

Newborn Screening Long-term Follow-up (LTFU) Assessment

Association of Maternal and Child Health
Programs (AMCHP)

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Long-term Follow-up

“LTFU begins after short-term follow-up ends; that is, with the initiation of treatment. For the purposes of maternal and child health (MCH) program responsibility, LTFU ends upon transition to the adult service delivery system at 21 years of age. Concurrent with such a transition, public health agencies should assure the formal transfer of LTFU responsibility from MCH to an appropriate public health program to continue LTFU throughout affected individuals’ lifespans.”

Basic Components of Long-term Follow-up (LTFU)

- Assuring that ongoing, high-quality medical management – including specialty care and care coordination, when needed – are provided within the context of a medical home to children, adults and families affected by heritable disorders
- Assuring transition of young adults to appropriate adult medical care



Components of LTFU (cont.)

- Periodically assessing patient progress through review of defined outcome indicators
- Collecting and analyzing state LTFU data
- Engaging in continuous quality improvement at the local, state and national levels



Current State LTFU Activities

- States are most actively engaged in the first component of LTFU – assuring high-quality medical management and care coordination
- The level of clinical tracking varies greatly for each disorder category
- States have experimented with innovative approaches to LTFU, particularly when dedicated federal funding has been available.



Challenges

By far the biggest challenges facing those who wish to strengthen LTFU systems are the *low priority* accorded to LTFU compared to other newborn screening activities and an associated *scarcity of resources*.



Opportunities

- Timeliness
 - American College of Medical Genetics report 2005
- Ongoing Projects
 - Regional Genetics Collaboratives
- Uniform Core Datasets
- Building on Existing Data Systems



Next Steps

1. Publicize and advocate that LTFU is an essential part of a quality newborn screening program and a public health responsibility.
2. Develop an implementation plan for the LTFU components outlined in this report.



Next Steps (cont.)

3. Secure funding for LTFU
4. Develop standards for data collection related to newborn screening LTFU
5. Provide resources and technical assistance to states as they develop LTFU activities