KIDSNET DATA BOOK 2010

A report from KIDSNET, Rhode Island's integrated child health information system

RHODE ISLAND DEPARTMENT OF HEALTH

KIDSNET Data Book Overview

THIS DATA BOOK PROVIDES A SAMPLE OF WAYS TO LOOK AT KIDSNET'S INTEGRATED DATA.

In the early 1990s, managers from a variety of maternal and child health programs expressed an increasing need for data and capacity to track preventive health services provided to children. In addition, states were called upon to develop immunization registries in the aftermath of a measles outbreak. Not surprisingly, examination of existing data in Rhode Island showed that children who were missing one preventive health service were also likely to be missing other preventive health services. Primary care providers and families expressed the view that separate contact from each public health program was inefficient and frustrating. Certainly, stand-alone data systems would be inefficient to develop and would not show the entire service profile for an individual child.

KIDSNET grew out of a desire to create child-based profiles of preventive health services that addressed these identified data needs. KIDSNET is not intended to be a comprehensive electronic medical record. Using a child's preventive health profile, categorical programs can not only see who has received services, but perhaps more importantly, who hasn't received services. This information

is useful in developing strategies for outreach to families. Community partners such as primary care providers, visiting nurses, school nurses, and others can also access relevant information from various sources not previously available to them to assure and coordinate services for children in their care.

KIDSNET began operating in 1997 with initial immunization registry development funding from the Robert Wood Johnson Foundation. Strict security and confidentiality policies protect the information gathered by KIDSNET and assure that only those authorized by law have access to the data. After 12 years, KIDSNET now holds data on over 280,000 children. All primary care pediatricians and family practice providers seeing children can access KIDSNET data and provide immunization information[1] on children receiving care in Rhode Island. Data related to newborn screening (developmental risk, bloodspot, hearing), vital records, WIC, lead[2], Early Intervention, and home visiting are also stored in KIDSNET. Through regular and ad hoc reports and online tools, KIDSNET data are used for quality assurance activities, coordination of care, reminders, and to inform policy decisions. KIDSNET has the advantage of having both individual child information and population-based data. As KIDSNET matures, more ideas to enrich and utilize the database are emerging.

This data book provides a sample of ways to look at KIDSNET's integrated data. A KIDSNET record is opened for every child born in Rhode Island. Most of the data presented in this data book reflect children born in Rhode Island who have received preventive services in the state. The data book is meant to paint pictures that would not be possible with stand-alone data systems.

1. Immunization data are recorded in KIDSNET for children receiving care in Rhode Island when their primary care provider submits data to KIDSNET. Historical immunization data in KIDSNET are based on what has been submitted and for some practices may under represent actual immunizations.

2. Lead information is included for children screened in Rhode Island and for children who live in Rhode Island but are screened in other states.

Early Intervention Referral, Evaluation, and Enrollment by Selected Risk Factors

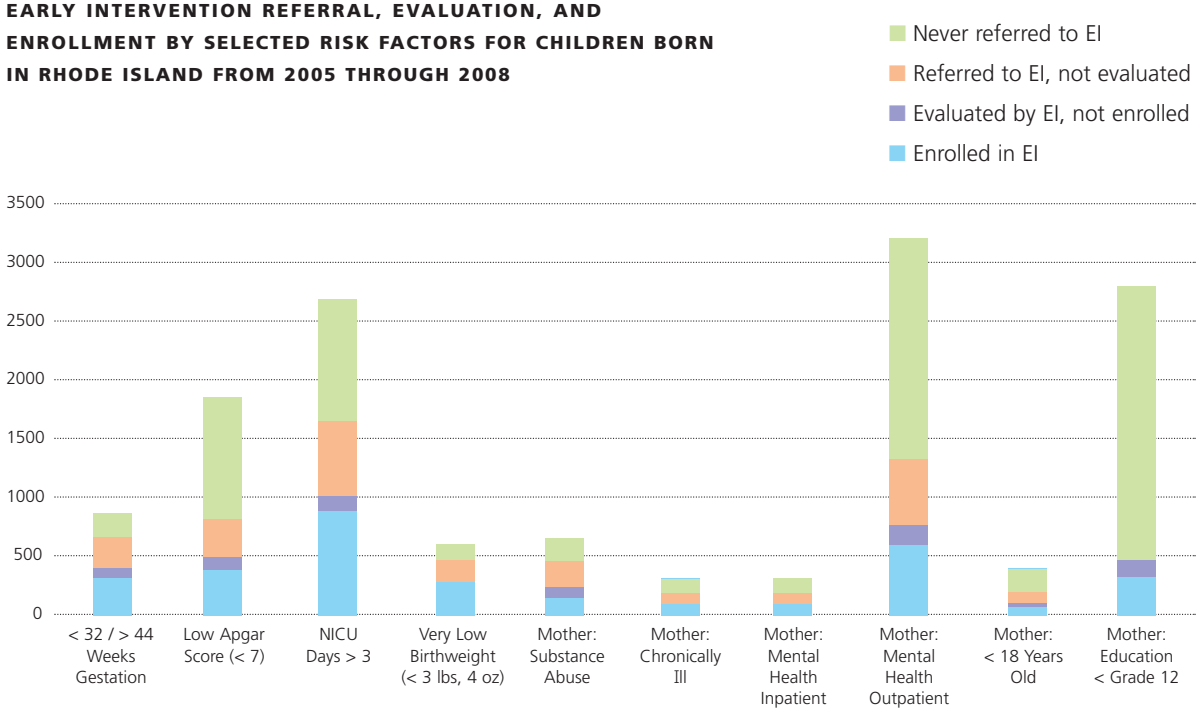
EARLY INTERVENTION IS A PROGRAM THAT PROMOTES THE GROWTH AND DEVELOPMENT OF INFANTS AND TODDLERS WITH DEVELOPMENTAL CHALLENGES.

Services provided through Early Intervention (EI) are intended to aid children through age three who have delays in physical, communicative, and/or social development. Children at risk for such delays are identified at birth using a set of risk criteria and referred for a public health home visit. Some will later be referred to EI for evaluation by home visitors or other health professionals. While a referral does not always result in an evaluation and an evaluation does not necessarily result in enrollment in one of the EI-provided services, several risk factors do help facilitate the identification of those children most likely to need EI services. Comparing the number of those at risk to those receiving a referral, an evaluation, or services may reflect referral patterns in the community related to individual risk factors.

The table and chart on the opposite page show the total number of children known at birth to have selected risk conditions and how many of those children have been referred to, evaluated by, and enrolled in EI services. These data represent 11,185 children who were born in Rhode Island from 2005 through 2008 and identified at birth to have selected risk factors. For most risk factors, the majority of infants who were evaluated went on to receive EI services. However, a majority of evaluated infants with three or more days in a neonatal intensive care unit (NICU) were not enrolled in EI, and 38% were never referred. Other infant-related risks, such as low birthweight and prematurity, were more likely to result in receipt of EI services if the child received an evaluation.

Overall, each risk factor shows a large percentage of at-risk infants who were not referred, evaluated, or enrolled. Provided these infants' development is being monitored by a primary care provider or other professional knowledgeable in child development, referral to EI may not have been warranted.

EARLY INTERVENTION REFERRAL, EVALUATION, AND ENROLLMENT BY SELECTED RISK FACTORS FOR CHILDREN BORN IN RHODE ISLAND FROM 2005 THROUGH 2008



	NEVER REFERRED TO EI		REFERRED TO EI, NOT EVALUATED		EVALUATED BY EI, NOT ENROLLED		ENROLLED IN EI		
	COUNT	PERCENT OF TOTAL	COUNT	PERCENT OF TOTAL	COUNT	PERCENT OF TOTAL	COUNT	PERCENT OF TOTAL	TOTAL AT RISK
< 32 / > 44 Weeks Gestation	226	26.13%	243	28.09%	19	2.20%	377	43.58%	**865**
Low Apgar Score (< 7)	1107	58.79%	311	16.52%	51	2.71%	414	21.99%	**1883**
NICU Days > 3	1078	40.71%	642	24.24%	96	3.63%	832	31.42%	**2648**
Very Low Birthweight (< 3 lb, 4 oz)	98	16.23%	197	32.62%	8	1.32%	301	49.83%	**604**
Mother: Substance Abuse	291	42.48%	160	23.36%	32	4.67%	202	29.49%	**685**
Mother: Chronically Ill	151	58.53%	46	17.83%	3	1.16%	58	22.48%	**258**
Mother: Mental Health Inpatient	91	44.61%	54	26.47%	6	2.94%	53	25.98%	**204**
Mother: Mental Health Outpatient	1945	61.53%	527	16.67%	103	3.26%	586	18.54%	**3161**
Mother: < 18 Years Old	276	69.00%	68	17.00%	10	2.50%	46	11.50%	**400**
Mother: Education < Grade 12	2402	84.16%	0	0.00%	81	2.84%	371	13.00%	**2854**
Totals	**7682**	**56.41%**	**2267**	**16.65%**	**409**	**3.00%**	**3260**	**23.94%**	**13618**

Trends in Childhood Influenza Vaccination

IN 2002–2003, WHEN THE FLU VACCINE WAS MADE AVAILABLE TO ALL CHILDREN AGED 6–23 MONTHS, RECORDED VACCINATIONS INCREASED BY 584%.

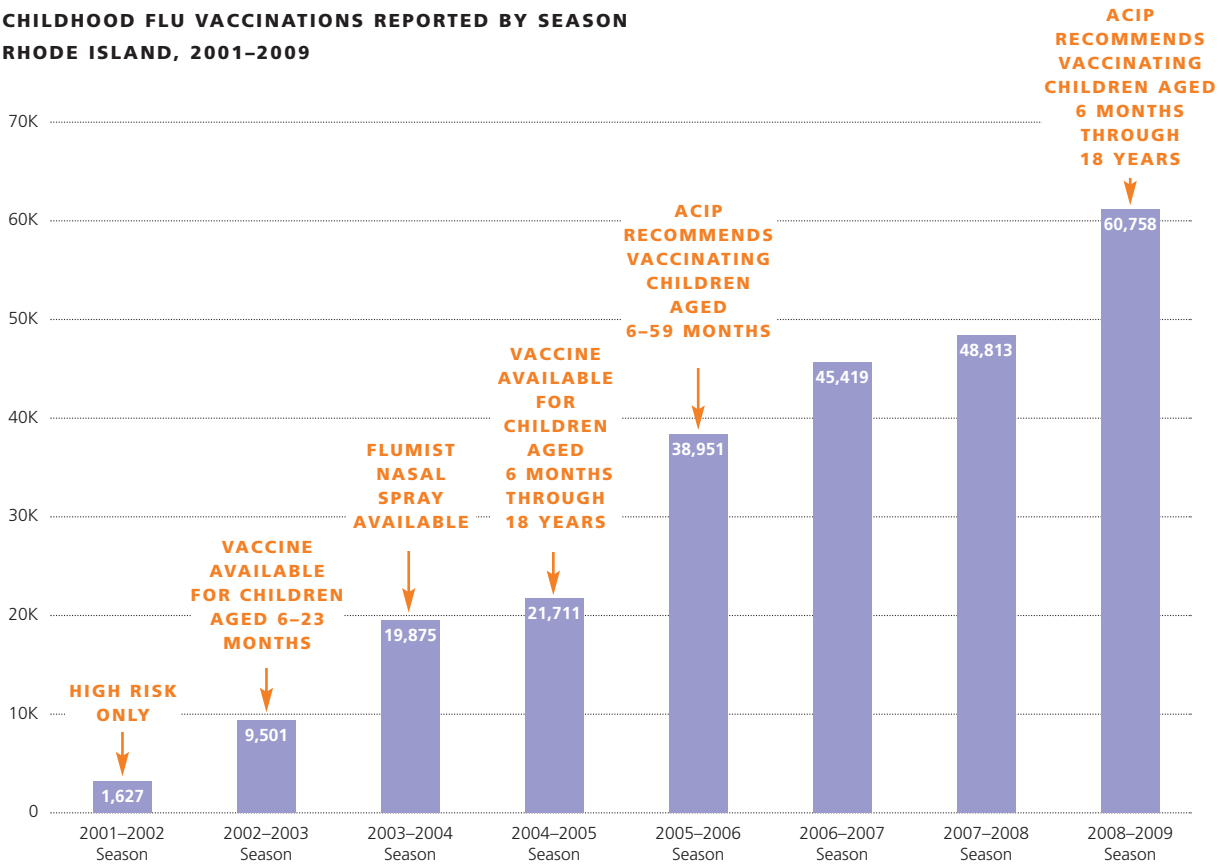
Over the past decade, recommendations for seasonal influenza (flu) vaccination in young children have changed numerous times. Prior to 2002, only children determined to be at high risk for complications from the flu were given the vaccine. From the selected provider practices included in this data set, KIDSNET only recorded 1,627 vaccinations in the 2001–2002 flu season. In the 2002–2003 flu season, the Rhode Island Department of Health made the vaccine available to all children aged 6–23 months, following an Advisory Committee on Immunization Practices (ACIP) statement encouraging routine vaccination of children in this age group. In that season, recorded vaccinations increased by 584%.

In 2003, FluMist nasal spray became available. In the next year, ACIP officially recommended routine yearly vaccinations for all children aged 6–23 months. The Department of Health made flu vaccine available to all children from 6 months through 18 years of age. When the vaccine was distributed, some providers began administering it immediately, while others waited for ACIP to officially recommend the vaccination of older children. These changes are reflected in a doubling of recorded vaccinations.

In 2006, ACIP expanded its seasonal flu recommendations to routinely include children aged 6–59 months. Recorded vaccinations nearly doubled again in that year. Between the 2005–2006 flu season and the 2007–2008 season, vaccinations rose steadily with no new ACIP recommendations. Two years later, in 2008, ACIP recommendations expanded to include routine immunization of children through age 18, encompassing the entire active population in KIDSNET.

The chart on the opposite page shows the number of flu vaccinations administered by flu season and indicates important changes in recommendations or policies. The data include only those healthcare providers who regularly reported immunizations through the entire period illustrated (August 2001–July 2009).

CHILDHOOD FLU VACCINATIONS REPORTED BY SEASON
RHODE ISLAND, 2001–2009



Notes: Vaccine administration reported to KIDSNET by 103 provider practices.
The flu season lasts from August 1 to July 31.

IN 2008, ACIP RECOMMENDATIONS EXPANDED TO INCLUDE ROUTINE IMMUNIZATION OF CHILDREN THROUGH AGE 18, ENCOMPASSING THE ENTIRE ACTIVE POPULATION IN KIDSNET.

Child Mobility Among Primary Care Providers and Zip Codes

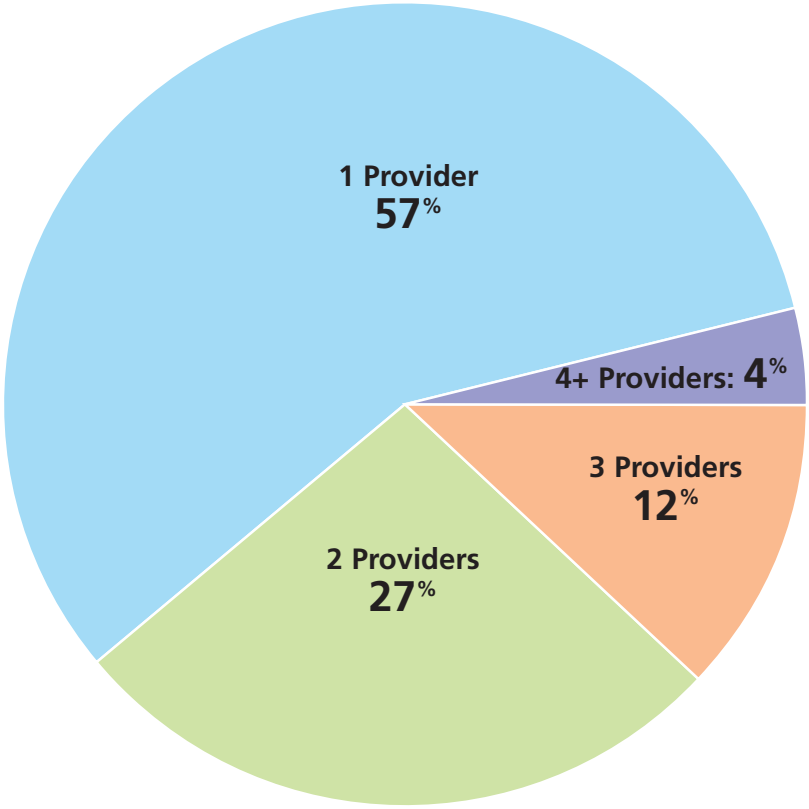
EACH TIME A CHILD CHANGES HIS OR HER DOCTOR, A NEW OPPORTUNITY FOR A LAPSE IN CARE IS CREATED, MEDICAL RECORDS MUST BE TRANSFERRED, AND NEW RELATIONSHIPS MUST BE ESTABLISHED.

Continuous medical care is a key component of a medical home. The observation of a child's development is an important platform from which to provide medical treatment and guidance, particularly during his or her early years. Without an ongoing relationship between doctor, patient, and parents, developmental guidance is difficult to provide. Each time a child changes his or her doctor, the potential for a lapse in care is created, medical records must be transferred, and new relationships must be established. Lacking first-hand knowledge of developmental progress and medical history of a young patient, a new doctor may miss important signals only visible by long-term trends, and problematic conditions may go unnoticed.

Based on immunizations reported to KIDSNET as of 2009, 57% of Rhode Island children born in 1999 benefited from a single source of primary medical care. However, a large number of children had more than one source, with 27% having two providers, 12% having three providers, and 4% having four or more providers, as demonstrated in the first chart on the opposite page. The second chart illustrates the movements of this same birth cohort based on the number of zip codes in which each child has lived. While a change in zip code does not necessitate a change in medical home, the distribution of the mobility data is very similar to the distribution of the provider data.

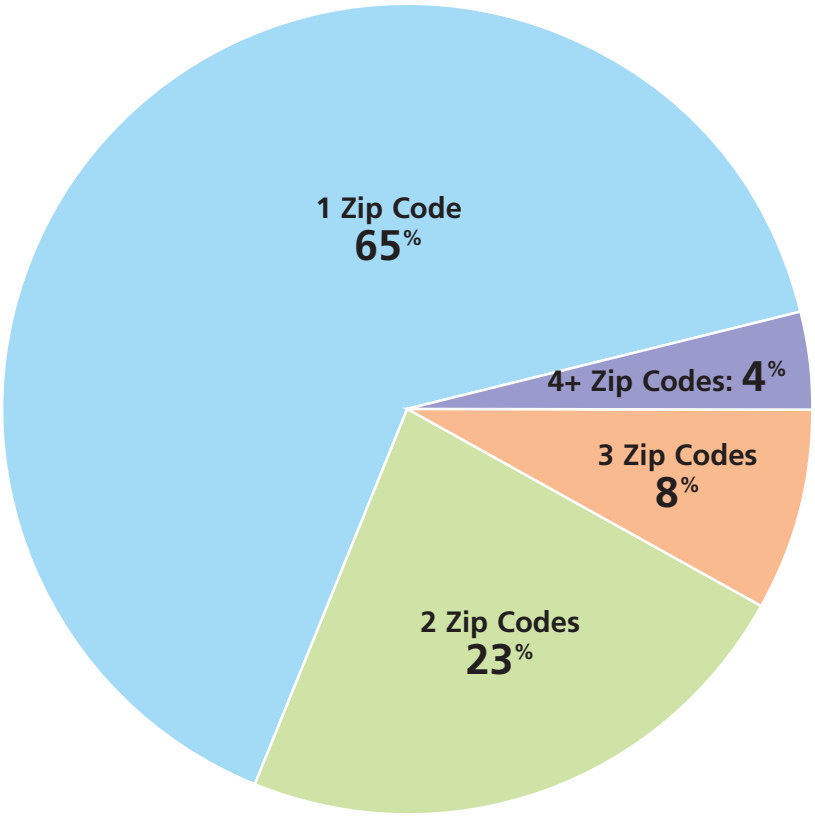
NUMBER OF HEALTHCARE PROVIDERS PER CHILD
CHILDREN BORN IN 1999
RHODE ISLAND, 2009

NUMBER OF PROVIDERS	NUMBER OF CHILDREN	PERCENT
1	8640	57%
2	4153	27%
3	1776	12%
4+	594	4%



MOBILITY BY ZIP CODE
CHILDREN BORN IN 1999
RHODE ISLAND, 2009

NUMBER OF ZIP CODES	NUMBER OF CHILDREN	PERCENT
1	11038	65%
2	3890	23%
3	1293	8%
4+	761	4%



Preventive Health Services Impacting School Programs for Kindergarten-Aged Children, 2010

AN INFANT OR TODDLER'S PARTICIPATION IN CERTAIN PUBLIC HEALTH PROGRAMS OFTEN INDICATES THAT THE CHILD WILL BE INVOLVED IN PARALLEL PROGRAMS WHEN HE OR SHE GOES TO SCHOOL.

While there are many different types of data that can indicate the status of a child's health, a certain set of characteristics is particularly pertinent to school administrators for planning purposes. An infant or toddler's participation in certain public health programs often indicates that the child will be involved in parallel programs when he or she goes to school. For example, a child who is enrolled in the WIC program may be more likely to utilize a free or reduced school lunch program. Former participation in the Early Intervention program may indicate future need for special education services.

Certain other factors recorded in KIDSNET may also help schools prepare for incoming students. For example, KIDSNET tracks the number of children who have tested positive for lead poisoning. High levels of lead in a child's blood may result in behavioral and learning difficulties.

Having these totals available before the beginning of the school year may be a valuable method for determining the needs of the incoming class. The table on the opposite page lists the number of students who may require the use of certain school programs based on specific health factors by city or town of residence. While KIDSNET does not have access to school-specific data, such as when and where a child will attend school, the table includes those children who will be eligible for kindergarten entry in September 2010 (i.e., those that were born between September 1, 2004 and August 31, 2005).

PREVENTIVE HEALTH SERVICES FOR KINDERGARTEN-AGED CHILDREN BY TOWN
RHODE ISLAND, 2010

	TOTAL CHILDREN IN AGE GROUP	TESTED FOR LEAD POISONING		TESTED POSITIVE FOR LEAD POISONING		ENROLLED IN EARLY INTERVENTION		ENROLLED IN WIC	
		Total	Percent	Total	Percent	Total	Percent	Total	Percent
BARRINGTON	224	202	90	3	1	19	8	18	8
BRISTOL	211	194	92	9	4	28	13	79	37
BURRILLVILLE	193	170	88	6	3	20	10	69	36
CENTRAL FALLS	436	376	86	24	6	54	12	393	90
CHARLESTOWN	76	64	84	5	7	8	11	22	29
COVENTRY	439	381	87	7	2	61	14	139	32
CRANSTON	942	832	88	33	4	111	12	404	43
CUMBERLAND	456	403	88	7	2	55	12	104	23
EAST GREENWICH	211	171	81	1	0	29	14	20	9
EAST PROVIDENCE	573	501	87	36	6	70	12	274	48
EXETER	59	53	90	3	5	8	14	14	24
FOSTER	62	55	89	1	2	9	15	18	29
GLOCESTER	79	66	84	3	4	4	5	12	15
HOPKINTON	81	72	89	3	4	7	9	19	23
JAMESTOWN	48	42	88	1	2	5	10	6	13
JOHNSTON	321	287	89	10	3	39	12	138	43
LINCOLN	218	205	94	8	4	26	12	68	31
LITTLE COMPTON	32	27	84	3	9	2	6	7	22
MIDDLETOWN	283	228	81	9	3	23	8	88	31
NARRAGANSETT	112	97	87	4	4	10	9	32	29
NEW SHOREHAM	13	6	46	2	15	0	0	4	31
NEWPORT	397	319	80	17	4	33	8	158	40
NORTH KINGSTOWN	360	321	89	5	1	49	14	83	23
NORTH PROVIDENCE	326	283	87	11	3	32	10	172	53
NORTH SMITHFIELD	92	82	89	2	2	8	9	16	17
PAWTUCKET	1248	1089	87	61	5	119	10	939	75
PORTSMOUTH	238	194	82	4	2	23	10	45	19
PROVIDENCE	3207	2745	86	232	7	328	10	2531	79
RICHMOND	67	56	84	2	3	9	13	18	27
SCITUATE	137	124	91	2	1	15	11	23	17
SMITHFIELD	193	167	87	2	1	18	9	33	17
SOUTH KINGSTOWN	311	283	91	10	3	35	11	62	20
TIVERTON	154	141	92	5	3	19	12	39	25
WARREN	116	111	96	7	6	14	12	44	38
WARWICK	962	830	86	15	2	111	12	344	36
WEST GREENWICH	62	53	85	1	2	7	11	12	19
WEST WARWICK	439	382	87	9	2	66	15	227	52
WESTERLY	300	259	86	11	4	40	13	115	38
WOONSOCKET	750	658	88	38	5	131	17	571	76

Note: Testing and enrollment numbers collected as of November 18, 2009.

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