



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

September 2018

**Theresa Sandidge, M.A.
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.

In order to determine whether the services provided to APORS families are of value to them, a survey was administered to a random sample of families to assess their views regarding the HRIF program. 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 82 community health agencies that provided HRIF services in 2018 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. The survey, available in English, Spanish, Arabic, Burmese, Chinese, French, and Vietnamese, was offered if an APORS-eligible family was seen in their home, or if the family came into the health agency. Surveys were distributed in May 2018. 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

Of the 82 agencies eligible to participate in the survey, 13 did not distribute it because they did not see families during the month of May. Among the sixty-nine agencies that participated, sixty-three (91.3%) had families respond. Altogether, 978 surveys were distributed and 723 were returned to APORS for processing. Fifteen surveys were excluded due to protocol not being followed, which left a total of 708 surveys returned by families for an overall response rate

of 72.4 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	694 (98.0%)	11 (1.6%)	1 (0.1%)	2 (0.3%)	0 (0.0%)
2. I found the visit helpful	657 (92.8%)	45 (6.4%)	2 (0.3%)	1 (0.1%)	3 (0.4%)
3. The visit made me feel less worried	614 (86.7%)	81 (11.4%)	7 (1.0%)	3 (0.4%)	3 (0.4%)
4. The nurse helped me understand my baby's health concern	668 (94.4%)	35 (4.9%)	1 (0.1%)	2 (0.3%)	2 (0.3%)
5. I need the services	536 (75.7%)	138 (19.5%)	19 (2.7%)	14 (2.0%)	1 (0.1%)
6. I feel comfortable contacting the nurse if I have more questions	687 (97.0%)	17 (2.4%)	2 (0.3%)	1 (0.1%)	1 (0.1%)

Parents were also asked how old their babies were; 39.5 percent were under six months old, 23.3 percent were between six months and a year, and 34.0 percent were over a year old. The age of the baby was not provided on 3.1 percent of the surveys.

Ninety-seven (13.7%) of the respondents provided comments. Their remarks were positive, with just a couple of unfavorable statements regarding the follow-up program. Some examples follow:

“I find the program and the nurse very helpful and informative.”

“My family is very appreciative of the visits and health education we receive from the nurse. Thank you!”

“(Nurse) was very helpful in answering all my questions and concerns and spent extra time to make me feel comfortable.”

“This is such a great service for babies that come home from the hospital with health issues. Great reassurance. Thank you!”

“Thanks for being there.”

DISCUSSION

Overwhelmingly, the responses to the survey questions were very favorable regarding the helpfulness of and need for services provided by the HRIF program. APORS did not find significant variation in type of response by the child’s age. Families agreed the visit was helpful (92.8%), the nurses explained the services they might receive (98.0%), and nurses helped the family understand the baby’s health concern (94.4%). Most families agreed they felt comfortable contacting the nurse if they had any questions (97.0%). Families also agreed (86.7%) or somewhat agreed (11.4%) that the visit made them feel less worried. Few families disagreed (4.5%) with the statement that they needed services.

Nearly all written comments provided by survey participants were positive, appreciating the services provided and the knowledgeable, dedicated and professional nursing staff.

For the second year, the family survey was administered in the spring rather than in the fall. The response rate has remained satisfactory, with fewer health agencies not participating for lack of seeing families during the survey month (13 agencies in 2018 versus 16 in 2017). Response rates and agency participation will be evaluated annually, as the survey continues to be offered in the spring.

The APORS program plans to partner with community health agencies in the future, asking APORS eligible families to participate in the family survey. To ensure all agencies fully participate in the survey process using established protocols, APORS will take two actions. First, APORS will recommend that the Department of Human Services HRIF program retain language addressing family survey participation in contracts with providers. Secondly, APORS will host an educational webinar for community health agencies to review protocols for survey administration.

