. (1996). Procedures for reducing dental fear in children with autism. *Journal of Autism and Developmental Disorders*, *26*(5), 547-556. https://doi.org/10.1007/bf02172275.

Lyons, R. A. (2009). Understanding basic behavioral support techniques as an alternative to sedation and anesthesia. *Specialty Care Dentistry*, 29(1), 39-50. doi: 10.1111/j.1754-4505.2008.00061.x.

Maguire, K. B., Lange, B., Scherling, M., & Grow, R. (1996). The use of rehearsal and positive reinforcement in the dental treatment of uncooperative patients with mental retardation. *Journal of Developmental and Physical Disabilities*, *8*(2), 167-177. https://doi.org/10.1007/bf02578447.

Mah, J. W., & Tsang, P. (2016). Visual schedule system in dental care for patients with autism: A pilot study. *Journal of Clinical Pediatric Dentistry*, *40*(5), 393-399. https://doi.org/10.17796/1053-4628-40.5.393.

Morgan, J. P., Minihan, P. M., Stark, P. C., Finkelman, M. D., Yantsides, K. E., Park, A., ... & Must, A. (2012). The oral health status of 4,732 adults with intellectual and developmental disabilities. *The Journal of the American Dental Association*, *143*(8), 838-846. https://doi.org/10.14219/jada.archive.2012.0288.

Nazir, M. A., Izhar, F., Akhtar, K., Almas, K (2019). Dentists' awareness about the link between oral and systemic health. *Journal of Family & Community Medicine, 26* (3), 206-212. https://doi:10.4103/jfcm.JFCM_55_19.

Nelson, T., Chim, A., Sheller, B. L., McKinney, C. M., & Scott, J. M. (2017). Predicting successful dental examinations for children with autism spectrum disorder in the context of a dental desensitization program. *The Journal of the American Dental Association, 148*(7), 485-492. https://doi.org/10.1016/j.adaj.2017.03.015.

Orellana, L. M., Martínez-Sanchis, S., & Silvestre, F. J. (2014). Training adults and children with an autism spectrum disorder to be compliant with a clinical dental assessment using a TEACCH-based approach. *Journal of Autism and Developmental Disorders*, *44*(4), 776-785. https://doi.org/10.1007/s10803-013-1930-8.

Potter, C. N., Wetzel, J. L., & Learman, K. E. (2019). Effect of sensory adaptations for routine dental care in individuals with intellectual and developmental disabilities: a preliminary study. *Journal of Intellectual & Developmental Disability*, *44*(3), 305-314. https://doi.org/10.3109/13668250.2017.1409597.

Prabhu, N. T., Nunn, J. H., Evans, D. J., & Girdler, N. M. (2008). Development of a screening tool to assess the suitability of people with a disability for oral care under sedation or general anesthesia. *Special Care in Dentistry*, *28*(4), 145-158. https://doi.org/10.1111/j.1754-4505.2008.00034.x.

Reed, D. D., Luiselli, J. K., Miller, J. R., & Kaplan, B. A. (2013). Therapeutic restraint and protective holding. In *Handbook of Crisis Intervention and Developmental Disabilities* (pp. 107-120). Springer, New York, NY. https://doi.org/10.1007/978-1-4614-6531-7_7.

Riba, H., Al-Zahrani, S., Al-Buqmi, N., & Al-Jundi, A. (2017). A review of behavior evaluation scales in pediatric dentistry and suggested modification to the Frankl scale. *EC Dental Science*, *16*(6), 269-275.

Savanheimo, N., Sundberg, S. A., Virtanen, J. I., & Vehkalahti, M. M. (2012). Dental care and treatments provided under general anaesthesia in the Helsinki Public Dental Service. *BMC Oral Health*, *12*(1), 45-53. https://doi.org/10.1186/1472-6831-12-45.

Schindel, R. H., Chahine, A., Anderson, N., Banville, M., Eaton-Bove, J., & Weidenbaum, N. (2014). Behavior modification of children with autism spectrum disorder in an orthodontic setting. *Journal of Clinical Orthodontics: JCO*, *48*(5), 285-291.

Sparrow, S. S., Cicchetti, D. V., & Balla, D. A. (2005). Vineland adaptive behavior scales (2nd ed.). Circle Pines, MN American Guidance Service.

Suresh, L. R., & George, C. (2019). Virtual Reality Distraction on Dental Anxiety and Behavior in Children with Autism Spectrum Disorder. *Journal of International Dental and Medical Research*, *12*(3), 1004-1010.

Szalwinski, J., Thomason- Sassi, J. L., Moore, E., & McConnell, K. (2019). Effects of decreasing intersession interval duration on graduated exposure treatment during simulated routine dental care. *Journal of Applied Behavior Analysis*, *52*(4), 944-955. https://doi.org/10.1002/jaba.642.

U.S. Department of Health and Human Services (2000). Report of the surgeon general's conference on children's mental health. Department of Health and Human Services, Washington, D.C. https://doi.org/10.1037/e303632003-001.

Ward, L. M., Cooper, S. A., Hughes- McCormack, L., Macpherson, L., & Kinnear, D. (2019). Oral health of adults with intellectual disabilities: a systematic review. *Journal of Intellectual Disability Research*, *63*(11), 1359-1378. https://doi.org/10.1111/jir.12632

WHO Global Oral Health Programme, 2003. Continuous improvement of oral health in the 21st century- the approach of the WHO Global Oral Health Programme. https://www.who.int/oral_health/media/en/orh_report03_en.pdf?ua=

Wilson, N. J., Lin, Z., Villarosa, A., & George, A. (2019). Oral health status and reported oral health problems in people with intellectual disability: A literature review. *Journal of Intellectual & Developmental Disability*, *44*(3), 292-304. https://doi.org/10.3109/13668250.2017.1409596

Zhou, N., Wong, H. M., Wen, Y. F., & Mcgrath, C. (2017). Oral health status of children and adolescents with intellectual disabilities: a systematic review and meta-analysis. *Developmental Medicine & Child Neurology*, *59*(10), 1019-1026. https://doi.org/10.1111/dmcn.13486.

Figure 1: Schematic of program enrollment and processes.

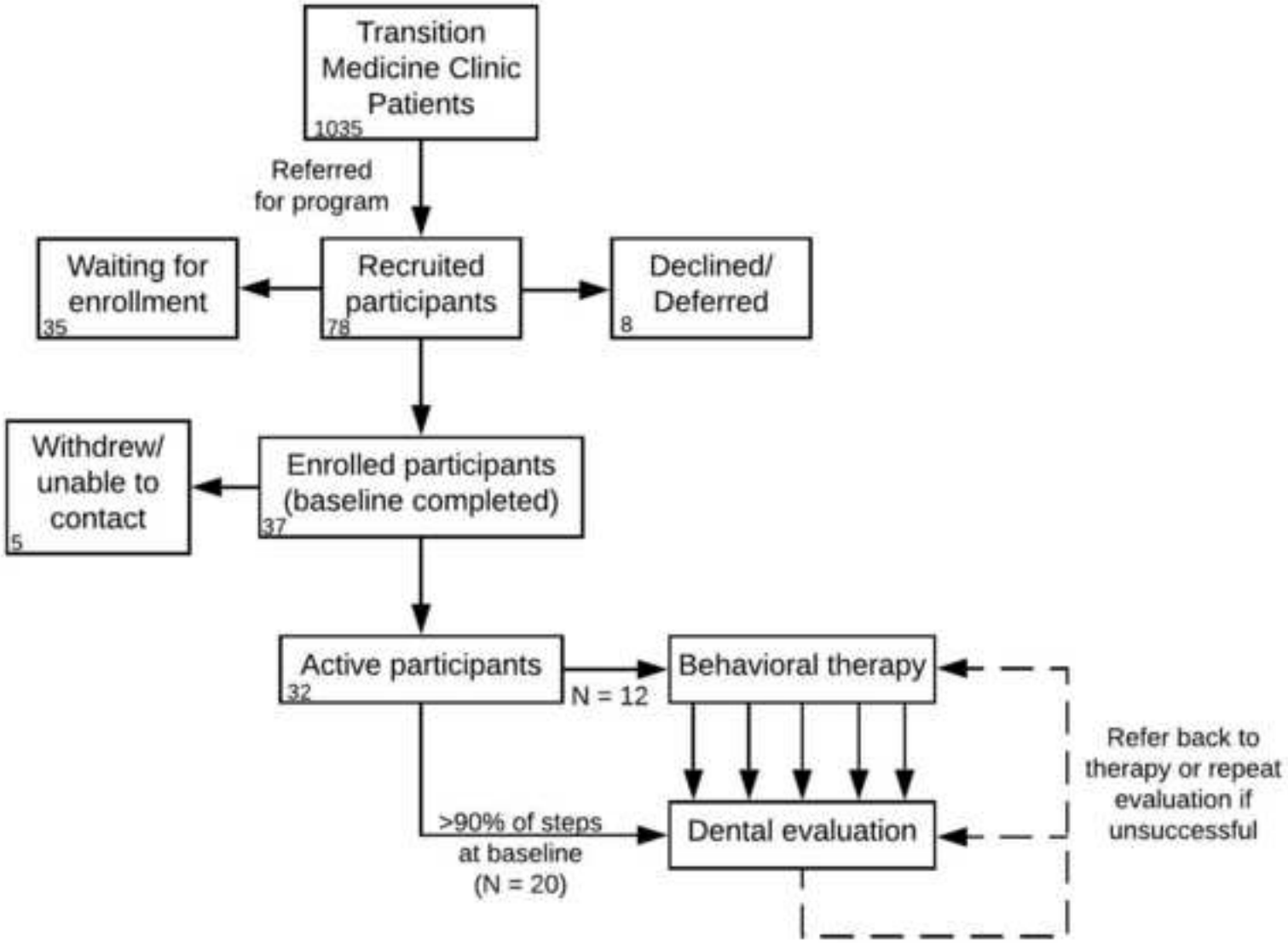
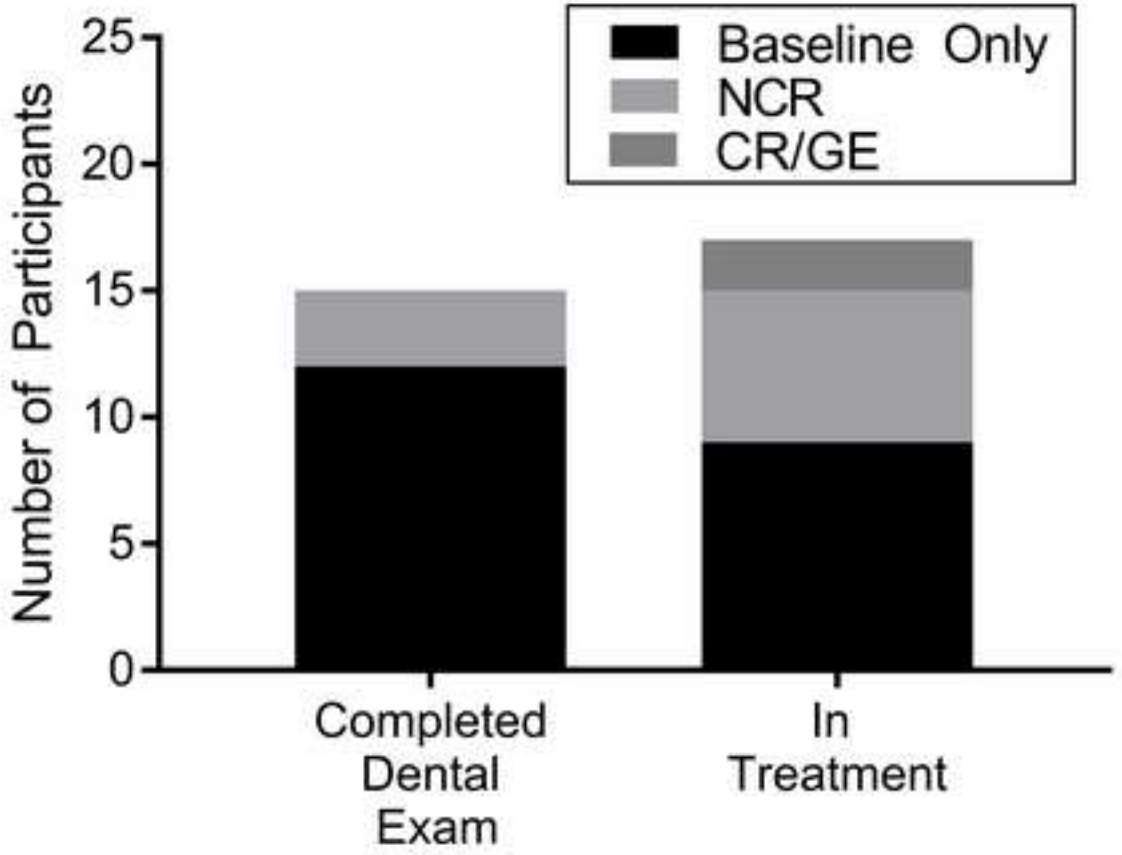


Figure 2. Summary of enrolled participants separated by current status (successfully completed dental exam or in treatment) and stratified by the maximum (or current) level of behavioral intervention utilized.



Note: NCR = noncontingent reinforcement, CR = contingent reinforcement
GE = graduated exposure

Table 1

Dental Exam Task Analysis

Before exam
1) Enter dentist office.
2) Stay in waiting room for 3-5 consecutive min.
3) Enters exam room.
Initial steps
4) Sits in chair for 30 consecutive sec.
5) Allows bib placed on chest and hooked around neck.
6) Stays in reclined position 180 degrees.
7) Accepts light for 30 s (does not turn head).
8) Opens mouth upon request.
Use of bite block
9) Allows the therapist to put the block in mouth for 5 seconds.
10) Allows the therapist to put the block in mouth for 10 seconds.
Inspection of teeth with mirror and pic
11) Allows the therapist to insert mirror into mouth for 5 seconds.
12) Allows the therapist to touch one tooth with pick (while mirror is in place).
13) Allows the therapist to touch 5 top teeth with pick/mirror.
14) Allows the therapist to touch 5 bottom teeth with pick/mirror.
15) Allows the therapist to touch teeth with pick/mirror in mouth for 1 min.
Brushing of teeth with electric toothbrush or manual toothbrush
16) Allows the therapist to hold manual brush close to mouth.
17) Opens mouth for manual brush.
18) Allows the therapist to touch one tooth with manual brush.
19) Allows the therapist to touch brush to all 3 surfaces of bottom teeth (one side) with manual brush.
20) Allows the therapist to touch brush to the teeth on other bottom side with manual brush (all 3 surfaces).
21) Allows the therapist to touch brush to all 3 surfaces of top teeth (one side) with manual brush.
22) Allows the therapist to touch brush to the teeth on other top side with manual brush (all 3 surfaces).
23) Allows the therapist to touch brush to both surfaces of front teeth (top and bottom) with manual brush.
24) Completes steps 16-23 with toothpaste (counts as 1 step).
25) Allows the therapist to squirt water in mouth twice.
26) Allows the therapist to turn on suction and have nearby.
27) Allows the therapist to place the suction device in mouth for 5 seconds.
Scaling
28) Allows the therapist to perform mock scaling on 2 surfaces of one tooth.
29) Allows the therapist to perform mock scaling on 2 surfaces of bottom teeth (one side).
30) Allows the therapist to perform mock scaling on 2 surfaces of other side bottom teeth.
31) Allows the therapist to perform mock scaling on 2 surfaces of top teeth (one side).
32) Allows the therapist to perform mock scaling on 2 surfaces of other side top teeth.

Flossing
33) Allows the therapist to touch flosser to one tooth (2 surfaces).
34) Allows the therapist to touch flosser to bottom teeth on one side.
35) Allows the therapist to touch flosser to bottom teeth on other side.
36) Allows the therapist to touch flosser to top teeth on one side.
37) Allows the therapist to touch flosser to top teeth on other side.

Table 2

Participant Demographic Information

Patient characteristic	N = 32
Gender (male), N (%)	23 (71.9)
Age (years), median (range)	23 (19-36)
Race, N (%)*	
White	9 (29.0)
Black or African American	16 (51.6)
Asian	1 (3.2)
Multiracial	2 (6.5)
Other	3 (9.7)
Ethnicity, N (%)	
Hispanic	6 (18.8)
Non-Hispanic	26 (81.2)
Primary diagnosis, N (%)	
Cerebral palsy	9 (28.1)
Autism	8 (25.0)
Down syndrome	9 (28.1)
Other genetic syndrome/diagnosis	5 (15.6)
Intellectual disability, etiology unknown	1 (3.1)
Intellectual disability, N (%)	32 (100)
Ambulatory status, N (%)	
Ambulates independently	21 (65.6)
Requires some assistance (e.g. walker, wheelchair for long distance)	2 (6.3)
Requires wheelchair for all ambulation	9 (28.1)
Insurance coverage, N (%)**	
Medicaid	31 (96.9)
Medicare	8 (25.0)
Private	11 (34.4)
Medicaid waiver active, N (%)	24 (75.0)
Aberrant Behavior Checklist score, median (range)	4 (0 – 44)
Vineland Adaptive Behavior score, median (range)	20 (20 – 75)

*Race information available for 31 participants

**Participants can have multiple insurance types

Table 3

Selected Dental History of Participants

Dental history	N = 32	
Have established dentist, N (%)	20 (62.5)	
Time since last dental evaluation, N (%)		
<6 months ago	7 (21.9)	
≥6 months but < 12 months ago	8 (25.0)	
≥1 year but <2 years ago	11 (34.4)	
≥2 years ago	6 (18.8)	
Person that brushes participant's teeth, N (%)		
Individual	5 (15.6)	
Caregiver	14 (43.8)	
Combination of individual/caregiver	13 (40.6)	
Frequency of in-home oral hygiene, N (%)	Brushing	Flossing
≥2 times per day	13 (40.6)	2 (6.3)
1 time per day	15 (46.9)	2 (6.3)
<1 time per day, ≥1 time per week	4 (12.5)	1 (3.1)
<1 time per week	0 (0)	27 (84.4)
Previous intervention required for preventative dental care, N (%)*		
Sedation (intravenous, gas)	11 (34.4)	
General anesthesia	17 (53.1)	
Protective stabilization (e.g. papoose)	9 (28.1)	
Unable to get dental care without above interventions but not yet received them	5 (15.6)	
Expected degree of compliance to dental procedures, median (range)**	4.3 (1.8, 6.0)	
Expected severity of problem behavior, median (range)**	0.0 (0.0, 4.2)	

*Total > 100% due to 12 participants reporting multiple interventions used

**Data collected for 23 participants only. Rating on a six-point scale.

Table 4

Results of Caregiver Survey on Expected Compliance and Problem Behavior Severity

Assessment Items	Median	Range
What is the expected degree of compliance for each step? (0 = not compliant; 6 = most compliant)		
Entering the building	6.0	3 – 6
Sitting in the waiting room	6.0	3 – 6
Entering the exam room	6.0	0 – 6
Sitting in the dental chair	5.5	0 – 6
Dentist examining teeth	2.0	0 – 6
Dentist cleaning teeth	2.0	0 – 6
What is the expected severity of problem behavior for each step? (0 = no problem behavior; 1 = not severe; 6 = most severe)		
Entering the building	0	0 – 1
Sitting in the waiting room	0	0 – 1
Entering the exam room	0	0 – 5
Sitting in the dental chair	0	0 – 6
Dentist examining teeth	0	0 – 6
Dentist cleaning teeth	0	0 – 6

Table 5

Results of Caregiver Feedback Survey

Question	Median (Range)
How acceptable did you find the behavioral procedures? (1 = Not at all acceptable, 7 = Very acceptable)	7 (1-7)
How acceptable did you find the dental procedures? (1 = Not at all acceptable, 7 = Very acceptable)	7 (1-7)
How acceptable did you find the amount of time spent on behavioral treatments? (1 = Not at all acceptable, 7 = Very acceptable)	6 (1-7)
How confident are you that the behavioral procedures will be effective during future dental visits? (1 = Not at all confident, 7 = Very confident)	6 (4-7)
How likely are the behavioral procedures to make permanent improvements in your child's behavior at future dental appointments? (1 = Unlikely, 7 = Very likely)	6 (1-7)
How did your child's cooperation with the dental exam compare to your expectations before enrolling in the project? (1 = Far below expectations, 5 = Far above expectations)	4 (2-5)

Note. This survey was administered after successful completion of the dental exam. Response rate was 13 of 15 possible surveys (86.7%).