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

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### **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**

Eighty community health agencies that provided HRIF services were asked 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 multiple languages including 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 2019. 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 80 agencies eligible to participate, 64 sent out surveys. Twelve agencies did not distribute the survey because they did not see families during the month of May and four didn't participate due to staffing or other issues at the agency. Among the 64 agencies that participated, 51 (79.6%) had families respond. The overall survey response rate was 84.8% (823 surveys distributed and 698 returned). One participating agency was excluded from the response rate

calculation, as two surveys were returned to the health department but there was no record of how many surveys had been distributed. The survey questions assessing the satisfaction with the services are listed in Table 1, along with the responses from all returned surveys.

**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	683 (97.6%)	14 (2.0%)	1 (0.1%)	1 (0.1%)	1 (0.1%)
2. I found the visit helpful	659 (94.1%)	37 (5.3%)	1 (0.1%)	0 (0.0%)	3 (0.4%)
3. The visit made me feel less worried	633 (90.4%)	54 (7.7%)	3 (0.4%)	8 (1.1%)	2 (0.3%)
4. The nurse helped me understand my baby's health concern	672 (96.0%)	23 (3.3%)	2 (0.3%)	1 (0.1%)	2 (0.3%)
5. I need the services	544 (77.7%)	119 (17.0%)	13 (1.9%)	20 (2.9%)	4 (0.6%)
6. I feel comfortable contacting the nurse if I have more questions	679 (97.0%)	16 (2.3%)	0 (0.0%)	1 (0.1%)	4 (0.6%)

Parents were also asked how old their babies were; 33.1% were under six months old, 24.7% were between six months and a year, and 39.3% were over a year old. The age of the baby was not provided on 2.9% of the surveys.

Eighty-seven (12.4%) of the respondents provided comments, and all of the remarks were positive. Some examples follow:

*“Nurse kept all appointments and assisted me in getting connected to several services programs...”(The Nurse) is awesome. We enjoy having her come into our house. I always feel more at ease after talking with her. This is our first baby and it is tough with her being a preemie.”*

*“It’s a great program. I learned a lot and it helped me keep my son on track with everything he’s supposed to do for his age.”*

*“Everything was fantastic; Nurse helped me a lot.”*

*”Very helpful and informative.”*

## **DISCUSSION**

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 (94.1%), the nurses explained the services they might receive (96.0%), and nurses helped the family understand the baby’s health concern (96.0%). Most families agreed they felt comfortable contacting the nurse if they had any questions (97.0%). Families also agreed (90.4%) or somewhat agreed (7.7%) that the visit made them feel less worried. Few families disagreed (2.9%) with the statement that they needed services. Additionally, all written comments submitted by survey participants were

positive, appreciating the services provided as well as the knowledgeable, dedicated and professional nursing staff.

Although health agencies were not required by contract to take part in the survey in 2019, APORS encouraged participation as one means of documenting performance. One month prior to the start of survey activities, APORS held an educational webinar for local health agencies to review purpose, protocol, and the timeline of activities for the survey. Forty-three agencies participated in the live session, and the webinar recording was made available online for those who could not attend. In the end, agency participation and survey response rates remained stable and comparable to previous survey years.

The APORS program plans to continue with assessments of family satisfaction and need in the future, enlisting community health agencies as partners. Acquiring participant feedback as services evolve will remain a critical component of shaping program development in the future.

