

## State Systems Follow-up

Terminology:

**Genetic Disorder Surveillance** the ongoing, systematic collection, analysis, interpretation and reporting of data (e.g., regarding agent/hazard, risk factor, exposure, health event) essential to helping families access services they need to address their diagnostic and treatment needs.

**Follow-up:** Follow-up assists individuals, families, groups, organizations, and communities to utilize necessary resources to prevent or resolve problems or concerns.

- ★ Long-term follow-up is a mechanism for determining if the newborn screening system is accomplishing its intended goal of **improving health outcomes**.
- ★ Long term follow-up refers to an infrastructure with the capacity for **periodic monitoring of selected outcome indicators** appropriate for evaluating the efficacy of newborn screening.
- ★ Data obtained through long-term follow-up can be useful in **improving and refining the newborn screening system**.
- ★ Long-term follow-up may include facilitation of services to **ensure coordinated, comprehensive health care.**”

**Referral:** Referral may include developing resources that are needed, but unavailable to the population. The key to successful referral is follow-up; making a referral without evaluating its results is both ineffective and inefficient.

- Who to call, how to call, what to say when you call
- How refer?
- To who refer?
- Referral form and disposition back
- Checklist for referral options

**Locate those lost to follow-up:** a continuous process of public awareness activities, screening and evaluation designed to *locate, identify, and refer as early as possible* all children with genetic conditions and their families who are in need of services.

- What factors make a child lost to follow-up?
- How far and to what extent are programs responsible for ensuring the child is still enrolled vs. parent choice?
- What is the responsibility of the service systems – ***When*** are you done following up on ***what?***

**Communication across service systems:** Methods of communicating data and information for the purposes updating contact information, referring clients to needed services and addressing other needs in the follow-up system

**Communication across data systems:** TBD