

State Systems Survey

Region 4 Genetics Collaborative

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2011

State Systems Follow-up Workgroup FOLLOW-UP PROGRAMS SURVEY

Organization Background Information

Region 4 Genetics Collaborative

Region 4 is one of seven regional collaboratives in the United States. Our Region includes seven states (Illinois, Indiana, Kentucky, Michigan, Minnesota, Ohio and Wisconsin) and a variety of stakeholders including: parents, primary care providers, specialists, laboratorians, and representatives from public health agencies and universities.

Vision

All newborns will receive state-of-the-art newborn screening and follow-up; children and youth with heritable disorders will have access to genetic expertise and coordinated care in the context of a medical home.

Mission

1. Increase access to information about newborn screening and genetic resources, services and family support systems
2. Facilitate data collection and analysis to guide decision-making regarding screening cut-offs, diagnosis and long term treatment of heritable disorders
3. Support state public health agencies in improving infrastructure for genetic service delivery to children with heritable disorders
4. Provide a forum for families, public health, and clinical providers to share best practices and models for improving newborn screening, follow-up and genetic care coordination
5. Link Region 4 states with regional and national initiatives for improving the quality of newborn screening and genetic service delivery.

State Systems Follow-up Workgroup

Working towards item #3 of the Region 4 mission, the State Systems Follow-up (SSFU) Workgroup is comprised of five public health agency representatives from each of the Region's seven states.

In April 2010, the workgroup met face to face to start work on improving public health infrastructure for more effective delivery of services. The group concluded that effective follow-up for children with heritable disorders provide “just in time information” to the child’s family and medical home. Statewide service systems such as newborn screening, early hearing detection programs, birth defects registries, children with special health care needs and early intervention programs provide opportunities to identify children with heritable disorders and initiate the continuum of follow-up activities. Given these statements, the SSFU will focus on protocols and practices for an integrated follow-up system that increases access to genetic services for children with heritable conditions.

Workgroup Charge

Explore models and outcomes to identify and recommended promising practices for state implementation (of whole model or parts) to improve their own systems for children with heritable conditions and their families.

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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.

Name: _____

State: _____

Service System: _____

GENERAL INFORMATION

1. What department is your state system* housed in?
 - a. Please send an organizational chart to Region 4 (info@region4genetics.org)
2. What is your total funding?
 - a. Please provide a breakdown of funding by organization/source and amount
 - b. How does this funding impact your ability to perform effective follow-up?

FUNDER/SOURCE	AMOUNT
CDC	
MCHB	
Newborn Screening Fees	
Other, please describe	

3. What are your program outcomes, and how do you measure them?

FOLLOW-UP ACTIVITIES

4. What does “follow-up” mean to your system?
[PROMPT]
 - Identification of CSHCN
 - Referrals to other state systems
 - Share information between state systems
 - Referral to services*
 - Provide educational materials
 - Provide notifications to healthcare providers
 - Record audit/review
 - Track services received
 - Other, please specify
5. How long does your program follow children once they are in your system?

* See the State Systems Terminology and Definitions on Pg 5 for more information

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6. Share how you obtain follow-up information: from what source, what forms/tools are used and at what interval are data collected.

SOURCE	INTERVAL	FORM	How well does this work?

[PROMPT] Please send any tools, algorithms, models to Region 4 (info@region4genetics.org) to assist in the development of models and promising practices.

7. Are you able to track referrals that you make from your system to other **systems**?
a. If yes, how

SYSTEM	METHOD FOR TRACKING REFERRALS	How well does this work?
NBS		
BDR		
CSHCN		
EI		
EHDI		

[PROMPT] Once a referral is made, how do you know the family took the next step?

8. Are you able to track referrals to **services**?
a. If yes, in particular, are you able to track referral to genetic services?

SERVICES	METHOD FOR TRACKING REFERRALS	How well does this work?
Mental Health (mental health therapy, skills training, etc)		
Public Health (immunizations, home visiting, WIC, etc)		
Educational (Part C, Zero to Three, etc)		
Family support (respite, support groups, transportation, etc)		
Insurance/medical coverage (Medicaid, etc)		
Other – please specify (faith or community-based)		

[PROMPT] Once a referral is made, how do you know the family took the next step?

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9. What written protocols or activities does your system engage in to contact the family
 - a. Initial contact
 - b. Follow-up for interval information
 - c. Lost to follow-up
 - d. Use another system to locate children lost to follow-up

10. What data system(s) does your system have in place to facilitate follow-up?
 - a. What written protocols or activities does your system engage in to share data?
(does system have authority to share; does it happen between systems)

11. What barriers does your system encounter when providing (or trying to provide) follow-up?

12. What happens when a family leaves your system’s service area jurisdiction?

13. What types of relationships do you have with border states?

14. Of the services you provide, is there a place to access (website, annual report, other report) quality improvement/other indicators of services received?

SUPPORTING COMMUNICATION AMONG SYSTEMS

15. What types of formal partnerships and mechanisms for communication are in place/exist across service systems in your state (specific to your service system)?

SYSTEM	PARTNERSHIPS/MECHANISMS FOR COMMUNICATION	How well does this work?
NBS		
BDR		
CSHCN		
EI		
EHDI		

[PROMPT] Please share examples of partnerships/mechanisms:

16. What have you observed to successfully integrate state follow-up systems in terms of:
 - a. Training for field staff (broadly, across systems)
 - b. Integrated data systems/capacity (get at what has made this work – cross training, sharing data system, job sharing, etc)
 - c. Data sharing agreements

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State Systems Terminology and Definitions

Section 1: General Information

For the purposes of this survey, state systems will be identified as Early Intervention (EI), Early Hearing Detection and Intervention (EHDI), Birth Defects Registry (BDR), Children (and Youth) with Special Health Care Needs (CSHNC), or Newborn Screening (NBS).

Section 2: Follow-up Activities

The **referring system** specifies your state system (EI, EHDI, BDR, CSHCN, or NBS).

The **other services** are the organizations where you are referring your client to for services. These services could be provided by other state systems or other organizations.

Types of Referral

Passive referral: the client is given contact for the appropriate service(s) and is left to make contact at his/her convenience

Facilitated referral: the referring system assists the client in accessing other services. For example, the referring system makes an appointment with the other service on behalf of the client.

Active referral: the referring system, with client consent, provides the other service with client information and needs.

Transfer referral: the client is shifted to another service without any immediate communication between the system and the other service. For example, transferring a client to a call center.

Dynamic referral: an in-person conversation with the client, referring system and the other service in which the referring system introduces the client and explains what has already been done to assist the client and their need for referral.

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Thank you for your participation in the Follow-up Programs Survey.

Next steps

Data from your state will be collected for each of the five identified service systems. Once this information is collected and summarized, you will be contacted to participate in a conference call with the other representatives from your state to contribute any outstanding information or clarify any responses.