

**PROGRAM DESCRIPTION**

<b>Department of Health and Senior Services</b>							<b>HB Section(s):</b> <u>10.700, 10.710</u>	
<b>Genetics and Newborn Services</b>								
<b>Program is found in the following core budget(s):</b>								
	<b>DCPH Program Operations</b>	<b>DCPH Programs and Contracts</b>						<b>TOTAL</b>
<b>GR</b>	209,840	940,743						1,150,583
<b>FEDERAL</b>	927,039	4,217,160						5,144,199
<b>OTHER</b>	78,718	1,534,281						1,612,999
<b>TOTAL</b>	1,215,597	6,692,184						7,907,781

**1a. What strategic priority does this program address?**

Reduce opioid abuse, Improve the health and safety of Missourians most in need, and Enhance access to care.

**1b. What does this program do?**

- The Genetics and Newborn Services program provides education, outreach, and interventions to improve women's prenatal, maternal, and child health; increase healthier births; promote normal growth and development outcomes; increase school readiness; and facilitate healthy outcomes throughout the lifespan. These outcomes are achieved through the following activities:
  - Promoting early entrance into prenatal care;
  - Promoting and providing education on healthy behaviors starting at preconception, examples include:
    - Developing and promoting educational materials, social media messages, and multimedia marketing campaigns to educate the public on healthy behaviors and available resources;
    - Promoting the Count the Kicks program to reduce still births;
    - Promoting use of folic acid to reduce birth defects;
    - Promoting the avoidance of smoking, alcohol, and other drugs during pregnancy;
    - Promoting breastfeeding; and
    - Promoting healthy parenting skills.
  - Administering a confidential, toll-free Maternal Child Health Information and Referral Line that connects families with programs and services (TEL-LINK);
  - Administering the provision of voluntary evidence-based home visitation model services to low income at-risk prenatal and postpartum women and their infants and children (up to age 5) to improve pregnancy and infant health outcomes;
  - Providing newborn screening tracking and follow-up for over 70 different rare disorders, including hearing loss and critical congenital heart disease;
  - Providing safe portable cribs and safe sleep education to low-income families;
  - Collaborating with child abuse medical resource centers to provide training, support, and mentoring to Sexual Assault Forensic Examination-Child Abuse Resource and Education (SAFE-CARE) medical providers;
  - Providing screening, diagnostic evaluations, treatment, and counseling for Missourians with genetic conditions; and
  - Providing metabolic formula for adults and children with metabolic conditions.

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**2a. Provide an activity measure(s) for the program.**

<b>Clients Served by Newborn Health Services</b>						
	FFY 2018	FFY 2019	FFY 2020*	FFY 2021 Proj.	FFY 2022 Proj.	FFY 2023 Proj.
Educational Materials Distributed	417,011	405,089	275,549	400,000	400,000	400,000
Safe Cribs Distributed	406	334	315	335	400	460
Safe Sleep Education Sessions	655	626	593	625	700	775
Number of TEL-LINK Referrals	2,167	2,912	3,267	2,900	2,900	2,900

\*Decrease in Safe Cribs Program utilization and education sessions as well as distribution of educational materials are due to the COVID-19 pandemic. TEL-LINK referrals continue to increase due to online search campaign success.

<b>Home Visitation Clients Served</b>						
	FFY 2018	FFY 2019	FFY 2020	FFY 2021 Proj.	FFY 2022 Proj.	FFY 2023 Proj.
Building Blocks	302	364	306	325	325	325
Maternal, Infant, and Early Childhood Home Visiting (MIECHV)	508	576	542	575**	575**	575**
Healthy Families Missouri Home Visiting	139	147	118	140	140	140
<b>TOTAL</b>	<b>949</b>	<b>1,087</b>	<b>966</b>	<b>1,040</b>	<b>1,040</b>	<b>1,040</b>

\*The FFY 2020 total is less than FFY 2019 due to caseload decreases related to the COVID-19 pandemic. These are expected to rebound to the projections for the subsequent years.

\*\*The increase of the projections for FFY 2021, 2022, and 2023 are due to redistribution of funding to support more caseload capacity as a result of a MIECHV supported agency declining the FFY 2021 contract and an award of a new RFP for expanded services in FFY 2021.

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**2a. Provide an activity measure(s) for the program. (continued)**

<b>Newborn Blood Spot Screening Tracking and Follow-up</b>						
The Missouri Newborn Blood Spot Screening Program tracked, followed, and provided educational information to the parents of:	<b>CY 2018</b>	<b>CY 2019</b>	<b>CY 2020 Proj.</b>	<b>CY 2021 Proj.</b>	<b>CY 2022 Proj.</b>	<b>CY 2023 Proj.</b>
Newborns referred to contracted referral centers for follow-up of abnormal newborn blood spot screening results.	676	577	625	625	625	625
Newborns diagnosed with disorders identified through newborn blood spot screening.	182	184	200	200	200	200
Newborns with hemoglobinopathy trait identified through newborn blood spot screening.	1,644	1,555	1,500	1,500	1,500	1,500
Newborns who need a repeat blood spot screening.	2,118	2,915	2,500	2,500	2,500	2,500
Newborns who missed the blood spot screening.	305	260	300	300	300	300

<b>Newborn Hearing Screening Tracking and Follow-up</b>						
The Missouri Newborn Hearing Screening Program tracked, followed, and provided educational information to the parents of:	<b>CY 2018</b>	<b>CY 2019</b>	<b>CY 2020 Proj.</b>	<b>CY 2021 Proj.</b>	<b>CY 2022 Proj.</b>	<b>CY 2023 Proj.</b>
Newborns who failed to pass their initial newborn hearing screening.	2,445	2,492	2,400	2,400	2,400	2,400
Newborns who missed their hearing screening.	575	445	500	500	500	500
Newborns who were diagnosed with permanent hearing loss and referred to early intervention via Missouri's Part C Program, First Steps.	98	95	95	95	95	95

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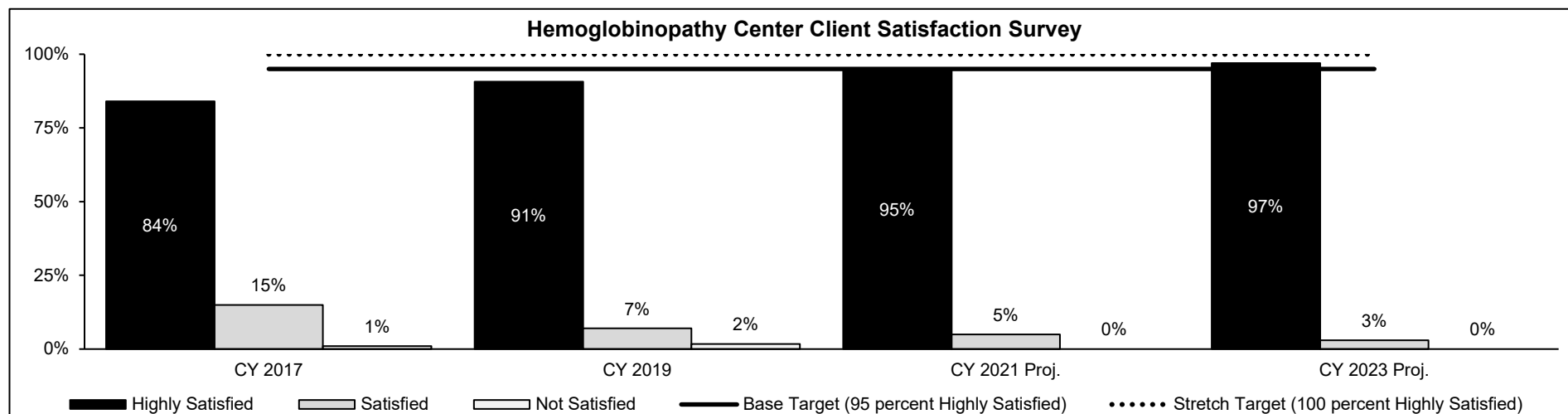
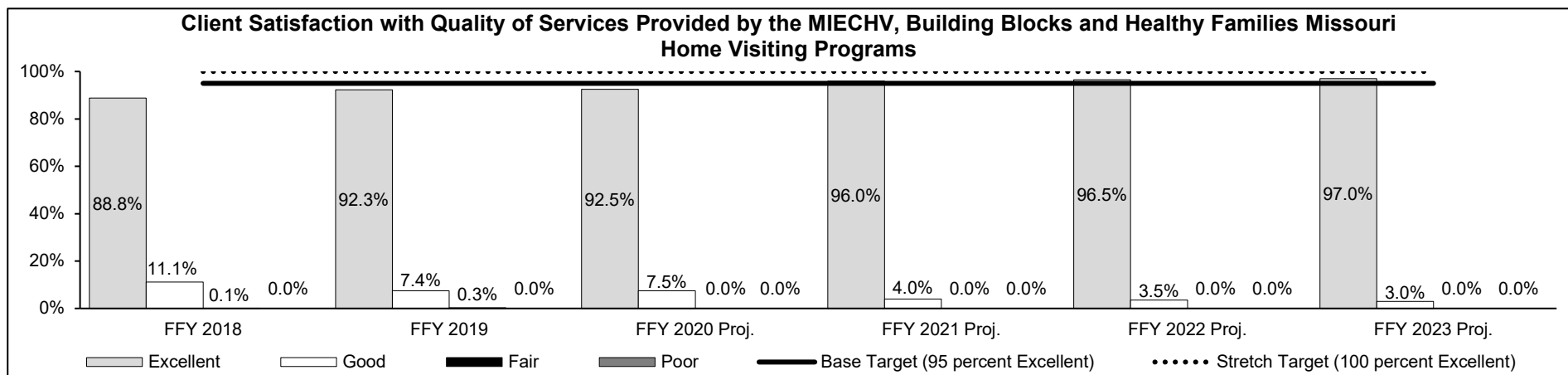
Department of Health and Senior Services

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Genetics and Newborn Services

Program is found in the following core budget(s):

2b. Provide a measure(s) of the program's quality.



This survey is given to hemoglobinopathy patients to evaluate their level of satisfaction with the care they receive at the hemoglobinopathy centers. DHSS contracts with four pediatric and three adult hemoglobinopathy centers to provide newborn screening follow-up and comprehensive medical services (i.e. inpatient, outpatient, and emergency care) for individuals and families with sickle cell disease and other related disorders. The survey is conducted every 2 years.

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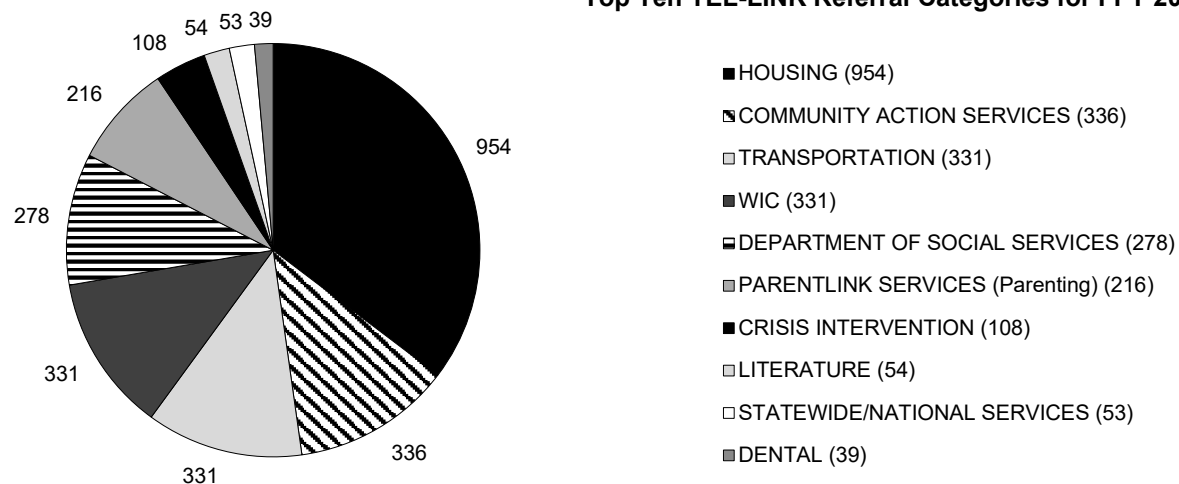
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**Genetics and Newborn Services**

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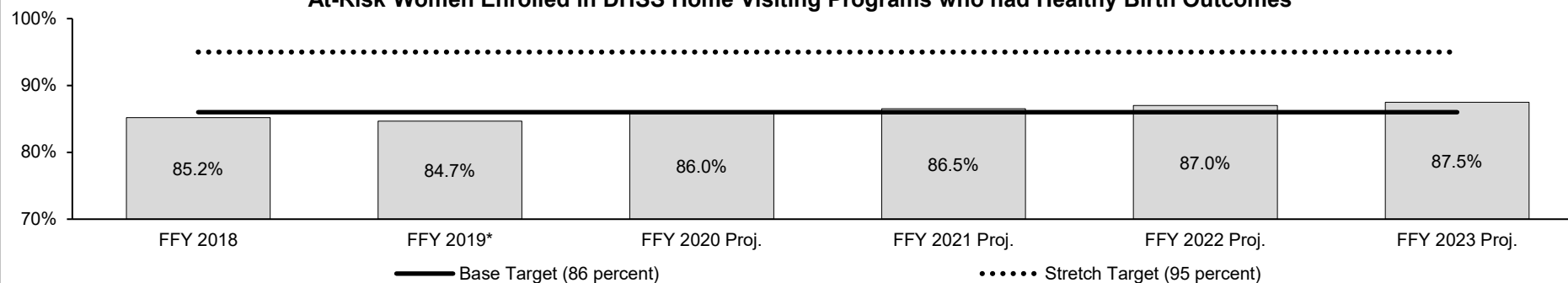
**2c. Provide a measure(s) of the program's impact.**

**Top Ten TEL-LINK Referral Categories for FFY 2019**



TEL-LINK is the DHSS's confidential, toll-free telephone line for maternal and child health care. The purpose of TEL-LINK is to provide information and referrals to Missouri residents concerning a wide range of health services. There are 52 different referral categories within the TEL-LINK database. The ten referral categories illustrated here represent 93 percent of the total referrals for FFY 2019. The number of referrals may fluctuate from year to year based upon available funding for advertising as well as the needs of the population.

**At-Risk Women Enrolled in DHSS Home Visiting Programs who had Healthy Birth Outcomes**



Healthy birth outcomes are defined as births occurring at 37 or greater weeks gestation.

\*The decreased percentage for FFY 2019 is likely contributed to the closure of a major birthing hospital in Kennett, MO, in Dunklin county, one of the five counties served by MIECHV home visiting. Several births from this population occurred between 35-36 weeks and are speculated to have been elective due to increased distance to the next closest birthing hospital to the client.

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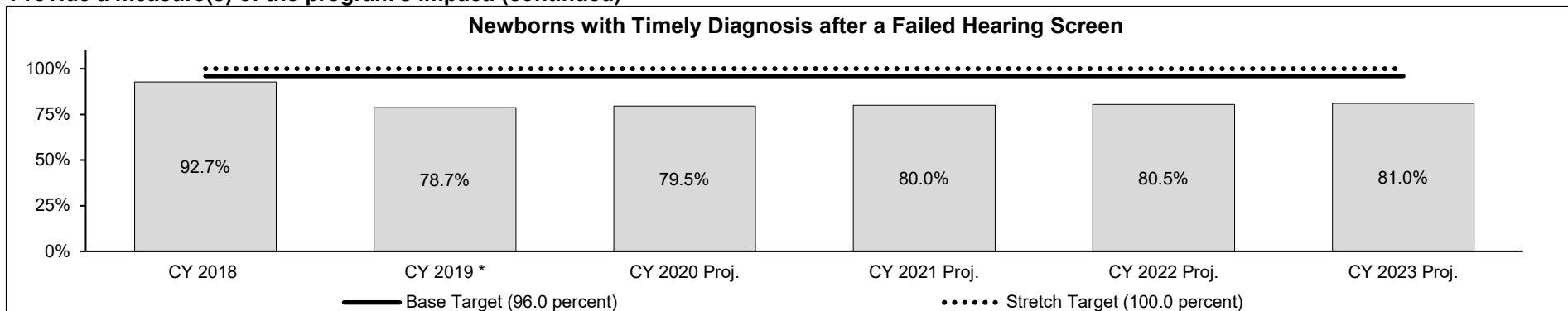
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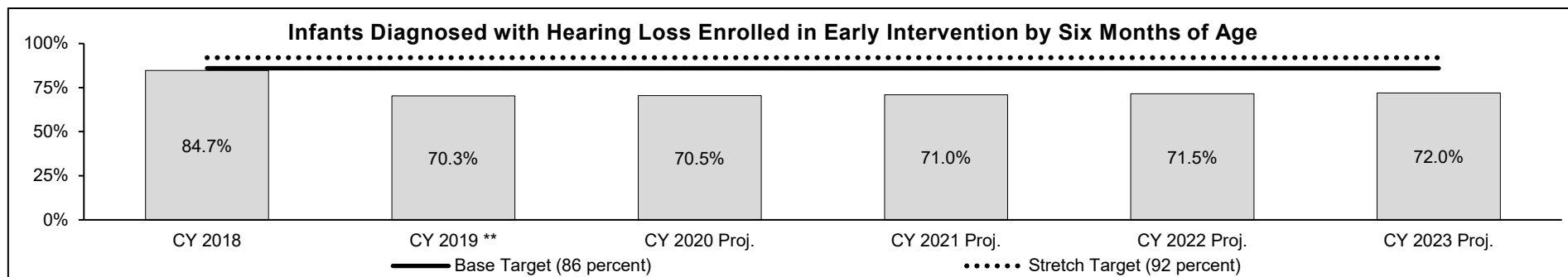
**Program is found in the following core budget(s):**

**2c. Provide a measure(s) of the program's impact. (continued)**



Universal newborn hearing screening, when accompanied by timely access to outpatient rescreening, audiologic diagnostic evaluation, and intervention services (e.g. training in sign language, hearing amplification services, and speech language services), can improve language, social, and emotional outcomes for children born deaf or hard of hearing and result in economic benefits to society. The purpose of Missouri's Newborn Hearing Screening Program is to screen all infants for hearing loss by one month of age, ensure those infants that fail screening are evaluated to identify hearing loss by three months of age, and ensure all infants diagnosed with permanent hearing loss are enrolled in an early intervention program by six months of age.

\*The drop in timely diagnosis after a failed hearing screen for babies born in 2019 is likely due to the increased number of failed hearing screens(1,090 in 2018 compared to 1,183 in 2019) leading to delays in scheduling diagnostic evaluations. Another factor may be Missouri's increasing preterm birth rate (10.7 in 2018 compared to 10.9 in 2019, according to the March of Dimes). The Newborn Hearing Screening Program is working to determine gestation-adjusted ages and recalculate in order to better understand the data.



Appropriate intervention must occur within the first six months of life in order for children born with hearing loss to develop language skills matching their typical hearing peers by five years of age. The purpose of Missouri's Newborn Hearing Screening Program is to screen all infants for hearing loss by 1 month of age, ensure those infants that fail screening are evaluated to identify hearing loss by 3 months of age, and ensure all infants diagnosed with permanent hearing loss are enrolled in an early intervention program by 6 months of age.

\*\*The drop in infants diagnosed with hearing loss and enrolled in early intervention by six months of age for babies born in 2019 corresponds with the decrease in the percentage of infants who did not receive a timely diagnosis in the same year. An infant diagnosed after three months of age is less likely to enroll in early intervention by six months of age.

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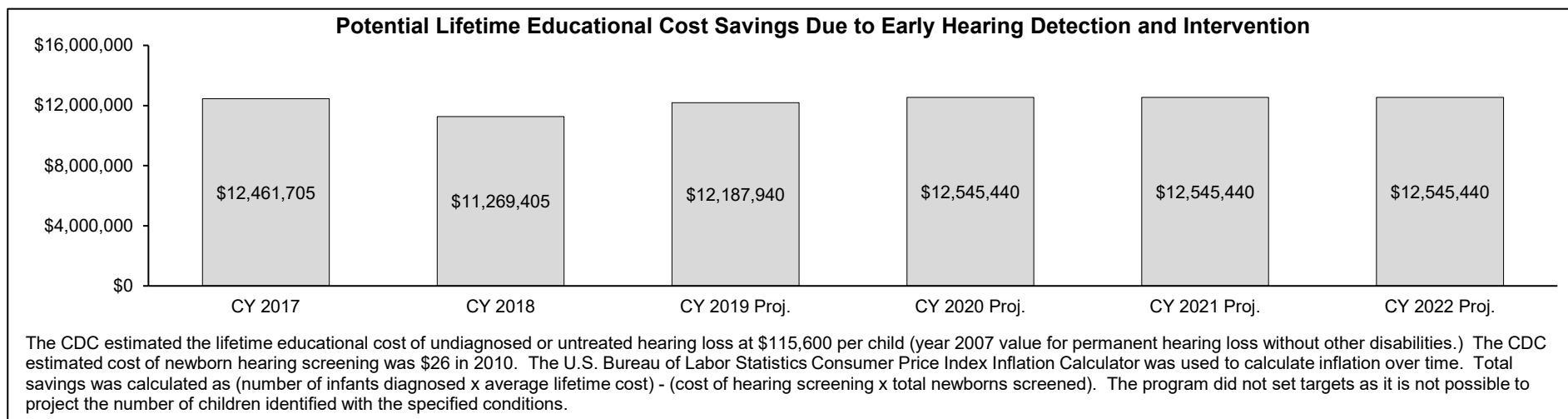
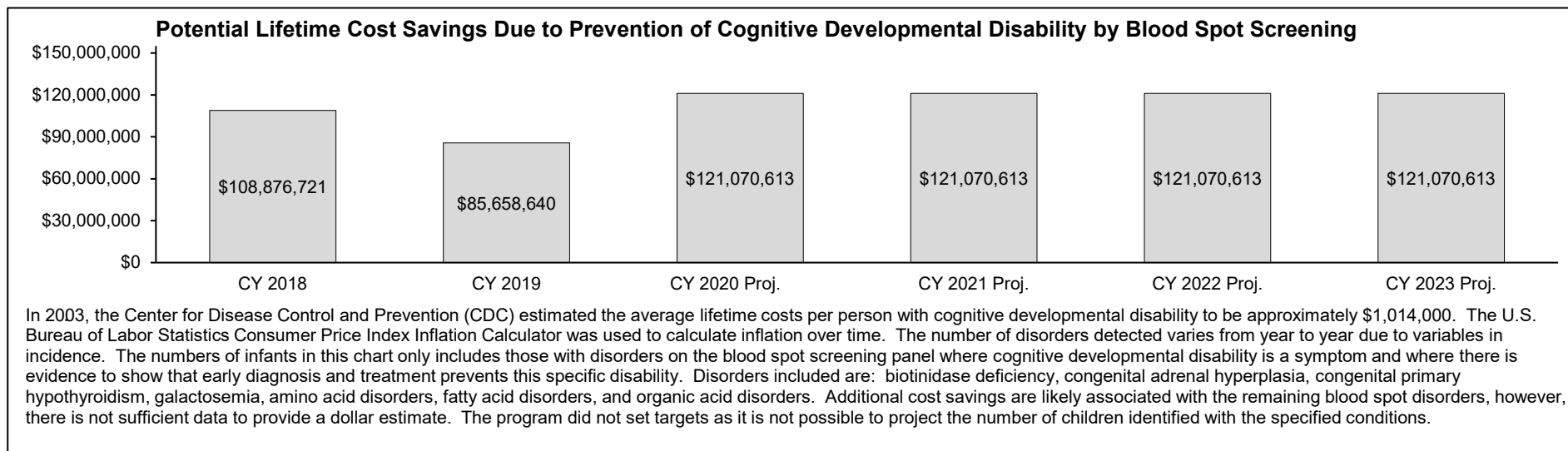
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Genetics and Newborn Services

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2d. Provide a measure(s) of the program's efficiency.



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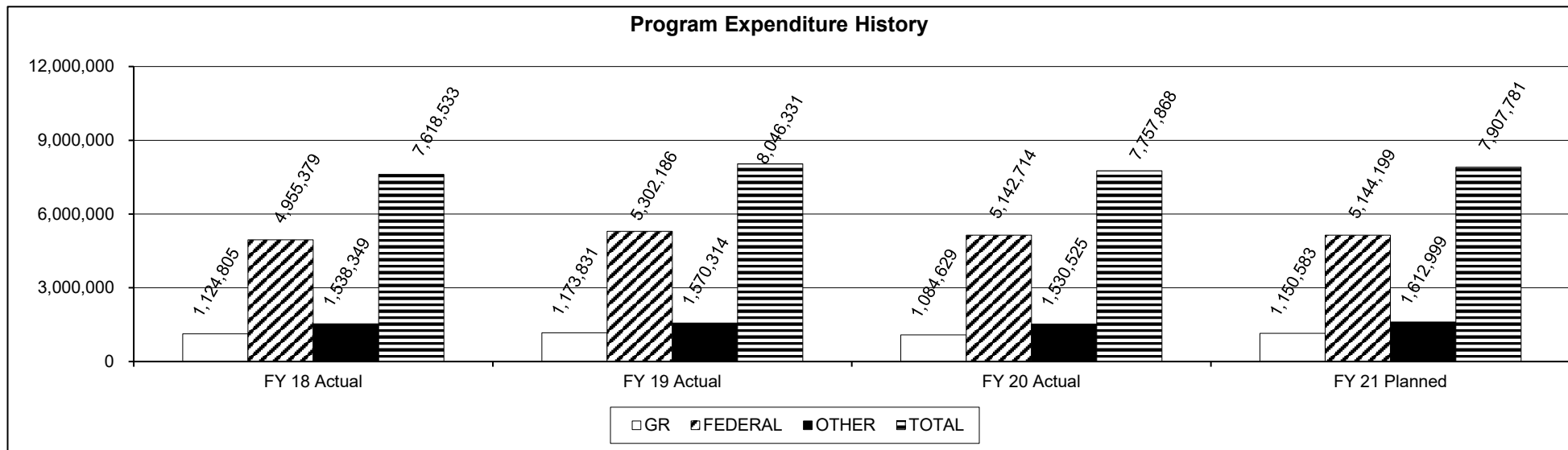
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**3. Provide actual expenditures for the prior three fiscal years and planned expenditures for the current fiscal year. (Note: Amounts do not include fringe benefit costs.)**



**4. What are the sources of the "Other " funds?**

Health Initiatives Fund (0275) and Missouri Public Health Services (0298).

**5. What is the authorization for this program, i.e., federal or state statute, etc.? (Include the federal program number, if applicable.)**

Sections 191.300 - 191.380 RSMo (Adult Genetics and Metabolic Formula; Sections 191.331 - 191.332 RSMo (Newborn Blood Spot Screening)); Sections 191.925 - 191.931, RSMo (Newborn Hearing Screening); Section 191.334, RSMo (Newborn Critical Congenital Heart Disease Screening); Sections 192.060 and 192.067, RSMo (Pregnancy Associated Mortality Review); Sections 191.725, 737, and 743, RSMo (Perinatal Substance Abuse); and the Federal Omnibus and Reconciliation Act (OBRA 89) and Maternal Child Health Information and Referral Line and Section 192.001.1, RSMo (TEL-LINK). This also includes the Social Security Act; Title V, Maternal and Child Health Services Title V Block Grant Sections 501 - 510; § 511 (c) Maternal, Infant and Early Childhood Home Visiting Programs (42 U.S.C. § 711 (c)), as added by § 2951 of the Patient Protection and Affordable Care Act (P.L. 111 - 148), reauthorization and appropriation for FFY16 provided through Medicare Access and CHIP Reauthorization Act (P.L. 114-10).



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<b>6. Are there federal matching requirements? If yes, please explain.</b>	
Yes. The Maternal and Child Health Services Title V Block Grant partially supports this program and requires a three dollar non-federal match for every four dollars of federal funds received, and requires maintenance of effort.	
<b>7. Is this a federally mandated program? If yes, please explain.</b>	
Yes. Federal Omnibus and Reconciliation Act (OBRA 89) and Maternal Child Health Information and Referral Link (TEL-LINK) and Social Security Act, Title V, § 511 (c) Maternal, Infant and Early Childhood Home Visiting Programs (42 U.S.C. § 711 (c)), as added by § 2951 of the Patient Protection and Affordable Care Act (P.L. 111-148).	