ABSTRACT OF FINAL REPORT

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This report is the culmination of the work of a large group of stakeholders to develop a Newborn Screening & Genetic Plan for Comprehensive Integrated Newborn Screening and Genetics Infrastructure for Children with Special Health Care Needs and Genetic Disorders. The plan identified approximately seventy particular needs grouped under nine main headings: Parent Education, Physician Education, Desirable Database, Legislation, HIPAA/Informed Consent, Medical Home, Transitioning, Policies/Procedures, and Expanded Services. These nine areas were further condensed into four primary areas of infrastructure needs, specifically: policies and procedures, financial and legislative support, education, and expanded services. Six core areas of action were then recommended in the plan: Education of parents and healthcare providers; Financial support to implement the recommended actions; Enhanced staffing and staff training; Legislation to establish long-term, sustainable funding sources with supporting policies and procedures; An integrated, or linked database system; Expanded services to establish a comprehensive CSHCN and Newborn Screening Program. With improved data capacity and integration of data systems, better measurement capacity should be realized. With the development of appropriate communication and service linkages, Nebraska should see an increase in the percent of CSHCNs with genetic disorders who receive timely, quality, integrated, comprehensive, family centered, culturally appropriate services coordinated through a medical home.