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Providing Modern Dentistry for Folk Who Cling to Old Way

Program to increase access to dental care and education for Amish children

SUMMARY

An Indiana University team organized a series of one-day dental clinics in Northern Indiana to treat Amish children for tooth decay and other oral health problems, which traditionally have been more prevalent in the Amish community than in the general population.

The 44-month project, which began in July 1996, also provided Amish families with kits for testing the fluoride level of their well water and handed out fluoride supplements when needed.

In addition, the staff developed a dental health education curriculum for Amish schools and implemented a fluoride rinse program for Amish students.

The project was part of the Robert Wood Johnson Foundation (RWJF) *Local Funding Partnerships* (LFP) national program (for more information see Program Results).

During the course of the project, the Amish community built, equipped and began operating its own permanent pediatric dental facility. The clinic—located outside the small town of Shipshewana, just south of the Michigan border—provides low-cost treatment to non-Amish as well as Amish children.

Key Results

- Project staff conducted 21 clinic sessions and, as of May 1999, had treated 665 patients.
- Staff handed out 300 fluoride testing kits, 275 of which were sent to the state health department for analysis. They gave out 307 fluoride supplements to families with insufficient fluoride in well water.
- Despite some parents' concerns about fluoride, nine schools involving a total of 379 students continued to participate in the weekly fluoride rinse program.

Funding

RWJF supported the project with two grants totaling $122,958 from July 1996 to February 2000.

INTRODUCTION

The Community Dental Clinic in rural Northern Indiana outside the small town of Shipshewana has two unusual but well-used conveniences: a hitching rail and a watering trough. This one-room, four-chair pediatric dental facility is in the heart of one of the nation's largest Amish communities, and many of the clients come by horse and buggy.

Katherine Ballard, DDS, a newcomer who previously practiced in inner-city Indianapolis, loves to listen to the clompity-clomp of the local transportation system. She appreciates the physical beauty of the area and the graciousness of the Amish people. "It's truly a Little House on the Prairie atmosphere," she says.

But as Ballard looks into the mouths of many of her young customers, she also sees another, less obvious aspect of Amish life: a need for improved dental care. "One kid can have 18 cavities," she says. "Like almost every tooth in their little head."

Ervin Miller, who is Amish and chair of the dental clinic board of directors, explains that traditionally members of the Amish community have not placed a high priority on dental care. Parents love their children, but "they just haven't seen the importance of teeth," he says—especially baby teeth since they are coming out anyway.

Economics is one factor. The Amish have income from family farming operations as well as outside jobs. But their families are large, often with five to 10 children, and regular dental checkups can be an expensive proposition, says Miller, who runs his own wood products business. The Amish do not believe in private insurance coverage or participate in federal health programs, and they are reluctant to accept charity from outside their community.

Transportation is another complication. The Amish do not own or drive cars, and getting anywhere out of horse-and-buggy range means the additional expense of hiring a van and driver. In addition, most Amish homes and parochial schools are in rural areas and dependent on well water, leaving the children no source of fluoridation beyond what occurs naturally.

All of that adds up to a long-standing deficiency in oral health. A 1988 survey by the Indiana State Health Department found the decay rate among the state's Amish children was three times higher than in the comparable general population.

The Community Dental Clinic—built in 1999 by the Amish—is an effort to improve the situation. Ballard and her staff are not just checking teeth and filling cavities, as important as that work is. Through education and fluoride supplementation, they also are working to change the community's fundamental approach to oral health. "We're trying to change a mind-set," says Miller, the board chair.

The clinic grew out of a pediatric dental care project supported by RWJF through a national matching-grant program called the *Local Funding Partnerships.* By collaborating with community foundations and other local givers across the country, *Local Funding Partnerships* seeks to stimulate innovative, community-based projects aimed at improving the health and health care of underserved and vulnerable populations.

THE PROBLEM

The Amish are a conservative Christian sect that tries to maintain elements of the old European culture in which the members' forebears lived. In addition to forgoing automobiles, the Amish do not have electricity or telephones in their homes and do not sanction marriage outside the faith. Many continue to speak a German dialect, and traditionally their children do not go to school beyond the eighth grade.

Amy D. Shapiro, MD, medical director of the Indiana Hemophilia and Thrombosis Center in Indianapolis, explains that long ago someone in the Amish community had the genetic defect known as hemophilia B, a clotting disorder that results in uncontrolled bleeding. Because of the stability of the Amish population and the large size of their families, this disorder is now more prevalent among the Amish than in the general population.

In the 1990s, Shapiro directed the Indiana Hemophilia Comprehensive Center at the James Whitcomb Riley Hospital for Children, a part of the Indiana University School of Medicine in Indianapolis. The center provided medical services to the state's Amish population, and through this work identified hemophiliac Amish children with multiple dental problems. Because of the bleeding risk, untreated dental disease in a hemophiliac can complicate and ultimately compromise medical care.

The center responded by organizing a temporary, part-time dental clinic to serve children in the large Amish community just below the Michigan border in LaGrange County and the eastern portion of adjoining Elkhart County. About 18,000 Amish live in this area of small towns and farms. There are some 110 church districts, each with its own bishop, and approximately 60 parochial schools. The schools, which go up to the eighth grade, range from 20 to 60 students, according to Miller.

The center established the clinic in the city of Elkhart, where a pediatric dentist donated the use of his office on his days off. The center provided a dentist and dental hygienist. Dental supply companies and the state health department contributed supplies.

The city of Elkhart, population about 50,000, is not in the Amish community. To get there, most families had to hire a taxi or make other arrangements for a car and driver. Nevertheless, the initiative drew families with hemophiliac children, and as a result of this effort, Shapiro learned that the nonhemophiliac siblings of her Amish patients also suffered from dental disease.

In response—and with the cooperation of an Amish bishop—an Indiana University team led by Shapiro organized a new series of dental clinic sessions in Elkhart aimed at helping financially disadvantaged families and children with special health needs, including Down's syndrome, cardiac defects and asthma. The clinic served primarily but not exclusively Amish children.

To publicize the program, the bishop placed an ad in an Amish newspaper explaining that families would be charged a maximum of $30 per child regardless of the services provided—a fee far below what families could expect to pay at other dental providers in the area.

Between August 1994 and August 1995, the center ran four clinic sessions in Elkhart and served a total of 83 children. The demand, however, exceeded staffing and financial resources, and Shapiro decided to seek outside support for an expanded effort. In November 1995, Indiana University applied to *Local Funding Partnerships* for support of a three-pronged, three-year intervention to improve the oral health of Amish children.

The project plan developed by Shapiro's team called for:

- Direct dental services through a series of 24 one-day clinic sessions.
- Testing of wells in the Amish community to determine fluoride content, followed, if necessary, by fluoride supplementation.
- Dental education during clinic visits and in Amish parochial schools.
- Institution of a fluoride rinse program in 25 schools.

At the end of the three-year grant period, the plan called for the Amish community to offer these services on its own. To prepare for this self-sustaining phase, the Amish were to build and equip a dental clinic and have it ready for operation at the project's conclusion.

The *Local Funding Partnerships* national program office staff considered the managerial and professional abilities of the project team to be a major strength of the proposal. In

addition to Shapiro, who was associate professor of pediatrics as well as medical director of the hemophilia center, the team included:

- Brian J. Sanders, DDS, then assistant professor (now associate professor) of pediatric dentistry, Indiana University School of Dentistry, and director of the Riley Dental Clinic.
- Janet Mulherin, a dental hygienist with the hemophilia center and Riley Hospital.
- Patricia Ann Yoder, a registered nurse who lived in the project area and was a member of the Mennonites, who are similar to the Amish in background and beliefs.

Shapiro's close relationship with the Amish community was another strength of the proposal. She consulted regularly with Amish leaders, and the project had their support. The community's commitment to build and staff its own clinic was another major plus.

THE PROJECT

In July 1996 RWJF awarded Indiana University School of Medicine a $122,958 grant (ID# 029812) to support the project. Subsequently—for reasons unrelated to the project—Shapiro moved her base of operations from the Indiana University Medical Center to St. Vincent Indianapolis Hospital. There she reestablished the Indiana Hemophilia Comprehensive Center as the Indiana Hemophilia and Thrombosis Center, a nonprofit corporation. As a result of the move, RWJF closed out the initial project grant and transferred the balance to Shapiro's new programmatic home through a second grant (ID# 035938). Also, RWJF extended the original three-year grant period by eight months.

Local Funding Partnerships requires a one-for-one match. The match for this grant came from the Indiana State Health Department, Memorial Health Foundation (which supports Memorial Hospital in South Bend) and the Amish community. In addition to providing volunteer labor to construct the clinic, the Amish raised and borrowed more than $100,000 to build and equip the facility.

Again using the office of the Elkhart dentist, the project staff held 21 clinic sessions that examined children for plaque and dental decay and provided treatment as necessary. The Amish bishops advertised the sessions in an Amish newspaper and referred eligible families for service.

Seventeen volunteer students from the Indiana University School of Dentistry assisted the project staff with the clinics. The university encouraged students to participate by offering extramural credit. The staff also recruited volunteer workers from the Amish community, including one woman who received training as a dental assistant and for a while held a paid position at the clinic. (That woman is not working at the new clinic in

Shipshewana, but another dental assistant from the Amish community is on the current staff.)

Originally, the project staff planned to hold eight of the clinic sessions in the Fort Wayne area. However, the Amish living near Fort Wayne showed little interest in the program. In contrast, the demand in the Elkhart area exceeded the project's capacity, requiring appointments to be scheduled four months in advance. As a result, with concurrence from the *Local Funding Partnerships* national program office staff, the project staff dropped the planned Fort Wayne effort and held all clinic sessions in Elkhart. (The Amish community in LaGrange and Elkhart counties is about 60 miles from Fort Wayne.)

Due to the demand for clinic services, the staff gave priority to children with special health care needs. To help identify those children, the staff distributed a medical survey form to Amish ministers, who disseminated the forms to parents of about 1,000 children.

The project staff handed out fluoride kits provided by the state health department. Using the kits, Amish families took water samples from their wells and dropped the samples off at a centrally located Amish health food store, where they were picked up and sent to the state health department for analysis. The state forwarded the results to the project staff, and staff members offered fluoride supplements—chewable fluoride pills—to families with inadequate fluoride levels in their well water. The staff also handed out tubes of fluoride gel for children to apply to their teeth to help prevent new cavities. In addition, with help from the Indiana University School of Dentistry, the project staff developed a once-a-week fluoride rinse program for children in Amish schools and instructed students and teachers on fluoride use.

Also, working with members of the Amish community, the project staff developed age-appropriate dental education materials for grades 1–8 and distributed the materials to teachers in Amish schools and to Amish school board members. The materials included eight dental education lesson plans plus teaching aids and tests. The staff also conducted two days of in-school dental screening of students for dental problems.

In the last year of the project, the staff focused on helping Amish leaders build a permanent dental clinic centrally located to serve a large number of Amish families. Before construction of the 40-by-60-foot building began, the staff held multiple planning meetings with the Amish bishops and school board members and helped organize a governing board for the facility.

Challenges

Cultural differences complicated communications between the project staff and the Amish community, the project staff reported to RWJF. The staff had to present project-related information to the bishops before disseminating it to community members—a

process that the staff felt delayed progress. Also, the absence of home telephones made letters and face-to-face discussions necessary. (Although the Amish do not have phones in their homes, some do maintain phones outside—usually in small enclosures at the end of the driveway by the road.)

Fluoride use—a new concept for many Amish—met with some resistance. The project staff implemented the weekly fluoride rinse program in 17 schools involving 684 students. However, eight of the schools dropped out of the program because of parental concern about the safety of fluoride. One of the schools withdrew in response to a single family's refusal to participate. The staff sought to alleviate these concerns by handing out fluoride information materials.

RESULTS

At the project's conclusion, the Indiana Hemophilia and Thrombosis Center reported the following to RWJF:

- The project staff conducted 21 clinic sessions and, as of May 1999, treated a total of 665 patients. Although the number of clinic sessions fell short of the 24 anticipated by the proposal, the number of clinic patients exceeded the project's minimum goal of 480.
- The project staff handed out 300 fluoride testing kits, 275 of which were sent to the state health department for analysis. Of those 275, only six showed an adequate fluoride level. (The initial proposal projected a minimum of 250 families would receive testing services over the project period.)
- The project staff gave out 307 fluoride supplements to families with insufficient fluoride in their well water. The staff also provided 580 tubes of fluoride gel.
- Despite some parents' concerns about fluoride, nine schools involving a total of 379 students continued to participate in the weekly fluoride rinse program.
- The project provided education materials and teaching tools to 17 Amish schools and screened 252 students in 10 schools for dental decay.
- The Amish community built, equipped and began operating its own dental clinic dedicated to providing low-cost care to area children, including non-Amish children. In addition to evaluating and treating dental problems, the staff of the Community Dental Clinic continued the project's fluoride testing program, supplementation effort, and oral health education. The Indiana State Health Department pledged $300,000 to support the clinic for the first three years. (See Afterward for details of the clinic operation, including staffing difficulties.)

Communications

The staff developed a fact sheet on the project and distributed it to Amish bishops, school board members and teachers, and gave copies to students in 25 Amish schools to take home. Early in the project period, the staff made a presentation on the planned activities to 60 Amish community members at a public meeting. In 1999, two local newspapers (the *Goshen News* and *LaGrange Standard*) published articles on the clinic's construction.

LESSONS LEARNED

1. **When working in a different culture, be a good listener.** Also, to avoid misunderstanding, communicate to the other person what it is you think he or she is saying to you. (Project Staff)

2. **When setting up a dental clinic in a rural area, staffing may be the biggest problem.** For the Amish community, putting up the building and attracting customers were easy. Finding a dentist to run the clinic on a permanent basis was not. (Clinic Board Chair Miller)

3. **Involving community members early in a project's development pays off in support for the finished product.** Before obtaining a building permit for the new clinic, Amish leaders held fund-raising suppers to which community members were invited. The purpose, however, was not so much to bring in money as to give out information about the planned facility and get the community involved in the undertaking. (Clinic Board Chair Miller)

AFTERWARD

Difficulty in recruiting and retaining a dentist forced the Community Dental Clinic to shut down periodically after the RWJF grant ended. However, as of January 2004, the clinic was in operation three days a week with Ballard, the dentist, averaging about 160 patients a month. In addition to Ballard, the staff included an office manager, a dental hygienist and two dental assistants, including one from the Amish community. A third dental assistant was to begin work in early 2004.

In addition, once a month, a group of Indiana University dental students under Sanders' direction makes the 190-mile drive from Indianapolis to Shipshewana and spends a day helping at the clinic. A second pediatric dentist from the university, Judith Chin, DDS, is on hand one Saturday every other month to handle specialty cases.

What makes the dentist's position hard to fill, says Sanders, is the clinic's remote location and the relatively low pay compared to a private dental practice. Immediately after its opening in fall 1999, the clinic relied on a part-time dentist until the board hired a South

Bend dentist to fill the position full-time. After about 18 months of four-day weeks, this full-time dentist took maternity leave and did not return, forcing the clinic to close.

In April 2003, Ballard agreed to take the job on a trial basis. She was working for the Marion County Health Department in Indianapolis when Mulherin, a former associate, urged her to consider the open clinic position. However, as a result of injuries suffered in an automobile accident and unrelated surgery to correct a hip problem, Ballard had to take medical leave from June through October 2003, again forcing the clinic to close.

In November, Ballard returned to work three days a week with plans to increase her schedule once she fully recovered from the operation. Both Ballard and Miller, the board chair, expressed optimism that her tenure would be a lasting one. "This is a place where there is a need," Ballard said in an interview.

Shapiro and Sanders share one of the nine seats on the clinic board, and a Mennonite dentist from Fort Wayne occupies another. The remaining seven board members are from the Amish community.

The clinic draws patients from outside as well as inside the immediate Amish community. Some families come from more than 100 miles away, says Miller. The fees are low enough that even with the added expense of a van and driver, a large Amish family can save money by using the clinic instead of a facility closer to home, says Miller. He estimates that in addition to the 18,000 Amish living nearby, the clinic serves outlying areas with another 10,000 Amish residents.

The clinic, however, is open to all children, not just Amish. Ballard says a good number of patients are Hispanic youngsters whose parents work in the region's large mobile home and recreational vehicle industry. The clinic accepts neither private insurance nor Medicaid, but a family with a large number of children or other financial pressure can request a fee reduction. Discounts range from 25 to 50 percent, Miller says.

The clinic someday may also offer adult care, Miller says. However, for now, he says, the goal is to be financially self-sufficient—to bring in just enough fees to cover expenses and put away a small amount for emergencies and not enough to finance expansion. (In April 2004—for the first time—the clinic's income exceeded expenses, according to Miller.)

The big advantage to the Amish of owning and operating their own dental operation is the ability to keep costs down, says Miller. He estimates the clinic's expenses run 40 percent below those of a regular dental office. Lower salaries, a strong work ethic among staff members, and hands-on maintenance by the board members all contribute to that, according to Ballard.

"I would say they do more with less," she says. "We don't have all the fancy bells and whistles. But if you need cabinetry, one of the Amish men comes over and builds it for you."

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