

State Systems Follow-up Workgroup FOLLOW-UP PROGRAMS SURVEY

Workgroup charge: Identify model state systems that increase access to services for children with heritable conditions and their families through: follow-up and supporting communication among programs.

GENERAL

1. What state do you represent?
2. Which program/service system do you represent on this workgroup?
3. What department is your program/service system housed in?
 - a. Please provide an organizational chart
4. What is your total funding?
 - a. Please provide a breakdown of funding by organization/source and amount
5. Do you have a legislative mandate?

FOLLOW-UP

6. Are you able to track referrals from this program to other systems?
7. Are you able to track referrals to services?
 - a. If yes, in particular, are you able to track referral to genetic services?
8. How long does your program follow children once they are in the program/system?
9. How does your program/system perform the follow-up?
10. From who/whom does your program/system obtain follow-up information?
11. At what intervals are follow-up activities conducted/information obtained?
12. What tools do you have/use for follow-up?
13. What protocols or activities does your program/system engage in to:
 - a. Get information about a child/client
 - b. Contact the family
14. What are the indicators you are trying to monitor, if any?

SUPPORTING COMMUNICATION AMONG PROGRAMS

15. What types of partnerships and mechanisms for communication are in place/exist across service systems in your state?
16. What happens when a family leaves your program/system's jurisdiction?
17. Can you use another system to locate children lost to follow-up?
18. Do you have a relationship with border states?
19. What data systems does your program have in place?
20. How can your data system(s) be used to facilitate follow-up?
21. What have you observed to successfully integrate state follow-up systems in terms of:
 - a. Training for field staff
 - b. Integrated data systems/capacity
 - c. Data sharing agreements