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Oral Health Services within Community-Based Organizations for Young Children with Special Health Care Needs

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Abstract

Purpose—To identify the types of oral health services offered by community-based organizations to young children with special health care needs (CSHCN) and the barriers and facilitators to the provision of these in a non-fluoridated community.

Methods—Thirteen key informant interviews with representatives from early intervention agencies, advocacy groups, and oral health programs who provide services to CSHCN in Spokane county, Washington. We used a content analysis to thematically identify oral health services as proactive or incidental and the barriers and facilitators to their provision.

Results—We identified four types of oral health services: screenings, parent education, preventive dental care, and dental referrals. Barriers to providing all four services included limited agency resources, restrictive administrative and system-level policies, and low demand from parents. A barrier to providing education and preventive dental care was community disagreement regarding fluoride. A barrier to providing dental referrals was the perceived lack of dentists who could treat CSHCN. Facilitators included community partnerships among the organizations and utilization of the statewide oral health program.

Conclusions—Oral health services for young CSHCN are limited and often delivered in response to oral health problems. Coordinated efforts between community-based organizations, health providers, and advocates are necessary to ensure the provision of comprehensive care, including preventive and restorative services, to all young CSHCN.

Keywords

oral health; dental utilization; dental education

INTRODUCTION

Oral health plays a crucial role in children's overall health and general well-being.¹ Optimal oral health is achieved through a combination of behaviors including preventive dental visits, toothbrushing with fluoride toothpaste, and eating a healthy diet low in fermentable carbohydrates.² Despite knowledge of how these behaviors can prevent dental caries and gum disease, many young children have poor oral health,³ which can cause pain and lead to long-term problems like school absences, poor performance in school,^{4,5} chronic diseases, need for hospitalization to treat severe dental problems, and reduced quality of life.^{6,7}

The US Department of Health and Human Services defines children with special health care needs (CSHCN) as those “who have or are at risk for developing a chronic physical,

developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”⁸ The prevalence of SHCN among all U.S. children increased from 13.9% (10.3 million) to 15.1% (11.2 million) between 2006–2010. Approximately 9.3% or 2.3 million of CSHCN are under age 6 years.⁹

CSHCN are at higher risk for dental caries and other oral diseases^{10–13} due to a variety of factors including compromised immunity,¹⁴ financial barriers for parents,^{15,16} and aversion to dental treatment.¹⁷ In addition, home-based oral hygiene, specifically toothbrushing, can be difficult for young CSHCN. Some have sensory impairments that make tolerating toothbrushes or fluoridated toothpaste difficult,¹⁸ while others lack the necessary motor function to independently brush their teeth.¹⁹ Oral health may be further compromised by high-carbohydrate diets often indicated for CSHCN who need to gain weight or correct a nutritional imbalance.¹⁸ Although CSHCN may be more likely to receive preventive dental care than children with no SHCN,^{20–22} CSHCN have more unmet preventive dental care needs.^{20–21, 23–24} This raises questions of where and how CSHCN use oral health services. A closer look at the resources available to CSHCN is merited, especially since young CSHCN (under age 6 years) are less likely to receive preventive dental care than school-aged CSHCN.²⁵

Vulnerable populations, including young CSHCN, typically receive needed therapies and other developmental services through community-based organizations that also educate caregivers^{26, 27} and advocate on behalf of families and children.²⁸ There is little information about how these community-based organizations address the oral health care needs of their clients. More specifically, research has not considered how these organizations’ efforts can be strengthened and coordinated within the broader oral health care delivery system. The aims of this study were to 1) identify the types of oral health services that community-based organizations provide to families and CSHCN under age 6 years, and 2) understand the barriers and facilitators to the provision of oral health services within these settings.

METHODS

Study Design and Setting

We conducted a qualitative study employing key informant interviews within community-based organizations that provide oral health services to CSHCN age birth to 5 years and their parents. Spokane county, a largely rural area in eastern Washington state was chosen as the study setting for two reasons we believed would foster active outreach and provision of oral health services for young children. First, Spokane county was the first to implement the Access to Baby and Child Dentistry (ABCD) program in 1995, a special state-wide program to improve dental care utilization rates for Medicaid-eligible children under age 6 years.²⁹ The long-standing presence of the ABCD program is likely to provide young CSHCN and their families with strong community-based oral health resources.³⁰ Second, Spokane county is a non-fluoridated community, thought to have widespread deliberate efforts to help parents prevent dental disease in children through other at-home and professional dental care methods.

In 2014, Spokane county had an estimated population of 484,318 and was majority non-Hispanic White (86%).³¹ In 2013, 16.3% children, age birth to 17 years, lived in households with incomes below the poverty level.³² In that same year, approximately 5% of children living in Spokane county had a disability, defined as “limitations of activities and restrictions to full participation at school, at work, at home, or in the community.”^{32,33}

Study Population

We conducted interviews with employees of three types of community-based organizations that provide oral health services for CSHCN under age 6 years: early intervention agencies, advocacy groups, and oral health promotion programs. Early intervention agencies, sometimes referred to as Birth-to-Three Centers,³⁴ provide services and therapies including speech, language, feeding and physical therapies, and child mental health counseling. Advocacy groups link low-income residents and CSHCN to oral health resources. Oral health promotion programs provide dental screenings and education to schools and other community-based organizations. Organizations were identified from publicly available online directories of health, education, social services, advocacy, and social support groups; Head Start and Early Head Start programs; dental hygiene programs; and recreational opportunities in Spokane county for CSHCN. Snowball recruitment was used to identify employees of schools and community-based organizations in Spokane county that were not listed in the directory. All participants in this study must have been with the organization for at least three months and able to converse in English.

Study Procedures

We developed a semi-structured interview script with questions about the organization, the types of oral health services provided, and the barriers and facilitators to the provision of these services. One of the authors conducted phone interviews in 2014. The interviews were 30–45 minutes in duration and digitally recorded. Each interviewee received a \$20 gift card as an incentive for participation. The University of Washington’s Institutional Review Board approved the study.

Data Analysis

Interviews were transcribed by a professional transcription service, verified against the digital record, and edited as needed to assure accuracy. Co-authors generated an initial codebook with 32 codes of interest developed from one author’s community-based evaluation research.³⁵ After reviewing three transcripts, the codebook was expanded to 34 codes (Table 1). Where coding for data was uncertain, authors made decisions by consensus. Data were analyzed through a conventional content analysis.³⁶ Oral health services were categorized into four major types, and then subcategorized as either “proactive” or “incidental.” Proactive efforts were direct, systematic actions on the part of the provider or agency to assess children’s oral health status or caries risk. Incidental efforts were actions secondary to the providers’ primary purpose, for example, notifying the parent of tooth decay observed in the course of speech or feeding therapy. Potential barriers and facilitators to the provision of oral health services were categorized according to frequency. One individual coded all 13 transcripts. All data were coded using NVivo 10 software (QSR International Pty Ltd, Victoria, Aus).³⁷

RESULTS

Participant Characteristics

Thirteen participants were interviewed (10 females and 3 males). All interviewees were clinicians with administrative roles (e.g., an occupational therapist and the business owner; a behavioral analyst and clinical director of the agency) or agency administrators (e.g., a program director). The interviewees represented 12 different community-based organizations: seven early intervention agencies, three advocacy groups, and two oral health promotion programs (Table 2). Organizational reach of the agencies represented by the interviewees ranged from serving 17 to 850 clients per year.

Oral Health Services Provided by Organization

All interviewees said that low-income children and families comprised a large portion of their client base. All served CSHCN in addition to children without SHCN. The interviewees described four types of oral health services offered to CSHCN and their families delivered proactively and incidentally: dental screenings, parent education, preventive dental care, and dental referrals (Table 3).

Early Intervention Agencies

Dental Screenings—Four of the seven agencies offered a mix of proactive and incidental dental screenings to their clients. Proactive practices included parent-report of child's oral health status on an intake questionnaire or, at one agency, through direct observation during a speech therapy evaluation where they "do a thorough oral motor examination, [and] take a count of how many cavities [CSHCN] have." Incidental screenings were more common and involved a staff member noticing an oral concern during other therapy sessions. One informant summarized it this way, "If we see something in therapy, then we will refer or heavily encourage the patient to go [see a dentist]."

Parent Education—Early intervention agencies' main focus is to provide therapeutic or developmental services. Proactive oral health education was more often provided to parents of CSHCN with specific oral conditions. One physical therapist explained that toothbrushing and cleaning the gums "is a huge issue for our feeding [tube] kids because they are pretty aversive in the mouth and so [therapists] will work on that in therapy... and they try to get the parents to do it." Using a toothbrush or "whatever [the parents] can do, a soft washcloth or something", to practice desensitizing the child's mouth at home was suggested by a majority of the agencies' representatives. Some agency representatives also mentioned that therapists would provide proactive education when having "conversations with families about [the therapists'] concerns about [the] child's dental health and [if they] have a plan." However, education about oral disease was not provided routinely, as some agency representatives expected "the pediatrician is going to talk more about the oral health risks."

Preventive Dental Care—None of the early intervention agencies provided on-site proactive preventive dental care, such as, applying topical fluoride varnish or dental sealants.

Dental Referrals—Five of the seven agencies provided referrals incidentally. Early intervention agencies, like other community-based organizations, relied on a statewide oral health program for vulnerable children (i.e. the ABCD program) to provide them with a directory of dentists willing to treat young CSHCN. One interviewee said: we “give [families] the whole list we have and encourage them to call and find one that works best for them.” Another early intervention agency noted their approach to dental referrals was “a poster with the various dentists in town, [with] their names on it [from] the ABCD program. We post that, and that is about as far as we go.”

Advocacy Groups

Dental Screenings—Advocacy groups surveyed provide services to CSHCN through “wellness screenings, audiometric screenings, [or] developmental screenings.” Parents of children who do not already have a dental provider are encouraged to establish dental care for their child.

Parent Education—Some proactive oral health education was provided by the advocacy groups. One interviewee specified that for young CSHCN served by Early Head Start programs, parents are given a finger brush to massage the gums of the child. These groups also held parent education nights or conferences during which they attempted to address the needs of families, because “dental health and digestive health are two really huge issues for our families.” Representatives of advocacy groups considered oral health education important to “really helping the parents understand that if we get kids to care early, it is about prevention; it is not about treatment.”

Preventive Dental Care—Two interviewees said their groups recommended that parents use fluoridated toothpaste with their children at home and take their CSHCN to a provider for professionally applied fluoride. None of the groups provided on-site proactive preventive dental care.

Dental Referrals—Two of the three advocacy groups were reported to provide dental referrals proactively to all families. Two groups placed family service coordinators in early intervention agencies to help connect families of CSHCN with dentists. Service coordinators were personnel who connect families with “whatever community resources are needed at any given time for any child,” including finding a dentist. Another proactive approach was letting families know of “a dentist who is maybe doing some free dental work...and we will send that out in our newsletter.” Advocacy groups made use of the ABCD program for dental referrals both proactively and incidentally. For instance, at one agency, family service coordinators were encouraged to recommend ABCD dentists to families whereas another simply added the ABCD list of dentists to “a list on our website of dental providers.”

Oral Health Promotion Programs

Dental Screenings—One program provided dental screenings one or two times per year at schools. The screenings were conducted by dental hygienists who would assess each tooth in the mouth of the child.

Parent Education—Oral health promotion programs provided education to children in schools and early identification agencies, attempting to “bring up the educational level, [by] getting the little kids to play with puppets and talk about toothbrushes.” Another aspect of their work was to conduct “a needs assessment [asking], ‘what does this [early identification] agency need in terms of oral health education?’” Proactive education for parents was not common. Education was mostly provided incidentally as a response to an “acute need.” One program representative said, “Depending on the school, I will talk with the parents and say, ‘This child needs some help. We need to make sure the child gets help because they have an acute situation.’”

Preventive Dental Care—Only one program provided preventive dental care in the form of fluoride varnishes and dental sealants for CSHCN in schools.

Dental Referrals—Dental referrals by these programs consisted of incidental practices, such as giving parents a list of local dentists. One interviewee said, “I don’t get into the signing up [of] parents, but I give them all the information to get signed up, and the follow through is from the ABCD coordinator.”

Barriers to Oral Health Services: Factors that limit provision of oral health services across all organizations

Limited Agency Resources—Community-based organizations’ focus on oral health was limited by time and funding. One early intervention agency owner said his “focus is providing PT [physical therapy], OT [occupational therapy], and speech therapy...we don’t get paid for [oral health services].” Some organizations lacked adequate staffing to coordinate oral health services or as one informant described, “in order to administer a program, you have to have an individual there who is answering calls and scheduling.” Similarly, for one oral health promotion program, time and resources were barriers because partner sites needed to “have someone who can help us coordinate...if [they] don’t, then I’m sorry we just can’t do it. I can’t schedule all those sites; there is just not enough time in the week.”

Administrative and System Barriers—We identified administrative and system-level barriers that interfered with the provision or continuation of oral health services to CSHCN. Interviewees perceived that parents of CSHCN faced a lack of continuity in services because “once they leave that Birth-to-Three services...[families] are kind of getting thrown out into the system, and they really haven’t got a clue where to reach out.” Some interviewees shared that their organizations were dependent on school contracts that restricted the content implemented. A clinical director specified that schools might not allow toothbrushing as part of their developmental health collaboration with some agencies because of their narrow definition of what education is and can consist of. One oral health promotion program was restricted to “hav[ing] to be in public schools... limited to [an organization] that has the name school after it.”

Availability of Qualified Dentists—Although community-based organizations made use of the list of ABCD dentists, the availability of pediatric dentists was limited to “two or three

dentists in town who specifically cater to kids with special needs.” Interviewees mentioned the need to avoid “overburdening” certain dentists. A clinical director explained, “Many times [dentists] don’t want us to put them as a resource on our website because they don’t want to be inundated with [referrals for CSHCN].” At one early intervention agency, staff and families worked together to “put together [their] own list [of dentists]” given their experience of encountering “a lot of dentists out there that don’t want to work with special needs kids.”

Low Demand from Parents—Limited recognition of the importance of oral health by caregivers was another barrier discussed by interviewees. A common perception was that oral health is not a priority because families of CSHCN are overburdened. As one person described, “These are families who have kids who a lot of times have conditions that are life threatening...Dental care, especially when they are younger and the teeth are growing and they seem to be okay, just isn’t on their thing-to-worry-about list.” Some interviewees noted low demand was linked to parents’ own dental fears. A parent educator observed, “A lot of the parents... we work with are fearful of the dentist. Maybe their experience as a child wasn’t the greatest.” One dental hygienist experienced “a couple of [CSHCN] families where the parent was very under-educated and defiant... I think they think I am being critical of them sometimes.” A speech therapist remarked, “Parents don’t realize, when we talk to them about one of the primary causes for absences from school and the overall long term effects of poor oral care and poor dental health in general, what the impacts are.”

Politics of Fluoride—Community water in Spokane county is not fluoridated. When discussing oral health services, representatives of five community-based organizations brought up fluoride. Early intervention agencies mentioned coordinating with pediatric dentists and pediatricians to “administer fluoride varnish” or that “pediatricians will do the fluoride drops.” Interviewees from early intervention agencies stated that education about and administration of fluoride were medical and dental issues. The agencies’ position was not “necessarily to recommend, but to present it as an option.” One clinical director described her agency’s protocol was to “talk to the family and coordinate with their pediatric dentist [on] how to deal with the fluoride issue...because the thing that [we] don’t want to do is start doing anything that might be more of the dentist’s stuff...even something as simple as fluoride could be a prescription here in our county.” Only representatives of the oral health promotion programs and advocacy groups said they recommended fluoride use to all clients and their families. One of the dental hygienists mentioned having to “do a lot of fluoride education because a lot of these low-income parents are very scared of it. You know there are a lot of scare tactics about fluoride in the water, so we try to dispel all those rumors.”

Facilitators to Oral Health Services: Factors that would ease provision of oral health services across all organizations

Ties to the ABCD program—All of the community-based organizations used the ABCD program in Spokane county to connect families of CSHCN with ABCD dentists. A representative of one advocacy group mentioned having to “constantly educate our family resource coordinators about encouraging parents to seek out a dentist, preferably a dentist

that is ABCD-certified.” Although some organizations described the ABCD program as “a list of pediatric dentists that are available for [CSHCN],” others identified the ABCD coordinator as someone who could provide care coordination services to families.

Established Partnerships—Early intervention agencies have well-established partnerships with other community-based organizations within Spokane county created through referrals from pediatrician’s offices, hospitals, the Infant Toddler Network, and even dental offices. Additionally, the majority of the agencies partner with schools to deliver health transition services, oral therapy, or oral health services. A speech therapist remarked “a lot of those kids have feeding plans. Maybe [they] can’t chew, so we are trying to help them have a safe plan for school.” Some advocacy groups’ partnerships with schools focused on identifying SHCN and coordinating transition services for CSHCN at age 3 years as well as “partnering with them around dental care.” Staff of an oral health promotion program started “a toothbrush club at [a local] elementary” school to “open people’s eyes up to oral health, how it relates [to overall health], and how we can bring this to the schools.”

The oral health promotion programs considered education and screenings central to their mission since “dentistry is not just going into your office to treat patients from 8 to 5. It’s about giving back to the community.” Moreover, representatives of these programs saw collaborations with other community-based organizations as beneficial because “if these sites do not have some kind of educational program annually, they lose their state and federal funding.”

DISCUSSION

The study aims were to survey the oral health services provided to young CSHCN within community-based organizations and to identify barriers and facilitators to oral health service provision. We found that all community-based organizations surveyed devoted resources to oral health promotion for young CSHCN, although services are not standard, not always delivered proactively, or even consistently within an organization. Barriers that hinder efforts to improve the oral health of CSHCN included organizations’ lack of personnel to help CSHCN find a qualified pediatric dentist and low demand from parents for oral health services (Table 4). These barriers point to opportunities to strengthen the role of community-based organizations in oral health promotion of young CSHCN.

Community-based organizations in Spokane county are attuned to the oral health needs of CSHCN, given that all of the organizations had implemented oral health promotion services, including dental screenings, parent education, preventive dental care, or dental referrals. This is in contrast to findings of non-dental care providers’ low engagement with and lack of knowledge of the oral health issues of CSHCN.^{35, 38–40} We found proactive efforts on the part of community-based organizations when demonstrating toothbrushing and gum wiping with CSHCN and their parents. Some advocacy groups and oral health promotion programs advocated for fluoride use and varnishes, with one program directly providing the service. However, the majority of the oral health services were provided incidentally. Most organizations told parents to brush the CSHCN’s teeth or clean their gums as a response to an oral concern or a child’s specific medical condition and rarely explained why the

procedure was important for overall oral health. Additionally, organizations did not make referrals to specific ABCD dentists or follow-up with families to ensure they had seen a dentist. Even if it is not in the purview of early identification agencies or advocacy groups to provide preventive dental care, more proactive steps could be taken by organizations to ensure a meaningful, universal delivery of oral health services to all CSHCN and their families. For example, organizations and their partner agencies could conduct direct observation screenings of all CSHCN, not only those with oral conditions. Therapists could integrate parent education on oral hygiene as a larger part of their therapy session. Community-based organizations are uniquely positioned to promote good oral health to families of young CSHCN because of their close-interaction with parents.

While these findings are encouraging, community-based organizations experienced barriers to the proactive promotion of these oral health services. Like other studies that have found CSHCN's access to oral health services challenged by resource constraints,⁴¹ administrative burdens,⁴² lack of available dentists,^{17, 43–44} and low demand from parents,⁴⁵ our study identified similar barriers. Additionally, all the organizations brought up fluoride as a preventive oral health tool but did not uniformly recommend fluoride to families of CSHCN. Spokane county has chosen not to fluoridate its community water supply, and dialogue around fluoridation is contentious. Given the high effectiveness of fluoride as a preventive oral health measure,^{46–47} we believe early intervention agencies should be provided with the materials and training needed to advocate for fluoride. These agencies can in turn better bridge the educational gap on fluoride for parents of CSHCN and provide proactive oral health services to highly vulnerable children and their families.

Strengthening partnerships with the ABCD program would be a boon to the provision of oral health services to CSHCN. ABCD program coordinators and staff can be the liaisons linking dental providers to community-based organizations because the ABCD coordinator understands the needs of providers and families, making them an invaluable but underutilized resource. One way to encourage more proactive use of the ABCD program would be to act on parent-report screening data to provide referrals to dentists known to accept Medicaid-eligible CSHCN or to coordinate with ABCD dentists to conduct on-site screenings and provide preventive dental services (e.g., topical fluoride). Expanding the pool of ABCD providers to include registered dental hygienists would be one way to increase the number of providers able to deliver preventive dental care. Early intervention agencies and oral health promotion programs need to work with ABCD dental providers to help CSHCN establish a dental home by the child's first year to greatly reduce their risk of poor oral health.^{18, 48} Future collaborations with dental providers can strengthen organizations' abilities to provide proactive oral health services, like better education to parents about preventive care and mollifying dental fears. The result would be a continuum of proactive support for oral health services within the community.

LIMITATIONS

This is the first known study to use a systematic approach to identify the oral health services provided to young CSHCN through community-based organizations. This study has two main limitations. The first was the small sample size; only 12 community-based

organizations are represented. Interviews with more organizations could have highlighted additional barriers and facilitators to the provision of oral health services. However, the organizations interviewed represent a wide spectrum of services and sizes and are in a part of Washington state with high preventive dental care utilization.⁴⁹ Second, all interviews were held with representatives from community-based organizations and did not include dentists, physicians, teachers, school-based therapists, or the ABCD director. In order to understand the broader context of oral health issues along the CSHCN lifespan, these key informants could be added to provide additional information on the barriers and facilitators to oral health for young CSHCN. To achieve successful interventions, it is essential that future projects coordinate among the various existing service systems to reach and benefit young CSHCN.

CONCLUSION

Young CSHCN are at high risk for poor oral health. We found that community-based organizations are well-situated to provide oral health services to young CSHCN and all organizations represented in this study provided at least some of the following: dental screenings, parent education, preventive dental care, and dental referrals. Barriers to the proactive provision of these services include: limited agency resource, administrative and system barriers, availability of qualified dentists, low demand from parents, and contention over fluoride. Facilitators include: ties to established dental access programs, specifically the ABCD program, and existing partnerships between early identification agencies and other organizations. Future research is needed to identify effective ways to improve coordination of oral health-related activities across community-based organizations that serve young CSHCN and gain insight from parents, dentists, and medical providers on ways to improve delivery of oral health care services to young CSHCN.

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Table 1

Codebook for Analysis and Verbatim Examples

Domain Label	Description	Verbatim Example
Organization and Informant Attributes		
Organization Client Demographics	Socioeconomic status, Medicaid eligible, severity of conditions, high special needs	<i>"All of our kids are under six years. We serve only birth to three, so kids leave on their third birthday."</i>
Organization Employee Makeup	Number of therapists, specialty of therapists,	<i>"I have three OTs [occupational therapists], eight speech therapists, seven physical therapists, and one physical therapist assistant."</i>
Organization Geographical Location	Location of the organization within Spokane county	<i>"We are located in Spokane Valley, Washington."</i>
Organization Size	Number of children served	<i>"We typically see somewhere up to 180 Birth-to-Three kids."</i>
Role of Organization Representative Interviewed	Role of interview participant (e.g. owner, speech therapist, Clinical Director)	<i>"I am the director and I am also a developmental specialist."</i>
Supervisor	Supervises a staff	<i>"I supervise six people and they operate eight programs."</i>
Onsite Programs for Children Age 0–6 Years	For children under age 6 years	<i>"We offer therapy preschool, and therapy toddler group."</i>
Partnerships with Other Community Organizations	Partnerships between the organization and...	
Head Start Affiliation	Affiliation with Head Start or Early Head Start programs in the county	<i>"If we have kids who go to Early Head Start, we will see them there if that is what they choose."</i>
Elementary School Affiliations	Affiliation with public school programs in the county	<i>"Because of our geographic location, we have a high level of families that are in the biggest school district in the county which is Spokane County Public Schools."</i>
Healthcare Affiliation	Affiliation with healthcare programs in the county, external to the organization	<i>"We collaborate with WSU [Washington State University], Eastern, the Deaf and Hard of Hearing Program"</i>
Other Affiliation	Affiliation with other community-based programs for young children in the county	<i>"We do pair up with Parents as Teachers."</i>
Community Presence	How the organization advertises, gets referrals, and provides information; integration into community	
Client Recruitment	Organization's advertising and client recruitment strategies	<i>"We do Valley Fest. Yeah. To get out there in the community."</i>
Referrals From	Referrals to the organization, such as: hospitals, physicians' offices, clinics, dental offices	<i>"Most referrals come from doctors or the Infant Toddler Network...every once in a while we get parent referrals; and then the hospital."</i>
Outreach	Forms of outreach and communication, includes resource sharing	<i>"We do Facebook. We have our Facebook page, our internet."</i>
Services Provided by Organization	Types of services the organization provides	
Education	Organization provides some form of education	<i>"Our base services are special education, physical therapy, occupational therapy, speech/language therapy."</i>
Medical	Organization provides some form of medical therapy	<i>"Physical therapy, occupational therapy, speech therapy and feeding therapy."</i>
Transitions	Organization helps transition clients/children/families	<i>"With all of the school districts in Spokane County... when a child reaches the age of three there is a transition meeting to transfer their case over to the school district."</i>

Domain Label	Description	Verbatim Example
Social Support Resources for Parents	Parent support groups, meals and healthcare advice, outside speakers	<i>"We have a Parent to Parent program which provides support groups, literally support groups, and also what we call 'helping parents', a kind of mentoring parent."</i>
Oral Health Services Provided	Types of oral health services provided	
Oral Health Education Offered	The organization provides an oral health education component	<i>"I do have a little program that somebody gave me on dental, a long time ago. And we have a dental week where we send some [materials] home to the parents and talk about teeth and we do lots of little fun [activities], like we brush pretend teeth on Mr. Potato Head."</i>
In-Person, 1-1	Organization assigns therapist or hygienist to do one-on-one teachings (includes therapist +family+child=1-1)	<i>"For example, I had a little person who isn't eating, has a feeding tube, and we are going start on trying to get them to eat. The thing I talk to the parents about first, the primary most important thing is desensitizing their mouth with non-food items. So, I try to start with a soft-bristled tooth brush if they will tolerate it."</i>
In-Person, Small Groups	Education is offered in small groups (classroom size) to children	<i>"If it is a time with a lot of infants, we obviously are not doing a lot of tooth brush instruction, but if it is little 4-year-olds running around, we do."</i>
Parent Education	Education offered specifically for parents	<i>"Because if adults are present, then we want to actually do something with the kids and then pull the parents aside and do a little educational piece."</i>
Printed Matter	Information that is distributed or used as an educational guide	<i>"I had a really cute book about how to brush your teeth, like a popup book. Oh, it's actually through Delta Dental. It's called 'Cavity Free Kids: Oral Health Education for Preschoolers.'"</i>
Fluoride	Organization mentioned fluoride (water, rinses, toothpaste, etc)	<i>"We do a lot of fluoride education because a lot of these low income parents are very scared of it."</i>
On-site Dental Services	Provides a form of dental services on-site	<i>"It is part of our speech therapy evaluation process to do a thorough oral motor examination, so we check for... we take a count of how many cavities they have."</i>
Dental Screenings Offered	Dental professionals, Eastern Washington University clinic, rotating hygienist	<i>"When I do a screening, I've taken kind of a combination of charting ideas from research, Head Start, and then a regular dentist office."</i>
Referrals To	Organization offers referrals to dental professionals	<i>"We know pediatric dentists, so when families are looking for them we give the names of pediatric dentists preferably, and then there is the Access to Baby and Child Dentistry (ABCD) program."</i>
Preferred Providers	Preferred providers and how they are found	<i>"I can give you the one that we use the most, our dental champion."</i>
Follow-up Process	Any follow-up process after referring a patient to dental care	<i>"We usually just ask, 'Did you make an appointment?' But we don't really pursue it a lot."</i>
Observation of Oral Health Issue	Actions taken by organization when they observe oral disease/health issue	<i>"If we see something in therapy, then we will refer or heavily encourage the parent to go [to the dentist]."</i>
Informant Evaluation of Oral Health Service		
Working well	Oral health service that is having good results/good adoption	<i>"We have them fill out a questionnaire about the child's nutrition. We added some dental questions to that to make sure kids were getting hooked up with dentists."</i>
Challenges	Most challenging piece of implementing or having oral health service	<i>"Because a lot of our kids have sensory issues, they don't even want to brush their teeth and they have all those severe [conditions]."</i>
Needs	Needs of the organization to implement an oral health service	<i>"I don't know that a physical therapist or an occupational therapist or a speech therapist is qualified to do dental work; to screen that. It would have to be a dental professional that would have to participate and be willing to participate."</i>
Collecting Feedback	Organization collects feedback on oral health service	<i>"We call and they will, especially if it doesn't go well, we [get] feedback from parents in general about, 'This isn't a</i>

Domain Label	Description	Verbatim Example
		<i>good place for my child; I need another dentist.' They might have barriers about getting to the dentist and taking those fears and manifesting them over to the child."</i>

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Table 2

Characteristics of Community-Based Organizations Represented (N=12)

Type of Community-Based Organization	Professional Role of Key Informant	Total number of clients served by organization/year	Services Provided
Early Intervention Agency	Nurse/Coordinator	140	Developmental Health Therapy
Early Intervention Agency	Parent Educator	17–20	Child Mental Health Counseling Services for Families and CSHCN *
Early Intervention Agency	Clinical Director/Behavioral Analyst	32	Individualized Education Program Care Coordination
Early Intervention Agency (Same as above)	Community Connections Director	32	Individualized Education Program Care Coordination
Early Intervention Agency	Owner/ Physical Therapist	480	Developmental Health Therapy
Early Intervention Agency	Owner/ Physical Therapist	400	Developmental Health Therapy
Early Intervention Agency	Early Childhood Special Education Teacher	50	Developmental Health Therapy
Early Intervention Agency	Therapy Director/ Speech Therapist	140	Developmental Health Therapy
Advocacy Group	Director of Advocacy and Family Support	500	Family Care Coordination Services
Advocacy Group	Program Manager	850	Early Support Coordination for Infants and Toddlers with SHCN **
Advocacy Group	Health Services Specialist	813	Health, Education, and Funding Program
Oral Health Promotion Program	Dental Hygienist	708	Oral Health Education and Dental Referrals for Schools and Community-Based Organizations
Oral Health Promotion Program	Dental Hygienist	850	Dental Screenings, Education and Dental Referrals in Schools

* Children with Special Health Care Needs

** Special Health Care Needs

Table 3

Oral Health Services Provided by Community-Based Organization

Oral Health Service	Service Provided Proactively to Clients	Service Provided Incidental to Another Service or in Response to Parent's Request
Dental Screening		
by parent report	Parent-report of child oral health status is included on the intake questionnaire. <i>"We have them fill out a questionnaire about the child's nutrition. We added some dental questions to that to make sure kids were getting hooked up with dentists."</i>	n/a
by direct observation	On-site dental screening of the organization's clients by dental providers. <i>"I go around to every tooth and say what is on it."</i>	Non-dental professionals identify an oral health concern while performing other health or developmental services. <i>"If we are seeing a lot of rotting teeth, which unfortunately, we do for little kids, we ask them if they are connected to a dentist."</i>
Parent Education		
	Organization provides or hosts a parent night session on children's oral health. <i>"We are hoping to put together a break out on just general health issues, including dental health, actually."</i> Oral health information is provided to parents in a newsletter or other direct communication with parents. <i>"I encourage them to brush, especially if there is a problem, encourage them to brush longer, brush every day, which is sometimes just trying to get them to brush every day, not twice a day, but every day."</i>	Parent receives pamphlet or other print information in response to questions or concerns about child's oral health. <i>"We have over-the-counter mouthwash information. So, I have a handout on that, so they know that can be a cavity prevention."</i>
Preventive Dental Care		
	Organization provides or hosts on-site preventive dental care (e.g., topical fluorides or dental sealants). <i>"My services that I'm limited to with this type of practice are the screening, plus screening for decay, screening for problems, and screening to see if a child needs help. I also do fluoride varnish, dental cleaning, and sealants if needed."</i>	n/a
Dental Referrals		
	Organization provides contact information for local dentists who accept Medicaid-eligible young CSHCN in newsletter, mailing, or other direct communications with parents. <i>"On occasion, we will get notices that a dentist who is maybe doing some free dental work and stuff like that, and we will send that out in our newsletter."</i>	Organization displays information about local dentists who accept Medicaid-eligible young children. <i>"Other than the brochures we have from the ABCD Dental [program] and the pull-off poster access information... we are not distributing a lot or doing any special dental information nights or that kind of thing."</i>

Table 4

Direct Quotes Describing the Top Most Cited Barrier and Facilitator by Type of Community-Based Organization

Type of Community-Based Organization	Most Commonly Cited Barrier and Facilitator
Early Intervention	
Barrier	Limited Agency Resources- <i>"We are spending all this time doing something other than therapy, and we don't get paid for that."</i>
Facilitator	Established Partnerships- <i>"There are a lot of pediatric dentists in town and we have one who has come to our clinic and given us presentations, and we tried to create a relationship with [them]."</i>
Advocacy Group	
Barrier	Low Demand from Families- <i>"Getting to the hard to reach kids and families and really trying to discover, 'Are these long held notions among families? Maybe they had dental fears; maybe they had bad experiences.'"</i>
Facilitator	Established Partnerships- <i>"Spokane Public Schools in general are starting to put social workers and nurses back into their school districts, so we have been collaborating with them to let them know about the ABCD program and the dental services that could be offered."</i>
Oral Health Promotion	
Barrier	Limited Agency Resources- <i>"Scheduling is always the tough part. It always comes down to scheduling."</i>
Facilitator	Established Partnerships- <i>"The people who see more special needs kids, the teachers, will come up and tell you how grateful they are that there is somebody helping these kids, and they know that a lot of times the parents are not able to."</i>