Chancellor's Community Award for Excellence in Civic Engagement 2011

Nominee: Community Dental Clinic of LaGrange County

Nominating IUPUI Faculty Member: Karen M. Yoder, PhD, IU School of Dentistry

The Community Dental Clinic of LaGrange County is a not-for-profit safety-net dental clinic that serves children and adults in northeastern Indiana. Patients are predominantly members of the Amish community, but others are welcome and an increasing proportion is non-Amish from the rural areas of LaGrange and Elkhart Counties. Approximately 5,000 patients are treated annually with the benefit of affordable fees and a sliding fee scale. Collaborative research has been conducted and plans are underway to work in cooperation with Indianapolis entities to build a medical clinic, beside the dental clinic, that will engage in primary care and genetics research.

1. <u>The Nature and quality of the collaborative work between the organization and IUPUI</u>

In 1996 a small team of Indiana University School of Dentistry (IUSD) faulty, staff and students began making monthly trips to Shipshewana and Elkhart to increase access to dental services for Amish children, especially the disproportionately high number of children with bleeding disorders. After identifying the children who had untreated dental disease, the team transported the children to the office of a pediatric dentist in Elkhart; Dr. Gregory Robbins (IUSD DDS'85, MSD'88) where the dental team treated the children. It became apparent that there was great need for dental services in this population. In 1997 the project applied for and received a $200,000, three-year grant funded by the Indiana State Department of Health, IUSD Oral Health Research Institute, and the South Bend Memorial Health Foundation. The Robert Wood Johnson Foundation served as a matching-fund partner. The grant was awarded to IUSD faculty member Brian Sanders, DDS and former Indiana University School of Medicine (IUSM) faculty member, Amy Shapiro, MD, now the Director of the Indiana Hemophilia and Thrombosis Center at St. Vincent's Hospital.

The grants were used as start-up funding to build a fully equipped, state-of-the-art dental facility in the midst of cornfields and pastures in LaGrange County. The Amish community contributed financially to the project and in traditional barn-raising style built the structure for the dental clinic in little more than a day with the help of dozens of members of the Amish community.

Having a readily accessible dental clinic is especially important to the Amish community. A higher proportion of the people from the Amish community have bleeding disorders such as hemophilia and Vonwillebrand Disease; therefore, when dental decay is allowed to progress and requires an extraction it can be a life-threatening event. The required therapy is to administer clotting factor which is an extremely expensive medication. Such situations make the concept of prevention truly meaningful. Prevention and early intervention for the affected children were the goals of the original team from IUPUI. These goals soon broadened to include the siblings of the children with bleeding disorders, and that goal broadened to include children, Amish or not Amish, from throughout the area who did not have access to dental services. More recently the clinic is also treating adults from an area including LaGrange and Elkhart Counties. A sliding fee scale is available for underemployed families.

Indiana's population includes 43,000 people who are Amish and live exclusively in rural areas[i]. There are 23 well defined settlements in Indiana that are predominantly located around the circumference of the State. People who are Amish experience barriers to dental services that are not encountered by the

non-Amish. They live exclusively in rural locations, which, in Indiana mean that there is typically an unfavorable dentist to population ratio. Their mode of transportation is typically by horse and buggy; therefore securing dental services in dental offices that are predominantly located inside towns or cities presents traffic dangers for them and driving a buggy to a dental office in a nearby town may take a great deal of time. They tend to hire a van to take them to dental and medical appointments, which escalates the cost. As part of their belief system, the Amish refuse to accept charity; they expect to pay out-of-pocket for their care, and they share expenses when the costs for health care are overwhelming for a family.

Because LaGrange and Elkhart Counties have been extensively dependent on the recreational vehicle industry, their incomes have been severely affected by the economic downturn and many of the men do not have factory work available to augment their income from traditional farming. These factors contribute to barriers to access to dental services.

Because IUSD is Indiana's sole school of dentistry, it is responsive to the needs of residents throughout the State including those in more remote and underserved areas. It has been interesting and rewarding to witness the development of a close and mutually beneficial partnership between the people of the Amish culture and IU School of Dentistry.

2. <u>The impact of the collaboration with IUPUI to the organization</u>

IUSD faculty members provide technical assistance and professional development for CDC dentists and the Board of Directors. The CDC board of directors is comprised of ten members, seven or more of whom are members of the Amish community. Most of the Amish members of the BOD are business men and are astute in matters related to operating a business, but, by their own admission, have limited dental practice experience. The clinic has had one or more IUSD faculty as members since the clinic's inception. Dr Brian Sanders was an original member, followed by Drs. Keith and Karen Yoder. These faculty members provide technical consultation for practice related topics and practice administration assistance for the administration of the clinic. Mr. Eric Gray represents the Indiana Hemophilia and Thrombosis Center of St. Vincent's Hospital which is an ongoing contributing partner with CDC. The IUPUI faculty members also provide linkages with resources based in Indianapolis such as Indiana State Department of Health and Indiana Primary Care Association.

Dental student rotations provide dental services for the community. IUSD has benefited CDC by establishing voluntary fourth year dental student rotations. Dental students who are competent in clinical procedures and near graduation, are invited to volunteer to provide a day of dental clinical services at CDC. More than half of the 100 students in the fourth year dental class annually volunteers for this assignment. The Dental Director, Dr. Lisa Leniski, is a graduate of IUSD and its pediatric residency program. She is the only pediatric dentist in LaGrange County and is an adjunct faculty member at IUSD.

IUSD is a conduit for contributions of dental equipment and supplies. IUSD has benefited CDC through the dental school's affiliation with the National Children's Oral Health Foundation (NCOHF). This organization is a not-for-profit that promotes health for disadvantaged children. The Foundation links dental professionals, industry leaders, philanthropic individuals to form a network of groups committed to making oral health the standard for all children. When NCOHF received donations of dental equipment from a large manufacturer, an IUSD faculty member, Dr. Judith Chin, secured $30,000 worth of equipment for the CDC.

IUPUI is developing a healthcare workforce that is better prepared to provide culturally appropriate dental services for people who are Amish. As a result of the IUSD-CDC collaboration, a significant number of the Indiana dental workforce, especially IUSD graduates are now more familiar with the Amish culture and better prepared to serve them. The IUSD graduates who volunteered to work in the CDC clinic, or who heard the presentation by the members of the CDC BOD, know that the young children speak only Pennsylvania Dutch, not English, and know that they need the parents' help to communicate with them. They know that the children will respond to conversations about their pets and farm animals, but not about television and cartoon characters. They also know that the Amish use many traditional and herbal healing practices that can impact their health. They know how to ask questions respectfully and without making assumptions. They know that they have to watch the children carefully when treating them because if they feel pain, they will not make a sound or complain, but tears may be flowing down their cheeks. More than one dental student has emotionally related how badly they felt when they saw tears when the child sat unmoving with his hands tucked under him, without voicing any complaints.

3. <u>The significance and impact of the collaboration to IUPUI</u>

The willingness of the Amish community to contribute to the collaborate with IUPUI can be illustrated with this example: In 2004 IUSD applied for a Robert Wood Johnson Dental Pipeline Grant. The requirement was for dental schools to assign fourth year dental students to 60 days of clinical work in community-based safety-net dental clinics. CDC was approached to inquire about agreeing to host dental students for rotations. They readily agreed, but in typical Amish fashion, they demonstrated their support. They were in the process of building additional operatories to enlarge the clinic, so they decided to build two additional rooms to house the dental students that they anticipated hosting. The grant proposal made the first cut, but for curricular reasons Dean Goldblatt withdrew the application. The rooms are now being used as offices for the clinic dentists, but we'll never forget the concrete way in which the CDC board of directors demonstrated, "Yes, we will welcome IUSD students."

Research Accomplished In 2008, IUSD researchers, Drs. Jeffrey Platt and Margherita Fontana obtained $250,000 in National Institutes of Health funding[ii] and $20,000 from Delta Dental Foundation to study dental caries progression and effectiveness of dental sealants. The then President of the BOD, Dennis Lehman, agreed to be liaison with the community and assisted in recruiting a sample of the 62 Amish schools that exist in LaGrange County to participate in the study. This recruitment required meeting individually with presidents of the school boards by visiting their homes. An IUSD faculty member, Dr. Karen Yoder, accompanied Mr. Lehman on these home visits. The research that was accomplished was highly successful and is expected to result in additional, more extensive funding. This research, which was intended to examine the progression of dental caries over time, and the effectiveness of dental sealants over time required that a significant number of children could be reexamined periodically for several years. In the eight years that IUSD has conducted the Seal Indiana Program, it has become apparent that in typical title I (low income) Indiana schools, many of the children who were examined and treated one year are simply not there the next year, their families have moved on to another location; therefore obtaining epidemiologic data over time is not possible. The Amish community tends to remain in one location throughout their life or certainly through their school years. NIH was very impressed with the IUSD research that close to 100% retention of subjects over several years.

Future Research Plans. Mr. Dennis Lehman, a founding past-president of the CDC is formally working with Dr. Amy Shapiro, Director of IHTC and to raising funds and lay the groundwork for establishing a medical facility adjacent to the dental clinic that would provide primary care and conduct genetics research. Dr. Wade Clapp, Director of Pediatrics, and Dr. Nancy Swigonski , a pediatrician at Riley Hospital for Children have recently joined this effort and are working with those planning the clinic to incorporate a collaborative primary care component. Last summer Mr. Lehman and his colleagues were instrumental in organizing an auction in Shipshewana, selling items contributed by the Amish community that raised $40,000 for the medical clinic fund. Significant progress has been made toward raising funds and the medical clinic is scheduled to be built next to the dental clinic in Lagrange County. The new clinic has unlimited potential for genetic and translational research.

Mentors for lessons in cultural competence: Annually, four or more members of the community who are on the dental clinic board of directors, and the dental director, Dr. Lisa Leniski come to Indianapolis to provide a presentation for third year dental students in their dental public health class. Their goal is to provide orientation to the dental clinic and to help the students understand the culture, values and practices of people in the Amish community. They provide a forum for the students to begin to understand some of their practices, for example; that they do pay taxes, but don't accept the benefits of Medicaid or Social Security. Some, especially business men, use technology, have a mobile phone and some use computers, but they adhere strongly to not allowing electric lines to enter their homes and not owning or driving cars. Their education, usually in an Amish parochial school, will end at after the eighth grade and developing trust between outsiders and the Amish communities typically takes a considerable amount of time.

Dental students are invited to volunteer to come to LaGrange County to work in the dental clinic and treat the Amish children. There are always more volunteers than can be accommodated and typically half of the class of 100 students engages in this opportunity. Although the Amish universally live in rural setting, their lives intersect with faculty, staff and students at IUPUI. It's rare to walk through Riley Hospital for Children without seeing an Amish family. Their access to specialty care is limited by their rural residences; therefore, Indianapolis becomes the center for their more complex medical needs. IUSD prepares students to interact respectfully, sensitively, in a spirit of community, and with some level of understanding about the culture.

Modeling, for the future dental workforce, the benefits of practicing in a rural setting
Indiana has wide geographic disparities in the ratio of dentists to population by county with rural counties having a much less favorable ratio. Having an opportunity to visit and work in the LaGrange County clinic or even to stay there and live with an Amish family as two dental students did, helps future dentists see the benefits of a rural lifestyle. This experience may encourage a greater proportion of IUSD graduates to settle in underserved rural counties, and may also increase the number of graduates who benefit from student loan repayment options offered to those working in federally designated dental health professions shortage areas. Both of these potential outcomes are of great importance when considering the value of this partnership.

Significant lessons learned about civic engagement from the Amish Community After we were invited to become members of the dental clinic board of directors, we were welcomed and encouraged to participate in important community events. We were invited to weddings, church services and funerals. They showed us how they raised thousands of dollars by actively engaging the community in donating and buying at auctions and quilt sales. The taught us how to introduce the community to the dental clinic, not by a reception where people sipped wine, but by having an open

house on the lawn, grilling hamburgers for all who came, and having the dentists and board members sit on the seat above the dunk tank and let the children throw balls at the trigger to drop them into the water. At the clinic Christmas party, rather than have only a formal dinner and gift exchange, the board of directors performed hilarious skits and led the staff in a hula hoop contest. They taught us not to be shy about approaching authority figures. They invited Governor Mitchell E. Daniels, Jr. to the clinic's 10th anniversary celebration at a farm in LaGrange County….and he came.

4. Communication and Dissemination

To date professional dissemination of information about the partnership has been related to IUSD's research conducted on the effectiveness of using dental sealants to prevent and arrest dental caries. These presentations have occurred at the International and American Associations for Dental Research meetings and were presented by Drs. Jeffrey Platt and Margherita Fontana.

The community is not willing to shine a light on themselves personally, but is willing participate in and to highlight activities that will benefit the health and welfare of the community as a whole. Developing a trusting relationship with the Amish community requires honesty and time, but the relationship has developed over time and collaboration in research and writing is likely to move forward significantly. There are members of the community who are interested in participating in selected studies related to the health and welfare of people who are Amish

In conclusion, the IUPUI partnership with the Community Dental Clinic and Amish community in LaGrange County has been a mutually beneficial endeavor with enormous potential for future translational research outcomes. After the Amish community decides that the goals are worthy they contribute significantly to making a program successful. IUPUI has many resources that can benefit the Amish community in addition to the Community Dental Clinic. Recognizing this partnership by conferring the Chancellor's Community Award for Excellence in Civic Engagement will endorse its accomplishments and encourage future collaboration.

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[i] Http://www2.etown.edu/amishstudies/Population_by_State_2010.asp

[ii] NIH-NIDCR/R21 DEO18115-01: Effectiveness of Sealing Caries: A Way to Reduce Disparities in Dental Caries- $250,000. Delta Dental Foundation: Effectiveness of Sealing Caries: Monitoring Sealed Early Caries - $20,000.