Oral Health Care for Adults with IDD

A Summary of Evidence-based and Promising Practices

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Note: This document is intended to extend the field's knowledge about promising practices. It is not an exhaustive list, however it includes examples from the field that indicated some level of effective outcomes, demonstrating the value of looking beyond peer reviewed literature to advance the knowledge base in this field.

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Introduction

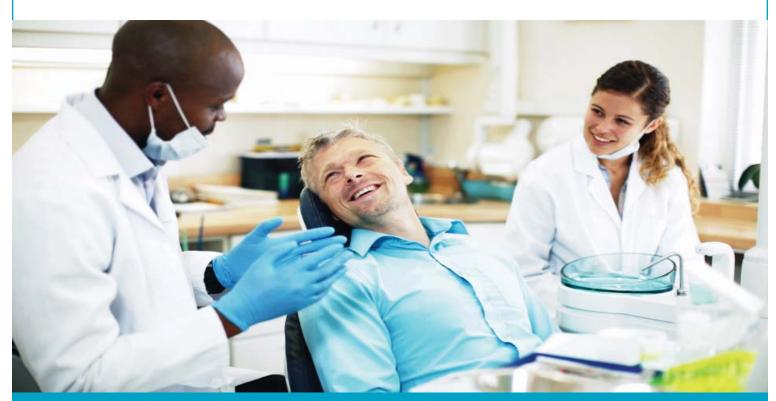
People with intellectual and developmental disability (IDD) are more likely to have poor oral health as compared to the general population.

For many people with Intellectual and Developmental Disability (IDD), it is challenging to get good oral health care. Barriers to good care for these individuals range from being unable to participate in personal oral hygiene; to apprehension, unwillingness or inability to cooperate on dental visits; to lacking transportation; or not having a local dentist. Local dental clinics do not provide services to those with special needs, as many lack the training and/ or the adaptive technology to provide care.

We know that people with IDD experience poorer oral hygiene, higher prevalence and severity of periodontal disease, and higher incidence of untreated caries than the general population (Anders & Davis, 2010). Dental issues left untreated in the IDD population can lead to more serious health conditions and even more severe health outcomes than in the general population (Krahn, Hammond & Turner, 2006).

In a systematic review conducted by the Eunice Kennedy Shriver Center at the University of Massachusetts Medical School and funded by the Centers for Disease Control and Prevention National Center on Birth Defects & Developmental Disabilities (NCBDD), researchers rigorously evaluated evidence for a wide range of oral health interventions for people with IDD. The limited available evidence and research findings are summarized throughout this report.

To date, there has not been enough research to develop a good evidence base for interventions specifically for people with IDD, so the research team developed this "promising practices" report. The examples presented are considered "promising practices" because they have been adopted by clinicians or programs, are well described, and have some limited reports of good outcomes. However, there has not been enough research to clearly show the effectiveness.



Review of Literature

Clinical decision making blends best available evidence, expertise, and individual needs and preferences.

For oral health clinicians who treat people with IDD, as well as those who develop the systems to support people with IDD, the BEST AVAILABLE evidence is hard to come by. In many cases, clinicians use what they know works in "special needs populations," but this may not include the particular needs of the population with intellectual disability.

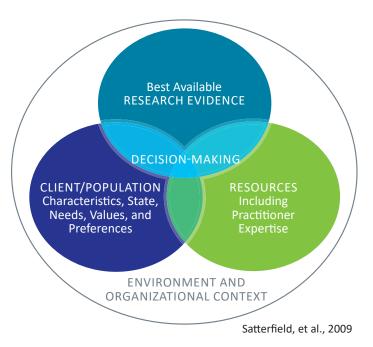
In this review, the research team identified literature with outcomes of oral health interventions specifically aimed at the population with IDD.

The four focus areas reviewed include:

- 1. Education and Behavioral Interventions
- 2. Interventions that improve access to oral health services
- 3. Strategies to prevent cavities and other oral health problems
- 4. The use of sedation to facilitate treatment

The research team reviewed programs, practices, and policies to assess an intervention's efficacy in improving oral health outcomes. In addition to exploring the peer reviewed (formal) literature, the team reviewed the gray literature which includes white-papers, newsletters, websites, and other sources of information describing interventions. The team used consistent criteria in both the gray literature and peer reviewed literature review.

FIGURE 1: Transdisciplinary Conceptual Model



Gray literature can still be constituted as "evidence" and help to build the evidence base. Without access to such material, we would be in an ongoing "loop" of demonstrating the same evidence over and over, without room for innovative practice or new understandings of emerging trends.

(Lawrence, Houghton, Thomas & Weldon, 2014)

Two key questions guided the review of literature:

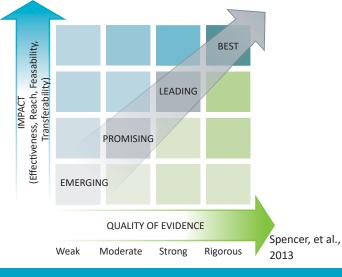
- 1. What effective interventions/strategies exist to improve access to oral health care for the IDD population?
- 2. What effect do interventions that support good oral health behaviors have on improved oral health care for the IDD population?

Differences in Methodology Peer Review versus Gray Literature

	Peer Review	Gray Literature
INCLUSION CRITERA	 Population with IDD identified/ defined Oral health intervention described Outcomes or results of intervention are reported English language Peer reviewed 1990–June 2013 	 Population with IDD identified/defined Oral health intervention described English language Fair to moderate evidence Limited but good outcomes reported
EVIDENCE COLLECTION AND REVIEW METHOD	 Data extraction structured with Systematic Review Data Repository (SRDR) Specific extraction questions designed for each of the four topics Results analyzed across comparable interventions 	 Anecdotal Non-comparison figures of outcomes, for example: Oral health measures Numbers of practitioners trained Numbers of patients served Changes between fixed points (pre- and post-intervention, points during the intervention) Published reports with supporting data (may or may not have peer review)
QUALITY REVIEW	Each article reviewed twice: Clinical Review for quality and relevance by dentists, hygienists, students, and researchers <i>AND</i> Statistical Review for quality of design and findings by biostatistician	Clinical Advisory Group: Reviewed process and reported promising practices Provided clinical expertise to approve reported promising practices and available evidence

Merging examples of promising practices with the bestavailable peer reviewed literature serves as a model for synthesizing research and developing interventions in areas of need for the IDD population, such as other health, wellness, or behavioral interventions.

Promising practices guide clinicians through showing best available evidence. Clinicians may review this to understand the state of the evidence, and as a resource to direct them to programs where they may learn more. Researchers wishing to conduct further evaluations of practices may also find it useful.



EDUCATION AND BEHAVIOR STRATEGIES TO IMPROVE ORAL HEALTH FOCUS < THROUGH BEHAVIOR CHANGE

The interventions in this caregory have the overarching outcome of behavior change and include both educational and behavioral strategies. Behavior change can be achieved through education and training of any party in the oral health care relationship, or through procedures developed by behavior specialists to facilitate patient oral care in a home or dental setting.

INCLUDED IN THIS CATEGORY:

Behavioral interventions targeted at the patient to facilitate patient cooperation with dental procedures. Included are:

- · Desensitization-types of interventions
- **Prompting**
- Task analysis for teaching skills
- Environmental modifications to accommodate sensory sensitivities or manual dexterity differences

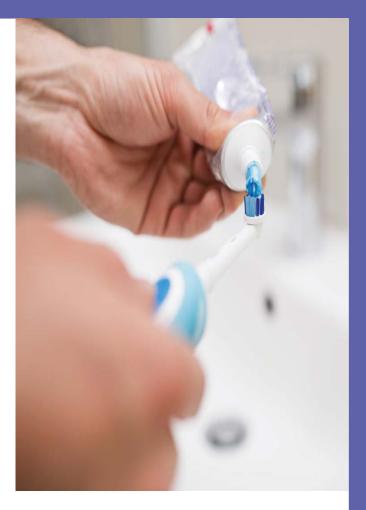
(e.g., adapted toothbrushes)

Education for patients and caregivers in oral hygiene instruction and disease prevention education aimed at improving overall oral health. Common interventions include:

- · Instruction, both didactic and experiential
- Prompting
- Task analysis

Common outcomes include:

- · Knowledge and skill acquisition in performing oral hygiene
- · Cooperation with hygiene routines
- · Improved oral health indicators (e.g., Gingival Index, plaque scores)



Interventions delivered to providers include:

- · Educational experience/knowledge acquisition
- · Assessing curricula for orthodontists, dentists, and hygienists
- · Measuring attitudes toward treating persons with
- · Educational models that included: Virtual patient, service learning, interprofessional collaboration, and provider comfort/satisfaction with technique or materials of behavior management

WHAT WE KNOW FROM THE RESEARCH

Behavioral Interventions

The literature points to several examples of behavioral interventions aimed at improving compliance with oral care, both at home and in the dental practice. Desensitization (Convers, 2004), sensory adapted environment (Shapiro, et al., 2009), and other behavioral interventions, such as distraction (Isong, 2014), showed promise in promoting cooperation and compliance, and/or reducing anxiety in the dental setting. One program that shows success at providing care to patients with IDD is Practice without Pressure (Practice Without Pressure, n.d.) which has expanded to providing support and care for patients in both medical and dental settings.

EXAMPLE — *Practice without Pressure (PWP)*

Description:

Trained practice specialists support patients and caregivers in preparation for and during care. Routine dental care is provided at the PWP center and in concert with local providers to provide urgent care with sedation, if needed.

Evidence:

In a group measured, sedation for some medical procedures was reduced.

- · PWP recognized by RWJ through award
- · PWP trained 34 medical/dental providers and 43 dental/hygiene students
- · PWP served more than 800 patients and trained 800 medical/dental providers and students (Jablow, 2015; Jastrewski, 2012; Brohawn, 2011)

Tooth Brushing

Several studies compared the efficacy of various types of toothbrushes with people with intellectual and developmental disability, including multi-headed manual and electric toothbrushes. Electric toothbrushes in particular, but also multi-headed brushes, are more effective than typical manual toothbrushes at improving oral health measures (Carr, et al., 1997; and Dogan, 2004).

EXAMPLE - Oral Health Pilot Program for Adults with Intellectual and/or **Developmental Disabilites**

Description:

This program evaluated the efficacy of various types of toothbrushes as combined with a program of social support for individuals with IDD.

Evidence:

Significant changes including improved oral health were found on all measures from baseline to study end (Research and Training Center on Disability in Rural Communities, 2004).

Training Direct Care Staff

Lange, et al. (2000) conducted a study in a large state institution serving consumers with intellectual disability. It found that training direct service staff in oral hygiene, coupled with periodic feedback from dental hygienists about the quality of care the consumers were receiving, yielded significantly improved oral hygiene scores. The gray literature also has examples of effective staff training and behavioral support programs such as the Elks Mobile Dental Van.

EXAMPLE – Elks Mobile Dental Van, Caregiver training in oral hygiene and behavioral support

Description:

Staff were trained in oral hygiene techniques: both brushing and in encouraging cooperation.

Evidence:

All patients improved on oral hygiene and on cooperation level as measured by staff (Dane, n.d.).

WHAT WE KNOW FROM THE RESEARCH

Dental Students

While the literature points to the need for didactic training in special needs dentistry, including in non-pharmacologic means of behavior management (Humza bin Saeed, et al., 2012), hands-on experiences also seem to positively increase the attitudes of dental students toward serving patients with IDD (DeLucia & Davis, 2009). An experience mentioned in DeLucia and Davis (2009) was volunteering through Special Olympics Special Smiles program, an example from the gray literature as well.

EXAMPLE – University of Washington School of Dentistry Dental Education in Care of Persons with Disability (DECOD) Program

Description:

The DECOD program at the University of Washington included a mix of didactic and clinical training followed by a competitive pre-doctoral program for dental students, visiting scholar training, and online continuing education (CE) courses, as well as training material for caregivers.

EXAMPLE – Special Olympics Special Smiles

Description:

Special Olympics is a vast international enterprise through which health-related services are provided by volunteers. The Special Smiles program provides screening and education services to thousands of Special Olympians around the world. Their annual reports provide data on the numbers of individuals served (Special Olympics, Special Smiles, n.d.).

Evidence:

DECOD operates off-site clinics and has use of a mobile van for patients who can't get to the clinic and maintains an online registry of dentists who serve patients with special needs (Dental Education in Care of Persons with Disability (DECOD), 2007).

Evidence:

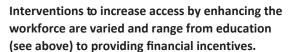
Special Smiles, Memphis, TN: As of 2007, 4,000 athletes have participated in the Special Smiles program. This reflects approximately 95% participation rate among Special Olympians. Exit forms for volunteers indicated that the experience was worthwhile — and most volunteers return the following year. Anecdotally, those providers that serve patients with IDD note that the SOSS experience was an influencing factor (Greater Memphis Special Olympics, 2007).

CONCLUSIONS

- Education programs directed at individuals and caregivers can improve oral health and plaque scores. In addition, proper tooth brushing technique also improves plaque scores.
- Behavioral management techniques work better when they are part of a complete education and training program on oral health.
- Exposure to individuals with IDD, whether through curriculum, practical
 experience, or other means, has a positive impact on provider attitudes toward
 treating individuals and including individuals with IDD in their practice.

FOCUS 7 **ACCESS STRATEGIES TO** AREA# 🚄 **IMPROVE ORAL HEALTH**

Interventions aimed at increasing access at the patient level include case management services to inform, enroll, and ensure continuity of services. One example from the literature is a pilot program in California, in which dental hygienists acted as dental coordinators. Each had a caseload and was responsible for triage and follow-up for severe dental needs, and provided support and education to patients. They also served to facilitate communication between dental providers and social service providers. Improvement was seen in oral health outcomes and access to care, especially as more than 223 dental practices agreed to see or increase the number of patients with IDD, as well 102 dental hygiene or assistant programs that agreed to see patients (Glassman & Miller, 2009). Increasing Medicaid coverage for preventive care for patients with IDD is also widely recommended in policy statements.

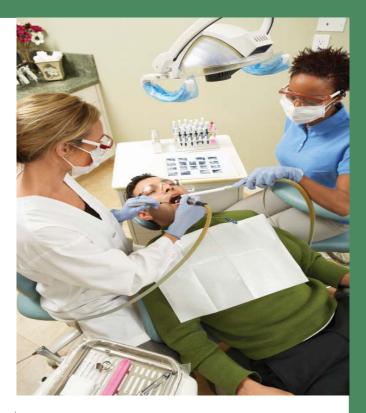


Financial or economic solutions are widely suggested as a way to incentivize providers to treat individuals with IDD, especially those insured through Medicaid. These solutions include:

- Increasing Medicaid reimbursements
- · Adjusting the fee structure to reflect the time and resources required to treat patients with complex medical and behavioral needs
- Pursuing private funding and donated services for treatment

In addition to fair reimbursement rates, other financial incentives, such as tuition reimbursement, are suggested as a way to increase the numbers of providers willing to treat underserved populations.

Another approach proposed is to broaden the number and categories of people who can provide treatment. This includes allowing dental assistants



and hygienists to carry out preventive care, such as providing school-based sealants, and training pediatricians and general practitioners to address oral health issues. These changes require legislative or regulatory changes and address administrative and economic system changes.

Other practices that are designed to improve access to the physical care delivery system include:

- · Mobile vans
- · Addressing transportation issues
- · Adapting equipment and office space to improve the accessibility of dental offices, especially for those patients with physical or sensory needs
- · Simplification of forms
- Repurposing or utilizing existing resources, such as clinics, institutions, or setting up community based services

At this systems level, but also at a broader public health level, the need for more partnerships and collaborations is cited as being needed to address disparities in access, and seems to be a common practice.

WHAT WE KNOW FROM THE RESEARCH

Access

Within the literature, there are examples of pilot programs that have shown success at increasing access and meeting the unmet needs of people with IDD through school-based dental clinics.

York & Holtzman (2004) describe a pilot program partnership between University of Medicine and Dentistry of New Jersey and the Atlantic County Special Services School District. The district provided space at one of their three schools, while the university provided a dentist, hygienist, equipment and supplies. Over three years, the number of patients served increased and was deemed self-sustaining through insurance and fees collected on a sliding scale. A grant provided start-up funds. Other agencies have developed partnerships to provide services, as seen in the examples below.

EXAMPLE — Financial Incentive – Loan

Description:

Massachusetts tuition loan repayment

Promising Practice:

For dental professionals (dentists and hygienists) who serve individuals with IDD, Massachusetts will provide reimbursement of tuition up to \$50,000 (Massachusetts Loan Repayment for Dental Professionals, n.d.).

EXAMPLE — Dental Lifeline Network (formerly Foundation of Dentistry for the Handicapped)

Description:

The Donated Dental Services (DDS) program provides free dental treatment provided by volunteer dental professionals to people with disabilities, as well as the elderly or medically fragile.

Evidence:

"Since its inception in 1985, our DDS program has surpassed \$300 million in donated dental therapies, transforming the lives of more than 108,000 people (Donated Dental Services, n.d.)."

EXAMPLE — Missouri Elks Mobile Dental Care Program

Description:

The program is a partnership between Missouri Elks Association, Bureau of Special Health Care Needs (SHCN) of the Missouri Department of Health and Senior Services, and Truman Medical Center. Basic dental services (preventive, restorative, oral, surgical) are provided at sites throughout the state. Operating revenue is provided through Title V Block grants from the Bureau of SHCN and from the Elks (Dental Services Elks Mobile n.d.; Missouri Elks Mobile Care Program, 2007; Elks Mobile Dental, n.d.).

Satisfaction surveys, focus groups, and individual interviews indicate patient satisfaction with quality and value of the service (Books, et al., 2002).

WHAT WE KNOW FROM THE RESEARCH

Access

EXAMPLE — Carilion Clinic Dental Care: Virginia, Carilion Clinic, Hospital-Based Pediatric Clinic

Description:

Carilion Clinic Dental Care is a hospital-based pediatric clinic that provides service in rent-free space at Carilion-Roanoke Community Hospital. Services are provided to uninsured and underinsured children and those with special health care needs and developmental disabilities.

Evidence:

The report notes increased access and significant improvement in oral health in patients. School nurses report absences due to toothache dropped following the opening of the clinic. Emergency Department physicians in the area reported satisfaction with the ability to refer uninsured patients (Association for Healthcare Research Quality (AHRQ), Innovation Exchange, 2015).

CONCLUSIONS

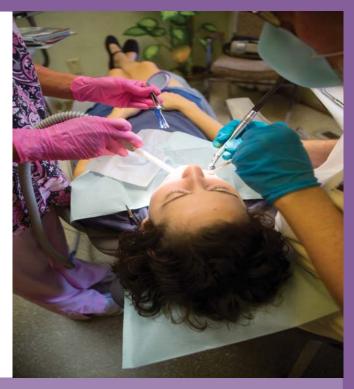
- There are multiple approaches to increasing access to oral health.
- Specialty clinics based in settings that are more accessible for people with IDD and mobile clinics provide opportunities for people with IDD to access oral health care and reduce physical access barriers.
- Increasing opportunities for oral health professionals to learn about treating people with IDD enhances the likelihood that professionals will be wiling and able to treat people with IDD in the future.
- Typical insurance models have not supported specialty clinics. Funding for specialty clinics is
 often supported at least in part through supplemental grants or through donated professional
 services.

PREVENTION IMPROVE ORAL HEALTH PREVENTION STRATEGIES TO

Fluoridation and the use of sealants for patients who can tolerate them are recommended, as are antimicrobial agents, such as chlorhexidine and xylitol, with the caveat that some patients may not be candidates for them or will require modifications.

The National Maternal and Child Oral Health Resource Center offers an online resource guide

- "An Oral Health Professional's Guide to Serving Young Children with Special Health Care Needs." The resource guide includes a module focused on preventative agents and adaptations for children with special health care needs, offering practical guidance for clinicians. It can be found at: http://mchoralhealth.org/ SpecialCare/index.htm.



WHAT WE KNOW FROM THE RESEARCH

Prevention

Chlorhexidine spray appears to improve plaque scores of people with intellectual and developmental disabilities regardless of concentration or length of application. Most common indices used to measure improvement were the Loe & Sillness Gingival Index and Sillness & Loe Plaque Index. The lack of consistent measurement and reporting methods within the literature make it difficult to effectively compare results across studies that include people with intellectual and developmental disability.

CONCLUSIONS

- · Chlorhexidine and fluoride have been found to be effective in prevention of tooth decay and caries in both the general population and in those with IDD.
- · Prevention interventions considered standard practice in the general population should also be considered standard practice to those with IDD.

*Note: There is no gray literature to report on prevention strategies.

SEDATION STRATEGIES TO IMPROVE ORAL HEALTH

Adults with IDD may need additional or special support in order to receive dental care, and in some cases this may include sedation. Existing literature describes the relationship between sedation methods and oral health outcomes as well as indicators used to determine the need for and what type of sedation used when providing oral health care.

Studies

- · Measured effectiveness of drug/device
- · Measured complications and outcomes of sedation use such as completion of treatment and recovery
- · Reviewed or developed criteria to select individuals for general anesthesia
- · Described and measured acceptance of behavior management techniques



WHAT WE KNOW FROM THE RESEARCH

Sedation

A portion of people with IDD may need sedation to manage behavioral issues; however, outcomes indicate general anesthesia can be replaced with other types of sedation. Assessing the level of sedation required for a procedure needs improvement. Vomiting and nausea are common outcomes and these risk factors should be considered, along with level of cooperation, acuity and urgency of treatment, and level of IDD, as indicators to determine the type of sedation (Boynes, 2010; Hung, et al., 2005; Hung, et al., 2003; Faulks, 2000; Collado, 2013).

CONCLUSIONS

- · Sedation can be an effective tool in providing oral health care to people with IDD.
- · Conscious sedation or behavior management techniques should be attempted prior to use of General Anesthesia.

*Note: There is no gray literature to report on sedation strategies.

Summary

In the search for effective approaches to oral health care for people with IDD, this research team cast a wide net with which to identify and then summarize the evidence base with the goal of informing and supporting clinical practice in this area.

We learned of a broad range of interventions including multiple approaches that have demonstrated improved oral health outcomes for this population.

In some cases, structured data collection allowed for an assessment of the evidence of effectiveness. In others, the programs were well described, however it was not possible to assess effectiveness beyond that. Despite these limitations, we believe that these are promising practices, and that clinicians and researchers will benefit from this brief summary of findings as a 'jumping off place' for future efforts to expand and enhance oral health care for people with IDD.

The gray literature is a valuable source for emerging interventions that are considered effective by clinicians and their patients, but successful oral health outcomes have not yet been demonstrated with robust research methods. We included reports identified in the gray literature as a means to advance awareness of promising practices and to spur additional research.

The variety of interventions examined in this study points to several promising areas to reduce oral health disparities. Continued research efforts in partnership with practicing clinicians are needed to further develop the evidence base.



Appendix A: Project Contributors

Each person listed contributed to either the development, implementation, or review of the research project.

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Appendix B: Methods

Evidence Based Methods

The research team framed and refined a systematic plan to collect and review the literature, applied inclusion criteria, conducted data extraction, and assigned a level of evidence based on both clinical and statistical review.

The team conducted a robust search of on-line databases such as PubMed, along with sites that included non-peer reviewed material, or gray literature. The search included any literature from 1990 to 2013 with an oral health intervention and for the population of interest — people with intellectual and developmental disabilities. Identi fied effectiveness studies fell into the four topic areas previously mentioned: **prevention strategies**, **sedation use**, **education & behavioral strategies**, **and access & potential models of care**. Literature that did not meet the standard for inclusion was reviewed for inclusion in the Promising Practices document. This "gray" literature encompassed resources that did not meet the strict peer review criteria. Several common themes emerged from the review. The recommendations spanned all levels of care — from the patient through the provider, oral healthcare system and finally the broader public health context at state and national levels, and encompassed the topic areas we were evaluating in the systematic review.

Data extraction was conducted using the Systematic Review Data Repository (SRDR), an electronic repository. The study team tailored the extraction tool to address specific Key Questions for each specific topic. For more detailed methodology see:

http://shriver.umassmed.edu/programs/cdder/oral-health-disparities

Or contact email: ChristineJ.Clifford@umassmed.edu

Gray Literature Methods

The initial literature search for the project yielded peer-reviewed articles for inclusion in a systematic review. Material that did not meet criteria was archived in RefWorks, and examined once data entry for the systematic review was complete. The archived material consisted of policy statements, peer-reviewed articles that did not focus on the target population or which did not fall within the chronology of the review, white papers, and other non-peer reviewed print and online material, which provided a base for the compendium of practices that have been implemented in an effort to meet the demand for oral health care among people with IDD. An Internet search for follow-up information was conducted to provide updated information for material compiled in RefWorks, and to seek out further innovations in oral health practices for people with IDD. While the original collection of documents included populations other than IDD, those documents have been subsequently excluded to limit the scope and keep it consistent with the literature included in the systematic review.

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^{‡ =} Evidence Based Literature from the Systematic Review

^{* =} Promising Practices no symbol= in body of paper

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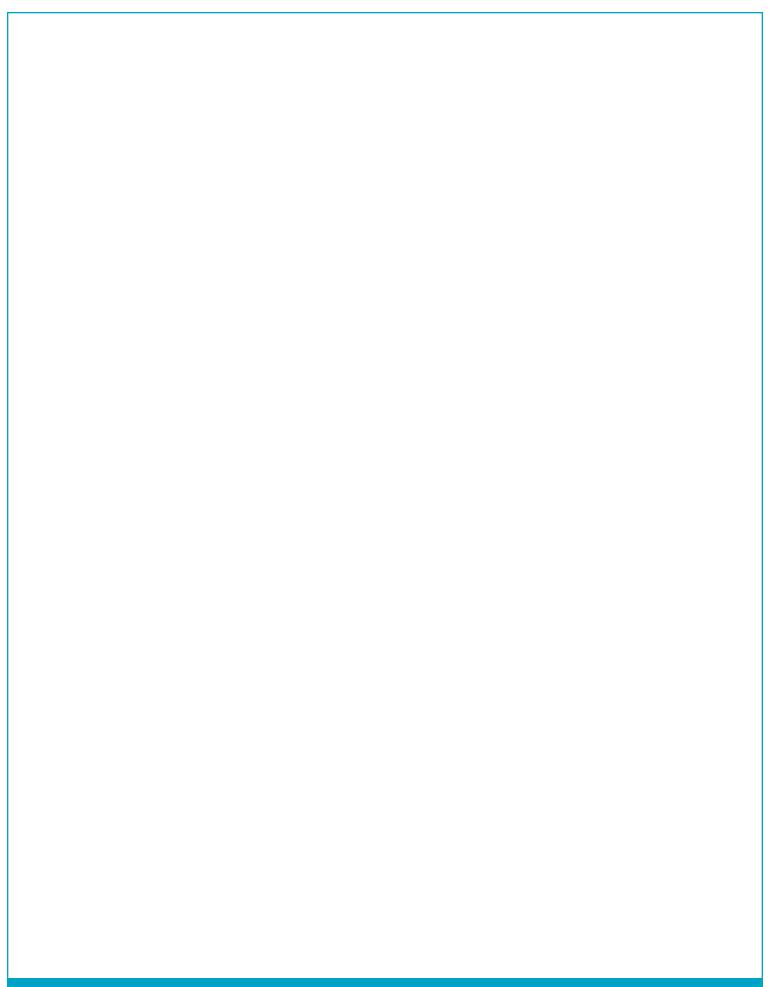
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