

**State Systems Follow-up Workgroup
FOLLOW-UP PROGRAMS SURVEY**

GENERAL

1. What state do you represent? [*provided by the previous survey*]
 - a. IL; IN; KY; MI; MN; OH; or WI
2. Which program/service system do you represent on this workgroup? [*provided by the previous survey*]
 - a. BDR; CSHCN/CYSHCN; EHDI; EI; or NBS FU
3. Is your program/service system housed in the department of public health?
 - a. YES
 - i. Can you provide an organizational chart of the program/service system
 - ii. Can you also describe program/system relationships with other state systems
 - b. NO
 - i. Please share where the program/service system is housed
 - ii. Can you provide an organization chart of the program/service system
 - i. Can you also describe program/system relationships with other state systems
4. How is your program funded?
 - a. Centers of Disease Control
 - b. Maternal and Child Health Bureau
 - c. Other, please designate

PROGRAM/SERVICE SYSTEM

5. What functions does your program/service system perform? [*choices provided by the previous survey, will be confirmed, also new choices identified by group, i.a.*]
 - a. **BDR**
 - iii. Surveillance
 - iv. Referral
 - v. Medical record audit and review
 - vi. Monitor and maintain a centralized program to provide diagnosis and support to families
 - vii. Prevention
 - viii. Linking families to services
 - ix. Follow-up of families (children with spina bifida)
 - x. Notification
 - xi. Education activities
 - xii. Identification of CYSHCN
 - xiii. Pay for some services
 - xiv. Reporting
 - b. **EI**
 - xv. Identification and services for children 0-3 who meet eligibility
 - xvi. At-risk program for children

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- c. **CSHCN**
 - xvii. Care Coordination
 - xviii. Payment for specialty care
 - xix. Payment for diagnostic evaluations
 - xx. Reimbursement for family travel expenses related to specialty care
 - xxi. Medical home QIT facilitation
 - xxii. Transition planning
 - xxiii. Diagnostic evaluations
 - xxiv. Well/sick child care
 - xxv. Community referrals and information
 - xxvi. Follow-up after diagnosis
 - xxvii. Referrals
 - xxviii. Fund regional centers to support, provide information, referrals and education/training for families and providers
 - xxix. Fund family voices
 - xxx. Fund parent to parent matching program
 - d. **NBS FU**
 - xxxi. Follow-up on abnormal test results
 - xxxii. Follow undiagnosed cases until child is 16 years of age
 - xxxiii. Provide metabolic treatment formulas
 - xxxiv. Collaborate with MCH programs
 - xxxv. Collaborate with family service agencies
 - xxxvi. Refer families to local public health agencies
 - xxxvii. Monitor and maintain a centralized program to provide diagnosis and support to families
 - xxxviii. Confirm diagnosis
 - xxxix. Enroll children in specialty follow-up clinics, as appropriate
 - xl. Monitoring and surveillance of birthing facility for UNHS
 - xli. Follow-up on children who did not pass UNHS
 - xlii. Heelstick test
 - xliii. Coordination with clinicians to initiate diagnostic follow-up
 - xliv. Follow until diagnosis is confirmed/treatment started
 - xlv. NBS referral for diagnosis
 - xlvi. Birth defect referral to EI
 - xlvii. Follow up of all positive, borderline and unsatisfactory screens
 - xlviii. Contact and train hospital staff, follow up clinics
 - xlix. Outreach to families
 - e. **Other category (to further define any unlisted functions)**
6. What is the CHARGE of your program/system?
7. What are the OBJECTIVES for your program/system?
8. What are the GOALS of your program/system? [*provided by the previous survey and will be confirmed*]
- a. **Is there any added information by including this in the summary?**

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FOLLOW-UP ACTIVITIES

9. Average number of children who receive services from your program/system per year?
10. Average number of children referred from this program to other systems per year?
[Specify each system and number]
11. How long does your program follow children once they are in the program/system?
[choices provided by the previous survey, will be confirmed]
12. How does your program/system perform the 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 follow-up information does your program/system obtain?
15. From who/whom does your program/system obtain follow-up information?
16. At what interval are follow-up activities conducted? (or should it be is follow-up information obtained)
17. What tools do you have/use for follow-up? *[choices provided by the previous survey, and additional options identified by the workgroup, i.a.]*
 - a. EARS (used by EHDI system)
 - b. Highly capable staff
 - c. Network of family support
 - d. Regional (Audiology) consultant network
 - f. Letter generation
 - g. Alerts
 - h. Certified email
 - i. Phone calls
 - j. Educational materials for clinicians
 - k. Educational materials for parents/families
 - l. Protocol templates for hospitals
 - m. IT system
 - n. Medicaid system access
 - o. Vital statistics access
 - p. Reports for missing screens
 - q. Health Survey form
 - r. CH 3-year form
 - s. Actual follow-up is done by other agencies

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- t. Algorithms
 - u. Follow-up templates
 - v. Local staff in genetic centers provide f-up on BDR, NBS and genetic disorders
 - w. Local public health nurses
 - x. Strong parent network
 - y. EI has a data system called Early Track
 - z. Regional CYSHCN Center staff contact all families in the record
 - aa. Note sure
 - bb. WE-TRAC (Used by EHDI)
 - cc. SPHERE – MCH data collection system
 - dd. Care coordination tools (assessments, ISP)
 - ee. Dedicated staff
 - ff. Databases
 - gg. Relationship with local public health agencies to refer hard to locate families
 - hh. Building a web-based application to track short term and long term follow-up (NBS)
 - ii. Integrated data system
 - jj. Program specific applications
 - kk. Collaborations/contracts with parent support groups and specialists
 - ll. None that I am aware of
 - mm. Other, please describe
 - nn. **[Prompt] If tools are used, request they be sent to Region 4.**
18. What are your program/system follow-up outcomes?
- a. If the child has a medical home
 - b. Timeline
 - c. Seeing specialist at recommended intervals
 - d. Enrolled in WIC (or other assistance program) if needed
 - e. Feedback from family or clinic
 - f. Others, please describe

EXISTING RELATIONSHIPS – MECHANISMS AND BARRIERS

19. What types of partnerships exist across service systems in your state? [*choices provided by the previous survey, additional options identified by workgroup, i.a.*]
- a. First identify the service system, then clarify the type of partnership
 - i. Memoranda of understanding
 - ii. Payment systems for services
 - iii. Proximity/convenience
 - iv. Sharing data
 - v. Advisory committees/councils
 - vi. Partnerships with border states/programs

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- vii. Systems are integrated
 - viii. Liaisons
 - ix. Data linkages/sharing agreements
 - x. Referrals for coordination of services
 - xi. Contracts with specialty clinics
 - xii. Common database platform
 - xiii. Work with same regional/local organizations
 - xiv. Working to develop more partnerships
 - xv. Reciprocal relationship
 - xvi. Data input only
20. What mechanisms are in place for COMMUNICATION across the different service systems in your state? [*choices provided by the previous survey; additional options identified by workgroup, i.a.*]
- a. First identify the service system, then clarify the mechanisms of communication
 - i. Paper referrals
 - ii. Monthly reports
 - iii. Designated liaisons
 - iv. Committee participation
 - v. Connected via database
 - vi. Proximity/convenience
 - vii. Shares data annually
 - viii. Email, fax, phone
 - ix. External links
 - x. Quarterly meetings
 - xi. Meetings, as needed to address specific issues
 - xii. Communications between managers
 - xiii. Nothing formal; trying to integrate
 - i. Others?
21. [Follow up for each mechanism] Does this mechanism work for your program/system?
22. [Follow up for each mechanism] What are the barriers with this mechanism?
23. What mechanisms are in place for JOINT ACTIVITIES across the different service systems in your state? [*choices provided by the previous survey, and additional options identified by workgroup, i.a.*]
- a. First identify the service system, then clarify the mechanisms for joint activities
 - i. Minimal
 - ii. Regular meetings
 - iii. Email
 - iv. Many join education opportunities
 - v. Data linkage
 - vi. As needed
 - vii. Managerial level communication
 - viii. NBS Data supplement BDR case finding

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- ix. No broad mechanisms in place
- x. Early on shares pertinent information with EI team/ Dept of Ed
- xi. QI committees meeting quarterly and involve all
- xii. NBS advisory board meetings
- xiii. BDR and NBS FU have some joint activities
- xiv. Steering committees; involve reps for CSHCS, EI, EHDI and NBS
- xv. Quarterly meetings with EI and EHDI
- xvi. EI and EHDI work together to conduct follow-up on children
- xvii. Shares aggregate follow-up data annually
- xviii. Representative to the first steps interagency coordinating council
- xix. Others, please describe

24. [Follow up for each mechanism] Does this mechanism work for your program/system?

25. [Follow up for each mechanism] What are the barriers with this mechanism?

26. What are the barriers to an integrated follow-up system? [*choices provided by the previous survey*]

- a. EI cannot report back on referrals
- b. Legislation prohibits data linkage; registry must stand along
- c. Different systems for each
- d. Data is not integrated
- e. Funding is not integrated
- f. Different priorities
- g. Need to improve communication and funding streams
- h. Data linkages does not equal integrated systems; systems need to talk to each other
- i. Data sharing
- j. Funding, staffing, common data dictionary
- k. Programs in different divisions within MDH
- l. HIPAA prevents programs from sharing up-to-date information to help programs find families who've moved
- m. Others, please describe

SYSTEMS OPPORTUNITIES

27. What data systems does your program have in place?

28. How can your data system(s) be used to do follow-up? [*choices provided by the previous survey*]

- a. Some uniformed responses; may need to get the right person
- b. Research information about child/family – address, name
- c. Refer families to local public health agencies
- d. Verify/indentify better information on the child

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- e. Currently building web-application to health providers track short/long-term follow-up health outcomes for children with positive NBS
 - f. Used to follow-up with children with hearing loss, CH and HGBs
 - g. EARS – allows EHDI staff to communicate with hospitals, staff and first steps personnel; use algorithms to receive and respond to status alerts (remind to send letters/call)
 - h. Tracking and repeat screening requested and notifying parents if one is not received within 14 days of request
 - i. System needs to directly link to lab for ease of sharing info/reporting
 - j. NBS care management system for NBS FU
 - k. BDR data use by other system is not easy; pull cases by diagnostic code and demographics; current contact information is not maintained
 - l. Early Intervention not used for follow-up
 - m. More epidemiology work
 - n. Upload electronic birth record (EBR) faster so that MCIR can be up within 7 days
 - o. BDR provides specific information for appropriate service agencies within limits of data privacy restrictions
 - p. Data system tracks key dates and items for follow-up
 - q. Identifies children not known to services programs who need referrals
 - r. Needs a lot of work
 - s. Tracks status of all services identified for the child listed on IFSP
 - t. BDR allows staff to access records for region
 - u. EHDI does direct data transfer to EI to assure enrollment in EI and reduce loss to follow-up
29. Can your data systems(s) be used to locate children who are lost to follow-up? If so, how?
30. Can your data system(s) be used to prevent lost to follow-up cases? If so, how?
31. What opportunities have you observed for integrating state follow-up systems? [*choices provided by the previous survey*]
- a. New legislation
 - b. Databases
 - c. Funding for data system development
 - d. Training for field staff
 - e. BDR /NBS are integrated; current discussing integrating with other programs
 - f. BDR and NBS in MCH Division
 - g. Child-centric data sharing agreements between agencies and programs
 - h. New data system – anticipated there will be many integrated systems
 - i. Increased QA to ensure identified cases receive services

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- j. DBR/?NBS for true positive cases will be integrated
 - k. Rush grant
 - l. MCIR
 - m. BDR/NBS both using surveillance system
 - n. BDR/Genetics use VS data system platform; to add NBS disorders to BDR in 2010
 - o. Unsure
 - p. Linking MCH data system to WIC
 - q. Linking birth records to hearing screening records to birth defects records
 - r. Prevent duplicate activities
 - s. EHDI does direct data transfer to EI for diagnosed infants to assure enrollment in EI and reduce loss to follow-up
32. What types of surveillance does your data system(s) support?