

Access to Genetic Services For Underserved Populations



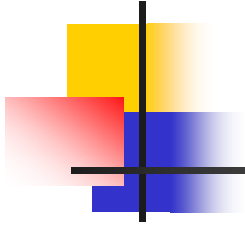
Workgroup Charge

- Develop and implement a regional action plan to address access to genetic services for underserved populations



Defining Key Terms

- **Genetic services** include, but are not limited to genetic counseling, education, diagnosis and treatment for those with or at risk for genetic conditions, congenital abnormalities and conditions with a genetic component and are provided by medical geneticists, genetic counselors and/or genetic nurses.



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- **Underserved** populations include those that are difficult to reach, do not receive needed services, and/or are disadvantaged in one or more ways.



Literature Review

- Keyword 1: Genetic ... Services, Counseling, Education, Diagnosis, Testing, Treatment, Conditions, Predisposition, Disorder
- Keyword 2: Access, Barriers, Poverty, Socioeconomic, Geographic Isolation, Rural, Health Professional Shortage, Minority, African American, Hispanic, Latino, Linguistically Isolated, Disparity, Underserved, Amish
- 42 articles reviewed and summarized on template



Identified Key Issues

- Lack of Awareness
- Communication Systems
- Payment Issues
- Geography
- Cultural Competency
- Lack of Providers

Access Monday March 20 th 2006		Continuum of Services for Families of Children with Heritable Disorders				
		Identification/Referral		Diagnosis and Genetic Counseling	Treatment/Management	Transition to Adult Services
		NBS	Non-NBS			
Issues Impacting Access to Services	Lack of Awareness	Parents lack awareness of NBS Providers lack of awareness of NBS	Community service providers*, health providers, and families unaware of how/when to make referrals	Knowledge, attitudes, and beliefs about genetic services (families & providers) impact use of genetic services	<u>Lack of Knowledge of</u> <ul style="list-style-type: none"> o Specialty clinics (providers/families) o Community supports (providers/families) o CPT Codes (providers) o Rapidly evolving treatments (Medical Homes Website) 	Families and providers don't know how to facilitate transition to adult services
	Communication Systems	Addressed by Short Term Follow-up WG	Inadequate communication among community service providers, health providers, and families	Families may need assistance to navigate the system (e.g. paperwork)	Inadequate communication medical home and genetic specialist	<u>Inadequate communication between</u> <ul style="list-style-type: none"> o Pediatric and adult provider o Youth, family, and provider of adult services
	Payment Issues State Programs Private Insurance	NBS may not be paid for in the case of home births	Lack of state funding for follow-up	No billing codes for genetic counseling	<u>No/limited reimbursement for</u> <ul style="list-style-type: none"> o Foods/formulas o Some treatments for genetic disorders (e.g. experimental tx's) 	State subsidized programs end Insurance coverage through parent's insurance ends
	Geography	NBS tests are mandated by states (no barriers identified).	Limited access to community supports or medical homes in remote areas	Services not available in remote areas Frequency of outreach clinics may not meet need		
	Cultural Competency	Lack of culturally competent NBS materials	Lack of culturally competent educational materials Services aren't culturally competent Lack of culturally diverse providers			
	Lack of Providers	NBS tests are mandated by states (no barriers identified).	Lack of Specialists to refer to	Lack of genetic counselors and specialists to diagnose	Lack of genetic specialists to manage disorders	Lack of trained adult specialists
	*Birth Defects, EHDI, Early Intervention, CSHCN, Primary/Specialty Providers, Families, WIC, EPSDT, Mental Health System, Support Groups, MSS/ISS, Local Public Health					



Work Group Priorities

- Family awareness of why, when and how to access services
- Family and provider awareness of, and ability to facilitate, transition to adult services
- Telemedicine
- Reimbursement strategies/legislation



Collect and Assess Educational/Awareness Models

- Request for materials from state genetics coordinators; distributed by regional collaborative
- Materials for providers or families on making referrals for genetic services (non-newborn screening, focused on children 0-21 years)
- All materials: pamphlets, brochures, CD-Roms, web-based



Joint Meeting

- Community Collaboration and Family Support
- Review of all materials
- Selection of materials to adapt for regional use



Key Components

- Who would use genetic services?
 - Why use? What value? Why beneficial
 - When
 - What (services)
- What to expect – the process
- Indications for referral
- Preparing for the visit
 - Questions to ask



Key Components (Cont'd)

- Discuss cost
- Family stories
- Privacy Protection
- How to refer? Who can refer?
- Link to resources/groups
- Link to contact information



Next Steps

- Finalize regional materials
- Identify gaps
- Develop FAQs
- Pilot test materials
- Develop strategy for dissemination



Work Group Members

- IL – Twyla Hopkins, Luna Okada
- IN – Ellen Kucharski, Bob Bowman
- KY - Joyce Robl
- OH - Carol Closson, Colette Glynn-Gaba,
Shelley Nottingham, Anna Starr
- MI- Carrie Curell-Langbo
- MN- Kristin Peterson-Oehlke, Amy Powers
- WI- Christine Cronk, Lindsay Zetzsche



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