Diet for Life Work Group: Strategy Prioritization Sheet

1= not necessary at all, should not be included
2= not very important
3= neutral, may or may not be helpful
4= very important
5= absolutely essential, must be included

Strategies for Component #1: A Coordinated Metabolic Treatment Program		Rank importance of each strategy on scale of 1-5
A	Maintain a comprehensive metabolic disease treatment program supported by MDCH to assure qualified clinic personnel are available to provide appropriate diagnostic and follow-up services for all patients with inborn errors of metabolism	
B	Develop policies that strive to minimize disruption of current system for providing medical formula/food shipped directly to the patient's home based on metabolic dietitian and physician recommendations	
C	Establish a centralized Durable Medical Equipment Supplier (DME) as a single source supplier for medical foods*	
D	Establish a centralized pharmacy as a single source supplier for medically necessary single amino acids, amino acid mixtures and vitamins*	
Other		

*Part of consensus recommendation to establish a centralized DME as a single source supplier for nutritional treatment products, as identified at November work group meetings

Strategies for Component #2: Family Education and Advocacy		Rank importance of each strategy on scale of 1-5
A	Clarify timeline for implementation of changes with families	
B	Clarify out of pocket expenses for families- how much they should expect to contribute	
C	Address concerns re: Children's Special Health Care Services (CSHCS) from families of children with inborn errors of metabolism (IEM)	
D	Develop metabolic clinic process to work with each family to assess insurance coverage and explain available options	
E	Assist families with appeal process for denied claims, as needed • Educate individuals and families about calling helplines such as beneficiary line for Medicaid • Develop factsheet for parents and individuals with IEM regarding tips to approach payers; consider adapting National PKU recently developed factsheet on tips for families in dealing with payers; consider what is incentive for families to approach payers	
F	Disseminate work group's recommendations and solicit feedback from other MI families and individuals with IEM	
G	Continue Diet for Life work group or similar group to implement recommendations and continue to address needs of MI individuals and families with IEM who require nutritional treatment	
Other		

1= not necessary at all, should not be included
2= not very important
3= neutral, may or may not be helpful
4= very important
5= absolutely essential, must be included

Strategies for Component #3: Maximum Use of 3rd Party Insurance Benefits		Rank importance of each strategy on scale of 1-5
A	Develop and implement process for families of children under 21 to enroll in CSHCS	
B	Develop and implement process for eligible individuals to apply for Medicaid and Healthy Michigan enrollment • Assure income-eligible women of reproductive age are enrolled prior to pregnancy	
C	Assess implications for Medicaid Health Plans; consider "carve out" for IEM nutritional treatments	
D	Bill all existing public or private insurance for all forms of nutritional treatment*	
E	Assign MDCH staff to assist clinic and families with payer and billing issues regarding nutritional treatment for individuals with IEM	
F	Assign metabolic clinic staff to become billing expert and liaison for families and payers (i.e. 'insurance navigator') regarding nutritional treatment for individuals with IEM	
G	Attempt to find at least one contact at each health plan that is aware and knowledgeable about this issue	
H	Develop methods for metabolic clinic to track results of all attempted billing- including rates of coverage, denials, reimbursement levels, health plan responses, problems with DME, etc.	
I	Summarize current coverage and gaps in coverage for all three sub-types and various patient types and payer types	
Other		
	* Consensus recommendation to have clinic start billing insurance, as identified at November work group meetings	

Strategies for Component #4: Increased Access To Low Protein Modified Foods		Rank importance of each strategy on scale of 1-5
A	Develop centralized single source supplier for low protein modified foods (to leverage group purchasing power) • Use "metabolic food store" model or DME	
B	Investigate possibility of providing a monthly low protein modified basic food package based on patient's age and dietary needs, with annual review of covered medical food products • Consider placing limits on quantities of food provided (rather than limits on types and/or sources of food)	
C	Investigate if fundraising is possible to support a medical food store (like Colorado)	
Other		

1= not necessary at all, should not be included
2= not very important
3= neutral, may or may not be helpful
4= very important
5= absolutely essential, must be included

Strategies for Component #5: A Safety Net		Rank importance of each strategy on scale of 1-5
A	Develop and implement process for coverage when other means exhausted • Consider developing process of payment and receipt for nutritional treatments when ineligible for coverage by payers or state programs (similar to Kentucky) • Determine what NBS (or other state) funds can be used for nutritional treatment	
B	Provide nutritional treatment based on diagnosis without means testing	
C	Investigate sliding scale for costs related to nutritional treatment for families	
D	Explore whether CSHCS would be able to cover adults with IEM (like adults with cystic fibrosis and hemophilia)	
E	Investigate hardship programs offered by pharmaceutical companies, product manufacturers and others	
Other		
Strategies for Component #6: Coordination with State and Federal Supplemental Food Programs		**Rank importance of each strategy on scale of 1-5**
A	Determine supplemental foods (i.e. naturally occurring low protein foods) available to eligible recipients of WIC, food stamps, school lunch programs, etc.	
B	Develop and implement process for eligible families of children 0-5 and pregnant/post-partum women to enroll in WIC	
C	Approach other state departments (i.e. Dept. of Human Services) about possible food coverage (i.e. food stamps/MI Bridges and MI school breakfast/lunch programs)	
Other		

1= not necessary at all, should not be included
2= not very important
3= neutral, may or may not be helpful
4= very important
5= absolutely essential, must be included

	Strategies for Component #7: Possible Legislation, if needed	Rank importance of each strategy on scale of 1-5
A	Consider state mandate for third-party/private insurers to cover medical foods, regardless of age or gender* • Include possibility of covering those without insurance coverage as 'protected class' (similar to Kentucky)	
B	Introduce legislation to create a state metabolic food program that provides coverage for all patients with genetic inborn errors of metabolism for all three sub-types of treatment • Include all patients regardless of age or gender, whether or not detected by NBS • Include coverage for shipping or distribution costs, protein reimbursement and family costs	
C	Explore feasibility of amending NBS law to include coverage for nutritional treatments (similar to Wisconsin) • Could this be added to the Michigan law and still remain budget neutral? • Leverage funds from other state programs and/or raise NBS fee?	
D	Investigate introduction of legislation for state tax credit for costs of medical food for families and individuals with IEM	
E	If state legislation is pursued, ensure we can demonstrate need, is budget neutral and will be effective • Investigate if health economic studies have been done and results available regarding nutritional treatment for inborn errors of metabolism • Investigate if other states have budget information available to show that their programs are budget neutral or that ultimate savings are beyond actual cost	
F	Monitor federal bills regarding medical food legislation	
G	Determine impact of ACA on nutritional treatment for inborn errors of metabolism and potential impact on current payers if new state legislation introduced	
H	Identify patient advocates to work on nutritional treatment issue and lobby for legislation if needed	
Other		

* Part of consensus recommendation to mandate insurance coverage for medical foods, as identified at November work group meetings

1= not necessary at all, should not be included
2= not very important
3= neutral, may or may not be helpful
4= very important
5= absolutely essential, must be included

Other Strategies		Rank importance of each strategy on scale of 1-5
A	Investigate if restaurants can be more 'IEM-friendly'	
B	Attempt to change reimbursement based on calories amount	
C	Attempt to determine if flavor of medical food can be improved	
Other		

Name and Contact Information:
(OPTIONAL)

Any other comments you would like to share: