Community Empowerment to Reduce Childhood Immunization Disparities in New York City

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This paper reports on the impact of the community-based Start Right program on childhood immunization coverage in 2 communities of color in New York City. Fully launched in 2002, Start Right operates through the major social service programs of its 23 member organizations. Immunization promotion strategies are based on the following guiding principles: community leadership; integration with community programs; parental empowerment; peer health educators; tracking and feedback; and linkage with health providers. By September 2003, 2,433 children under age 5 years (14% of that age group in the community) were enrolled in Start Right. The rates for the cohort of children enrolled in 2003 were substantially higher than for those enrolled in 2002. Among the 2003 cohort of 19- to 35-month-old children, the coverage rate was 88%, significantly more than national rates: 75% for total population, 68% for African Americans, and 73% for Hispanics. The rate for our 2003 enrollment cohort exceeded the rate for New York City (78%) but did not exceed the New York City average for Hispanics (79%). Of the 2003 enrollment cohort, the Washington Heights children had the highest rates for enrollment (89.6%), exceeding New York City rates. Parents reported a high level of satisfaction with the program. (*Ethn Dis.* 2004;14[suppl 1]:S1-135–S1-142)

Key Words: Immunization, Community-Based Programs

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Introduction

Despite tremendous progress in childhood immunization coverage nationwide, communities of color continue to have coverage rates 5%–15% below the national average.[1–3] These racial and ethnic disparities are multifactorial in origin. In these are communities, insurance rates lag behind the rest of the nation, families juggle competing and essential priorities, families frequently change doctors and healthcare plans, language and cultural differences reduce the opportunities for communication with health providers, and discrimination and stereotyping result in a lower quality of care.[4] Therefore, increasing immunization rates for members in communities of color requires a multifaceted strategy that empowers families to smooth the pathway for routine immunizations.

Because racial and ethnic immunization disparities are specific to a community, a community-based solution is required. Our approach is to embed the immunization promotion activities within the community in such a way that they are available and supportive to the families throughout the child's first 2 years of life when most immunizations are due. Based partly on our own experience and partly on best practices in other communities, we have adopted the following guiding principles for our strategies: community leadership, integration with community social service programs, parental empowerment, peer health educators, tracking with multiple reinforcers and feedback, and linkage with community healthcare providers. First, our effort to increase immunization coverage was community-led, that is, designed, implemented, and directed by a coalition of community organizations.[5–9] Second, rather than creating a separate immunization program, we integrated immunization promotion activities into ongoing programs at community organizations, such as immunization education through WIC or Head Start.[10–16] Third, we sought to empower parents as active partners in keeping their children immunized and healthy.[17] Parents who know the diseases vaccines prevent, how vaccines prevent disease, and when their children are due for vaccines are more likely to adhere to immunization schedules.[12,18–23] Fourth, we trained a corps of peer health educators to provide the key immunization promotion activities in the community. Peer health promoters are not only vital to ensuring that immunization information is culturally and linguistically appropriate, but they also can help the family navigate the healthcare system.[6,24–29] Fifth, we incorporated opportunities for multiple contacts and feedback to both community organizations and parents. Promotion of immunizations is a repetitive, ongoing activity, and requires tracking, personalized reminders, and positive feedback to parents.[3,13,25,30–32] Finally, we worked in close partnership with community healthcare providers. While parents can be more proactive in requesting vaccinations, it is important for the providers to be more thorough in checking vaccination status at every visit and giving all recommended doses at that time.[33–36]

Northern Manhattan in New York City is a community where immunization rates have lagged 11% behind the

city and 19% below the nation.[37] Starting in the 1990s after the measles epidemic, we began developing our community-based approach to reducing immunization disparities, using the principles outlined above. In 1999, community organizations, healthcare providers, and the New York City Department of Health joined together to form the Northern Manhattan Start Right Coalition, and in 2000 we began piloting our strategies. This paper reports on the impact of our immunization promotion strategies on childhood immunization rates in this community.

METHODS

Study Setting

Northern Manhattan includes the communities of Harlem and Washington Heights, among the most disadvantaged communities in the city and nation. Almost two thirds of the community's families have incomes below 200% of the federal poverty line and 32% receive some form of income supplement.[38] In 2000, the population was 421,820, almost entirely a community of color, comprising Latinos (52%) and African Americans (38%). Harlem is predominantly African-American (77%), while Washington Heights is predominantly Latino (74%). Two out of 5 residents (40%) were born outside the United States, with the largest group coming from the Dominican Republic, but also from West Africa and other Latin American countries.[38,39] These communities have a very rich cultural heritage and are well-networked, with a variety of community organizations. Some of the city's largest multi-service organizations are based in northern Manhattan and have become leaders in developing innovative strategies for promoting health insurance, housing and community advocacy, community-based schools, and women's health initiatives. All the major, and several more specialized, community organizations are members of the Start Right coalition.

The Intervention

The Start Right program is a community-based, immunization promotion program of outreach and tracking for children under age 5 in northern Manhattan. Start Right operates through the major social service and community education programs of the member organizations of the Start Right coalition. The lead members are the Mailman School of Public Health (Columbia University), Alianza Dominicana, Inc., and Harlem Congregations for Community Improvement. The coalition encompasses major providers for Head Start and family day care, as well as parenting and case management programs. Two members are major multi-service and community advocacy organizations, 2 specialize in housing advocacy and one is a coalition of faith-based organizations. Our integrated program was piloted in 2000–2001, and finalized and launched in 2002. This study was approved by the Columbia University Medical Center Institutional Review Board (#9815).

The cornerstone of the Start Right intervention is integration of the immunization promotion activities into the ongoing social service programs of each organization. Coalition members can choose to integrate Start Right activities into one or more of their social service programs. Across all organizations, Start Right parents are recruited from 32 different programs. The most common programs referring parents to Start Right are: facilitated enrollment for health insurance (27% of children enrolled), WIC (33%), parenting classes or mentoring programs (18%), Child Care/Head Start, including family day care provider networks (9%), housing/tenant advocacy programs (5%), recruitment at welfare program offices (3%), and pediatrician's offices (4%).

The coalition developed a 5-part bilingual training program for staff from each organization. The curriculum includes Principles of Immunization (Immunization 101), Immunization Card Reading and Assessment of Immunization Status, Immunization Education for Parents; and Steps for Implementing and Tracking the Start Right Program. Between September 2000 and September 2003, 721 staff participated in one or more training sessions, with 57% participating in at least 3 sessions. Card reading is critical to the accurate implementation of the intervention, and the average post-test card reading accuracy after the card-reading session was 85% (N=126), which is at the upper end of the accuracy from a previous study of card reading by WIC personnel.[40] Between 4 and 73 staff at each organization have been trained, including virtually all staff involved in the primary programs implementing Start Right. At any given time, 70 individuals actively implement the Start Right intervention, and most (86%) are reading cards.

Recruitment for the program is entirely community-based. Parents participating in a variety of programs at coalition organizations are invited to participate in Start Right if they have a child under 5. For example, one outreach worker adds immunization promotion work to a parenting program for families in a nearby city housing project. She goes door-to-door and talks with families about getting immunizations on time, applying for child health insurance, finding a good doctor, and whatever parenting issues they have. In addition to her own program, she makes referrals to other programs offered by her organization, a large multi-service agency. Half (50%) of the parents are recruited through such personalized, one-on-one conversations with organizational staff, and the remainder through group outreach or workshops. Parents who choose to participate, sign informed consent forms and are enrolled into Start Right. Between January 2002 and September 2003, 2,433 children were enrolled into Start Right,

14% of the eligible children in the community.

The Start Right intervention involves a series of educational and counseling sessions, reminders, and feedback with enrolled parents. All parents receive a bilingual informational package developed by the coalition members. In addition to these written materials, the Start Right outreach workers provide educational sessions for parents, either one-on-one or in groups. At the time the child is enrolled, the child's immunization card is explained to the parent and she/he is given a Start Right reminder "When the Next Shots are Due." The Start Right outreach worker writes, calls, or speaks with the parent within 10 days of the due date for the next immunization(s), and again after the appointment to verify that the parent was able to get the child's immunizations. The reminder cycle is repeated until all immunizations are completed. Parents receive a congratulations and a "milestone" gift when their child completes the entire set of immunizations required for admission to the New York City schools. Each organization maintains records for the families they enroll and is responsible for follow-up reminders and card reading. Children leave the program at age 5 or when they have completed all immunizations required by age 4.

During a two-year period, increased delivery of the intervention activities was found. In 2002, the coalition staff provided each enrolled parent with an average of 3.6 educational sessions (1.9 one-on-one and 1.7 group) and 2.4 follow-up reminder calls, letters, or visits. In 2003, the parent educational sessions had increased to 6.6 per enrolled parent (3.0 one-on-one and 3.7 group), while follow-up reminders had increased to 3.0 per parent.

Through the linkage with community healthcare providers, we reinforced the relationship between the family and the child's medical home. The parent empowerment sessions train parents in communicating with their child's healthcare provider. If needed, we assist families with health insurance enrollment or finding a healthcare provider. Coalition members also recruit parents at healthcare providers' offices throughout the community. Finally, the coalition also works through the healthcare providers to track immunizations.

Statistics

The primary outcome measure for the Start Right intervention is up-to-date immunization status for the 4:3:1:3:3 series (4 diphtheria-tetanus-[acellular] pertussis [DTP/DTaP], 3 polio, 1 measles–mumps-rubella [MMR], 3 *Haemophilus influenza* b [Hib], and 3 Hepatitis B [HepB], as recommended by the Advisory Committee on Immunization Practices[1]). Coverage rates are reported for children as of September 30, 2003. The Start Right coalition promotes the varicella and pneumococcal vaccines, but because these are not normally included in the national immunization coverage assessments, they are not assessed in this report.

Because of the problem of record scatter,[41–43] we use 3 complementary data sources to track immunizations of each enrolled child: the parents' hand-held record, the New York Presbyterian Hospital immunization registry, and the New York City Department of Health Citywide Immunization Registry. For this report, we updated the database sequentially using immunizations reported to the hospital immunization registry as of September 30, 2003, additional immunizations reported to the Citywide Immunization Registry by that date, and finally additional immunizations reported for children not in the registry from the parents' hand-held cards, as read by the trained Start Right outreach workers as of September 30, 2003.

We compared the 4:3:1:3:3 immunization rates for children using all 3 sources with the National Immunization Survey 2002 coverage rates reported for the nation and New York City by racial and ethnic group (White non-Hispanic, African-American, and Hispanic).[1] This comparison is restricted to 19- to 35-month-old children. Comparisons were made for all Start Right children, and by community of residence: Harlem (predominantly African Americans) and Washington Heights (predominantly Latino) based on the ZIP code groupings for each community's catchment area. We repeated the same comparison using the 2002 New York City kindergarten enrollment survey from the northern Manhattan ZIP codes, which provides retrospective 4:3:1 immunization coverage rates, this time using comparable data for the Start Right children (4:3:1 for children 18 to 23 months of age). We assessed statistical differences by determining if the intervention's immunization rate fell outside the 95% confidence interval of the comparison group's rates and *t* tests.

In addition to the quantitative assessments, we also report on the satisfaction of the parents enrolled in the program. These comments were obtained using 2 sets of interview instruments. A sample of parents in 2002 provided feedback to the coalition using a Parent Feedback form completed 3 months after enrollment (N=82). An additional 14 parents participated in in-depth interviews in 2002–2003. We use comments from these parents to illustrate the significance of the intervention from the parents' perspectives.

RESULTS

From January 2002 through September 2003, 2,433 children were enrolled into Start Right. One-third of the children enrolled were under age 12 months at enrollment, another 15% were 12 to 18 months of age, 26% were 19 to 35 months of age, and 24% were 36 months or older. Of the children older than 18 months, 44.6% were current with the 4:3:1:3:3 immunization series at enrollment.

Table 1. Immunization coverage rates (4:3:1:3:3) for Start Right participants by enrollment year

Age (as of 09/30/2003)	Enrolled 2002		Enrolled 2003		Enrolled 2002–2003	
	N	% UTD	*N*	% UTD	*N*	% UTD
Under 12 Months	41	85.4%	217	94.9	258	93.4%
12–18 Months	229	56.8%	102	89.5%	331	66.9%
19–23 Months	164	67.7%	108	87.2%	272	75.4%
24–35 Months	381	61.7%	158	88.0%	539	69.4%
Subtotal 19–35 months	*545*	*63.5%*	*266*	*87.7%*	*811*	*71.4%*
36–59 Months	516	81.8%	244	83.6%	760	82.4%
60+ Months	243	77.8%	30	63.3%	273	76.2%
Subtotal >18 months	*1304*	*73.5%*	*540*	*84.4%*	*1844*	*76.6%*
Total	1574	71.3%	859	87.8%	2433	77.1%

As shown in Table 1, at the follow-up date of September 30, 2003, 71% of the cohort enrolled in 2002 were up-to-date compared to 88% of the cohort enrolled in 2003. Among children older than 18 months at follow-up, 76.6% were up-to-date, a 32% increase in the rates for these children at enrollment (see Figure 1). Children older than 18 months at follow-up, who were enrolled in 2002, had the largest absolute gains in their immunization rates, from 32% at enrollment to 74% at follow-up, but the children enrolled in 2003 had higher rates at follow-up than the 2002 cohort (84%, up from 58% at enrollment).

Among children older than 18 months of age, the age group of 19- to 23-month-olds is of particular interest because their immunization rates can be compared to those obtained through the citywide school enrollment survey. Of the children living in northern Manhattan who entered kindergarten in New York City public schools, 65.3% ± 3.4% were up-to-date at age 24 months (4:3:1 series, not including Hib or HepB) (V. Papadouka, personal communication, 1/12/2004, New York City Bureau of Immunizations, Department of Health and Mental Hygiene). The comparable 4:3:1 immunization coverage rate for 19- to 23-month-old Start Right children was 85.9% ± 4.0%, significantly surpassing the rate observed for northern Manhattan children ($t=-18.7$, $P<.001$).

Fig 1. Immunization coverage rates at enrollment and follow-up by enrollment cohort (children older than 18 months of age at follow-up)

The immunization coverage rates of Start Right participants were next compared to the national and city averages.[1] Among children 19 to 35 months of age enrolled in Start Right, there was a large increase in the coverage rates for the cohort of children enrolled in 2003, compared to those initially enrolled (see Figure 2). Among the 2003 cohort of 19- to 35-month-olds, the coverage rate was 88%, significantly more than the average for the total US population (74.8% ± 1.0), White non-Hispanics (77.7% ± 1.2), African-American (67.7% ± 3.1), or Hispanics (72.7% ± 2.4). The rate for the 2003 enrollment cohort rate also exceeded the rate for New York City (78.1% ± 6.2) but did not exceed the New York City average for Whites (84.9% ± 9.5%) or Hispanics (79.0% ± 8.9). Both Harlem and Washington Heights significantly increased immunization coverage for the 2003 enrollment cohort with rates of 79.5% and 89.6%, respectively. These rates fell above the 95% confidence intervals for the national averages for total, White non-Hispanic, African-American, and Hispanic populations, but only Washington Heights' rates significantly exceeded the New York City rates, including the rate for White non-Hispanics.

Parents reported a high level of satisfaction with the program. Of the 82

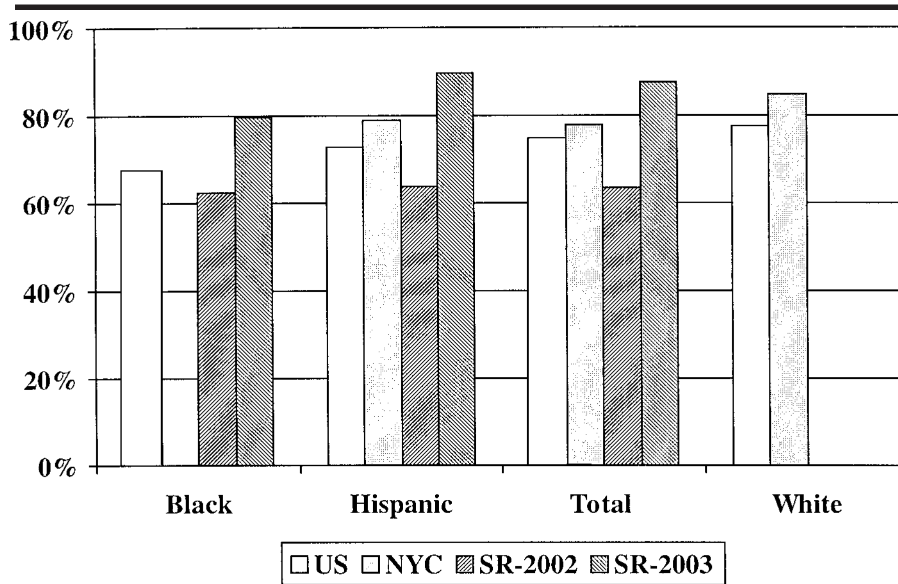

Fig 2. Comparison of 4:3:1:3:3 immunization coverage rates for Start Right participants versus US and New York City children (children aged 19 to 35 months). Note: US and NYC data from the 2002 National Immunization Survey. For Start Right, Black rates are represented by the rates for Harlem, while Hispanic rates are those for Washington Heights

parents who gave written feedback to the program, virtually all were enthusiastic about the program. Among the things they liked most were the personalized explanation from the Start Right coalition staff about why their children need immunizations and when to get the immunizations (cited by 51%). Many parents (24%) appreciated being able to read their child's vaccination card.

The following comments are typical of what parents said they liked most about the program:

> I got the card read and know what my baby needs.

> She made me understand my child's immunization card . . . I never knew what the different shots prevented and was happy to learn about the diseases they prevent.

> I like the information we got about the diseases you get when the children don't get vaccinated . . . Before I did not know what the shots prevented and when to get them.

> I learned how to inquire about the immunizations my baby should get. Now I know what shots the baby needs. . . . It helped me by giving me information on places to go for immunizations, and also handing out lots of materials on immunizations. . . . Some people are not aware of how important it is to keep your child's immunizations up to date.

> The program made me more aware about my children's immunizations, and how important it is to have them done on time.

> The program helped me get my child immunized because she kept getting on me about keeping my appointments . . . Short of taking my child to get her shots, I don't feel that they could have done much more.

DISCUSSION

Although the program is only 2 years since being fully launched, our community-based Start Right program in New York City is already showing promising results in reducing disparities in childhood immunizations. To date, we have enrolled almost 2500 families, one-fourth of the targeted families in the community. At our 2-year follow-up, we have closed the gap between the community and national immunization rates. Moreover, we have surpassed the immunization rates for both African Americans and Hispanics nationwide. Of particular note, we were able to achieve remarkable progress in Harlem, the African-American community, where the Start Right children's immunization rates not only surpassed the national average for African Americans but were up to the national average for all children.

The children enrolled in the program more recently had higher immunization coverage rates at follow-up than those enrolled when the program was newly launched. Part of the difference may be the lower rates for the initial group. As shown in Figure 1, more children were behind in their immunizations. The intervention helped to double the immunization rates in this cohort, but their immunization rates at follow-up still lagged behind the more recently enrolled cohort. What accounts for this difference in rates at follow-up? As described above, the Start Right staff became more creative and adept at reminding parents and tracking immunizations. Among the many changes, we developed score cards that highlighted children who needed "just one more" to be up to date, so that coalition members could prioritize follow-ups and make sure to contact families with children on the verge of becoming fully immunized. Groups developed a variety of additional follow-up strategies. The resulting additional push to follow-up increased the intervention intensity. It is likely that this increased intervention intensity was more pronounced for those enrolled in 2003, which resulted in additional gains in immunization coverage for this group. While the 19- to 35-month-olds enrolled in 2002 were still 10% below the national average, the same age group of children enrolled in 2003 attained a coverage rate of 88%, 13% above the national average for all racial and ethnic

groups and almost 10% above the New York City average. For this cohort, Washington Heights had surpassed the rates for all ethnic groups in the city and nation.

Several factors have contributed to our positive outcomes. We believe the most critical factor is the ownership of the immunization promotion effort by the community. The Start Right Coalition was conceived, planned, and implemented through a coalition of 23 member organizations. Community groups use their own creativity to integrate the Start Right strategies into their organizational programming. When something works for one group, others are quick to try it. For example, one group started using a booklet of pictures of children suffering from the vaccine-preventable diseases, and this was so effective at explaining to parents the reason why vaccinations are important that the coalition has now developed its own bilingual flyer with these disease images. Over the past 2 years, several members have introduced creative strategies for recruiting parents, reminding parents, and bringing them back in for card readings and congratulations.

Second, the immunization promotion is fully embedded into each organization. There are several immunization "champions" at each organization, and literally dozens of staff who have developed immunization competencies. In any of several programs at a community organization, a parent with young children can learn about immunizations and participate in the Start Right program. This is particularly important for reaching parents who may not go to a doctor regularly. Instead of waiting for an infrequent reminder from the children's doctor, parents can be reached directly, easily, and regularly through one of the programs in which they participate. Because the immunization intervention is offered as an "add-on" to several different types of community social service programs, Start Right has multiple points of entry and the coalition can cast a very wide net.

Third, we have taken immunization competencies out of the doctor's office and into the community. The feedback we received indicates that the training in card reading is immensely empowering to both community organization staff and parents. This has de-mystified and de-institutionalized the immunization process, emboldening parents to talk about immunizations with their healthcare providers and to know when and what shots their children need. This appears to be contributing to a change in the "immunization culture." The conversation has shifted from a "you need" to a "we want" basis.

Fourth, the central actors in the coalition are peers, community residents who advocate for immunizations among their family and neighbors. Whether as paid staff or volunteers, these women share a common cultural heritage and common situation with the families they enroll. They know well the difficulties of getting insurance, appointments, and of dealing with the "system," and they are eager to share their experience through counsel, referrals, and assistance. Members of the coalition can and do refer parents to each other for health insurance, WIC, English language courses, or other programs.

Fifth, the coalition relies on proven strategies of reminders, tracking, and positive feedback to parents.[13] The tracking is done through a dual system, both through the personal interaction between the Start Right staff and the parent and through healthcare provider sources. This reduces the problem of record scatter and strengthens our ability to fully track immunization. As a result, this minimizes the errors in providing reminders and expedites timely feedback to the parents. The coalition congratulates parents when their children have completed immunization milestones. Parents have told us that they appreciate not only understanding immunizations but also being recognized for doing something well.

This study has several limitations. The evaluation presented relies on comparisons of the immunization rates for children enrolled to aggregate immunization rates for comparable groups. This is subject to the usual limitations of ecological comparisons, namely that we did not control for other factors operating in the community that could affect these comparisons. While we are highlighting the ethnic distinctions between Harlem and Washington Heights for this comparison, this hides the racial diversity of both communities. Of particular note, we have not controlled for changes in the healthcare system, such as health insurance and the shift to Medicaid managed care throughout our community in 2003. We also did not control for various disruptions to the vaccine supply in 2001–2002, which adversely affected children's access to vaccines. Although a strength is that we rely on 3 sources of data for immunization, each data source has its own limitations. The healthcare provider sources, namely the 2 immunization registries, are subject to delays and incomplete reporting.

As we look to the future, there are several aspects of the Start Right intervention that we will work to improve. First, we want to obtain additional feedback from the parents regarding the specific components of Start Right that made the most difference, and then use this information to further tailor the intervention to enhance sustainability. Second, we want to further strengthen the partnership with healthcare providers and Start Right through additional sharing of information about the status of children enrolled in the program, shared reminders, and cross-referrals of children behind in their immunizations. Third, we want to continue to improve the reliability of our tracking systems, both the use of the children's vaccination cards and the immunization registries. Fourth, we want to use the full power of the immunization tracking system to evaluate the intervention on an individual basis, comparing northern

Manhattan children enrolled in Start Right to children not enrolled in Start Right. This evaluation also will include controls for the intensity of the intervention. Fifth, with controls for enrollment in Start Right, we want to assess the long-term impact of the coalition's intervention on the community's immunization rates.

In conclusion, our immunization strategy, which is deeply embedded in the community and integrated with the routine social service activities of many community groups, has quickly made great progress in reducing racial and ethnic disparities in immunization coverage. It is likely that the basic elements of our model, namely community empowerment for health promotion and integration of health promotion into community social service and education programs, can be applied to other community-based efforts to narrow racial and ethnic health disparities.

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