

Payment Issues – Literature Review

Identification/Referral		Diagnosis & Genetic Counseling	Treatment/ Management	Transition to Adult Services
NBS	Non-NBS			
Barrier 1: NBS may not be paid for as part of birthing experience for home births	Barrier 1: Lack of state funding for follow-up Barrier 2: Not Able to access other healthcare professionals without PCP referral.	Barrier 1: No billing codes for genetic counseling	Barrier 1: No/limited reimbursement for <ul style="list-style-type: none"> • foods and formulas • some treatments for genetic disorders 	Barrier 1: State subsidized programs end at adulthood Barrier 2: Insurance coverage through parent's insurance ends

Payment Issues - Strategies

Identification/Referral		Diagnosis & Genetic Counseling	Treatment/ Management	Transition to Adult Services
NBS	Non-NBS			
Barrier 1: NBS may not be paid for as part of birthing experience for home births	Barrier 1: Lack of state funding for follow-up	Barrier 1: No billing codes for genetic counseling State subsidy for genetic counseling (using a variety of funding sources, Title V, revenue from sale of NBS card,) Barrier 2: Testing/ diagnostic services not covered/limited coverage Michigan is assessing reimbursement for genetic testing and diagnosis through Medicaid	Barrier 1: No/limited reimbursement for <ul style="list-style-type: none"> • foods and formulas • some treatments for genetic disorders State legislation for reimbursement of foods and formulas Michigan has a parent group working on third party insurance coverage for medical foods and formulas PKU toolkit to help parents advocate for coverage by their third party insurance	Barrier: State subsidized programs end at adulthood Barrier: Insurance coverage through parent's insurance ends

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