



FAMILY SURVEY OF SERVICES PROVIDED THROUGH THE HIGH RISK INFANT FOLLOW-UP (HRIF) PROGRAM

February 2016

**Nicholas DeSuno, MPH
Jane Fornoff, D. Phil
Adverse Pregnancy Outcomes Reporting System**

PURPOSE

The Adverse Pregnancy Outcomes Reporting System (APORS) collects information on Illinois infants born with birth defects or other abnormal conditions. The purpose of APORS is to conduct surveillance on birth defects, to guide public health policy in the reduction of adverse pregnancy outcomes, and to identify children who require special services in order to correct and prevent developmental problems and other disabling conditions. Families of infants reported to APORS are eligible for follow-up services through the Illinois Department of Human Services' High Risk Infant Follow-up (HRIF) program. Community health agency nurses contact the families to offer case-management services, including a series of home visits and assistance with any identified needs. A family is eligible to receive six visits during an infant's first two years of life. The community health nurse conducts physical and developmental assessments, provides information and makes referrals for additional services.

It is important to determine whether the services provided to APORS families are of value to them. The HRIF contract with community health agencies therefore requires a survey be administered to a random sample of families to assess their views on the services provided. Respondents were asked to indicate their degree of satisfaction with follow-up services and the age of their infants participating in the program. The results are used to provide community health agencies specific feedback to improve the quality of follow-up services.

METHODS

The 84 community health agencies that provided HRIF services in 2015 were required to participate in the family survey. The surveys were provided to families either at first contact (whether or not they accepted services) or at a subsequent visit, if the family had already accepted services. A survey was offered if an APORS-eligible family was seen in their home, or if the family came into the health agency, and was available in English, Spanish, Arabic, Burmese, Chinese, French, and Vietnamese. Surveys were distributed in November 2015. Each parent was given the opportunity to fill out the form during the face-to-face contact or to complete it afterward. Postage-paid envelopes were provided for respondents to keep the survey responses confidential and to facilitate the surveys' return.

RESULTS

Community Health Agencies Reporting Rates. Eighty-three community health agencies participated in the survey. One agency forgot to distribute the survey. A total of 797 surveys were distributed using forms provided by the APORS Program. Of these, 604 surveys were returned by families participating in the program for a response rate of 75.8 percent. The survey

questions assessing the satisfaction with the services are listed in Table 1, together with the responses.

Table 1: Responses to Survey Questions Assessing Satisfaction with Services

	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Not answered
1. The nurse explained the services my baby or I might receive	594 (98.3%)	8 (1.3%)	0 (0%)	1 (0.2%)	1 (0.2%)
2. I found the visit helpful	561 (92.9%)	40 (6.6%)	1 (0.2%)	0 (0%)	2 (0.3%)
3. The visit made me feel less worried	549 (90.9%)	45 (7.4%)	3 (0.5%)	4 (0.7%)	3 (0.5%)
4. The nurse helped me understand my baby's health concern	574 (95.0%)	21 (3.6%)	2 (0.3%)	2 (0.3%)	5 (0.8%)
5. I need the services	499 (83.0%)	70 (11.6%)	19 (3.2%)	13 (2.2%)	3 (0.5%)
6. I feel comfortable contacting the nurse if I have more questions	596 (98.6%)	6 (1.0%)	1 (0.2%)	1 (0.2%)	0 (0%)

Parents were also asked how old their babies were; 40.7 percent were under 6 months old, 20.4 percent were between 6 months and a year; and 34.8 percent were over a year old. 4.1 percent of the surveys returned did not provide the age of their child.

Ninety (14.9 percent) of the respondents provided comments. Their responses were overwhelmingly positive, with a few negative comments regarding the follow-up program.

Some examples are listed on the next page:

“It's nice to know there is an extra pair of eyes watching my baby. [Nurse] is very knowledgeable.”

*“Nurse took the time to explain everything. In the hospital, everybody was too busy!”
“Program is well executed.”*

“This program has been very helpful especially having a nurse come out to my home to see my son. As a first time mom, it has been so helpful, answering all my questions. [Nurse] is so knowledgeable and answers all my questions. It is also very convenient that she is able to come out to my home to see [baby]. I really appreciate this program. It is extremely helpful!! Please keep funding this program for the families that need it. Thank you so much for this program. I am very thankful for it.”

“...I had a baby with the same problem. So, I did not need the service because I could just go to the infant's doctor.”

“[Nurse] has been nothing short of wonderful and helpful. It has been a relief to have her help out with my son's development and making sure he is on track.”

“I really like it. She helped a lot. She gave me a lot of information.”

DISCUSSION

Eighty-three community health agencies participated in the surveys. Fourteen agencies did not distribute any APORS surveys because no APORS eligible families were seen during the survey timeframe. One agency failed to distribute the survey. Fifty-five (79.7 percent) of the remaining 69 agencies had families that responded to the survey. There was no significant variation in responses by the child's age. The majority of responses were very positive; opinions of the APORS program ranged from “excellent, glad it is there for families” to “very good services for

families.” There was a slight decrease in the proportion of families who responded to the surveys from 78.9 percent in 2014 to 76.3 percent in 2015.

In 2014, there were 124 families (17.6 percent) who indicated that they disagreed or somewhat disagreed with the statement “I do not need the services”. In the 2014 survey, the statement “I do not need the services” had appeared to lead to confusion, and so, was changed for the 2015 survey to “I need the services”. For some, this may have been their introduction to the program and the services offered, and they did not need the support. Others may have needed the services when they were first offered, but are now able to manage their children’s conditions without support. This year, only 5.3 percent (32 families), indicated that they did not need services. The vast majority of families (94.7 percent) reported that they did need the services.

The APORS program will partner with these community health agencies again next year, again asking APORS eligible families to participate in the family survey. To ensure all agencies fully participate in the survey process, APORS will recommend to the Department of Human Services HRIF program coordinator that language is included in the FY16 provider contract that specifically addresses family surveys. The APORS and HRIF partner programs are clearly appreciated and valued by the families they serve. Together they will seek to further improve the effectiveness and efficiency of the programs.