

State Systems Follow-up

Terminology:

Public Health Surveillance the ongoing, systematic collection, analysis, and interpretation of data (e.g., regarding agent/hazard, risk factor, exposure, health event) essential to helping families access services they need to meet their needs.

Follow-up: 1) the process of assuring that family needs are being met.

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 child is still enrolled vs. parent choice?
- What is the responsibility of the service systems – **When** are you done following up on **what**?

Referral:

- 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

Communication across service systems: TBD

Communication across data systems: TBD

Time frame/continuum of care:

- Short Term Follow-up *is through* diagnosis
- **State System Follow-up starts with diagnostic confirmation.**
- **How long / to what age should a state systems model of follow-up be implemented?**

System Responsibilities:

- Follow-up
- Surveillance
- Communication across service systems
- Communication across electronic data systems
- Preventing lost to follow-up
- Locating lost to follow-up
- Referral

What exists?

- Activities and/or Specific protocol(s) for systematically
- Activities for each
 - Follow-up
 - getting data about the client/patient
 - contacting the family
 - communication across service systems
 - Surveillance
 - Communication across service systems
 - Communication across data systems
 - Preventing lost to follow-up
 - Locating lost to follow-up
 - Referral process

What do we need to know about each service system's follow up protocols to delineate models (or strategies within models) for consideration?