

FOLLOW-UP SERVICES PROVIDED TO CHILDREN WITH ADVERSE PREGNANCY OUTCOMES

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PURPOSE

The Adverse Pregnancy Outcome Reporting System (APORS) is the Illinois Department of Public Health's registry of birth defects and other adverse pregnancy outcomes¹. Illinois hospitals are mandated to provide information about children born with one or more conditions that meet the APORS case definition. Children reported to APORS are referred for follow up to the Illinois Department of Human Services' (IDHS) High Risk Infant Follow-up Program. The goals of follow-up services are to promote optimal growth and development, teach the family care of the high risk infant, prevent complications, decrease morbidity and mortality, decrease stress and potential for abuse, and ensure early identification and referral for further treatment and evaluation.

¹ The APORS case definition includes neonatal deaths; most structural birth defects; a serious congenital infection; an endocrine, metabolic or immune disorder; a blood disorder; birth weight less than 1,500 grams; diagnosis of a positive infant toxicology for any drug, or signs of drug toxicity or withdrawal; or certain other conditions, such as intrauterine growth retardation.

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When a child's parents consent, follow-up services are provided by public health nurses at local health departments. These services can be provided for two years and are prescribed in regulation (Section 640.100(b) of the Regionalized Perinatal Health Care Code (77 Ill. Adm. Code 640.)) The High Risk Infant Follow-up Program is a component of Family Case Management and relates to many other IDHS programs, including the Special Supplemental Nutrition Program for Women, Infants and Children (WIC), Primary Care, and the Early Intervention Program. Referrals to these and other programs are made, by public health nurses, depending on the needs of the family.

This report evaluates the timing and type of follow-up services provided to children referred by APORS. It also identifies certain areas that could be improved to allow better evaluation in the future.

METHODS

Two sets of data were selected for matching, one from APORS and the other from IDHS' case-management software (Cornerstone). In each case, the children included were born in 2002 or 2003. The APORS data included every child who might benefit from follow-up services reported to APORS by a hospital. (This condition excluded those who were reported as having died before discharge and those whose only reason for inclusion in APORS was a stay in a neonatal intensive care unit.) There were 16,583 children who were referred for follow-up over

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the two study years. The High Risk Infant Follow-up Program data contains all the case follow-up and case management reports entered by the responsible local health departments. It should be remembered that Cornerstone was designed as a service delivery system rather than a surveillance system. With this report, we are therefore trying to do more with the system than was originally intended and this impacts the results of this study. However, evaluation is an important component of program management and so it is important to examine the collected data as much as possible.

The matching was performed by IDHS staff and matched records were provided to APORS. Information about a child is only entered into Cornerstone if the parent or guardian signs a consent form. Thus children may not have been matched to the APORS data base because

1. the matching algorithm did not successful identify a pair of records that should have been matched, or
2. the child's family were not contacted and offered services, or
3. the child's family refused services.

However, 12,515 children (of the 16,583 referred for follow-up) were found in Cornerstone. The matching rate was 75.5 percent.

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Four large local health departments provided information about why children did not receive home visits. Each records this information in a different way, so it is difficult to quantify the results. However, the major reasons given were that:

- the local health department could not locate the child;
- the family had moved or the child was transferred to a different local health department;
- the problem had resolved and the infant was doing well;
- the family already had adequate follow-up;
- nursing visits were not needed.

A small number of children (204) died after discharge, but during their first year of life. More than half the children who died (60.7 percent) were in Cornerstone.

RESULTS

Children receiving at least one visit

Most of the APORS children (60.9 percent) were known to have received at least one visit.

Children who were in Cornerstone, but had no recorded visits (14.4 percent) may have been enrolled through a different case-management program. The percentage receiving visits did not vary by year (Table 1).

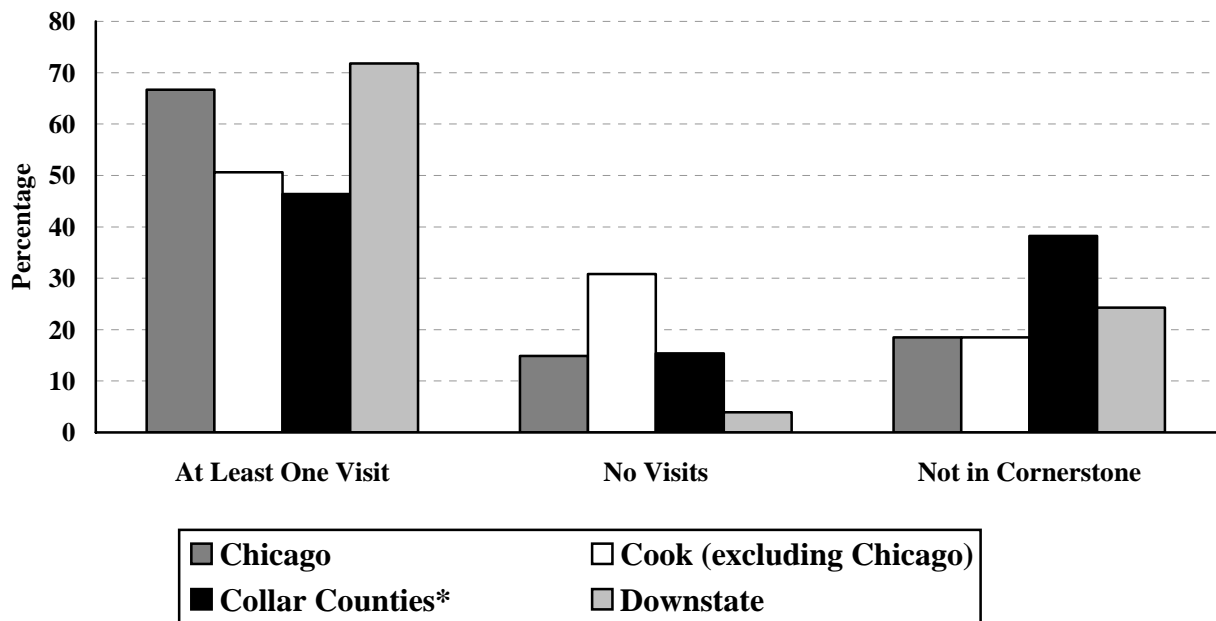
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Table 1. Number and percentage of children, by participation in follow-up, and birth year

Year	At least one visit		No visits		Not in Cornerstone		Total N
	N	%	N	%	N	%	
2002	4,568	60.5	1,141	15.1	1,838	24.4	7,547
2003	5,526	61.2	1,255	13.9	2,255	25.0	9,036
Total	10,094	60.9	2,396	14.4	4,093	24.7	16,583

However, there were significant variations by region of Illinois (Figure 1). Children in Cook County or the collar counties* were less likely to have a visit than children elsewhere. In addition, those residing in Cook County were more likely to be in Cornerstone, but have no visits (30.8 percent); those downstate were unlikely to be in Cornerstone with no visits (3.9 percent).

Figure 1. Percentage of children, by participation in follow-up and region of Illinois

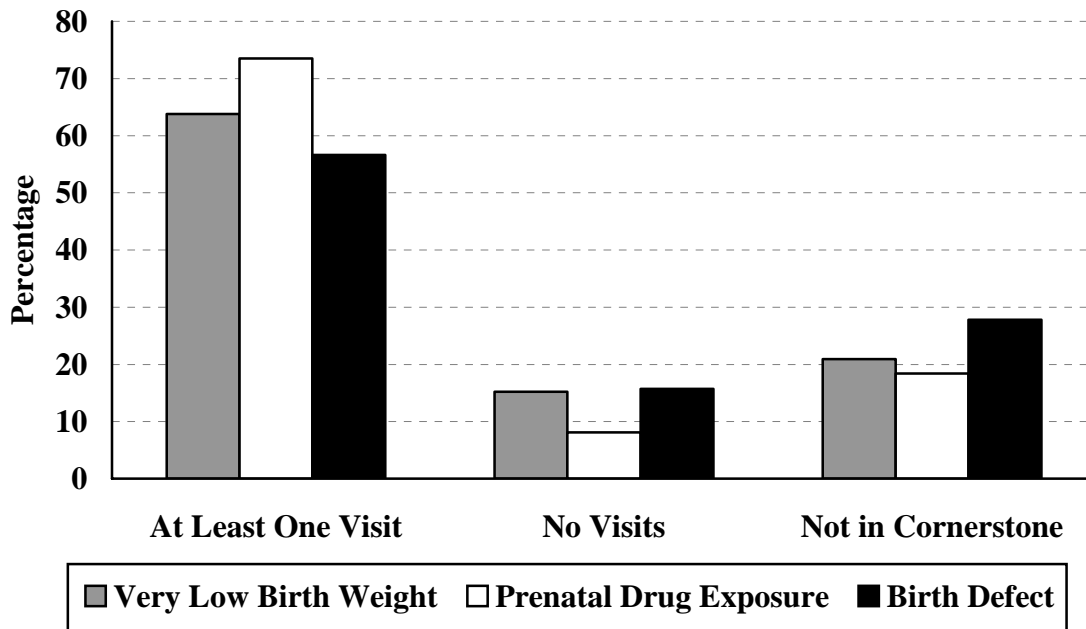


* The collar counties consist of Lake, McHenry, Kane, DuPage and Will counties.

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The percentage of children who received at least one follow-up visit also varied by APORS condition (Figure 2). Children with prenatal drug exposure were more likely to have at least one visit (73.5 percent), than those with very low birth weight (63.8 percent) or a birth defect (56.6 percent). Children with birth defects were least likely to be in the Cornerstone system at all (18.4 percent). There was no clear pattern in the variation of the percentage of children with at least one visit by birth defect type (Table 2).

Figure 2. Percentage of children by participation in follow-up, and APORS condition



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Table 2. Number and percentage of children, by participation in follow up, and birth defect type

APORS condition	At least one visit		No visits		Not in Cornerstone		Total N
	N	%	N	%	N	%	
Central Nervous System	493	65.6	98	13.0	161	21.4	752
Eye	675	61.0	161	14.5	271	24.5	1,107
Ear	423	55.9	114	15.1	220	29.1	757
Cardiovascular	3,141	58.4	879	16.3	1,357	25.2	5,378
Respiratory	281	56.5	85	17.1	131	26.4	497
Orofacial	212	57.6	63	17.1	93	25.3	368
Gastrointestinal	475	57.6	118	14.3	232	28.1	825
Genitourinary	1,174	52.2	350	15.5	727	32.3	2,251
Musculoskeletal	1,288	56.1	329	14.3	678	29.5	2,295
Chromosomal	334	57.6	103	17.8	143	24.7	580

The total percentage of children was not calculated, since a child may have more than one APORS condition and would be counted multiple times in this table.

Age at first visit

The High Risk Infant Follow-up Program requires that contact be made within a week of discharge and that a home visit should be made at 2 months of age. The families of a substantial number of children (11.2 percent) were documented as having received their first home visit before their baby was discharged from hospital. This cannot be correct since the High Risk Infant Follow-up Program does not carry out home visits prior to discharge. For 644 children (46.1 percent of those with invalid dates), the first visit date was recorded as date of birth or the following day. Some of these erroneous dates may be Cornerstone data entry problems, since

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APORS quality control studies have shown hospital reporting of discharge data as being more reliable than this².

Almost half the children in Cornerstone were recorded as having received their first home visit by 2 months of age (Table 3), with 57.5 percent receiving their first visit before 3 months of age. Of the 8,698 children who had at least one visit after discharge, 82.6 percent received their first home visit by 3 months of age. Between 2002 and 2003, there was a 5 percent increase in the number of children having their home visit by 2 months of age (Figure 3).

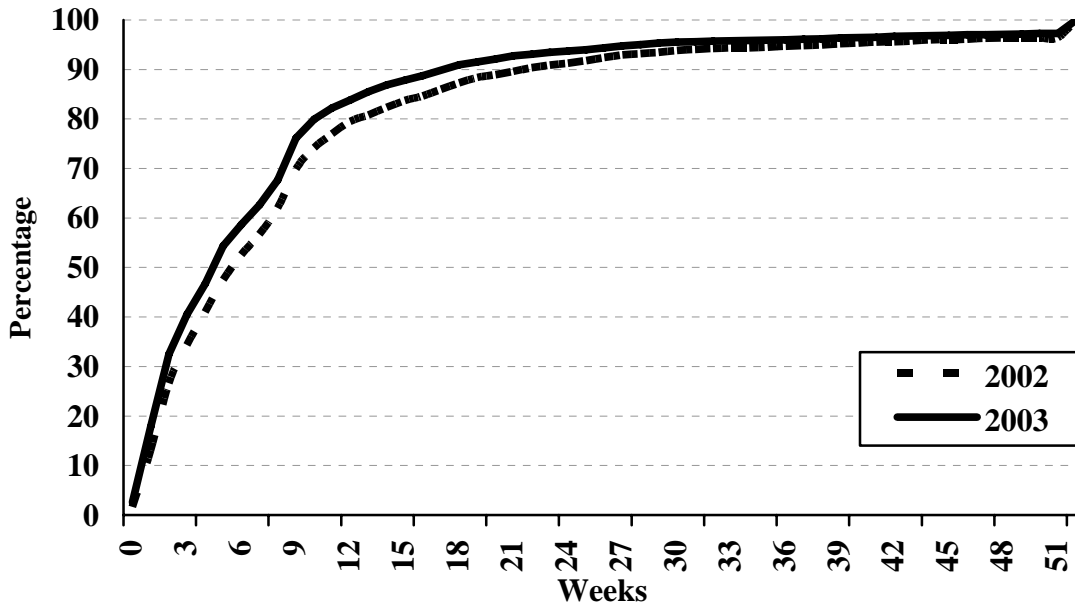
Table 3. Age at first visit, among children in Cornerstone

Age at First Visit (days)	Number of First Visits	Percentage of Visits	Cumulative Percentage
< 7	876	7.0	7.0
8-14	1,238	9.9	16.9
15-30	1,630	13.1	30.0
31-60	1,979	15.8	45.8
61-90	1,461	11.7	57.5
91-180	909	7.3	64.8
180+	605	4.8	79.6
In Cornerstone, but no visit	2,396	19.2	88.8
Invalid (first visit before birth date)	1,396	11.2	100.0
Total	12,490		

² APORS quality control studies have been shown error rates of 1.7 percent in hospital reporting of the delivery date and 5.7 percent in hospital reporting of the discharge date (Reabstract Study – Hospital Reports of Adverse Pregnancy Outcomes, January 2005.)

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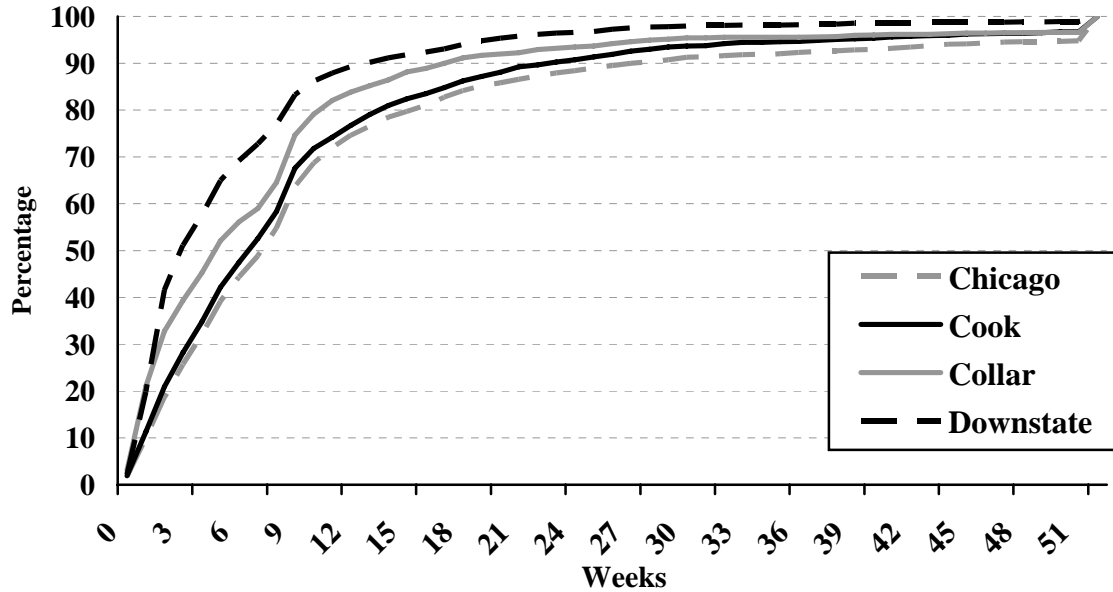
Figure 3. Cumulative percentage of age at first home visit, among children with any visit with a valid date, by birth year



There was significant variation in age at first visit among regions of Illinois (Figure 4). More than 60 percent of children in Cornerstone living in downstate counties were recorded as having been visited within two months of birth. One third of these children (32.1 percent), living in Cook County, had documentation of such a timely visit. However, when considering only those children who had a visit with a valid date, 74.6 percent of Chicago residents and 89.3 percent of downstate residents received their first visits by 3 months of age. There also was variation in time to first visit by APORS condition (Figure 5). Children with prenatal drug exposure were most likely to be seen by 3 months of age (67.4 percent). Just over half of the children with a birth defect (56.0 percent) were seen by the same age.

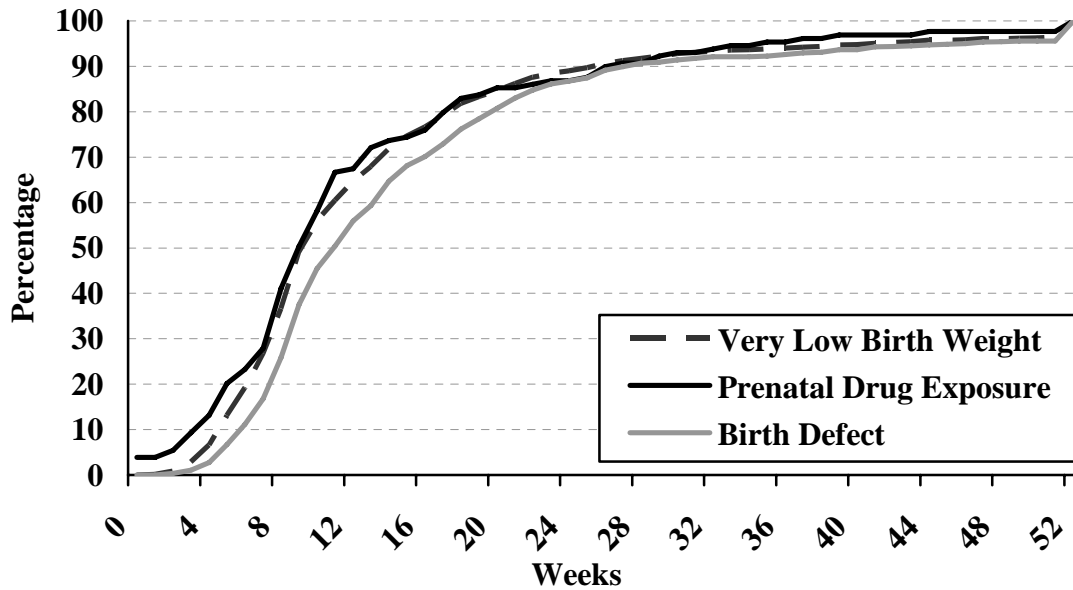
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Figure 4. Cumulative percentage of age at first home visit, among children with any visit with a valid date, by region of Illinois



*The collar counties consist of Lake, McHenry, Kane, DuPage and Will counties.

Figure 5. Cumulative percentage of age at first home visit, among children with any visit with a valid date, by APORS case criteria



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Completed Visit Schedule

The High Risk Infant Follow-up Program requires home visits be made at 2, 4, 6, 12, 18 and 24 months of age. A child is considered to have a completed visit schedule if he or she received a home visit at each of these time points. This is a demanding requirement, since a child who shows major improvement, has a non-compliant parent, moves out of state, or dies will not receive the full set of visits. If a child had 2, 4, 6 and 12 month home visits then the visit schedule was complete for the first year.

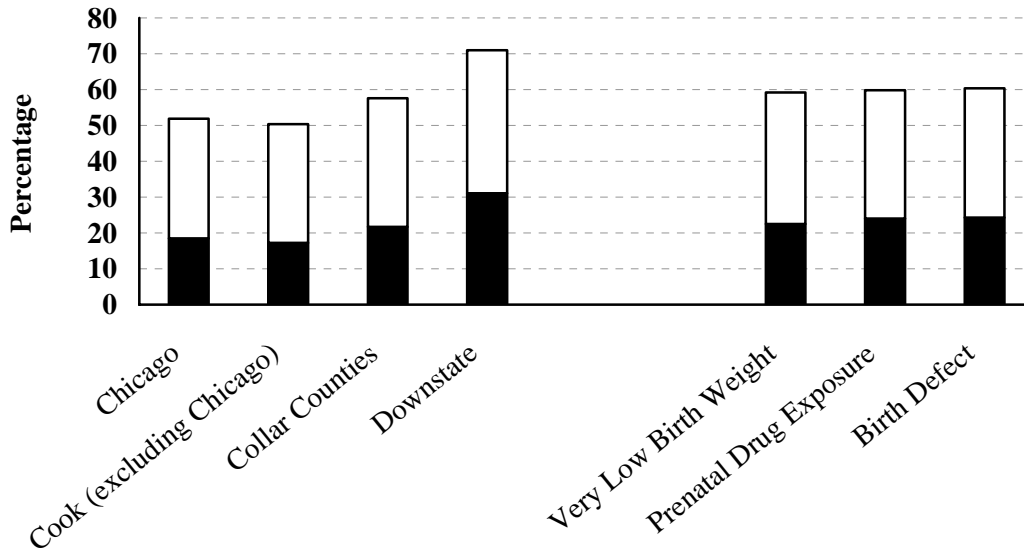
Table 4. Completed visit schedule, by birth year, among children with any visit

Birth Year	Number Completing Visit Schedule		% among those with any visit		% among those with valid first visit date	
	12 months	24 months	12 months	24 months	12 months	24 months
2002	2,664	1,070	58.3	23.4	67.4	27.1
2003	3,349	1,295	60.6	23.4	70.5	27.3
TOTAL	6,013	2,365	59.6	23.4	69.1	27.2

About one-fourth of children who received at least one home visit went on to have the complete set of visits (Table 4). A much higher percentage of children completed the first-year home visits. There was also significant variation in the percentage of children with a 12-month or 24-month completed visit schedule by region of Illinois (Figure 6). Children living downstate were more likely to receive the complete set of visits. There were no major differences between completing the visit schedule and the child’s original APORS condition(s) (Figure 6). Children with oro-facial clefts were somewhat more likely to have completed their 12-month visits than those with other birth defects (Table 5).

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Figure 6. Percentage with completed visit schedule, among those with any visit, by region of Illinois and APORS condition



*The collar counties consist of Lake, McHenry, Kane, DuPage and Will counties.

Table 5. Completed visit schedule, among children with any visit, by birth defect type

APORS condition	12 Month Visits Complete		24 Month Visits Complete	
	N	%	N	%
Central Nervous System	293	59.4	120	24.3
Eye	405	60.0	168	24.9
Ear	250	59.1	96	22.7
Cardiovascular	1900	60.5	752	23.9
Respiratory	166	59.1	67	23.8
Orofacial	138	65.1	54	25.5
Gastrointestinal	278	58.5	118	24.8
Genitourinary	715	60.9	286	24.4
Musculoskeletal	785	60.9	336	26.1
Chromosomal	193	57.8	79	23.7

Total number of children was not calculated, since a child may have more than one birth defect and would be counted multiple times in this table.

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Total Number of Visits

The High Risk Infant Follow-up Program requires a minimum of six home visits be made at 2, 4, 6, 12, 18 and 24 months of age. In practice many children receive more visits than this. In both 2002 and 2003, more than 60 percent of children received at least six visits, with around 12 percent receiving 13 or more visits (Table 6).

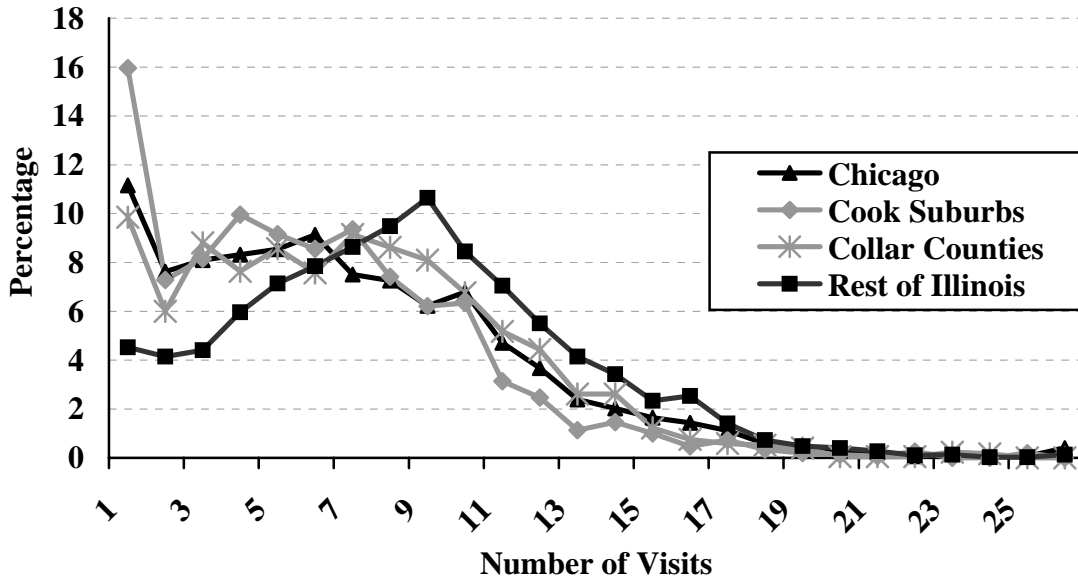
Table 6. Number of visits, among children with any visit, by birth year.

Number of Visits	2002		2003		Number of Visits	2002		2003	
	N	%	N	%		N	%	N	%
1	455	10.0	477	8.6	<6	1,781	39.0	2,041	36.9
2	294	6.4	315	5.7					
3	344	7.5	351	6.4					
4	331	7.2	435	7.9					
5	357	7.8	463	8.4					
6	371	8.1	468	8.5	6	371	8.1	468	8.5
7	407	8.9	448	8.1	7-12	1,924	42.1	2,312	41.8
8	370	8.1	470	8.5					
9	389	8.5	434	7.9					
10	341	7.5	398	7.2					
11	244	5.3	302	5.5					
12	173	3.8	260	4.7	13+	492	10.8	705	12.8
13+	492	10.8	705	12.7					
Total	4,568	100.0	5,526	100.0	Total	4,568	100.0	5,526	100.0

The number of visits depends on the region of Illinois in which a child lives. Those in Cook County have a median of four visits, while in Chicago the median number of visits is five. In the collar counties, children have a median of six visits, while in the rest of Illinois a child receives a median of seven visits (Figure 7). There was no variation by APORS condition (Figure 8).

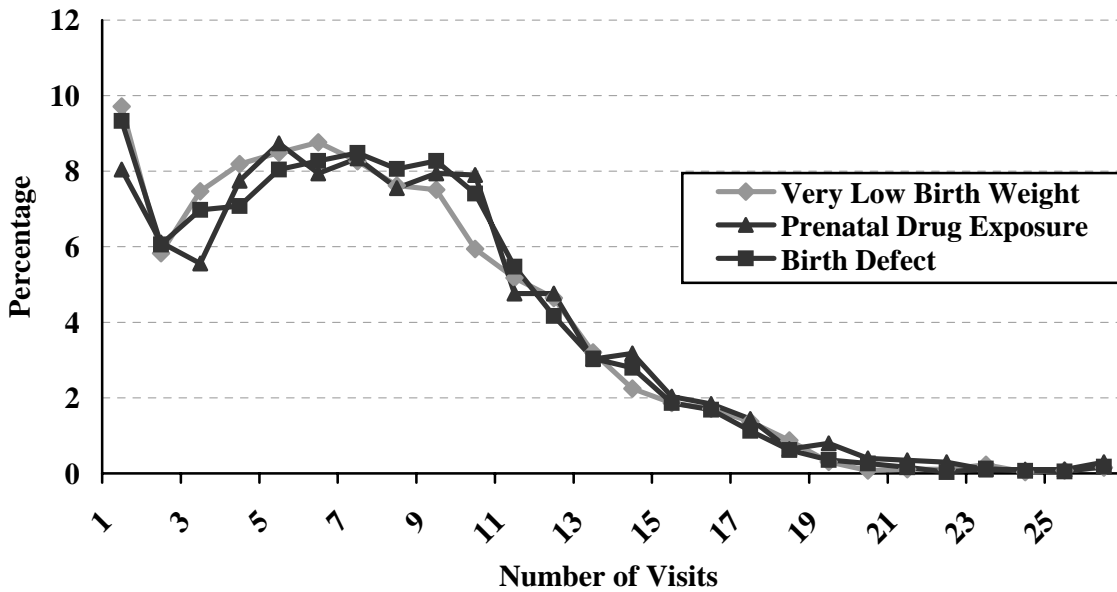
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Figure 7. Number of visits, among children with any visit, by region of Illinois



*The collar counties consist of Lake, McHenry, Kane, DuPage and Will counties.

Figure 8. Number of visits, among children with any visit, by APORS condition

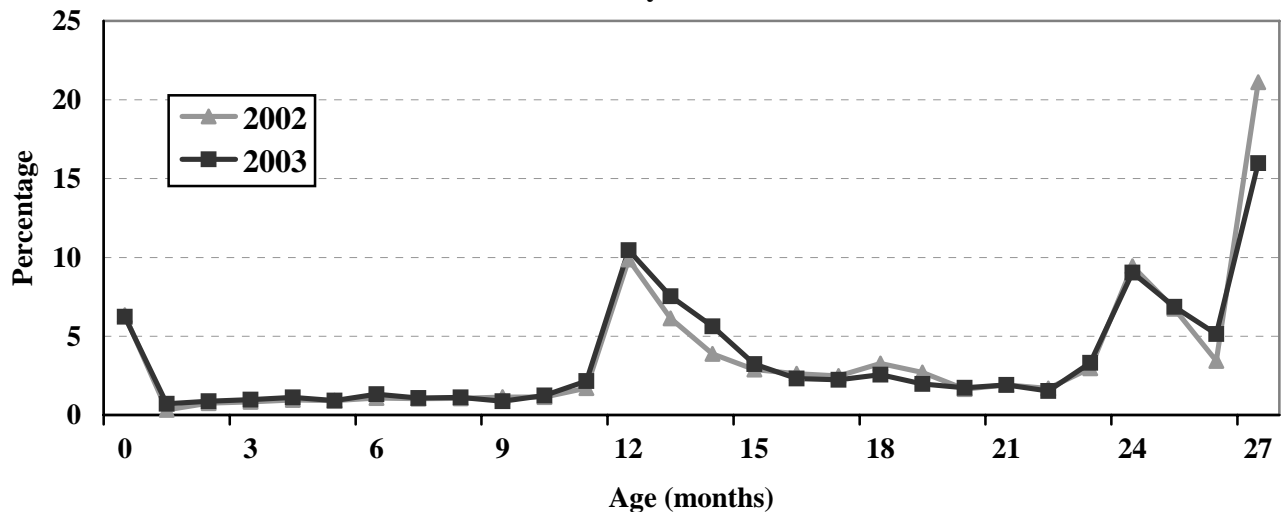


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Age at last contact

While many children receive more than the required number of visits, a substantial number receive fewer. Often this will be because the child does not need any further services. Figure 9 shows the age at which the child is terminated from the program. Almost 40 percent of the children are terminated after 24 months of age, a fourth of the children are terminated at about 1 year of age and 6.3 percent are terminated immediately.

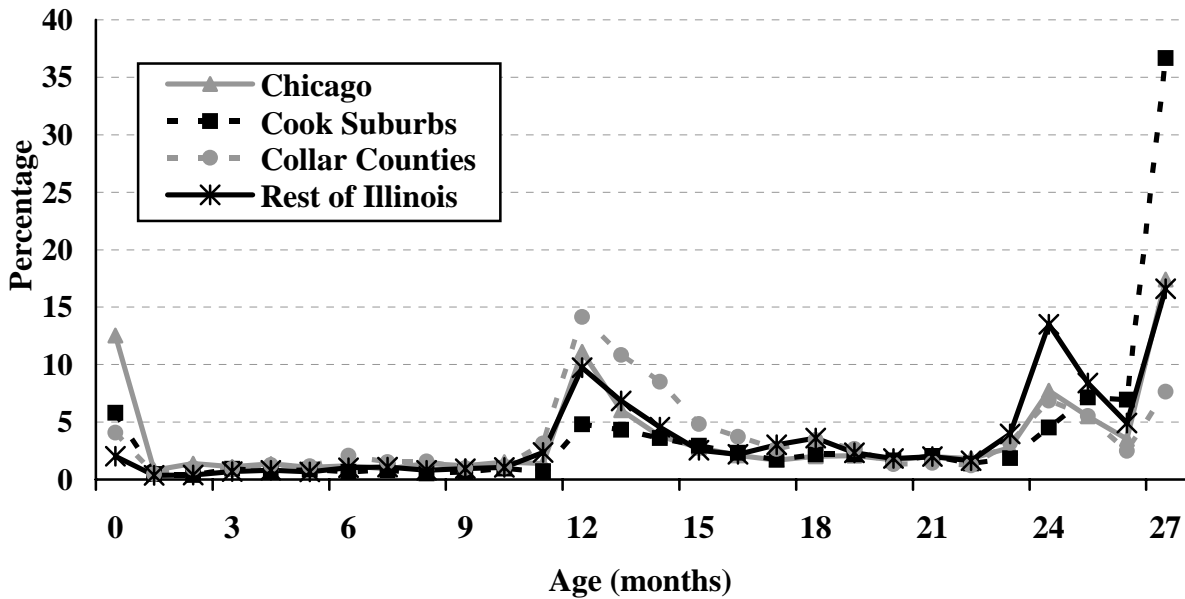
Figure 9. Age at which children, with any visit, are terminated from program, by birth year



In suburban Cook County, children are more likely to be terminated from the program at 27 months of age than in the rest of Illinois. Children in Chicago are more likely to be terminated from the program immediately. Children in the collar counties are more likely to be terminated at 12 months of age (Figure 10). There is not significant variation by APORS condition (Figure 11).

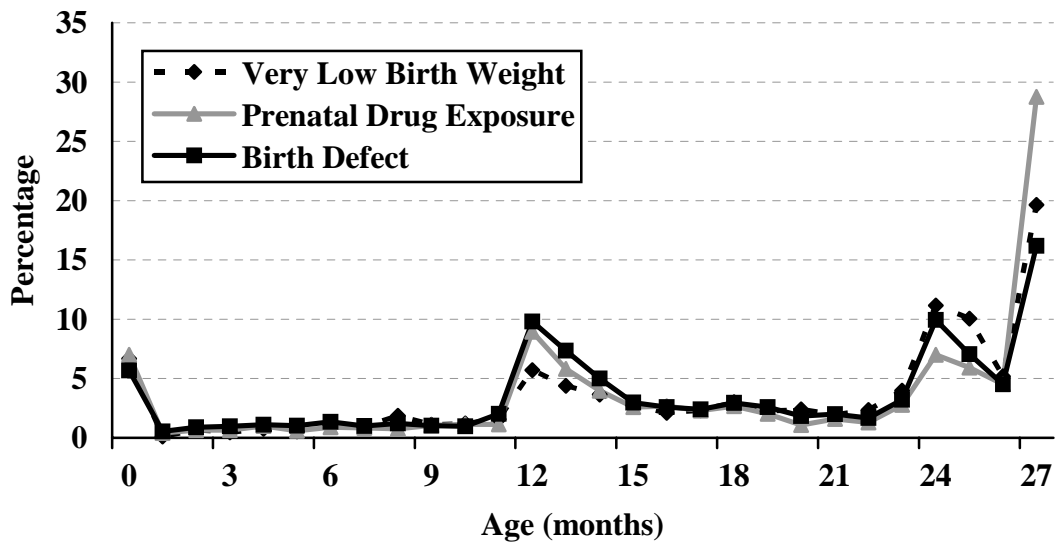
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Figure 10. Age at which children, with any visit, are terminated from program, by region of Illinois



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Figure 11. Age at which children, with any visit, are terminated from program, by APORS condition

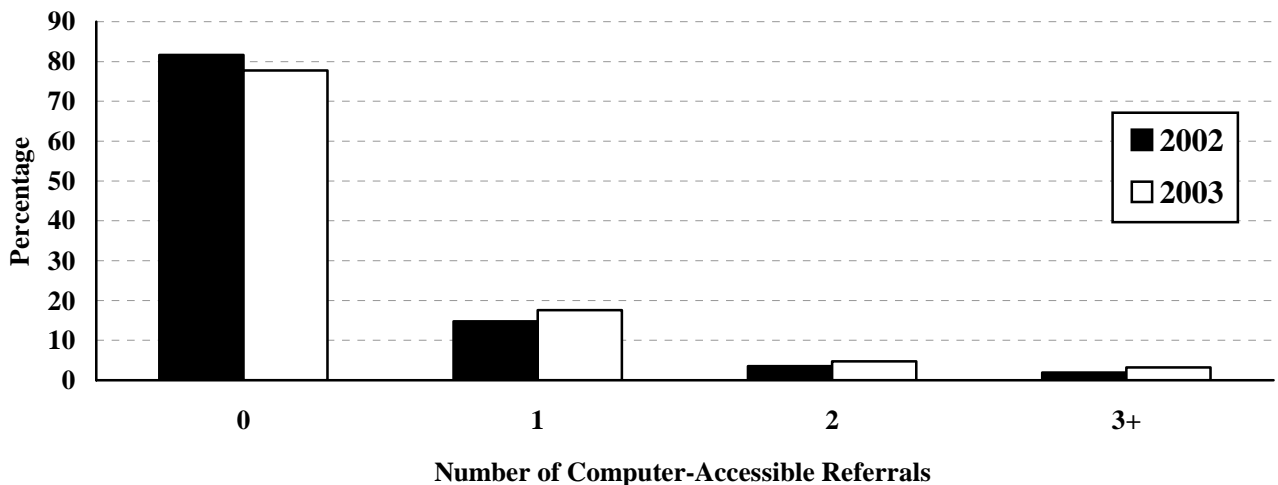


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Number of referrals

The number of referrals a child receives will depend greatly on that child's needs and on whether the family is already connected to the needed services or not. The number of referrals also depends on the documentation entered into Cornerstone. The High Risk Infant Follow-up Program is aware that referrals are often documented in the case notes, rather than on the database screen designed for this purpose. However, such documentation does not allow for ready evaluation of the number of referrals made. The referrals documented in the data screens designed for the purpose are called computer-accessible referrals. Three-fourths of the children (77.6 percent) had no computer-accessible referrals for services (Figure 12), 15.8 percent had one computer-accessible referral and 4.0 percent had two computer-accessible referrals. There was little variation by year of birth.

Figure 12. Number of computer-accessible referrals, among children with any visit, by birth year

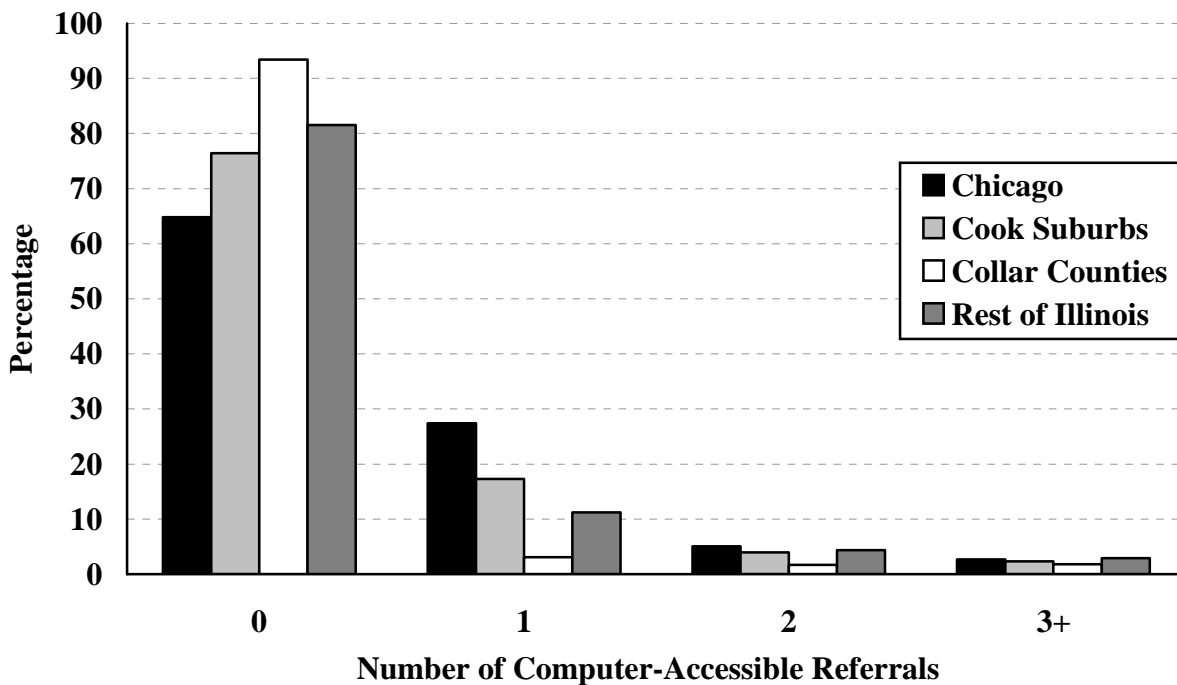


Computer-accessible referrals are those entered on the data screen designed for the purpose, rather than in the text of case notes. The chart is therefore not necessarily reflective of activities, but may be an artifact of reporting.

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Children who live in the collar counties³ were less likely to have computer-accessible referrals for services than elsewhere in Illinois, while Chicago children are more likely to have computer-accessible referrals than others in Illinois (Figure 13). Children with prenatal drug exposure are more likely to have computer-accessible referrals for services than others (Figure 14).

Figure 13. Number of computer-accessible referrals, among children with any visit, by region of Illinois

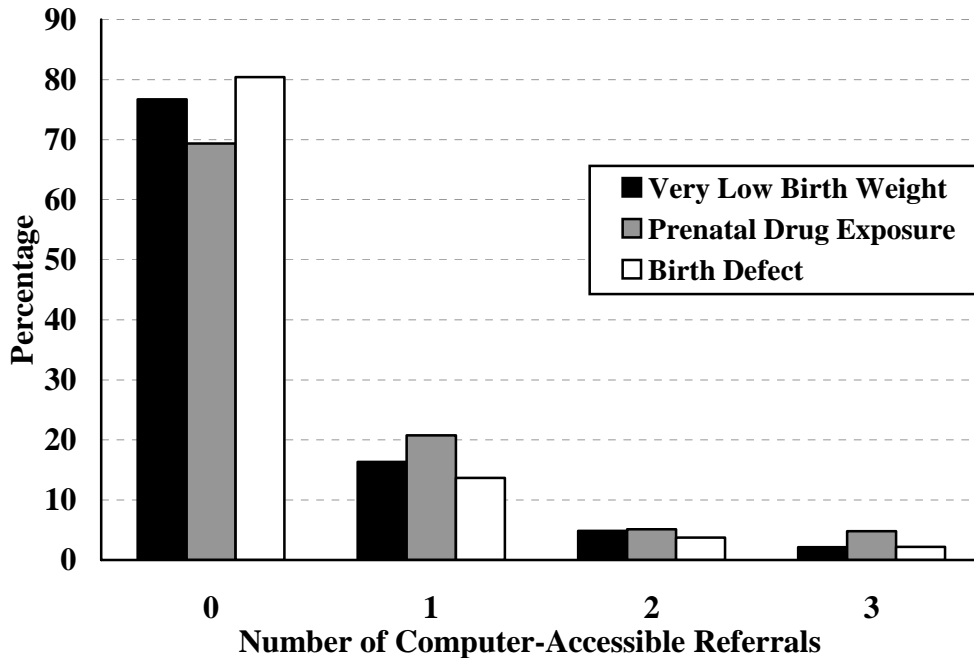


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³ The collar counties consist of Lake, McHenry, Kane, DuPage and Will counties.

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Figure 14. Number of computer-accessible referrals, among children with any visit, by APORS condition



Computer-accessible referrals are those entered on the data screen designed for the purpose, rather than in the text of case notes. The chart is therefore not necessarily reflective of activities, but may be an artifact of reporting.

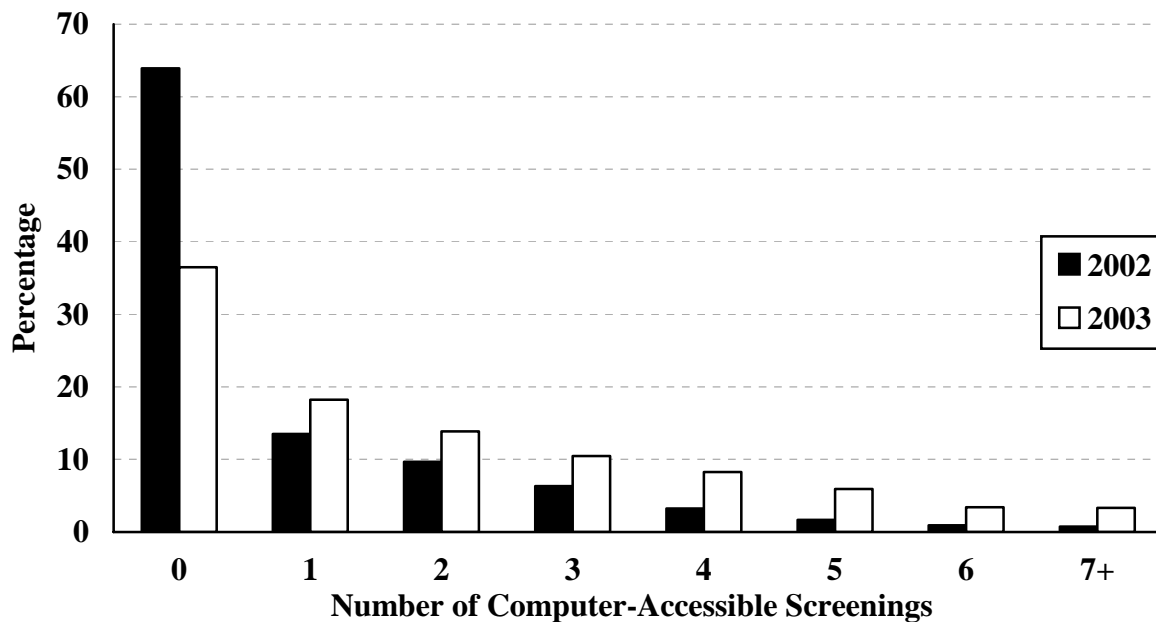
Number of Developmental Screenings

The number of developmental screenings a child receives depends greatly on whether there are continuing concerns about the child's development as he or she grows. The number of documented screenings also depends on the documentation entered into Cornerstone. The High Risk Infant Follow-up Program is aware that developmental screenings are often documented in the case notes, rather than on the database screen designed for this purpose. However, such documentation does not allow for ready evaluation of the number of referrals made. The

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developmental screenings documented in the data screens designed for the purpose are called computer-accessible screenings. Nearly half the children (49.3 percent) received no computer-accessible screenings (Figure 15), 16.0 percent were recorded as having received one computer-accessible screening, and 20.4 percent were recorded as having received two or three computer-accessible screenings. Children born in 2003 were documented as having received more computer-accessible screenings than those born in 2002.

Figure 15. Number of computer-accessible developmental screenings, among children with any visit, by birth year

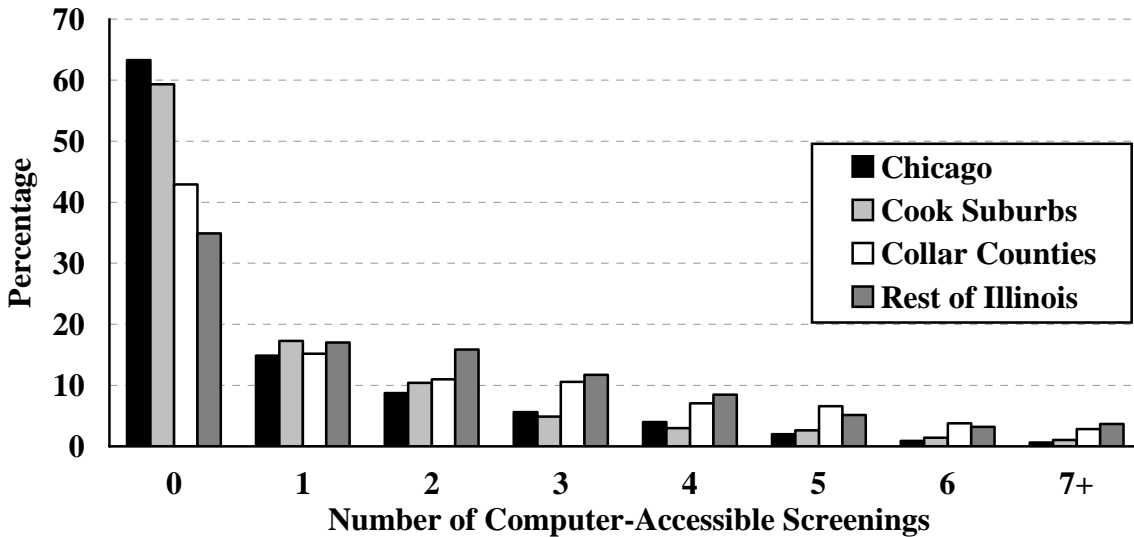


Computer-accessible developmental screenings are those entered on the data screen designed for the purpose, rather than in the text of case notes. The chart is therefore not necessarily reflective of activities, but may be an artifact of reporting.

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Children living in Cook County (including Chicago) were less likely to have computer-accessible developmental screenings than those living elsewhere (Figure 16)⁴. As for computer-accessible referrals, children with prenatal drug exposure were more likely to have computer-accessible developmental screenings documented than other children (Figure 17).

Figure 16. Number of computer-accessible screenings, among children with any visit, by region of Illinois

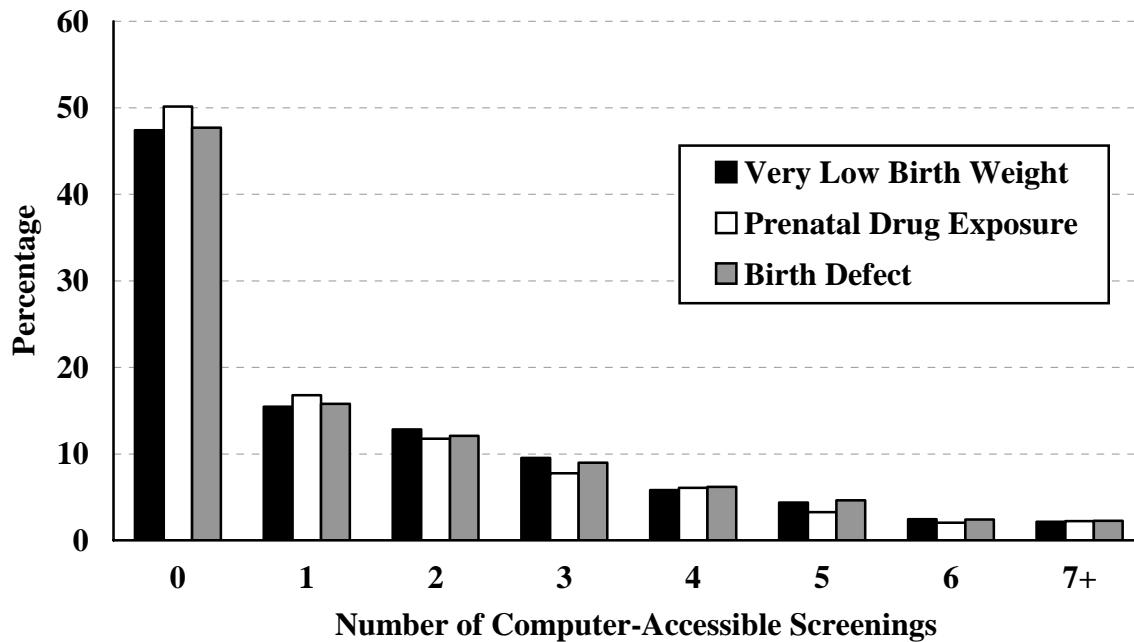


Computer-accessible developmental screenings are those entered on the data screen designed for the purpose, rather than in the text of case notes. The chart is therefore not necessarily reflective of activities, but may be an artifact of reporting.

⁴ The collar counties consist of Lake, McHenry, Kane, DuPage and Will counties.

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Figure 17. Number of computer-accessible screenings, among children with any visit, by APORS condition



Computer-accessible developmental screenings are those entered on the data screen designed for the purpose, rather than in the text of case notes. The chart is therefore not necessarily reflective of activities, but may be an artifact of reporting.

SUMMARY AND RECOMMENDATIONS

The High Risk Infant Follow-up Program is doing a good job of contacting APORS cases.

Sixty-one percent of the APORS cases had a home visit, and a further 14 percent received other services from their local health department. It would be helpful to have a better idea of why families are not enrolled. We recommend each local health department be asked to use a standardized set of reasons (perhaps those listed on page 3) to document the reasons that families refuse services.

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The High Risk Infant Follow-up Program has been doing well at providing services to children and their families. Most children received their first visit at around 2 months of age, as required. More than half the children with a visit received 12 months of home visits and about one-fourth received 24 months of home visits. Better documentation of visits would be helpful; in particular, it is important to make sure the correct dates are entered for visits.

With the High Risk Infant Follow-up Program demonstrably performing well in many areas, it seems unlikely the local health departments' health nurses are not making appropriate referrals and performing developmental screenings. Indeed, High Risk Infant Follow-up staff report that referrals and developmental screenings were recorded when they perform routine audits. It is regrettable that this strong performance cannot be clearly demonstrated as it can in other aspects of the program. Performance evaluation would be easier with improved computer documentation.

Overall, the process used by the APORS program to refer cases to the High Risk Infant Follow-up Program is working well. Illinois is a leader in the nation in referring and providing follow-up services to children with adverse pregnancy outcomes.

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ACKNOWLEDGEMENTS

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