Open Arms
Children's Health

Dental Service

Evaluation Report

May 2014

Prepared for Home of the Innocents
by REACH Evaluation

Open Arms
children's health

Open Arms Children's Health Dental Service

EVALUATION REPORT—May 2014

A Service of **Home of the Innocents**

home of the innocents

REACH EVALUATION

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Funded by the Social Innovation Fund through the Foundation for a Healthy Kentucky

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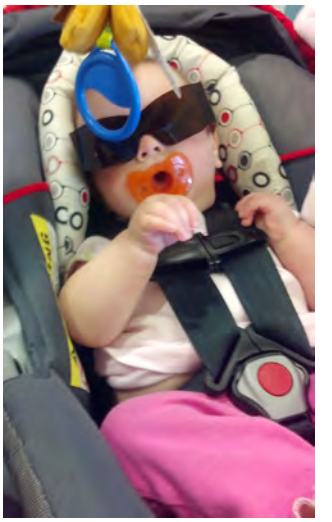


Open Arms Children's Health *is a service of Home of the Innocents and provides compassionate, expert care for children who are medically fragile, children with autism, children in foster care and children with other exceptional needs. The Dental Service is a component of Open Arms Children's Health.*

OpenArmsChildrensHealth.org

A Satisfied Patient and Her Parents

While there are many, many stories of satisfied patients, Rebecca's experience provides some insight into the special nature of this service.

An interview with a dad and his daughter provided a stunning case study of the uniqueness of the Open Arms Dental Service. Tim and his wife and their daughter Rebecca were "early adopters" of the Open Arms Dental Service and very satisfied customers. Rebecca has been diagnosed with Down syndrome and autism.* She comprehends verbal communication but uses signs to communicate with others. Rebecca had a history of being extremely anxious about going to the dentist, and she was particularly anxious about sitting in the dental chair and having to be reclined.

The family's gratitude for the sensitivity and patience of the staff was evident in Tim's review of their early visits to Open Arms and the change that has occurred since that time. In his words, "I expected them to be patient, I just didn't realize they would be THAT patient." "THAT" degree of patience turned out to be three visits to Open Arms, scheduled for time with the dentist, during which Rebecca was able to become increasingly more comfortable with the atmosphere, the dentist, and especially the chair. On the third visit, she agreed to sit in the dental chair and allowed Dr. B to recline it.

Open Arms staff took time to get to know Rebecca and to discover a routine that would work for her. The established "routine" begins the moment Rebecca arrives. Rebecca's favorite color is red, and staff make sure that she can sit in the red chair for her appointment. Dr. B. gave Rebecca her own nitrous oxide mask to take home and handle, so that she could get used to the idea and comfortable with the feeling of a mask on her face. She brings it to every appointment.

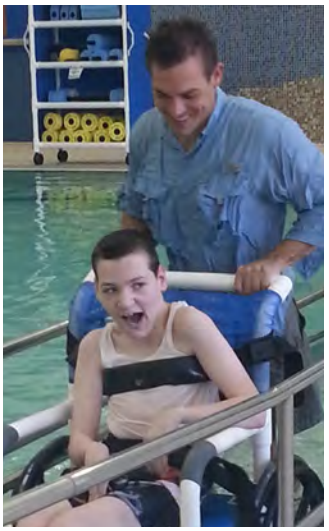
At Open Arms, the dentist views Rebecca's dental care as a collaborative process. He informs her parents where she needs to target particular attention, and he has prepared them for the kinds of new issues for which they will need to plan in the future. Tim noted that "you can see he has an agenda in his head. He has good notes and he knows exactly what has been done so far. I'm very satisfied that we've never detected a sense of indecision." And perhaps the best endorsement comes from Rebecca. She has become very comfortable with him, and trusts that he will stop what he is doing as soon as she objects. Dental appointments are no longer terrifying for Rebecca, or disturbing for her parents.

***Seventy-five (75) children with autism were served during the evaluation period, and these children are included in the other priority populations served by the Open Arms Dental Service** (details are on page 19).

"I expected them to be patient, I just didn't realize they would be THAT patient."

"As long as [you} have that patience at the beginning and set up that routine, all the stress is gone and she knows nothing bad is going to happen."

Tim, Rebecca's dad



Open Arms Dental Service, Courtesy of Home of the Innocents, Louisville, KY

"The Open Arms Dental Service uses a variety of behavioral aids and techniques to make the experience as positive for children and their caregivers as possible."

Report Highlights

This report summarizes the evaluation activities and the findings associated with those activities. Although the Open Arms Dental Service opened in March 2011, data collection had to be postponed until IRB approval was received (June 18, 2012). This report, therefore, includes data on children served between July 1, 2012 and the end of the grant period, March 31, 2014.

Highlights of Preliminary Findings

- Home of the Innocents (HOTI) exceeded its annual goal of serving 880 children within a year. During the first 12 months of the evaluation period (July 1, 2102 – June 30, 2013), they served 920; in the final 12 months (April 1, 2013 – March 31, 2014), they served 1,411. This report analyzes data from seven quarters and includes 1,488 patients (unduplicated count).
- HOTI met its annual goal of serving 80 dental students and 6 pediatric residents.
- The Open Arms Dental Service is a resource for children throughout the Commonwealth, with children from 78 Kentucky counties represented, along with one county in Indiana.
- The Open Arms Dental Service is fulfilling its objective of serving special needs children. Participation by priority population during the 21-month period was as follows:
  - Medically Fragile: 134
  - Intellectually/behaviorally disabled: 28
  - Foster care or residential care: 682
  - Other Medicaid eligible children at-risk for poor dental health outcomes: 631 *(+13 missing data)*
- The Dental Service has been a welcome resource for refugees (136 during the 21 month period), many of whom have experienced years of impoverishment in war-torn countries and refugee camps. They are included among the "other Medicaid eligible children" above.
- The Open Arms Dental Service uses a variety of behavioral aids and techniques to make the experience as positive as possible for children and their caregivers *(see page 20)*. The tools are directed not only at lessening a child's anxiety, but also of positioning the child in a manner that is both comfortable and conducive to a thorough examination. One unique example includes transitional visits to the Open Arms Dental Service where children can meet with a therapist to reduce anxiety and promote a positive experience prior to receiving treatment.
- There has been a dramatic improvement in the completeness and quality of the dental staff notes, allowing for a more thorough note and better continuity of care.
- Most children are accepting of treatment. When parental expectations of their child's acceptance of treatment were compared to the dentist's assessment of the child's acceptance of treatment, there was agreement in 39.8% of the cases. In

50.5% of the cases, however, the dentist's assessment was more positive. (The parent provided a pre-visit expectation and the dentist provided an end-of-visit assessment; suggesting that the reality may be more positive than the parental expectation.)

- When the mean scores of treatment acceptance were compared (mean scores at Time 1 compared to mean scores at all subsequent visits), there was a significant difference in a favorable direction (at the .05 level). When the scores of the 279 children who had four measures of treatment acceptance (Time 1, 2, 3, and 4) were compared; there was slight movement in a positive direction. The high scores, even at Time 1, reflect the attention given to the child and the willingness of staff to move at the child's pace. This also explains the relatively modest change in treatment acceptance among these children, in that it is difficult to improve on scores that already are positive.

- Medically fragile children, refugees, and children in out-of-home care with other agencies, had poorer scores on three oral health measures (plaque, calculus, oral hygiene) than other children served by the Open Arms Dental Service. These results point to the severity of the need within these populations.

- In analyzing change in oral health scores over time, there was very little difference in the assessments between Time 1 and Time 2. Greater differences are found between Time 2 and Time 3, among children who have had more exposure to the Open Arms Dental Service.

- In interviews and focus groups with staff of the Kosair Charities Pediatric Convalescent Center (KCPCC) and staff and youth in HOTI's residential treatment program, they commented on the changes brought about by the opening of the Open Arms Dental Service. Themes from the staff at KCPCC involved improvements in the quality of the services, enhanced oral health quality of life, enhanced treatment acceptance, increased convenience for the client, and more efficient use of staff time. Themes from staff and youth in the residential treatment program dealt with the attitude and responsiveness of staff, the accessibility of the service, and the attractiveness of the facility and the quality of its supporting equipment. Overwhelming, the comments addressed the quality of the interactions between staff and patients.

In conclusion, the Open Arms Dental Service has emerged as a significant resource for special needs children throughout the Commonwealth and as an excellent teaching venue for the dental profession. Throughout the implementation period, Jean O'Brien, vice president of Open Arms Children's Health, has worked closely with the dentists and dental staff to make ongoing improvements. The result is a welcoming environment with highly skilled professionals who believe in the mission and who enjoy serving a previously underserved population.

"You have a first rate facility and a dedicated staff who believe in what they do. I have been telling many people about the good work of the Home of Innocents and hopefully it will not only generate goodwill and patient care but also collaborations with like-minded individuals and organizations."
Dr. Mofidi

Dr. Mofidi with Open Arms patient.
Dr. Mofidi is a Dental Officer and Branch Chief within the federal Health Resources and Services Administration (HRSA). He heard about the opening of the Open Arms Dental Service and came to Louisville to take a tour and to learn more about the model.

Program Background and Problem Definition

The Home of the Innocents (HOTI) partnered with the University of Louisville School of Dentistry's (ULSD) Pediatric Dental Program to deliver state-of-the-art dental services within its newly constructed Hockensmith Pediatric Assessment Center (HPAC). This partnership, between one of Kentucky's most comprehensive child-caring agencies and a prominent research university, focuses on better oral health outcomes for children with special needs through enhanced access to quality oral health services. One component of enhanced access to quality care is provided through an on-site dental service within HOTI's Open Arms Children's Health program. A second component provides for expanded access in other locations as a result of the additional knowledge, skills, and comfort level of the students and residents who participate in this specialized component of their training and who continue to serve this population upon entering practice.

Open Arms Dental Service, Courtesy of Home of the Innocents, Louisville, KY

The result of this partnership has been the development of an outpatient dental service and teaching environment that provides compassionate, coordinated, high quality preventive and restorative dental care that is further enhanced by adaptive technologies and supportive techniques. Projected benefits of care in this setting were projected to include:

The result of this partnership has been the development of an outpatient dental service and teaching environment that provides compassionate, coordinated, and high quality preventive and restorative dental care.

- Children with special health care needs would experience increased treatment acceptance, which would lead to decreased oral symptoms and limitations, and therefore decreased missed appointments.
- Patients would, over time, experience improved oral health, with a long-term goal of improved oral health quality of life being achieved for children with special health care needs and their families.
- Parental/family stress would be decreased, in a concurrent fashion, as short and intermediate goals are achieved.

Significant support for the project was provided by the Foundation for a Healthy Kentucky (http://healthy-ky.org/) through their Kentucky Healthy Futures Initiative (KHFI), which is funded through the federal Social Innovation Fund (SIF), enacted under the Edward M. Kennedy Serve America Act.

Populations of Focus

The Open Arms Dental Service provides opportunities for specialized treatment of some of the most underserved children from across the region and state. The overarching mission of the dental service is to improve the oral health of any child who comes to their attention who has an unmet need (and, through insurance, Medicaid or other payer source, an ability to pay).

More specifically, the Open Arms Dental Service at HOTI provides oral health services for children from the following groups:

- Children who are medically fragile, children with complex medical needs, and children with severe physical anomalies that make the delivery of oral health treatment more difficult;

- Children with intellectual, behavioral, or emotional disabilities, including children with autism spectrum disorders;
- Children in foster care;
- Children of refugees; and,
- Other, low income children, whose only resource may be Medicaid.

Most children in foster care are victims of abuse and neglect and have experienced the trauma of being separated from their parents. These traumatic events can lead to behavioral and emotional problems that complicate their ability to establish relationships and receive consistent care. Neglect takes an additional toll on children's health, growth and development as a result of poor nutrition, unsafe housing, inadequate supervision and the absence or delay of preventive medical and dental care.

The severity of the needs of Kentucky children in out-of-home care are assessed to determine their "Level of Care" and the amount of funding that is proportional to the child's level of need. These levels are described below:

Level 5 = severe impairment, disability or need: severe risk of causing harm to self or others.

Level 4 = moderate problems: moderate risk of causing harm to self or others.

Level 3 = occasional problems requiring flexible levels of intervention from low to moderate

Level 2 = minor but frequent problems

Level 1 = adequate functioning

Open Arms Children's Health Dental Service accepts children at all levels of need, including those in residential settings and youth in inpatient psychiatric treatment.

Many of the children served in the dental service are current or former recipients of other HOTI services; including crisis and residential services; pediatric convalescent center services; foster care services; and community-based, in-home services for children with autism and other behavioral health needs. However, eligibility is not limited to current or previous recipients of HOTI services; rather, the Open Arms Dental Service is a resource to children with unmet needs throughout the region and state.

Dental Student Training

In addition to offering much-needed dental health care, HOTI's dental service is a specialty teaching site for dental professionals-in-training at the University of Louisville School of Dentistry (ULSD) and their Pediatric Dental Program. With the opening of the Open Arms Dental Service in 2011, fourth-year dental students and post-doctoral residents have had access to a training environment that specializes in serving some of the state's most physically, behaviorally, emotionally, and socially challenged children.

Fourth-Year Dental Students—Fourth-year dental students from the ULSD have the opportunity to receive a total of 20-32 training hours during a four-day rotation

Open Arms Dental Service, Courtesy of Home of the Innocents, Louisville, KY

In addition to offering much-needed dental health care, Home of the Innocent's dental service is a specialty teaching site for dental professionals-in-training at the University of Louisville School of Dentistry and their Pediatric Dental Program.

at the Home of the Innocents' Dental Service. The students complete two rotations – one each during the fall and spring semesters. During the fall semester, between 2.5 – 3 hours are spent in orientation. The orientation includes information sessions with the Home's clinical staff to talk about the populations of children served, and an information session with the on-site pediatric pharmacist to discuss the effects of some medications on the children's teeth.

During the orientation, the students also are asked to complete a pre-test to assess their awareness, confidence and willingness to treat children with special health care needs. The students learn about the basics of dental care, including room set-up, instrument sterilization, work ethic, and appropriate bedside manner. They observe and sometimes assist with the examination and treatment of children from the targeted populations. The students are taught alternative techniques for addressing children with behavioral issues (e.g. desensitization pre-visit to reduce fear, weighted blanket, use of TV above child's head) and adaptive technologies for treating children with physical restrictions (e.g. use of motorized lift for children in wheelchairs so treatment can occur in a dental chair instead of bedside only).

Pediatric Dental Residents—Six (6) pediatric dental residents serve with the Open Arms Dental Service for two years. The rotation consists of approximately 20 days per year per resident.

The actual dental procedures that are being performed on the patients are not different than procedures that they would receive at any other setting—the dentists are doing cleanings, treating dental caries, and completing extractions and scalings. Unique to this service is the implementation of these procedures on behalf of the most medically fragile population of children in the state, who are housed in the convalescent center located on the property. The dental staff provide this care in a specialized setting and in a manner that is most appropriate and safe for a given child, by using different instruments, therapeutic aides, and adaptive technologies.

Examples of the therapeutic aides are described in more detail on page 20, but they include the use of bean bags for positioning, special holds to comfort and stabilize, weighted blankets to reduce anxiety, lifts to transfer from wheel chair to dental chair, and "pre-visits" to desensitize and familiarize the child with the setting and the staff.

Documentation of the Need

The Home of the Innocents' application for funding documented, through a review of the literature and available data, the high need for oral health services among particular populations of children and the implications of poor oral health for their overall health and well-being. Key elements of that review are provided below:

- Research has increasingly linked poor oral health to illness, chronic disease and early mortality. Poor oral health has been linked to preterm births, pancreatic cancer, coronary heart disease and stroke. It can also make it difficult to eat a balanced diet, impacts self-confidence, and affects adults' ability to find employment (Childress & Smith-Mello, 2007).

- Research into the health of foster children has documented a broad range of health needs. In the first national overview of the well-being of children involved with the child welfare system researchers found that children in the child welfare system are more likely to have health problems than those living with one or both parents (Kortenkamp and Ehrle, 2002). In the area of dental care, an earlier study of children entering foster care found that for children >3 years of age, more than half needed urgent or nonurgent referrals for dental services (Chernoff et. al, 1994). The national overview provided a comparison of children in out-of-home foster care and children living with their parents. This national study found that 37% of children in out-of-home care through Child Welfare had not seen a dentist in the past year as compared to 28% of all children in parent care. The same study found that 28% of children involved in the child welfare system had a "limiting physical, learning, or mental health condition" as compared to 8% of children in the care of their parent(s) (Kortenkamp and Ehrle, 2002). These conditions, some of which are caused by or exacerbated by the abuse and neglect they have experienced, can make the delivery of care more difficult and more time-consuming. This is particularly true in the area of dental care, when the oral cavity has been the (a) site of abuse. The primary conclusion drawn from the national study was that addressing the broad range of health needs of children in foster care necessitates the design an implementation of better models of health care delivery (Kortenkamp and Ehrle, 2002).

- Kentucky has the highest percentage of edentate persons (those who have lost all their natural teeth due to tooth decay or gum disease) ages 18 to 64, and the second highest percentage among individuals 65 and older. Additionally, Kentucky ranks eighth in adults who have lost at least one permanent tooth due to tooth decay or gum disease and fourteenth in adults who have lost six or more teeth (Childress & Smith-Mello, 2007).

- A 2001 state survey suggested that a high percentage of even very young Kentucky children may be in pain daily, affecting their overall health as well as their capacity to learn. The survey found disturbingly high levels of cavities in two- to four-year-olds (47%) and visible, untreated tooth decay in 29% of third and sixth graders (Childress & Smith-Mello, 2007). Only one-third of Kentucky's low-income Medicaid or Kentucky Children's Health Insurance Program (KCHIP) enrolled children received dental care in 2002. Jefferson County fared only slightly better with a rate of 41% (McNary, 2005).

Open Arms Dental Service, Courtesy of Home of the Innocents, Louisville, KY

The primary conclusion drawn from the national study was that addressing the broad range of health needs of children in foster care necessitates the design and implementation of better models of health care delivery (Kortenkamp and Ehrle, 2002). The Home of the Innocents' Open Arms Children's Health is one such model responding to this need.

- The Pew Center on the States graded Kentucky a "C" in terms of providing disadvantaged children with dental health and access to care they need. One measure of how children are faring in terms of dental health is the percentage with untreated cavities. The national goal is to have no more than 21% of third graders with untreated tooth decay; Kentucky achieved a substandard 34.6% (Pew, 2010).

- Kentucky trails the nation in Children with Special Health Care Needs (CSHCN) who have received routine preventative dental care in the past year by 3.7% (74.8% in Kentucky versus 78.5% nationally) (CDC, 2007). Individuals with SHCN have a heightened risk for oral diseases, which further jeopardizes their health. Those who have mental, developmental or physical disabilities, who lack the ability to understand, assume responsibility for or cooperate with preventative oral health practices are especially vulnerable (AAPD, 2008). The root of this problem has three components: mental and physical impairments frequently keep individuals from properly caring for their mouths; disabilities and sensitivities can make dental visit experiences unpleasant; and families struggle to find dentists who can meet patients' special needs (Pew, 2010).

- Dr. C. Lewis' 2009 study, Dental Care and Children with Special Health Care Needs: A Population-Based Perspective, provides a comprehensive current look at the need for dental care among CSHCN nationally. This study found that 81% of CSHCN were reported as needing preventative dental care and 24% as needing other dental care in the past 12 months. The frequency of need for preventative dental care was second only to prescription medications. Overall, 8.9% of CSHCN who needed dental care were unable to get it, making it the most common unmet need for CSHCN.

- Specific condition, severity of condition, insurance status and poverty all played a role among CSHCN who had disproportionate levels of unmet dental care needs. Children with Down's syndrome had the highest instance at 17.4%, followed by other forms of intellectual disabilities, cerebral palsy, autism, and ADHD. Publicly insured and uninsured CSHCN had unmet dental care needs at rates of 14.3% and 36.3%. CSHCN living below poverty level and up to 299% of poverty level had a disproportionate unmet need for dental care, ranging from 17.6% to 9.3% respectively. Poor and low-income children with the most severe special health care conditions have more than 13 times the adjusted odds for unmet dental care needs compared with high-income unaffected children (Lewis, 2009).

The American Dental Association (ADA) adopted a resolution supporting access to oral health care for persons with special needs in 2002. Through this resolution, the ADA supports appropriate initiatives and legislation aimed at improving the oral health of persons with special needs.

- The American Dental Association (ADA) adopted a resolution supporting access to oral health care for persons with special needs in 2002. Through this resolution, the ADA supports appropriate initiatives and legislation aimed at improving the oral health of persons with special needs. The resolution also challenges dental programs to educate students about oral health needs and issues among people with special needs (Fenton, Hood, Holder, May, & Moradian, 2003).

Similarly, HOTI's application also detailed the need for training for dental professionals in working with special needs populations and the benefits of the medical home model of service delivery for this population.

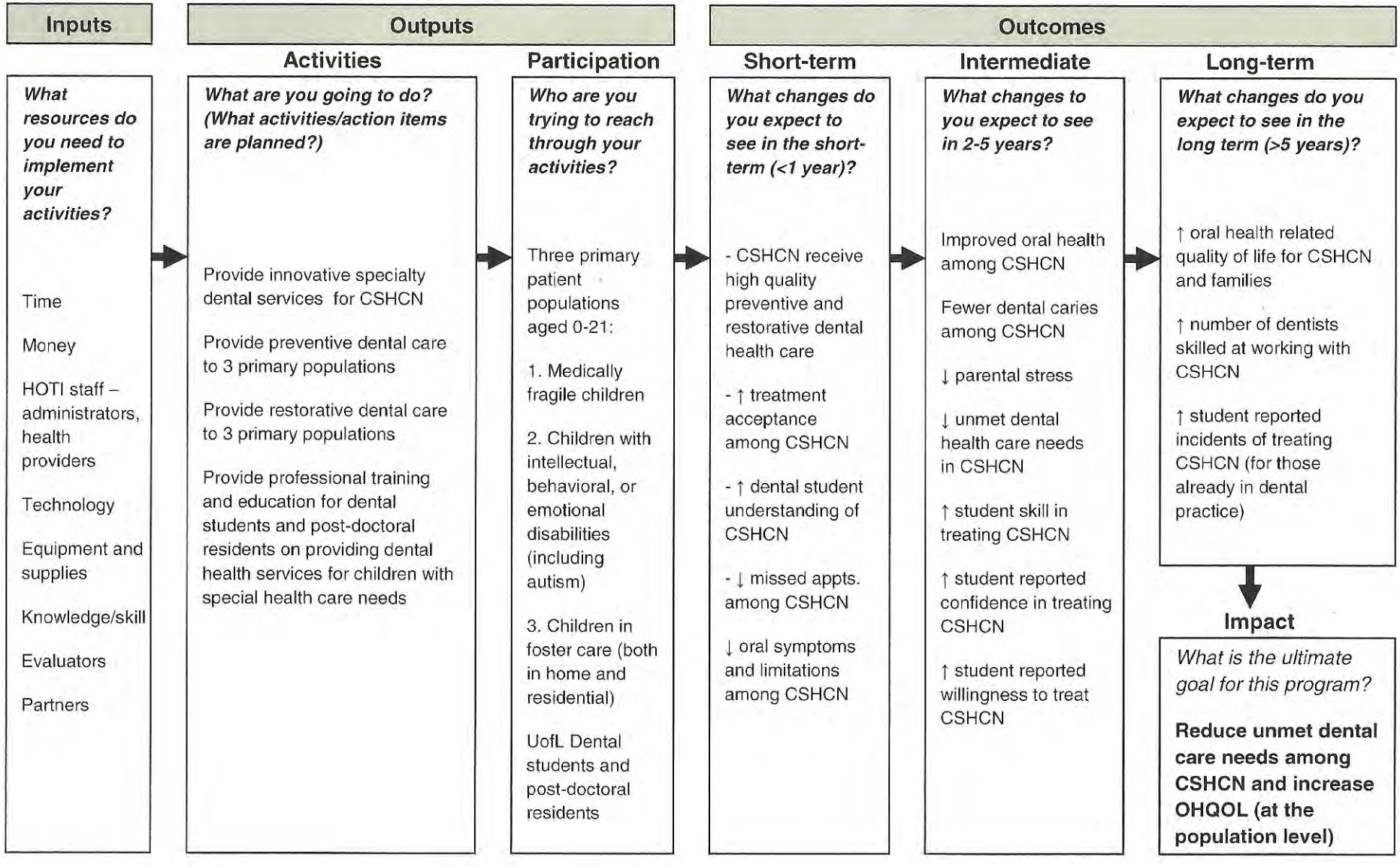
- Several surveys have documented the lack of an adequate curriculum for predoctoral dental students, and the average number of lecture hours devoted to the subject actually decreased from 12.9 hours to 5 hours from 1993 to 1999. This educational environment makes it difficult for future dentists to develop necessary skills for working with this population (Fenton et al., 2003).

- Pediatric dentists receive special training in treating children ages birth through teen years, and are particularly skilled at making sure a child has a comfortable and positive visit. Most dental schools, however, only require five hours or less of classroom instruction and less than five hours of clinical time devoted to children and adolescents (McNary, 2005).
- A study regarding dental education and acceptance of patients with special needs was conducted by T. H. Brickhouse, DDS, PHD, of the Virginia Commonwealth University School of Dentistry. Dr. Brickhouse found that members of the Virginia Dental Association who had post-graduate or continuing education were more likely to routinely treat adult and pediatric patients with special needs. Additionally, providers who felt it was part of their mission to treat patients with special needs were more likely to routinely treat patients with special needs (2007).
- Lack of specialized training is not the only issue impacting availability of dental care in Kentucky. The state also saw 77% of its dental school graduates leave the state in 2006 (only 30 out of 130 stayed in Kentucky), and less than one-fourth of Kentucky dentists participate in the Medicaid program (Childress & Smith-Mello, 2007).
- The American Academy of Pediatric Dentistry's guidelines for evidence-based best practices state that "health care for individuals with special needs requires specialized knowledge, increased awareness and attention, adaptation, and accommodative measures beyond what are considered routine" (AAPD, 2008).
- A medical home model which includes dental care is one recommended approach to decreasing disparities in dental care among CSHCN (Lewis, 2009).
- Finally, a recent study conducted by REACH Evaluation under the auspices of the Louisville Metro Primary Care Association (LPCA), found that only one-third (33.5%) of Louisville Metro dentists were willing to accept Medicaid or KCHIP (the Federally supported children's health program).

Open Arms Dental Service, Courtesy of Home of the Innocents, Louisville, KY

Pediatric dentists receive special training in treating children ages birth through teen years, and are particularly skilled at making sure a child has a comfortable and positive visit.

Logic Model for Evaluation of Home of the Innocents' HPAC Pediatric Dental Clinic



Evaluation Questions, Methods, and Level of Evidence

REACH evaluators consulted with Open Arms Dental Service staff and evaluators from the Center for Community Health and Evaluation to design an evaluation that was as rigorous as possible within the parameters of the project and the amount of available funding. The evaluation design sought to yield information in two major domains: child patient care and dental professional training.

Evaluation Questions

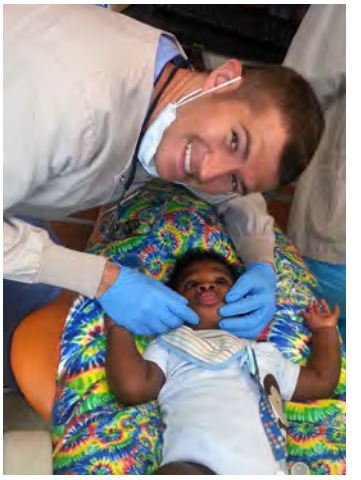
The following evaluation questions were designed to provide a focus for the evaluation, meet the expectations of funders, and provide Open Arms Dental Service staff and key stakeholders with relevant information about the project:

Child Patient Care

- How many children are being served by the Open Arms Dental Service? What are their demographic, oral health, and special health condition characteristics? Is the Open Arms Dental Service serving the intended populations of focus?
- What is the rate of missed appointments among children being served by the Open Arms Dental Service? How many children complete treatment? [measured by "completed" Treatment Plans created for patients in electronic medical records system]
- Do children that complete treatment at the Open Arms Dental Service demonstrate:
  - increased acceptance of dental treatment, compared to baseline?
  - improved oral health quality of life, compared to baseline?
  - reduced oral symptoms, compared to baseline?
  - reduced functional limitations, compared to baseline?
  - improved emotional well-being, compared to baseline?
- Do parents/caregivers of children that complete treatment at the Open Arms Dental Service report decreased parental distress/negative impact on family functioning, compared to baseline?
- What barriers to adequate dental care exist among CSHCN served at the Open Arms Dental Service? How has the Open Arms Dental Service reduced these barriers?

Dental Professional Training

- How many post-doctoral residents and dental students participated in professional training at the Open Arms Dental Service? Were annual targets reached in terms of numbers trained?
- Do dental students that participate in professional training at the Open Arms Dental Service demonstrate:
  - increased understanding of CSHCN?
  - increased confidence in treating CSHCN?
  - increased willingness to treat CSHCN in future dental practice?
  - increased skill in treating CSHCN?



Open Arms Dental Service, Courtesy of Home of the Innocents, Louisville, KY

The evaluation design seeks to yield information in two major domains: child patient care and dental professional training.

Open Arms Dental Service, Courtesy of Home of the Innocents, Louisville, KY

Methods

Child Patient Care

Evaluators gathered data about the program's participants, services received, and results. Several indicators and outcomes related to oral health, oral health quality of life, treatment acceptance, and family well-being were measured. The evaluation also sought to identify the existence of any factors (emerging techniques) involved in the delivery of the oral health service that could be studied in more controlled situations.

Dental Professional Training

The evaluation of the dental training component rested primarily on assessing of the degree to which the dental students (N=80 per year) exhibited increased confidence in their ability to effectively treat a child with special health care needs; and, their anticipated willingness to serve this population in the future. These factors were measured at the beginning of the rotations and again just prior to graduation via a survey (modified from Cushing & Brickhouse, 2007, for the purpose of this evaluation). The confidence and skill of dental post-doctoral residents (N= 6 per year) to effectively treat CSHCN was assessed through annual focus groups, which served to document their unique perceptions about the (a) "key ingredients" of the innovative model of dental health care provided by the Open Arms Dental Service for CSHCN, (b) the elements of the model that might be suitable for replication, (c) specific barriers to adequate dental care that exist for CSHCN served at the Open Arms Dental Service, and (d) ways in which the Open Arms Dental Service reduced these barriers.

The primary design for measuring the effectiveness of child patient care involved pre- and post-comparisons of outcomes before and after services were delivered.

The data that has been generated is consistent with "preliminary" levels of evidence, as outlined in the guidance provided on behalf of the Corporation for National and Community Service's Social Innovation Fund, by their evaluators, JBS International.

Level of Evidence

Preliminary Level of Evidence—Child Patient Care

The primary design for measuring the effectiveness of child patient care involved pre- and post-comparisons of outcomes before and after services were delivered. Outcomes that relate to global ratings of oral health, decreased oral symptoms, decreased functional limitations, increased emotional well-being, increased family well-being, and parental perceptions of treatment acceptance were measured with the Parental-Caregiver Perceptions Questionnaire (P-CPQ). The P-CPQ was originally developed by Jokovic et al (2003) as one part of a larger Oral Health Related Quality of Life measure (OHRQoL), and was later adapted by Nelson (2007) to include fewer items and incorporate the Family Impact Scale also contained in the original OHRQoL measure.

The psychometric performance of both the P-CPQ and Family Impact Scale were previously tested (Locker, Jokovic, & Thompson, 2005; Jokovic, Locker, Thompson & Guyatt, 2004). Regarding the P-CPQ, Cronbach's alpha for internal consistency was reported as 0.94, and the intraclass correlation coefficient for test-retest reliability was 0.85 (Jokovic et al, 2003). The Cronbach's alpha and intraclass correlation coefficients for the Family Impact Scale were 0.83 and 0.80, respectively (Locker et al, 2002). For this evaluation, two items assessing parental perceptions of treatment acceptance (see below for explanation) were added to the questionnaire.

Parents/Caregivers complete the P-CPQ at the first appointment in the dental clinic and every 6 months thereafter. Dental clinic staff are responsible for collecting the P-CPQ, entering the data into an electronic database, and flagging 6-month follow-ups.

Other child patient care data is collected from Dentrix, the electronic medical records system used by the dental services. Quarterly data mining produces data that allows for an assessment of program implementation (e.g. number of children served, characteristics of children served) as well as outcomes relating to rates of missed appointments, treatment completion, treatment acceptance, and measures of oral health. Treatment acceptance is measured through a 4-point, behaviorally anchored rating scale developed by Frankl, Shiere, & Frozels (1962) that has been widely used. The scale classifies children's behavior into four groups according to their attitude and cooperation during dental procedures. The scale is reported to have good reliability (Baier, Milgrom, Russell, Mancl, & Yoshida, 2004), including an inter-rater reliability index of 0.96 (Machen & Johnson, 1974). The treatment acceptance score is noted by the treating dentist at every visit using a procedure code in Dentrix developed specifically for this purpose.

In addition to the procedure code for treatment acceptance, two other custom procedure codes were developed that are used by the treating dentist at every visit. One procedure code documents any special aids (designed to facilitate success) that were used during dental treatment, from a list of 18 options (e.g. use of motorized lift, weighted blanket, desensitization pre-visit, pedi-wrap, holding hands, use of TV above child's head, etc.). The second procedure code documents the setting in which the child's last dental care experience took place, and includes the following: (a) child has had no prior dental care experience, (b) emergency care, (c) care in hospital, or (d) care in dental office.

Data data collection officially began on July 1, 2012, following the receipt of approval from the Institutional Review Board at the University of Louisville.

The pre-post design is limited in terms of validity, and this has been factored into summary statements related to the preliminary findings described in this report. The largest threat to internal validity exists because of the lack of a comparison group; other threats to validity also exist (e.g. history) but are attenuated somewhat by the use of instrumentation that has been previously tested and been found to have acceptable reliability.

Preliminary Level of Evidence - Professional Dental Training

In addition to elements of the evaluation of dental training described earlier (e.g. focus groups with post-doctoral residents, completion of specific training objectives), the evaluation design included a comparison of outcomes related to increased awareness, confidence and willingness to treat CSHCN within dental students from U of L that complete rotations at the Open Arms Dental Service. A pre-post survey design was used. Also anticipated was a between groups post-test only comparison of U of L dental students with a group of newly licensed dentists (recent graduates) in Kentucky from (a) other dental schools within the state or outside the state (grads who move to Kentucky to practice), and (b) who did not have exposure to the unique training experience at the Open Arms Dental Service. The names and practice addresses of newly licensed dentists were obtained from the Kentucky Board of Dentistry and a survey was mailed to them.

Evaluators modified an unpublished survey used in a thesis project by Cushing and Brickhouse (2007) that assessed the relationship between dental education and future acceptance and treatment of special needs patients among dentists in Virginia. The pre-survey was administered in August (2012 and 2013) and coincided with the beginning of the rotation at the dental clinic. The post-survey was administered after the completion of the rotation, just prior to graduation.

Similar to child patient care, the proposed designs for professional dental training were limited in terms of validity, and these limitations are factored into statements about the effect of the dental clinic in this report.

Open Arms Dental Service, Courtesy of Home of the Innocents, Louisville, KY

Challenges to the Data

Although the Open Arms Dental Service opened in March 2011, approval was not received from the Institutional Review Board (IRB) until June 2012. Data collection for the evaluation could not begin until approval was obtained.

The 15-month period between the start of the program and approval to collect data was consumed by efforts to get the evaluation plan approved by the two different evaluation teams under contract with the Corporation for National and Community Services. Upon approval of the evaluation plan, in January 2012, and upon learning that approval from an Institutional Review Board was required, documents were submitted to the University of Louisville's Human Subjects Protection Program Office. Notice of approval was received from the Biomedical Review Board on June 18, 2012.

In addition to the late start of the data collection process, there were several challenges to obtaining a robust data set for each of the planned measures. These are listed below:

- The majority of the children served by Open Arms Dental Service do not reside with their parents; instead, they are in a residential, out-of-home placement. Because the Parental-Caregiver Perception Questionnaire demands intimate/extensive knowledge of the child's oral health, data from the P-CPQ is only available on a limited number of the children served (216 of 1,488 during the 21-month time period).
- The Home of the Innocents has an electronic medical record and an electronic dental record (Dentrix). Information on the child's oral health and dental treatment is contained in Dentrix. Other information is included in the EMR. While the two systems are linked, the linkages do not always yield accurate data. Additionally, the Dentrix system was created (over 10 years ago) for use in a dental office to track health status and procedures that support the treatment planning and billing processes. It was NOT developed to support a research process; and, retrieving aggregate data for research purposes has been extremely difficult.
- The evaluation design called for surveying newly licensed dentists (Kentucky license) from schools other than the University of Louisville. Surveys were sent to 39 dentists who had a recent license date (licensed after May 2012) and who graduated from a school other than the U of L. The response rate was 38%.

In summary, while the evaluation is final, the results provide only a preliminary level of evidence.

NUMBERS	
1,114	NEW Patients between 7/1/12 and 3/31/14 (time period)
1,488	Unduplicated count of children served in time period; includes children who began services before 7/1/12
2,670	Appointments scheduled in time period
2,219	Appointments kept in time period

Findings: *Characteristics of Patients Served*

Open Arms Dental Service, Courtesy of Home of the Innocents, Louisville, KY

THE ANNUAL GOAL of serving 880 children was surpassed. During any four consecutive quarters of the project period covered by this evaluation, the Open Arms Dental Service served more than 880 children. During the first 12-month period the goal was exceeded by 80 children. During the last 12-month period, the goal was exceeded by more than 180 children. Throughout the 21 months of the evaluation period, 1,488 children were served (unduplicated count).

The following charts provide detailed information on the characteristics of the children served during the twenty-one (21) months for which data are available (July 2012 through March 2014).

Children of all ages are being served, including a substantial portion of children of preschool age. The mixture of patients by gender and race are portrayed below. The racial and ethnic diversity of the patients exceeds the diversity of Kentucky's citizens. This may be a factor of the overrepresentation of African American children in out-of-home care (a population of focus for Open Arms), and a factor of Open Arms Health Services' openness to underserved populations, including refugees.

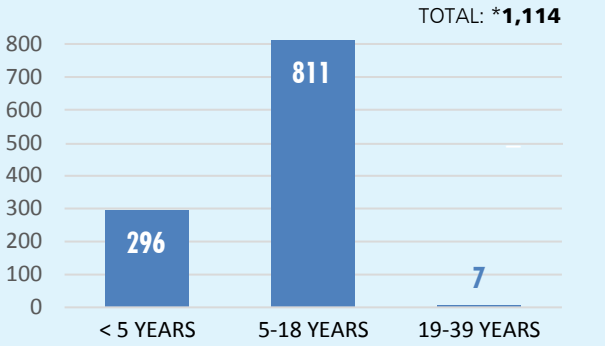
While not portrayed in the charts on these pages, a brief listing of some of the diagnoses of children served by the Dental Service reveals the complexity of the children's physical, mental and emotional needs. Prominent among them are: anxiety disorder, sleep apnea, scoliosis, bipolar disorder, Cushing's syndrome, gastroesophageal reflux disease (GERD), blood disease, heart disease, respiratory problems, hepatitis, Down's syndrome, and abuse (physical, mental, sexual).

Characteristics of Children Served

THE ANNUAL GOAL OF SERVING 880 CHILDREN WAS SURPASSED.

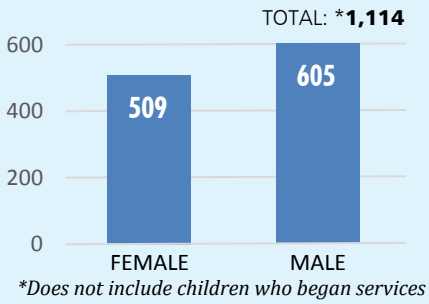
The charts on pages 18 and 19 reflect only those whose first visit to the Open Arms Dental Service was July 1, 2012 or after **(N=1,114)**.
On subsequent pages, all children who received services during the period (even those who began the service prior to July 1, 2012) are included. (N=1,488).

Age



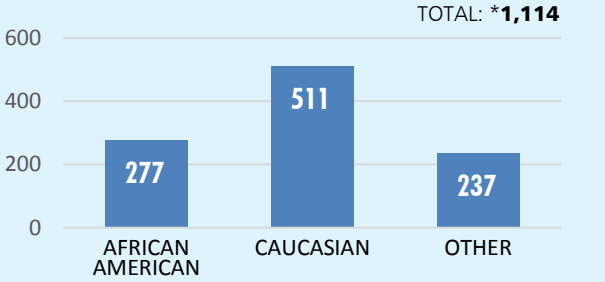
**Does not include children who began services prior to July 1, 2012.*

Gender



**Does not include children who began services prior to July 1, 2012.*

Race or Ethnicity



Does not include children who began services prior to July 1, 2012; and missing data on **89 children.*

Priority populations share one common feature: their history of being an underserved population or their difficulty in accessing dental services. Beyond this common characteristic, the populations vary greatly. Some are grouped by the type of out-of-home setting in which they live; others are grouped by a physical disability, others by an emotional/behavioral/intellectual disability; and others by their status as new arrivals in this county.

Consistent with the original intent of the service, the majority of the children served by Open Arms have some form of Medicaid as their payer. These numbers are evidence of the value of the resource, in that Open Arms is a place where children with challenging needs are accepted and treated. Because of the low reimbursement rates for dental care and the time-intensive needs of these patients, many dentists are unwilling to serve them.

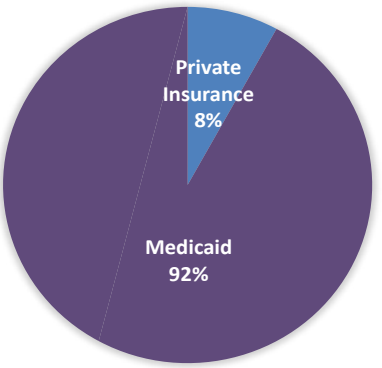
The Medicaid reimbursement structure allows the scheduling of medically fragile children on a three-month cycle through Early and Pediatric Screening, Diagnostic, and Treatment (EPSDT). Other insurance plans do not recognize the need for some children to be on a similar three-month cycle. Therefore, the financial responsibility of the oral health and hygiene falls solely on the caregivers who are many times already overwhelmed with the daily challenges of caring for these children.

Open Arms has provided needed dental care to children from many other parts of the state who are in residental care at the Home of the Innocents or other similar programs in the area. The map below represents the various counties and the number of children served from each county.

Reimbursement of Preventive and Restorative Treatment

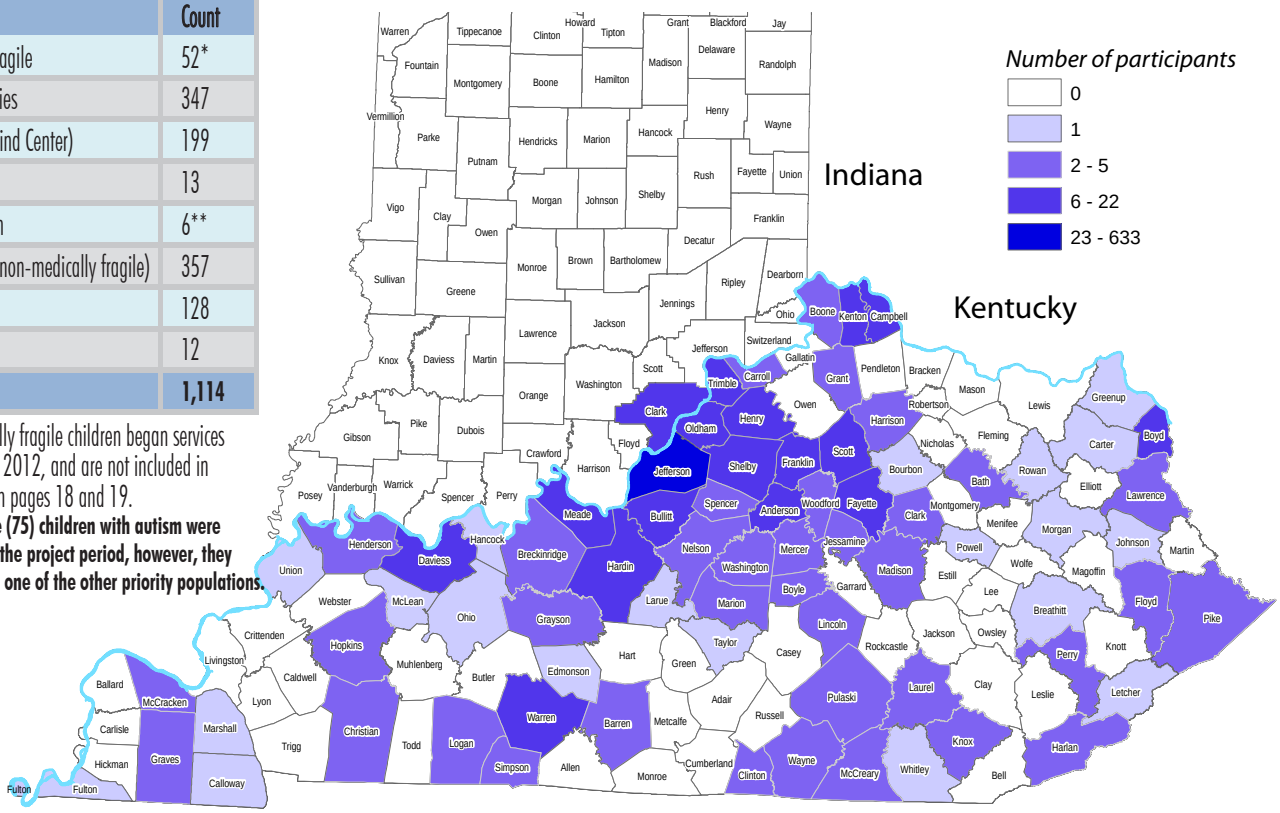
DISTRIBUTION OF PAYER RESOURCES

Sources of funding for clinical services (preventive and restorative).
As envisioned, the Open Arms Dental Service is serving a low income population, with 92% of the children qualifying for Medicaid.



Priority Population	
Population	**Count**
Medically Fragile	52*
Other Agencies	347
CKC (Child Kind Center)	199
Impact Plus	13
CKC - Autism	6**
Outpatient (non-medically fragile)	357
Refugee	128
Unknown	12
Total	**1,114**

*Many medically fragile children began services prior to July 1, 2012, and are not included in the numbers on pages 18 and 19.
**Seventy-five (75) children with autism were served during the project period, however, they are counted in one of the other priority populations.



Findings: *Description of Clinical Encounters*

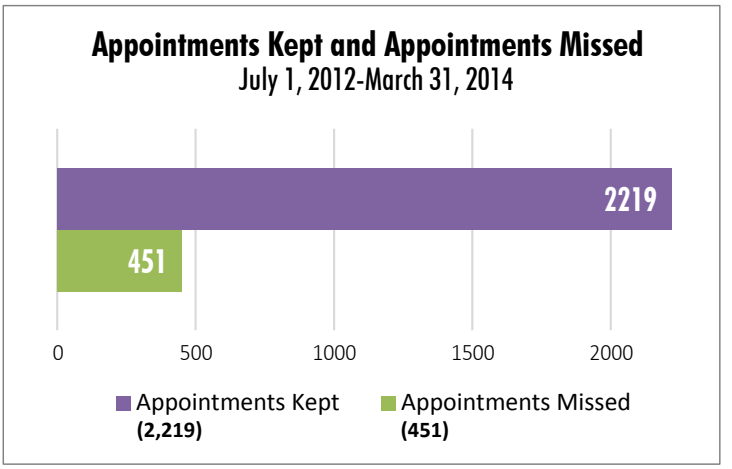
Open Arms Dental Service, Courtesy of Home of the Innocents, Louisville, KY

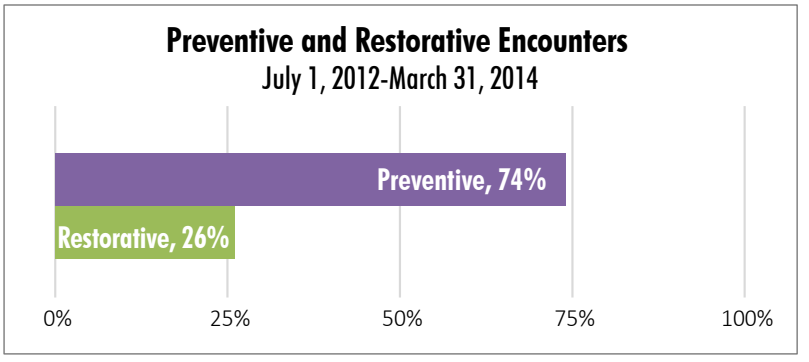
The three charts below portray information from July 1, 2012 through March 31, 2014.

Of the 2,670 appointments scheduled, 16.9% were missed. The rate of missed appointments remained fairly consistent across the time period, and is lower (better) than the rates experienced by other dental clinics that serve people who have Medicaid or are medically indigent. For example, data were obtained from the Family Health Centers* regarding their missed appointment rates for dental services among patients age 18 and under. Within a recent 5 month period (12-1-2013 to 4-29-2014), their missed appointment rate was 38.5%. *(Note: More than 25% of the Open Arms patients live, at least temporarily, on the HOTI campus and have staff assistance in keeping their appointments).*

The chart in the lower left corner differentiates between preventative and restorative encounters. One-quarter of the office visits involved a restorative service. Restorative dentistry is concerned with the restoration of existing teeth that are defective because of disease, trauma, or abnormal development to normal function, health, and appearance; it includes fillings, crowns and bridgework. The majority of the visits (74%) are devoted to preventive work, including cleanings, exams and x-rays.

The dentists and staff of Open Arms Dental Service work closely with each child to make the experience in the dental office as positive and supportive as possible. To accomplish this, they use a variety of behavioral aids. The frequency of use varies: from the television, positioned above the child's head, which is used for most patients to the desensitization pre-visit which is used for children with autism or other children with high levels of anxiety about the dental experience. Also available at Open Arms is a lift for children who are unable to move to the dental chair without assistance.





* Family Health Centers, Inc. is a not-for-profit community health center that provides a variety of health care services regardless of a person's health insurance status or ability to pay for services. Family Health Centers serve more than 42,000 patients annually through seven sites throughout Louisville Metro. The payer mix among the dental patients in the 5-month period was: 47% Medicaid, 41% indigent, and 11% commercial insurance.

Behavioral Aids Used During Treatment
(Type by Number of Children)

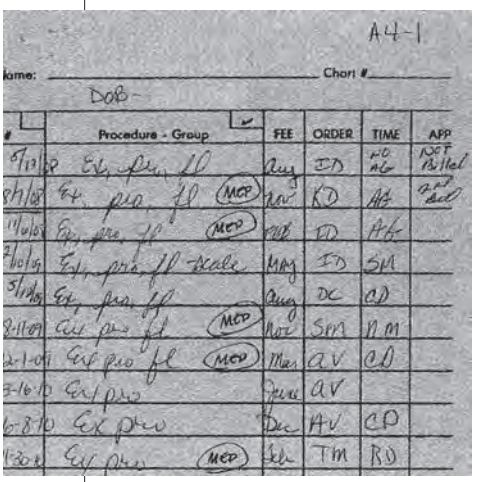
Aids	Count
Use of TV above Child's Head	1470
Bean Bag	180
Holding Hands	164
Holding Hands and Legs	134
Mouth Prop	138
Holding Head	82
Caregiver on Chair with Patient	61
Lap to Lap	50
Weighted Blanket	21
Desensitization Pre-Visit	17
Lift	5
Visual Aids	2

Difference in Patient Records and Implications for Continuity of Care

(sample of staff notes before and after the opening of Open Arms Dental Service)

The photocopied pages presented here provide a compelling picture of the differences in the dental services before and after the opening of the Open Arms Dental Service. Both documents contain the medical notes of the treating dentist. Both documents reflect services to the same child. However, the level of detail and specificity of the content are dramatically different. The hand-written notes typically entailed one to two lines of data in handwritten form per visit. These visits occurred at the child's bedside, with no ability to provide proper positioning, lighting, or medical equipment for a thorough examination.

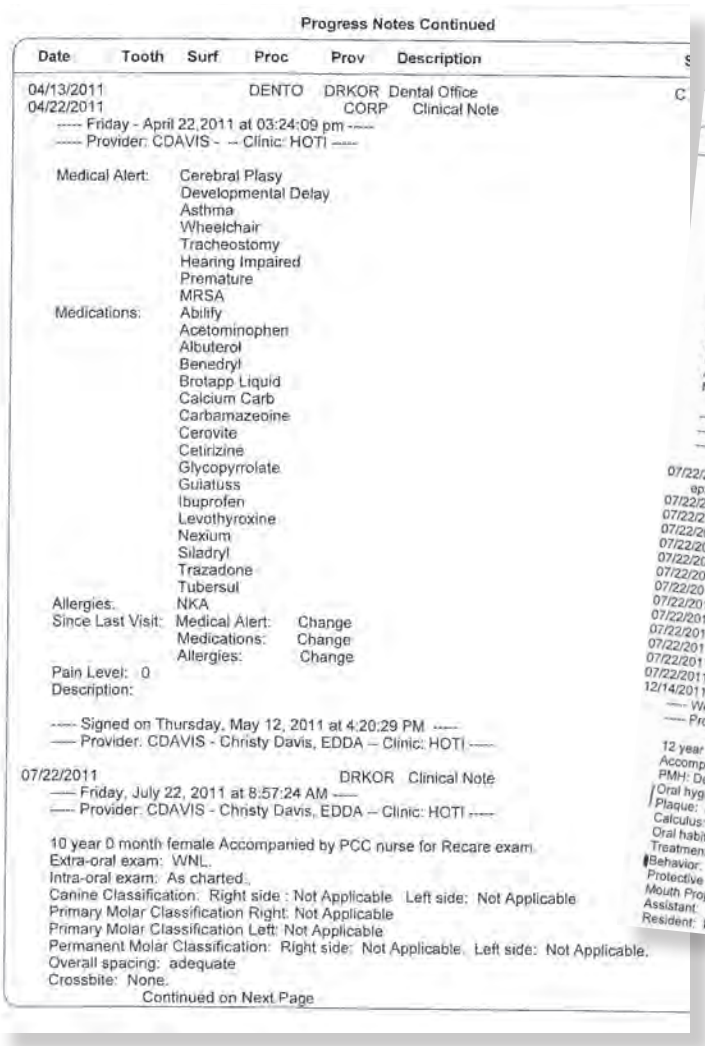
These brief notations present a stark contrast to the current documentation. Since its opening, the Open Arms Dental Service has used an electronic medical record. This format captures detailed information about medications, allergies, dental spacing, existence of crossbite or overbite, type of treatment, status of oral hygiene, and measures used to address behaviors or emotional needs. Rather than the one or two lines of information, the Open Arms progress notes for this child average a full page of detailed, easy-to-read information. Easy access to detailed information about the child's recent history is particularly important for children with complex needs and for practitioners who are working in a teaching environment.


A4-1

Name: _____ Chart #_____

DOB-

#	Procedure - Group	FEE	ORDER	TIME	APP
5/13	SP Ex, pro, fl	Amy	ED	NO MC	NOT Billed
8/11/09	Ex, pro, fl (MCP)	Nov	KD	AB	
11/06	Ex, pro, fl (MCP)	Mar	ED	AB	
2/06	Ex, pro, fl scale	May	ED	SM	
5/11/09	Ex, pro, fl	Amy	DC	CD	
8-11-09	Ex pro fl (MCP)	Nov	SM	NM	
2-1-01	Ex pro fl (MCP)	Mar	AV	CD	
3-16-10	Ex pro	June	AV		
6-8-10	Ex pro	Dec	AV	CD	
1-20-11	Ex pro (MCP)	Feb	TM	RD	


Progress Notes Continued

Date	Tooth	Surf	Proc	Prov	Description
04/13/2011			DENTO	DRKOR	Dental Office
04/22/2011			CORP		Clinical Note

---- Friday - April 22,2011 at 03:24:09 pm ----
---- Provider: CDAVIS - -- Clinic: HOTI ----

Medical Alert: Cerebral Plasy, Developmental Delay, Asthma, Wheelchair, Tracheostomy, Hearing Impaired, Premature, MRSA

Medications: Abilify, Acetominophen, Albuterol, Benedryl, Brotapp Liquid, Calcium Carb, Carbamazepine, Cerovite, Cetirizine, Glycopyrrolate, Guiatuss, Ibuprofen, Levothyroxine, Nexium, Siladryl, Trazadone, Tubersul

Allergies: NKA

Since Last Visit: Medical Alert: Change; Medications: Change; Allergies: Change

Pain Level: 0
Description:

---- Signed on Thursday, May 12, 2011 at 4:20:29 PM ----
---- Provider: CDAVIS - Christy Davis, EDDA -- Clinic: HOTI ----

07/22/2011 DRKOR Clinical Note
---- Friday, July 22, 2011 at 8:57:24 AM ----
---- Provider: CDAVIS - Christy Davis, EDDA -- Clinic: HOTI ----

10 year 0 month female Accompanied by PCC nurse for Recare exam.
Extra-oral exam: WNL.
Intra-oral exam: As charted.
Canine Classification: Right side : Not Applicable Left side: Not Applicable
Primary Molar Classification Right: Not Applicable
Primary Molar Classification Left: Not Applicable
Permanent Molar Classification: Right side: Not Applicable. Left side: Not Applicable.
Overall spacing: adequate
Crossbite: None.

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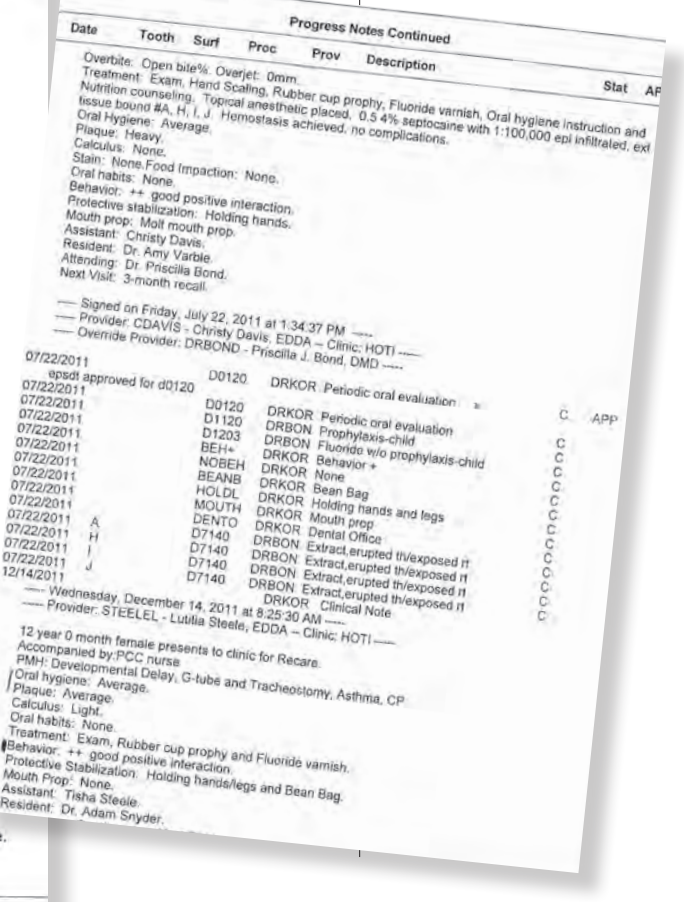

Progress Notes Continued

Date	Tooth	Surf	Proc	Prov	Description	Stat	AP
07/22/2011			D0120	DRKOR	Periodic oral evaluation	C	APP
07/22/2011			D1120	DRBON	Prophylaxis-child	C	
07/22/2011			D1203	DRBON	Fluoride w/o prophylaxis-child	C	
07/22/2011			BEH+	DRKOR	Behavior +	C	
07/22/2011			NOBEH	DRKOR	None	C	
07/22/2011			BEANB	DRKOR	Bean Bag	C	
07/22/2011			HOLDL	DRKOR	Holding hands and legs	C	
07/22/2011			MOUTH	DRKOR	Mouth prop	C	
07/22/2011		A	DENTO	DRKOR	Dental Office	C	
07/22/2011		H	D7140	DRBON	Extract,erupted th/exposed rt	C	
07/22/2011		I	D7140	DRBON	Extract,erupted th/exposed rt	C	
07/22/2011		J	D7140	DRBON	Extract,erupted th/exposed rt	C	
12/14/2011				DRKOR	Clinical Note		

Overbite: Open bite%: Overjet: 0mm
Treatment: Exam, Hand Scaling, Rubber cup prophy, Fluoride varnish, Oral hygiene instruction and Nutrition counseling. Topical anesthetic placed. 0.5 4% septocaine with 1:100,000 epi infiltraled, ext tissue bound #A, H, I, J. Hemostasis achieved, no complications.
Oral Hygiene: Average.
Plaque: Heavy.
Calculus: None.
Stain: None,Food Impaction: None.
Oral habits: None.
Behavior: ++ good positive interaction.
Protective stabilization: Holding hands.
Mouth prop: Molt mouth prop.
Assistant: Christy Davis.
Resident: Dr. Amy Varble.
Attending: Dr. Priscilla Bond.
Next Visit: 3-month recall.

---- Signed on Friday, July 22, 2011 at 1:34:37 PM ----
---- Provider: CDAVIS - Christy Davis, EDDA -- Clinic: HOTI ----
---- Override Provider: DRBOND - Priscilla J. Bond, DMD ----

07/22/2011
epsdt approved for d0120

---- Wednesday, December 14, 2011 at 8:25:30 AM ----
---- Provider: STEELEL - Lutilia Steele, EDDA -- Clinic: HOTI ----

12 year 0 month female presents to clinic for Recare.
Accompanied by:PCC nurse
PMH: Developmental Delay, G-tube and Tracheostomy, Asthma, CP
Oral hygiene: Average.
Plaque: Average.
Calculus: Light.
Oral habits: None.
Treatment: Exam, Rubber cup prophy and Fluoride varnish.
Behavior: ++ good positive interaction.
Protective Stabilization: Holding hands/legs and Bean Bag.
Mouth Prop: None.
Assistant: Tisha Steele.
Resident: Dr. Adam Snyder.

Findings: *Impact of Clinical Service*

Treatment acceptance is measured through a 4-point, behaviorally anchored rating scale developed by Frankl, Shiere, & Frozels (1962) that has been widely used. The scale classifies children's behavior into four groups according to their attitude and cooperation during dental procedures. The scale is reported to have good reliability (Baier, Milgrom, Russell, Mancl, & Yoshida, 2004), including an inter-rater reliability index of 0.96 (Machen & Johnson, 1974).

Treatment Acceptance

One of the indicators used to measure success is "treatment acceptance." The evaluation of the Open Arms Dental Service includes data on treatment acceptance from the perspective of both the treating professional and the parent. The treating dentist makes a notation about the child's acceptance of treatment at the end of every dental office visit and parents report their expectations for their child's acceptance of treatment at the beginning of the appointment

Both the dentist and the parent use the following "Treatment Acceptance Scale" (a validated scale taken from the literature). The scale allows for one of four scores, chosen on the basis of one of the following descriptions:

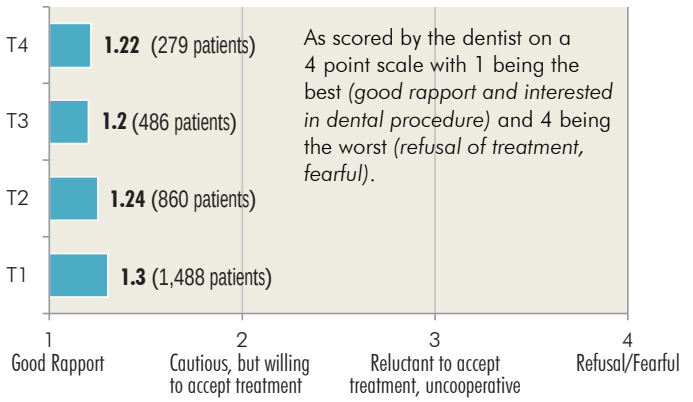
1. Good Rapport with dentist, interest in dental procedures (++)
2. Cautious but willing to accept treatment (+)
3. Reluctant to accept treatment, uncooperative (-)
4. Refusal of treatment, fearful (--)

Treatment Acceptance as Rated by Dentist

The analysis of treatment acceptance as perceived by the treating dentist involved extracting data from the Dentrix database on all patients who received a dental service between July 1, 2012 and March 31, 2014. There were a total of 1,488 patients who were served during this period and who had at least one notation of treatment acceptance by the attending dentist. Evaluators looked at the overall level of treatment acceptance as determined by the treating professional at the end of the visit and at the change in mean scores over time. Of the 1,488 patients with a "Time 1"* score, there were 860 patients with a "Time 2" score, 486 patients with a "Time 3" score, and 279 patients with a "Time 4" score. The limited period of the analysis (nine months) and the ongoing acceptance of new patients are reasons for the much higher number of patients with only one visit during the time frame.

The chart below depicts the mean scores of patients, as recorded by the dentist, at the initial and subsequent visits. There was a significant difference in a favorable direction (at the .05 level) for patients between Time 1 and all subsequent time periods. *See Appendix A, pages 44-48, for additional analysis.*

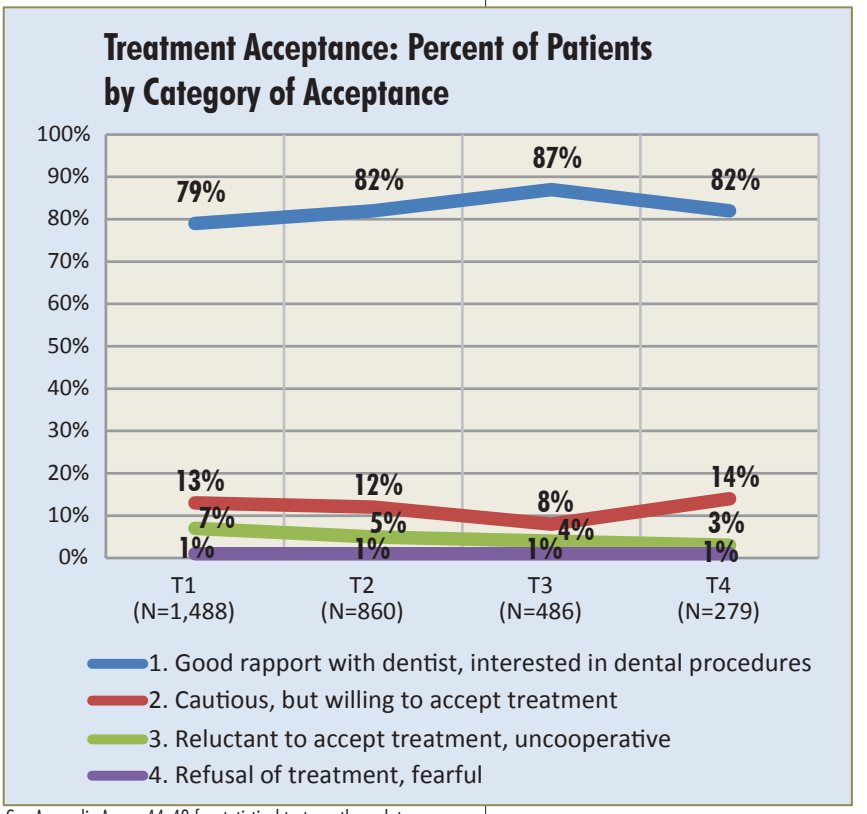
Mean Treatment Acceptance Score



* Time 1 is the first time the child was in the Open Arms Children's Health Center for dental care after July 1, 2012, the date on which data collection began.

The chart below portrays the dentist's perceptions of the child's acceptance of treatment within the four categories. Regardless of whether this was the first office visit in the time period or the fourth, at least 90% of the children were deemed to be cooperative and willing to accept treatment. For the children with at least four dental visits at Open Arms, the scores were even higher, with 96% of the patients demonstrating an acceptance of treatment.

A second analysis looked at the difference in the acceptance scores among the various priority populations. The following chart depicts the mean Treatment Acceptance scores for "Time 1". The first two priority populations (CKC and Other Agencies) relate primarily to children and youth who are dependent, abused or neglected and in out-of home care (crisis and longer term). The second group of priority populations (Medically Fragile, Outpatient, Impact Plus and CKC Autism) are predominantly patients who seek care at Open Arms because of a special health care need (behavioral or medical). The third group includes patients who are relatively new to the United States, most of these patients entered the United States as refugees from war-torn countries where dental care was limited or not available. There was a greater reluctance to accept treatment and more fear of treatment among children with extraordinary medical, behavioral, social or emotional needs. While the number of patients is low (10), the highest (worse) treatment acceptance scores were noted for children with autism who were in crisis or out-of-home care. The most favorable scores were noted for children and youth who were in the care of the Home of the Innocents or other child-caring agency for reasons of abuse, neglect or abandonment/dependence.



See Appendix A, pp. 44-48 for statistical tests on these data.

Priority Population		
Population	**Count**	**Mean Score**
Childkind Center	249	1.12
Other Agencies	433	1.14
Medically Fragile	134	1.60
Impact Plus	18	1.39
CKC - Autism	10	2.10
Outpatient	495	1.41
Refugee	136	1.32
Unknown	13	1.62
Total	**1488**	**1.30**

Two Groups: CKC and 'Other Agencies' have lower (better) scores.

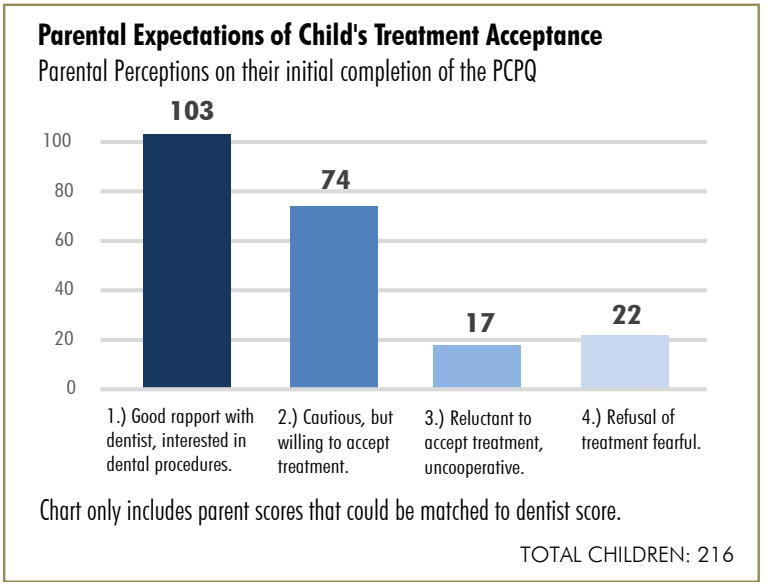
There was a statistically significant difference between Autism and all other populations. See Appendix A, pp. 44-48 for details.

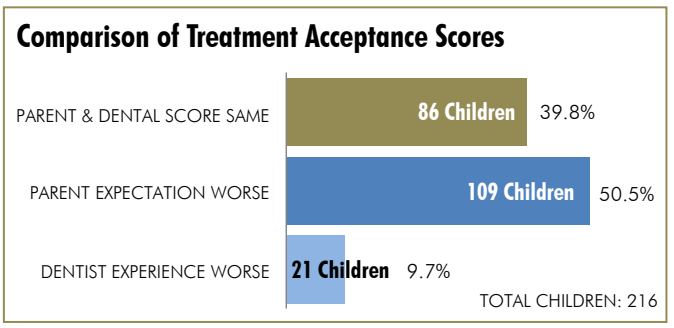
Expectations of Treatment Acceptance as Rated by Parent

The treatment acceptance measure is a component of the Parental-Caregiver Perceptions Questionnaire (P-CPQ). The P-CPQ was originally developed by Jokovic et al (2003) as one part of a larger Oral Health Related Quality of Life measure (OHRQoL), and was later adapted by Nelson (2007) to include fewer items and incorporate the Family Impact Scale also contained in the original OHRQoL measure.

The specific wording, as found in the questionnaire, is as follows:

- ***My expectations for my child's acceptance of treatment during this visit can best be described as: (select only one option)***
- ***Good rapport with the dentist; interested in the dental procedures, laughing and enjoying the situation.***
- ***Acceptance of treatment; at times cautious, willingness to comply with the dentist, at times with reservation, but follows the dentist's directions cooperatively.***
- ***Reluctant to accept treatment, uncooperative, some evidence of negative attitude but not pronounced, i.e./sullen, withdrawn.***
- ***Refusal of treatment, crying forcefully, fearful or any other overt evidence of extreme negativism.***





Parents/Caregivers complete the P-CPQ at the first appointment in the dental clinic and every 6 months thereafter. Within the time frame of this report, 216 parent scores could be matched with dentist scores (same child/same visit).[1] The chart to the left contains parental expectations of their child's emotional/behavioral response to the dental office visit.

In comparing the scores of the parents with the scores of the dentists, parents anticipated more resistance than dentists experienced in dental visits associated with 109 children (50.5%); dentists experienced less acceptance than anticipated by the parents in 21 instances (9.7%); and the expectations of the parents and the experience of the dentist was the same in the dental visits associated with 86 children (39.8%). Among dentists and parents, the majority of the scores reflected an adequate to good level of acceptance.

[1] Because of the detail and the intimacy of the knowledge required in responding to the questions in the P-CPQ, it is typically completed by a custodial parent. Therefore, for the large number of children in out-of-home care who are served by Open Arms, a Parent-CPQ is not completed.

Status of Oral Health and Hygiene (Plaque, Calculus, Oral Hygiene)

Oral Health Measures

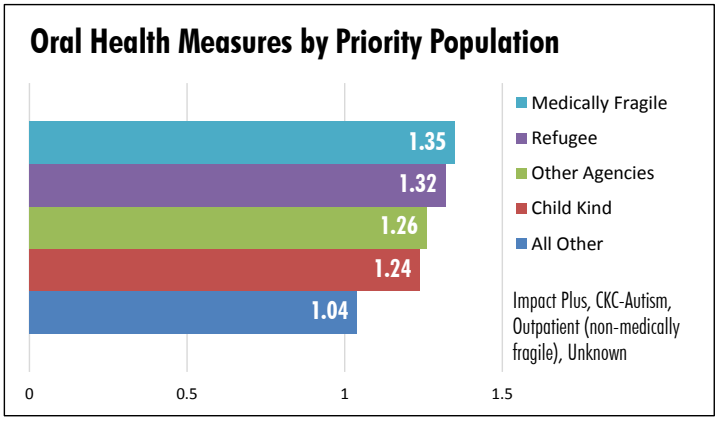
Embedded in the notes of the Dentrix records is the dentist's assessment of three oral health measures: the presence of plaque, the presence of calculus, and the overall state of the patient's oral hygiene. These measures, transferred to an Excel data base by staff at Open Arms Health Service, provided the basis of the following analyses.

Measures for one point in time were available for 711 children; two measures (Time 1 and Time 2) were available for 110 children; and, three measures (Time 2 and Time 3) were available for 35 children. The analysis considered changes over time for all children with two or more measures; and included an analysis of any differences between priority populations. The priority populations were: children in out-of-home care through HOTI's Childkind Center (CKC), children in out-of-home care through Other Agencies, Medically Fragile children though outpatient referrals and HOTI's KCPCC, children in the IMPACT Plus program, children in HOTI's CKC with Autism, Outpatient referrals of non-medically fragile children from the community, and Refugees.

Measurement was calculated on a scale of 0 to 3 (0 = no problem, 1 = light/ excellent, 2 = average, 3 heavy/poor).

Upon analyzing the data by priority population, evaluators found that dental problems were more common in four (4) of the eight groups of children than in the other four groups. The four groups with more problems were children classified as: Medically Fragile, Refugee, Other Agency, and ChildKind Center (crisis residential). There were no significant differences between the scores of the other four groups (Impact Plus, CKC-Autism, Outpatient/Non-Medically Fragile, and Unknown). These four groups are depicted on the bar labeled "All Other".

- On the scale of zero to three, the means of the four groups with more dental problems are: 1.35 for Medically Fragile, 1.32 for Refugees, 1.26 for Other Agencies, and 1.24 for ChildKind Center.
- The other four groups (All Others) have substantially lower scores, so the graph shows them collectively, with a mean score of 1.04.
- A t-test between the two groups of four (the four shown individually and the four shown collectively) indicates that the difference is one of nearly nine standard deviations (sig. .000, t=8.794).



See Appendix A, pages 44-48, for statistical analysis.

In analyzing change over time, there was very little difference in the assessments between Time 1 and Time 2. Greater differences are found between Time 2 and Time 3; among children who have had more exposure to the Open Arms Dental Service. The chart below depicts the degree of change among children, between Time 2 and Time 3, on the three measures for Plaque, Calculus, and Oral Hygiene. The only group for which the change was significant at the .05 level was Refugees. The chart below portrays the degree of change among Refugees and All Other Groups.

Measurement was calculated on a scale of 0 to 3 (0 = no problem, 1 = light/ excellent, 2 = average, 3 heavy/poor).

	Oral Health Values			T-Test		
	T2	T3	Change	*t*	*p*-value	*d*
Refugee (n=52)	1.35	1.08	-.269	-2.707	.009	.375
All Other Groups (n=630)	1.19	1.18	-.008	-.321	.749	.013

Note: Cohen's *d* calculation: *t*-value / (√n). A *d* value between 0 to 0.3 is a small effect size, 0.3 to 0.6 is a moderate effect size, and greater than 0.6 is a large effect size.

See Appendix A, pages 44-48, for additional analysis.

Oral Health Quality of Life: Overall Concerns and Impact on Child and Parent

Findings from the P-CPQ

The evaluation design included a semi-annual assessment by the parent of their child's oral health and their perceptions of the impact of their child's oral health on the child's and the family's well-being. The Parental-Caregiver Perceptions Questionnaire (P-CPQ) was used for this purpose. The P-CPQ was originally developed by Jokovic et al (2003) as one part of a larger Oral Health Related Quality of Life measure (OHRQoL), and was later adapted by Nelson (2007) to include fewer items and incorporate the Family Impact Scale also contained in the original OHRQoL measure. The questionnaire contains questions in the following domains: 1. Oral Symptoms; 2. Functional Limitations; 3. Emotional Difficulties; and 4. Family Impact.[2] *(See page 12 for psychometric performance of instruments)*.

Because the Parental-Caregiver Perception Questionnaire demands intimate/extensive knowledge of the child's oral health, and because the majority of the children served by Open Arms Dental Service do not reside with their parents, data from the P-CPQ is only available on a limited number of the children served (305 of 1,488 during the 21-month time period). *The chart on the next page contains the results of the first P-CPQ, on or after July 1, 2012 (when data collection related to the study began)*.

The value of the findings is further limited by the absence of more than one measure on most children. The study period encompassed by this report is twenty-one (21) months; and six-month follow up questionnaires were available for only 37 children. There was very little change in the Time 1 and Time 2 scores, with no more than a 1 point change on any item (on a 5 point scale: 0 = never and 4 = everyday). Items with a slight change for the better are noted in green on the chart to the right; items with a slight change for the worse are noted in a gradient from orange to red. The degree of the change is also noted.

QUESTION: During the last 3 months...	PRE	POST	DIFF
OVERALL WELLBEING AFFECTED	2.52	1.88	-0.6
how often has your child had pain in the teeth, lips, jaws or mouth?	1.57	1.27	-0.3
because of his/her teeth, lips, mouth, or jaws, how often has your child been irritable or frustrated?	1.57	1.27	-0.3
because of his/her teeth, lips, mouth, or jaws, how often have you or another family member felt guilty?	1	1.26	0.3
because of his/her teeth, lips, mouth, or jaws, how often has your child had trouble sleeping?	1.39	1.67	0.3
because of his/her teeth, lips, mouth, or jaws, how often has your child taken longer than others to eat a meal?	1.11	1.56	0.4

The P-CPQ included two global measures:

1.) How would you rate the health of your child's teeth, lips, jaws and mouth?

2.) How much is your child's overall wellbeing affected by the condition of his/her teeth, lips, jaws or mouth?

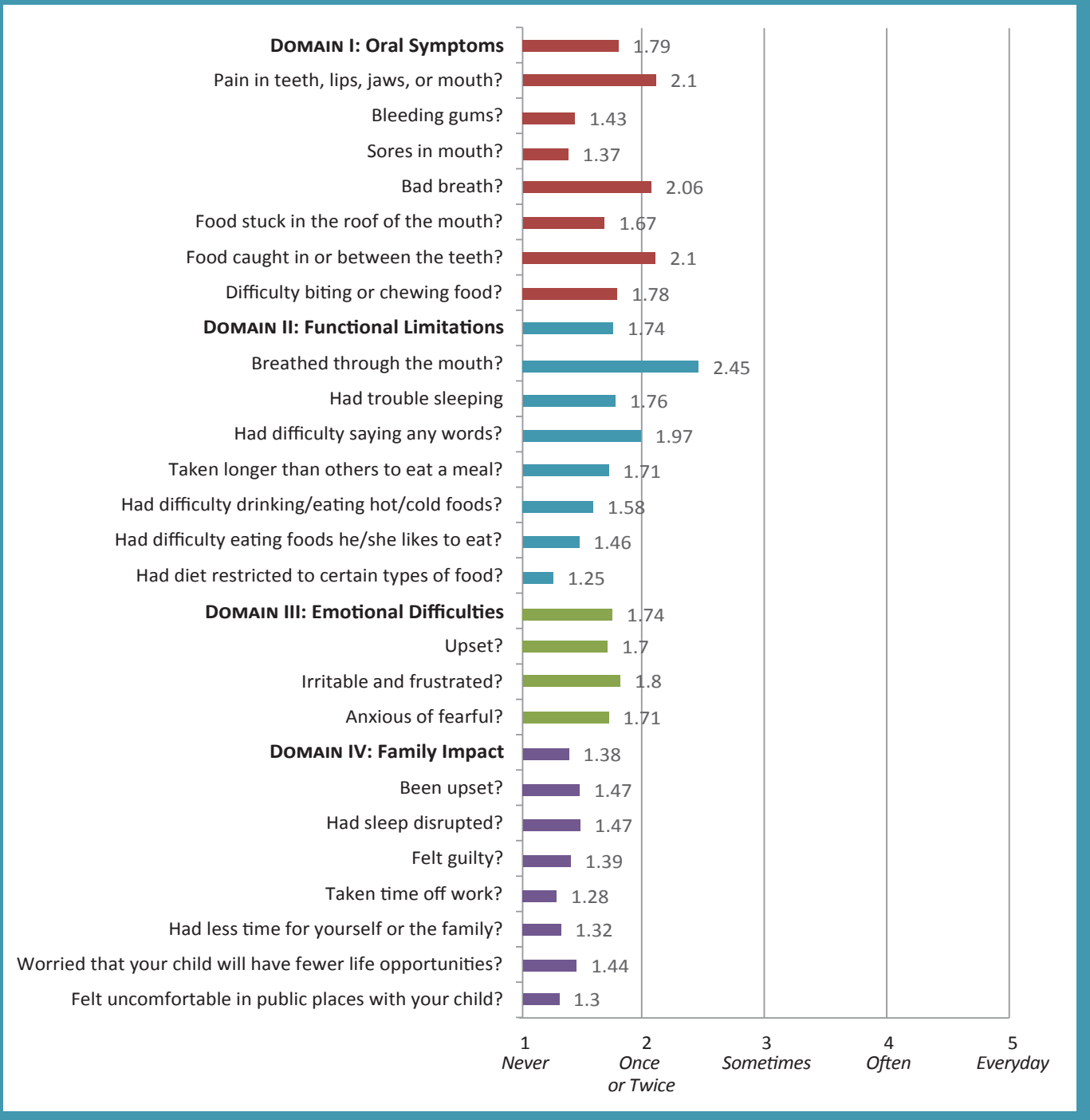
For the thirty-seven (37) children on whom Time 1 and Time 2 measures are available, parents noted an improvement in the impact of their child's oral health on his/her well-being. Other areas of significant change in a favorable direction were related to how often their child had experienced tooth pain, and how often their child had been irritable or frustrated as a result of problems with their teeth/mouth/lips.

[2]A fifth domain related to the parent's expectations for their child's acceptance of treatment was added to the P-CPQ for this study. This element is discussed on page 23.

Results of the Parental Caregiver Perceptions Survey

July 1, 2012-March 31, 2014

Symptoms, limitations and difficulties in the last three months...



N=305

Themes from the Focus Groups

To understand the impact of the Open Arms Dental Service beyond the quantitative data, evaluators conducted a series of interviews and focus groups. Through these efforts, findings from the surveys and the medical records were augmented with (1) the perspectives of several youth in residential treatment and the staff of that program and (2) the perspectives of staff at the Kosair Charities Pediatric Convalescent Center. Following the section entitled "Perspective of Staff and Youth in Residential Treatment Services" and the section entitled, "Perspective of Staff at KCPCC" is a brief sampling of the stories of the experiences of children and families

Perspective of Staff and Youth in Residential Treatment Services

The Home of the Innocents is the state's largest emergency placement center. It is staffed 24 hours a day and offers a safe place for children who have been removed from their homes because of abuse, abandonment or neglect. HOTI serves children and youth from infancy to age 18, through a variety of residential settings (on campus residential homes, therapeutic foster care homes, and relatives' homes through kinship care). In these settings, children benefit from individual treatment plans that include the use of the latest one-on-one therapies.

To better understand the impact of the Open Arms Dental Service on children and youth who have come to HOTI for reasons of abuse and neglect, evaluators conducted a focus group of residential services staff and youth. Two staff and three residents participated in the focus group discussion, held on March 28, 2014.

Themes from the focus group dealt with the attitude and responsiveness of staff, the accessibility of the service, and the attractiveness of the facility and the quality of its supporting equipment. Overwhelming, the comments addressed the quality of the interactions between staff and patients.

Attitude and Responsiveness of Open Arms Staff

The Open Arms Dental Service is in a beautiful new building and it has state-of-the-art equipment. While those things are important, what focus group participants wanted to talk about most was Dr. Brent and the Open Arms staff. Below is a summary of their comments:

- One resident had experienced quite a bit of dental work due to his need to have teeth fixed after damage from fights. He repeatedly described the office, the experience, the dentist and the staff as "chill" and "very relaxed." He felt that his prior dental experiences were not as "chill", and his previous dentist was not as accommodating as Dr. Brent. Dr. Brent always "explains in detail" what he is about to do. Dr. Brent provided this resident with special toothpaste that has greatly helped with his issues, and told him to "stop fighting and stop drinking Monsters (energy drinks)."

- Discussing Dr. Brent, another resident (youth) stated that after their first meeting, he felt as though "he had known him for months." Residents agreed that Dr. Brent includes his patients in their own care, and truly works to make the experience a collaboration. He "has a conversation with you", one resident noted. He is "just so nice about everything."

Open Arms Dental Service, Courtesy of Home of the Innocents, Louisville, KY

"My old dentist was rough. Dr. B is gentle and makes sure you're okay. He does everything in his power to make sure you're comfortable. He never tries to trick you. He's for real on his word."

—Adolescent in HOTI Residential Treatment Services

- It was also noted that the staff are "not judgmental", that they "treat everyone with respect," and that they "know how to work with kids."

- All participants in the focus group wanted to be sure that the Open Arms dentists and staff "keep the personal going." Participants acknowledged that current staff are great at knowing the personalities and preferences of each client. One participant commented, "Building a relationship [with Dr. Brent and the staff] makes you want to go back." Another described their mutual respect, and said that Dr. Brent is "everything a dentist should be."

Accessibility of Service

- Staff described the Open Arms Dental Service and the setup as "very accessible," and noted that residents no longer miss appointments because access is so convenient. Staff felt that they can very easily communicate any questions or concerns they have about a resident's dental health. One staff member described the dental office as "super comfortable."

- Staff noted that prior to the Open Arms Dental Service, a dentist came to HOTI for assessments, but only once or twice a week. Often, issues were not addressed for a week. In severe cases, residents had to be sent out to be seen. In the words of one staff member, the current setup is "just very convenient."

Attractiveness of Facility/Quality of Equipment

- All three residents felt that watching movies while in the chair receiving care helps them to relax. (Though one requested a better variety.) They did emphasize, however, that their extremely positive feelings about the dental service were based upon their experience with Dr. Brent and the staff, rather than the physical setting. One noted that "The dental clinic would be just another dentist without these people."

- Residents also agreed with the comment that "other dentists' offices look scary and depressing, but the HOTI clinic is happy." They noted the bright blue and orange, and felt that the colors "lighten up the mood."

All participants stated that they would absolutely recommend the Open Arms Dental Service to family or friends.

Perspective of Staff at Kosair Charities Pediatric Convalescent Center

Interviews with Staff of Kosair Charities Pediatric Convalescent Center (KCPCC)

The Kosair Charities Pediatric Convalescent Center (KCPCC) is a home away from home for medically fragile children, age birth to 21. KCPCC provides short-term, long-term and respite care for up to 76 children with severe developmental and/or physical disabilities, as well as ventilator dependency.

Each child receives individualized care from an experienced team of doctors, nurses and therapists. In addition to a highly skilled medical team, KCPCC provides around the clock staffing. Children at KCPCC typically have multiple medical and developmental conditions that make their care extremely difficult for parents to manage. The treating professionals, caregivers, and support staff make it possible to respond to the complexity, intensity and diversity of the needs of each child.

While parents have turned to the HOTI for support with the daily care of their children, families play a vital role in the continuing development of their children. From an open visitation policy to total involvement in the child's treatment program, KCPCC becomes an extended part of each child's family.

Because of their day-to-day contact with children in the KCPCC, evaluators scheduled a series of interviews with KCPCC staff. The purpose of the interviews was to gather staff perceptions of the impact of the Open Arms' Dental Service on the well-being of the children in their care.

Five staff were interviewed: the Director of Clinical Services, the Medical Social Services Coordinator, two Licensed Practical Nurses (LPNs) and one Certified Nurse Assistant (CNA). Tenure with KCPCC among those interviewed ranged from three to twenty years. Comments from KCPCC's Medical Director were provided through the Director of Clinical Services.

Themes from the interviews focused on quality of oral health services, quality of life as it relates to oral health, treatment acceptance and patient convenience, efficient use of staff time, and expanded reach to previously un-served patients.

Quality of Services

All staff mentioned the dramatic difference in the dental services provided prior to the opening of the Open Arms Dental Service and those that are available now. Previously, the service consisted of a resident from the University of Louisville School of Dentistry making a bedside visit to children at KCPCC. It was typically a brief visit, involving limited cleaning, a fluoride treatment, and an assessment of restorative needs. Because there was no dental office, the service was delivered in the child's bedroom and without any special equipment. Staff identified a number of difficulties associated with delivering a quality service in this manner:

- Without a dental chair or other physical aides for support, it was difficult to position the child in a way that made a full examination possible.

Open Arms Dental Service, Courtesy of Home of the Innocents, Louisville, KY

- Special lighting and examination equipment were not available for use by the resident/dentist.

- The service was provided by a resident who was at the KCPCC on a rotation associated with his/her degree. Because of the transience of a two-year student and the rotation involved in residency experiences, children rarely saw the same dentist twice.

- When restorative treatment was needed, a referral was made to the University of Louisville School of Dentistry. Within this setting and with this medically fragile/ developmentally disabled population; services were often performed with the patient under anesthesia.

In contrast, the Open Arms Dental Service provides:

- A collaborative partnership between the University of Louisville pediatric resident program and the HOTI dentists and staff who work along with students and residents to bring a higher level of expertise to the care management of these children.

- A fully equipped office setting with excellent positioning equipment, lighting, and medical instruments that makes both a thorough examination and restorative treatment (without the need for hospitalization or anesthesia) possible.

- A full-time dentist, employed by HOTI, and a dental staff who can provide consistent treatment to patients over time.

Children now receive a full cleaning and preventive exam on a regular basis (at least every 6 months). An individualized, dental/oral health plan has been developed for each child at KCPCC. Direct care staff are participating in video training to enhance their knowledge and skills in implementing the techniques prescribed in the plans.

Oral Health Quality of Life

All staff commented on the improved conditions of the children's oral health, including teeth, gums, and breath. The staff nurses noted that, since the opening of Open Arms, it was rare to see children with plaque buildup. The Medical Social Services Coordinator and the Director of Clinical Services also emphasized the link between good oral health and good overall health; and they readily acknowledged how important this new service has been to the medically fragile population within the KCPCC. One nurse offered a specific example of a child who was experiencing bleeding gums and extensive tooth pain. Since receiving care at the Open Arms Dental Service, his situation has greatly improved. The child is much more comfortable and much more accepting of staff efforts to provide daily preventive care. Paraphrasing the comment of one nurse: when a child isn't in pain, it's much easier to brush their teeth; and their breath smells better. A second case example was mentioned by the Director of Clinical Services. This child had stopped eating abruptly. He was given an appointment the next morning and his issues were resolved.

Treatment Acceptance and Client Convenience

Staff commented on several factors that make the experience at the Open Arms Dental Service more accommodating and less frightening for the children. These included:

- Because of the consistency of staff within the Dental Service, children have a chance to get comfortable with the dentist, the dental staff, and the service environment. This familiarity reduces anxiety.

- Because of the proximity of the service to KCPCC and the ease of scheduling, children no longer have to be transported off the grounds and wait in off-site clinics. They can simply be taken in their wheel chair across the parking lot to Open Arms. This proximity also encourages visits prior to appointments to become more comfortable with the surroundings and the staff.

- Prior to Open Arms, children received the dental service from a resident who was unknown to the child and, likely, had limited experience in working with children with such complex medical needs. This set the stage for an anxious child and an anxious treatment professional. Adding to the negative experience for the child was the fact that the service took place in the child's bedroom; detracting from the child's confidence that his room is his "safe place".

"Oral care is remarkably different. Reports now state 'continued good oral care'."
—Director of Clinical Services

Efficient Use of Staff Time

The convenience of the clinic has contributed to staff efficiency. Examples include:

- Transporting a child to the Open Arms Dental Service requires one staff member who can transport the child in the child's own wheel chair. In contrast, taking a child off campus to a clinic at the University of Louisville or other setting, demands both a nurse and a respiratory therapist and the transfer of the child and the child's equipment in and out of a van.

- Scheduling is handled by a staff member who knows the KCPCC children and their daily routines. She is able to schedule around activities that are important to the child; and she is able to schedule, or reschedule, an appointment without delay.

- With improved oral health, and with fewer infections and less pain resulting from tooth decay or diseased gums, staff are able to respond to the child's daily needs for personal care in ways that are more comfortable to the child and more efficient for the staff.

Expanded Reach to Other Children with Complex Medical Needs

- The KCPCC serves 74 children; many of whom reside at KCPCC for years. In addition, there is a population of children who reside with their parents, and who come to KCPCC for temporary care during a period of respite for their parents. Because of the growing reputation of the Open Arms Dental Service, parents are beginning to request that their child receive dental care through Open Arms. This can be done during the period of respite or once the child returns home.

- Word is getting out, through both official marketing and word-of-mouth among parents groups, about the extraordinary service that is now available through Open Arms. Not surprisingly, families of children with complex medical needs across Kentucky are beginning to take advantage of this new resource.

The final question asked the staff to evaluate the dental service before the opening of Open Arms and the dental service that Open Arms now provides. They were asked to rate the "before" and "after" on a scale of 1-5, with 1 being "poor" and 5 being "excellent". Average "before" score was 1.4; average "after" score was 4.9.

Findings: *Impact of Rotation on Dental Students at Open Arms*

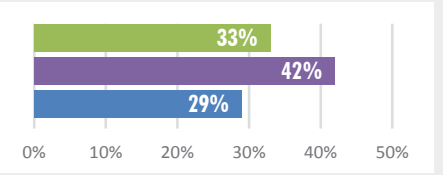
Eighty fourth-year dental students received part of their clinical training at the Open Arms Dental Service. The goal, as set forth in the grant, was achieved.

Fourth-Year Dental Students: Pre/post Measures

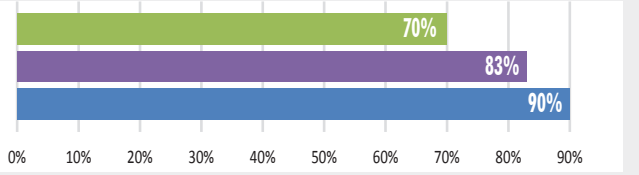
Prior to the beginning of their fourth year of dental school, dental students in the Class of 2013 and the Class of 2014 took the pre-survey. The surveys were distributed during an initial orientation meeting, with a request that all students who were willing respond to the questions. The vast majority of the students completed the survey (147 of 160). Responses (pre-test) to selected questions pertaining to their comfort level and willingness to care for special needs children are provided below.

Pre-test Responses (N=147)

Percentage of students who responded "very well" or "well" to the question, *"How well has your dental school education prepared you for serving children with special health care needs?"*



Percentage of students who responded "strongly agree" or "agree" to the statement, *"I am willing to treat children with special health care needs."*

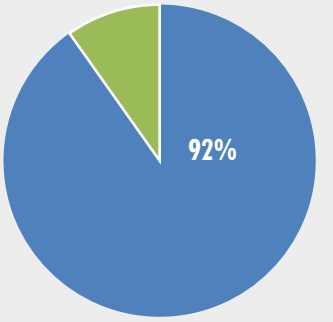


Children who are medically fragile, children with complex medical needs, and children with severe physical anomalies.

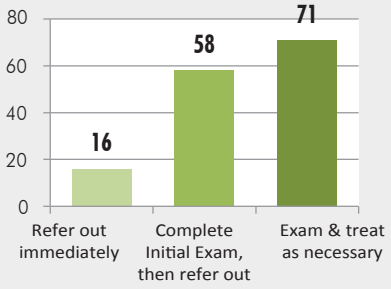
Children with intellectual, behavioral, or emotional disabilities, including children with autism spectrum disorders.

Children in foster care.

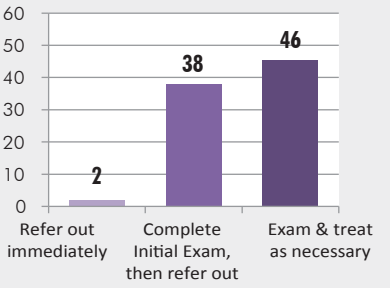
Percentage of students who responded "very much so" or "somewhat" to the question, *"To what extent has your dental education increased your awareness that oral healthcare for individuals with special needs requires specialized knowledge, increased awareness and attention, adaptation and accommodative measures?"*



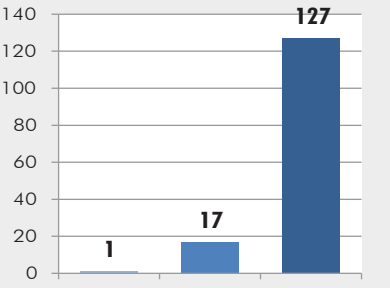
When contacted to serve a child with special health care needs (as noted below), my intentions are to:



Children who are medically fragile, children with complex medical needs, and children with severe physical anomalies.



Children with intellectual, behavioral, or emotional disabilities, including children with autism spectrum disorders.



Children in foster care.

U of L Dental School Students and New Graduates from Other Dental Schools: A Comparison of Results

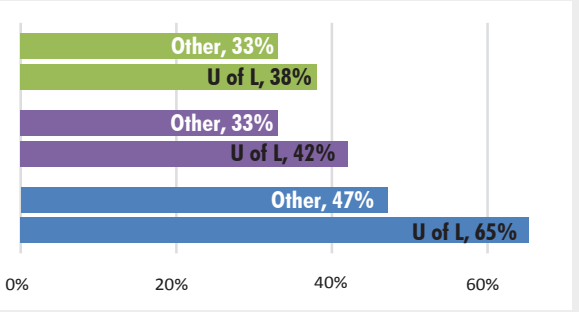
One of the evaluation questions addressed whether or not U of L dental students (who participated in professional training through the Open Arms Dental Service) expressed a greater willingness to treat children with special health care needs than new graduates from other dental schools. The post-test responses from the University of Louisville's fourth-year students were compared with the responses of recent dental school graduates from other universities who were licensed to practice general dentistry in Kentucky.

In the fall of 2012 and again in the fall of 2013, the Kentucky Board of Medical Licensure was contacted with a request to provide an electronic copy of all dentists licensed to practice in Kentucky. The lists were sorted to identify those for whom the date of graduation was May 1, 2012 or later. Among the licensed dentists on the two lists, there were thirty-nine (39) non-U of L graduates who were newly licensed to practice general dentistry in Kentucky. Letters explaining the project and surveys were mailed to the thirty-nine (39) individuals, along with a five dollar bill ($5) as an advanced thank-you for participating. Fifteen (15) surveys were returned, for a return rate of 38%.

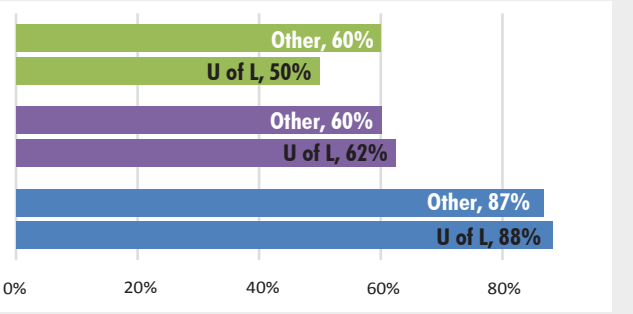
The fifteen (15) surveys from graduates of other universities were compared with the twenty-six (26) post-surveys from U of L dental students. (Only twenty-six (26) of the post-tests could be matched with the pre-tests. The majority of the responses were in a positive direction.) The U of L sample included students in their final semester: spring of 2014.

The charts on the following page depict the results.

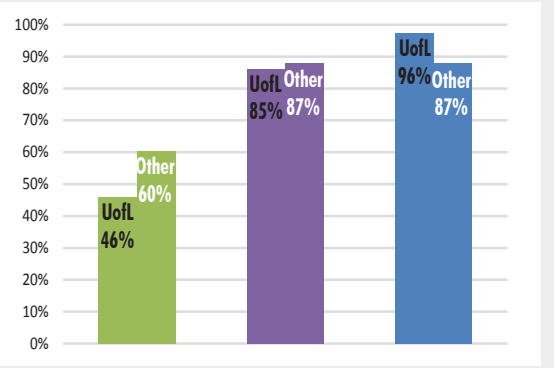
Percentage of fourth-year U of L students and new graduates from other dental schools who responded "very well" or "well" to the question, *"How well has your dental school education prepared you for serving children with special health care needs?"*



Percentage of fourth-year U of L students and new graduates from other schools who responded "strongly agree" or "agree" to the statement, *"I have confidence in my ability to treat children with special health care needs."*



When contacted to serve a child with special health care needs, my intentions are to *exam and treat as necessary*:



Children who are medically fragile, children with complex medical needs, and children with severe physical anomalies.

Children with intellectual, behavioral, or emotional disabilities, including children with autism spectrum disorders.

Children in foster care.

While no conclusions can be drawn from this limited number, it appears that the 4th year dental students who have experienced the rotation (2 days in fall and 2 days in spring) at HOTI have a greater appreciation for the challenges of serving children who are medically fragile. Among these challenges is the time involved in preparing these children for the experience and in treating them, as it is time that may not be adequately reimbursed within many dental insurance program payment structures. While all were willing to complete an initial exam on children with these conditions, only 46% of the students expressed their intention to "treat as necessary".

Pediatric Residents: Focus Group Summary

Evaluators conducted two focus groups, one at the end of the 2012 academic year and a second at the end of the 2013 academic year. The University of Louisville Pediatric Dentist Residency program is a two year program and graduates three pediatric dentists per year. During the year, each resident spends approximately 20 days at HOTI's Open Arms Dental Service. The summary below reflects the comments of six pediatric dentists in the classes of 2012 and 2013. As a result of the rotation at the Home of the Innocents, all residents indicated that their knowledge of behavior management techniques had increased and that their willingness to serve special needs populations in the future had increased. All but one resident who was "not sure", indicated that their comfort level in dealing with the needs of patients had increased.

- What aspects of the residency experience at HOTI were most helpful?

When asked what aspects of the residency experience at HOTI were most helpful to them, there were a variety of responses. The response of one resident in the class of 2012 was very clear and succinct, noting that working with Drs. Bond and Acord was the most helpful aspect of the experience and that they are "excellent instructors". Others responded to the question from the aspect of what they learned from the patients. They noted that their experience with patients who are medically fragile was extremely helpful in making them feel more confident in treating this population.

One resident said that the reason he chose the program at the University of Louisville was because of the rotation with HOTI involving medically fragile children. He was pleased with his choice and said that the experience had given him enough exposure to medically fragile children to gain confidence in treating them.

Another resident said that the experience had helped him "stretch" his understanding of who he could serve in an outpatient setting.

Residents indicated a better understanding of potential reactions of children with autism and a better understanding of how earlier trauma might affect how a child with a history of abuse might respond to touch and to oral care.

Comments included:

- "I was much more comfortable" (having had this experience);
- "Before (the rotation at HOTI), I had seen them as so fragile that I could hardly touch them."; "Now I know that they are not going to 'break'."
- "I'm feeling more comfortable with their reaction." Residents explained that they now understood that some children were going to express some resistance, but that it was okay.

- How (if at all) has the opening of the Open Arms Children's Health Dental Service led to better dental care of the patients/clients of HOTI? (e.g. better equipment, more staff, more time with the patient, greater involvement of the caregiver, better access to other members of the treatment team).

"Before (the rotation at HOTI), I had seen them as so fragile that I could hardly touch them."; "Now I know that they are not going to 'break'."
—Graduating Pediatric Dentist Resident

Residents noted their use of wheel chair lifts and bean bag supports as tools for making the experience more comfortable for the child. They also noted the difference the clinic is making in their ability to provide preventive and restorative care. Prior to the opening of the clinic, dental residents provided bed-side care. The new clinic, with its better positioning equipment and better lighting has made it easier to effectively and thoroughly deliver preventive care.

They also commented on the benefit to children at the pediatric care center of having an accessible service. The accessibility of the clinic to children at the pediatric convalescent center also enabled them to see the benefit of having a child follow the schedule of recall appointments.

Residents stated that the pace of the scheduled appointments enabled them to deliver the necessary services and provide adequate support without feeling rushed. Strategic access to other members of the treatment team was acknowledged in a discussion of a child with autism who was brought to the clinic by an aide on several occasions as a way of orienting the child to the setting and making the child feel more comfortable. These visits occurred prior to the actual dental procedure and were described as very helpful in gaining the cooperation of the patient.

- How could the residency experience at HOTI could be improved?

The residents were generally very positive about their rotation at Open Arms. They said the experience was "beneficial", "good", and "reinforced my confidence and knowledge". Residents expressed a clear preference for working with children with special needs (medically fragile, autistic) in the HOTI setting (rather than children without disabilities in the foster care system), as this was their best opportunity to work with these more challenging to serve populations. This point was stressed several times, with one resident explaining that, unless they were seeing a child with special needs, then their time was better spent at the University of Louisville clinic.

Rotation of the residents to the HOTI setting only occurs one to two times per week when other commitments at the University of Louisville does not take priority. Scheduling is based upon the request of the caregivers to provide better access and convenience for their child's dental care and may not always match the days when residents are present.

If logistically possible, an effort should be made to schedule the residents on days in which children from KCPCC or other special needs children are to be seen. Otherwise, the relative value of the experience to them as students of pediatric dentistry will be compromised.

Early Lessons Learned, Enhancements Underway, and Success Stories

The relationship between the Home of the Innocents and the University of Louisville School of Dentistry preceded the grant announcement. It consisted of consultation from Dr. Ann Greenwell, Program Director of the Pediatric Dentistry Division at the U of L and of bedside care provided by postdoctoral students in the Pediatric Dentistry Residency program. This prior relationship was strategic in defining the vision and mission of the service to be funded by the grant. The result was a teaching environment for U of L students that included children with a myriad of special needs and a resource to children throughout the community who had experienced barriers accessing needed services.

Open Arms Dental Service, Courtesy of Home of the Innocents, Louisville, KY

Lessons Learned and Enhancements Underway

- Fine-tuning of the working relationship is on-going. For example, a uniform process for orienting students to the rotation at HOTI was developed. Additionally, the relationship with the University of Louisville has evolved, with Dental School leadership seeing the value of the Open Arms Dental Service to both the oral health of patients and to the education of their students. The availability of a rotation at the Open Arms Dental Service has been used by the University in their recruitment of pediatric residents.

- Several strategies for staffing the Open Arms Dental Service have been tried. In the first iteration, the Dental Service was staffed by two part-time pediatric dentists. These individuals were on the U of L School of Dentistry's faculty and they each maintained a private practice. Currently, the Dental Service is staffed by a full-time general dentist (Dr. Brent Hurst) and at least one day each week, University of Louisville Pediatric Dentistry faculty and residents. Having a full-time dentist employed by HOTI along with additional staff from the university has meant that the work at the Open Arms Dental Service is the highest priority. It also has eliminated the potential for a conflict of interest that is present when an individual is both on staff with one service and is offering a similar service in a private practice environment. A full-time general dentist also had been a better "fit" for the extensive amount of restorative treatment that is needed within the foster care, adolescent and residential populations.

- While medically fragile children are receiving dramatically different care with the opening of the Open Arms Dental Service than they did at their bedside, the condition of their teeth and oral cavity can deteriorate quickly. This is particularly true of children who use feeding tubes. Under the leadership of Dr. Brent Hurst and the directors of Open Arms Children's Health and KCPCC, an enhanced regimen of oral hygiene is being supported within KCPCC. Training of direct care staff is given and electronic tooth brushes are provided. As a result, the daily care of teeth and gums has been made more comfortable for the child and easier for staff to perform.

  With children who do not reside on the HOTI campus, Dr. Hurst uses part of his time with the patient to educate the parents or other caregivers about caring for the child's teeth and gums.

"This prior relationship [between the Home of the Innocents and the University of Louisville School of Dentistry] was strategic in defining the vision and mission of the service to be funded by the grant. The result was a teaching environment for U of L students that included children with a myriad of special needs and a resource to children throughout the community who had experienced barriers accessing needed services."

- While the Dental Service was designed to provide access to vulnerable and underserved populations (medically fragile, behaviorally disordered, intellectually disabled, victims of abuse or neglect), the students, and particularly the pediatric residents, are most interested in gaining experience with children who are medically fragile or who have a mental or behavioral condition that requires particular sensitivity. To fulfill student expectations and to address the goal of making new dentists more comfortable in treating children with medical, intellectual, emotional disabilities, Jean O'Brien continues to work with the University on finding a schedule that is compatible with the Dental Service and other demands being placed on the students.

- Additional emphasis may be needed on educating the students and pediatric residents on the special needs of children in foster care and residential care. While the majority of these children have no obvious physical anomalies and most do not have a behavioral health diagnosis, they, nevertheless, are at risk for poor health outcomes and for being re-traumatized. Open Arms staff will make sure that the special needs of these youth are addressed in the orientation. Also, to the extent possible, elements of the training associated with Trauma-Informed Care will be incorporated into the orientation and education process. A related article in Pediatrics, the official journal of the American Academy of Pediatrics, acknowledges the value of having dentists who are familiar with issues of child abuse and neglect, in that physicians may not always pick up on the oral and dental aspects of child abuse and neglect.

In an effort to summarize the uniqueness of the Open Arms Dental Service in ways that many thousands of lines of data cannot, evaluators asked parents, youth, and staff what they considered to be the key ingredient that makes this service special. The response can be distilled down to two words: "patience" and "gentleness". If a third word were to be added, it would be "relationship". From the moment a patient walks through the door, into the bright, attractive waiting room, to the time they get up from the dental chair, administrative and clinical staff create a patient-friendly and family-friendly experience. Staff understand that every child is unique, and that, with patience and understanding, the child's experience at Open Arms can be a positive one. With a scheduling pattern that doesn't overload the waiting room, children and families typically encounter a calm and supportive environment. However, when a child is unusually active or expressive, staff take it in stride. They work to support the parent or caregiver in dealing with the child's behavior and anxiety and they work to build a relationship with the child. From the receptionist to the dentist, staff at Open Arms get to know their patients. They learn what works, and what does not work, in providing a particular patient with the care that is needed. As a small example, this evaluation report began with Rebecca's story. Staff became aware that Rebecca's favorite color is red… and that Rebecca is happier if she is in the red dental chair. They make sure she gets that chair.

Also at Open Arms, the dentist focuses on one child at a time. While he has support staff, the model provides for more intensive time with the dentist and for private patient rooms. Unlike large practices where several patients might be in the same room, separated by partitions, and where the dentist checks the work of other staff, the experience at Open Arms allows for more direct contact between the dentist and the patient, and the building of a relationship. In the words of Dr. Hurst as he spoke about his patient interactions at Open Arms, "The quality of the relationship is very different", and because of the time I have with the patient, "I'm always able to give the best quality care".

The challenge to the Open Arms Dental Service in the future, now that the grant funds have ended, will be to manage this highly individualized, patient-centered service within a managed care, fee-for-service model. Values associated with being patient, and moving at the pace of the child, are inconsistent with a business model that rewards productivity and a high volume of billable units. This issue is particularly prominent in working with children with autism. While the proportion of children with autism spectrum disorders (ASD) is relatively small (less than 2% of American children and 5% of the Open Arms' patients), the quality of their care depends on an approach that is responsive to their disorder. Possible solutions for offsetting the time it takes to address the oral health needs of a child with ASD and the difficulty of assuring adequate oral hygiene between dental visits include:

- Approval of a differential (higher) rate for children with a confirmed diagnosis of ASD by the Department of Medicaid Services and the managed care companies that serve individuals with Medicaid.

- Use of the EPSDT option to cover an enhanced service for this population. Currently, Kentucky's Department of Medicaid Services, through EPSDT, provides for follow-up visits to the dentist every three (3) months; rather than the typical 6-month follow-up period, for children who are medically fragile. Because of the difficulty associated with assuring adequate oral hygiene among children with ASD, they would benefit from a similar health care benefit.

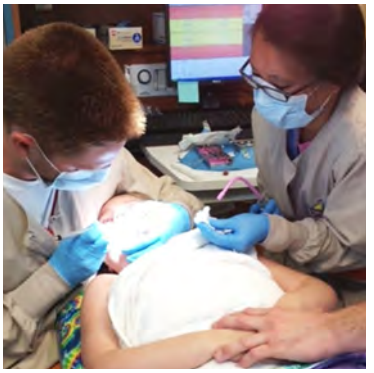
Finally, to meet the challenge of sustainability, Open Arms' staff will continue their outreach to the insurance companies, managed care organizations, and agencies that serve families. They also will continue their efforts to inform the larger community about Open Arms Children's Health and the many services they deliver. This will be done through community-wide health fairs, dental screens at child and family friendly events, educational materials and scheduled meetings with advocacy groups.

"The quality of the relationship is very different", and because of the time I have with the patient, "I'm always able to give the best quality care."

—Dr. Brent Hurst, DMD

The Open Arms Dental Service is a unique and extremely valuable component of the service array. Through the support of the Foundation for a Healthy Kentucky, and its Kentucky Healthy Futures Initiative (KHFI)*, the Home of the Innocents was able to respond to the charge of "increasing the scale of a community-based solution that has evidence of real impact." Now, with the community's support, it is positioned to continue its role as a driver of innovative and compassionate care.

*KHFI is funded by the Social Innovation Fund of the Corporation of National and Community Service.



Open Arms Dental Service, Courtesy of Home of the Innocents, Louisville, KY

"Because of Open Arms, "I didn't have to watch my child be wheeled off into surgery for a simple cleaning. It was a miracle."
—Mother of a patient served at Open Arms Children's Health

Success Stories

A testimonial:

A grateful parent described her experience with the Open Arms Dental Service in an email to the evaluator. She learned about the service in a training session and brought her two sons in for an appointment. She described her older son as "severely medically fragile;" and commented that her younger son had had a "horrible first dental visit" in another setting. That earlier experience involved her younger son being strapped into the chair and screaming, with seemingly little effort to calm him down.

Both her sons now receive their oral health care through Open Arms. In her words, "my special needs son is treated with great care and accommodated with what he needs to have his teeth care for properly. He cannot hold his head up or sit on his own. He requires frequent suctioning. Since attending Open Arms, he is more relaxed; and so am I."

She also described how different her younger son's experience has been at Open Arms. She warned the staff and the Open Arms dentist of his horrible first visit to another dentist. She was relieved with their response, saying "no one looked at me like I had three heads, and they didn't rush with cleaning his teeth. That helped my son feel more relaxed at his next visit."

As a busy, working mother, she also mentioned how helpful it is to be able to take both children to Open Arms. "The fact that I don't have to take them to different pediatric dentists is very exciting for me. It helps my younger son understand how important dental care is for his special needs brother; that even though they are different, they both have to have good healthcare and dental hygiene."

When asked what she considered to be the best thing about having the dental service at Open Arms, she responded: "When my special son had what I thought was an emergency, they got me right in, so I didn't have to take him to a hospital. Finally, when asked what Open Arms could do to make the experience even better, she said" I love the HOTI dental clinic! I believe they are doing a great job!"

—Parent and Advocate

Other stories of success:

Open Arms Children's Health served a child with autism who once had an explosive behavior in the waiting room and destroyed some items. After the staff worked with the child and parent beforehand, the actual dental visit was very successful. The clinic later contacted the parent to be assured the child was doing well and to comfort them about any concerns over the items that were destroyed. The parent was very happy with the care their child received and was pleased to come back for their six-month visit.

A child, who was a refugee from Congo, was served by Open Arms Children's Health. Their family had only been in the country a few weeks at the time of their visit. When seen in the medical area, the physician was so concerned that they sent the patient down the hallway immediately for evaluation in the dental area. The child was scheduled for surgery within a week and their extreme dental issues were addressed immediately. The remaining children in the family were also in similar need of dental care and were scheduled and treated right away.

A little girl who was both deaf and blind and only nine years old was served by Open Arms Children's Health. She suffered from chronic lung disease, seizures, and dysautonomia, a disease of the autonomic nervous system. She received dental care throughout her young life, but until recently a visit to the dentist for this child required a risky sedation procedure and a full day at the hospital. Routine dental care was anything but routine, and was one more fearful hospital visit for a fragile little girl.

Fortunately, the child's family discovered Open Arms Children's Health, and their first experience at Open Arms was one of surprise and delight. They entered the dental office and the nine-year old was situated on a big, body-sized tie-dyed pillow which was fitted to the dental chair. As the dentist began his initial examination, the mother noticed that he began to reach for instruments. Shocked, she asked what he was doing, and the dentist calmly told her he was cleaning her teeth. This was the first time in nine years that a dentist had ever tried to clean her teeth without sedation. The little girl never fought the dentist, and never cried. The mother wondered, "Why had no other dentist ever even tried?" She was overwhelmed by the experience and told the staff that that day she was able to revel in a simple joy—a joy that most moms take for granted. She said, because of Open Arms, "I didn't have to watch my child be wheeled off into surgery for a simple cleaning. It was a miracle."

Since that day, the little girl passed away but her mom was very thankful for this special moment in her life.

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Appendix A: Statistical Analysis

Dentist evaluation of Treatment Acceptance

p.22 mean scores (lower is better)

Last year			This year		
T1	1.37	(n=760)	T1	1.30	(n=1488)
T2	1.35	(n=347)	T2	1.24	(n= 860)
T3	1.34	(n=129)	T3	1.20	(n= 486)
T4	1.23	(n= 31)	T4	1.22	(n= 279)
			T5	1.24	(n= 156)
			T6	1.18	(n= 71)
			T7	1.27	(n= 26)
			T8	1.21	(n= 14)

Dentist evaluation of Treatment Acceptance - crosstab

p.23

	Last year			This year		
	score	count	%	score	count	%
T1	1		75	1	1175	79%
	2		16	2	198	13%
	3		9	3	102	7%
	4		1	4	13	1%
T2	1		72	1	709	82%
	2		21	2	103	12%
	3		6	3	39	5%
	4		1	4	9	1%
T3	1		77	1	421	87%
	2		13	2	38	8%
	3		7	3	20	4%
	4		2	4	7	1%
T4	1		84	1	230	82%
	2		13	2	38	14%
	3		0	3	9	3%
	4		3	4	2	1%
T5				1	126	81%
				2	25	16%
				3	3	2%
				4	2	1%
T6				1	62	87%
				2	6	8%
				3	2	3%
				4	1	1%
T7				1	22	85%
				2	2	8%
				3	1	4%
				4	1	4%
T8				1	11	79%
				2	3	21%

Dentist evaluation of Treatment Acceptance

p.23 for each of eight populations: count and mean rapport score

	Last year		This year	
Priority Population	count	mean	count	mean
ChildKind Center	173	1.13	249	1.12
Other Agencies	205	1.18	433	1.14
Refugee	36	1.53	136	1.32
Impact Plus	12	1.58	18	1.39
Outpatient	224	1.57	495	1.41
Medically Fragile	99	1.61	134	1.60
Unknown	5	1.60	11	1.73
CKC – Autism	6	2.00	10	2.10
All 8 groups	760	1.37	1486	1.30

Parental Expectations of Child's Treatment Acceptance and Comparison

p.24 Comparison of Treatment Acceptance Scores at T1

	Last year		This year	
Parent score	count	mean	count	mean
1 Good rapport	31		103	
2 Cautious	26		74	
3 Reluctant	9		17	
4 Refusal	8		22	
total	74		216	

Not every time & usually not collected for children in out-of-home care.

Comparison of Treatment Acceptance scores

p. 24 parents better (12, 16%), same (33, 45%), worse (29, 39%)

	Last year		This year	
	count	mean	count	mean
Parent & Dental Score Same	29	39.2%	86	39.8%
Parent Expectation Worse	33	44.6%	109	50.5%
Dentist Experience Worse	12	16.2%	21	9.7%
	74	100%	216	100%

Oral Health and Hygiene Measures

(pgs. 25-26)

The difference in total Oral Health scores between the high score groups and all other groups was statistically significant to a high degree:

		high	other	Diff	sig	t
MF & OA vs AO	All time periods	1.31	1.12	.187	.000	8.994
MF & Ref vs AO	"	1.35	1.14	.213	.000	9.144
All four	"	**1.28**	**1.04**	.244	.000	11.313
MF & OA vs AO	Only at T1	1.28	1.14	.145	.000	5.232
MF & Ref vs AO	"	1.34	1.16	.180	.000	4.833
All four	"	**1.28**	**1.04**	.242	.000	8.794

The numbers are large this year, so even small differences are statistically significant.

	Oral Health Values			T-Test		
	T2	T3	Change	*t*	*p*-value	*d*
Refugee (n=52)	1.35	1.08	-.269	-2.707	.009	.375
All but Ref (n=630)	1.19	1.18	-.008	-.321	.749	.013
These two groups are included above, but shown below to show the lack of significance.						
Medically Fragile (n=255)	1.38	1.35	-.039	.936	.350	.059
Other Agencies (n=106)	1.16	1.18	.019	.266	.791	.026

The mean scores for all time periods are:

Medically Fragile	1.35
Refugee	1.32
Other Agency	1.26
Childkind	1.24
All Other	1.04

Three Measures of Oral Health (from T2 to T3)

		Last year N=35	This year N=682
Improved	Oral Hygiene	4	15
	Plaque	7	46
	Calculus	10	42
Stayed the Same	Oral Hygiene	24	173
	Plaque	23	158
	Calculus	23	152
Got Worse	Oral Hygiene	7	43
	Plaque	4	21
	Calculus	2	32

Parental Caregiver Perceptions

(pgs. 27-28)

at T1 & T2 (combine 25pre & 25post)
last year N=11/143; this year N=37/305

3-month change	Last year			This year		
Problems	T1 Pre	T2 Post	Diff	T1 Pre	T2 Post	Diff
Saying words	1.7	1.3	-0.4			
Food stuck	1.2	0.9	-0.3			
Pain in mouth	1.2	1.4	0.2			
Sores in mouth	1.0	1.2	0.2			
Other felt guilty	1.0	1.2	0.2			
Worried	1.0	1.2	0.2			
Breathed through mouth	1.2	1.5	0.3			
Difficulty sleeping	1.0	1.4	0.4			
Difficulty eating	0.9	1.5	0.6			
Bad breath	1.6	2.3	0.7			

3-month change	Last year					This year		
Problems	T1 Pre	T2 Post	Diff	#	N	T1 Pre	T2 Post	Diff
Health of child's teeth, lips, jaws, mouth				1	37	2.27	2.35	.08
Overall wellbeing affected				**2**	33	2.52	1.88	**-.64**
Domain I: Oral Symptoms								
1 Pain				**3**	37	1.95	1.59	**-.35**
2 Bleeding gums				**4**	36	1.36	1.17	**-.19**
3 Sores in mouth				5	37	1.24	1.41	.16
4 Bad breath				**6**	37	2.19	2.00	**-.19**
5 Food stuck in roof of mouth				7	37	1.38	1.38	.00
6 Food caught in teeth				8	37	2.03	1.92	-.11
7 Difficulty eating or chewing				9	36	1.53	1.67	.14
Domain II: Functional Limitations								
1 breathed through mouth				10	36	1.61	1.50	-.11
2 trouble sleeping				**11**	36	1.39	1.67	**.28**
3 difficulty saying words				12	34	1.42	1.40	.03
4 taken longer to eat a meal				**13**	36	1.11	1.56	**.44**
5 trouble eating/drinking cold/hot food				14	35	1.20	1.37	.17
6 difficulty eating what he/she wants				**15**	36	1.00	1.19	**.19**
7 restricted diet				16	36	1.00	1.11	.11
Domain III: Emotional Difficulties								
1 upset				**17**	37	1.46	1.27	**-.19**
2 irritable or frustrated				**18**	37	1.57	1.27	**-.30**
3 anxious or fearful				19	37	1.32	1.32	.00
Domain IV: Family Impact								
1 been upset				20	36	1.03	1.11	.08
2 sleep disrupted				21	35	1.03	1.06	.03
3 felt guilty				**22**	35	1.00	1.26	**.26**
4 took time off work				23	35	1.03	1.03	.00
5 had less time for self or family				24	33	1.15	1.00	-.15
6 worried about child's opportunities				25	33	1.18	1.06	-.12
7 uncomfortable in public				26	33	1.00	1.00	.00

Parental Caregiver Perceptions at T1

(pg. 28)

N= 143 N=305

	Last year Means	This year means
Domain I: Oral Symptoms	**1.56**	**1.79**
1 Pain	1.50	2.10
2 Bleeding	1.38	1.43
3 Sores	1.13	1.37
4 Bad breath	2.07	2.06
5 Food stuck	1.31	1.67
6 Food in teeth	2.04	2.10
7 Difficulty eating	1.48	1.78
Domain II: Functional Limitations	**1.50**	**1.74**
1 breathed through mouth	1.97	2.45
2 trouble sleeping	1.59	1.76
3 difficulty saying words	1.83	1.97
4 taken longer to eat a meal	1.42	1.71
5 trouble eating/drinking cold/hot food	1.35	1.58
6 difficulty eating what he/she wants	1.20	1.46
7 restricted diet	1.14	1.25
Domain III: Emotional Difficulties	**1.45**	**1.74**
1 upset	1.40	1.70
2 irritable or frustrated	1.52	1.80
3 anxious or fearful	1.43	1.71
Domain IV: Family Impact	**1.28**	**1.38**
1 been upset	1.40	1.47
2 sleep disrupted	1.36	1.47
3 felt guilty	1.30	1.39
4 took time off work	1.10	1.28
5 had less time for self or family	1.21	1.32
6 worried about child's opportunities	1.30	1.44
7 uncomfortable in public	1.28	1.30

REACH Evaluation consults with organizations, communities, and programs to enhance effectiveness and accountability, facilitate change, and improve the welfare of people. Over the years, REACH has established an exceptional reputation in planning and evaluation of integrated health, human service, and community programs. With a multidisciplinary team of research and planning professionals, REACH specializes in delivering a product that is substantive, responsive, and practical.