

Chapter 6

Program Evaluation

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I. PROGRAM EVALUATION

INTRODUCTION

Program outcomes and evaluation are necessary activities for any program. As funding restrictions are imposed on state agencies and as the demand for services increases, it is critical to have data which document the delivery of program services and assess program outcomes. Data are used in reporting program activities and progress to our state and federal funding agencies. They are also utilized in formulating and calculating standards of performance and in program planning and budgeting. Data are also intended to be helpful to counties by validating nursing activities and evaluating the county's progress with Care Coordination.

II. FEDERAL PERFORMANCE MEASURES/OUTCOME MEASURES

The following are established National Performance Measures (NPM) that pertain to CSH. The number beside them indicates the specific performance measure of the 18 National Performance Measures:

- NPM#2 SSI - Social Security Office accepts and process applications for SSI, or Supplemental Security Income for low income disabled children. SSI benefits to the child include Medicaid. As part of the Federal efforts to coordinate services, the

Social Security Office notifies CSH of SSI eligible children. These children are eligible for care coordination. The State CSH Office will notify the PHN Office of an SSI eligible child who is not already enrolled in CSH. The PHN's responsibility is to contact the family and assess if a CSH application is appropriate or if care coordination services are needed. A report of the assessment visit is due to the State CSH Office within 30 days.

- NPM#2 Percent of children on CSH who have care coordination and specialty care. This standard will be calculated by the data system. Problems will be addressed systematically or case by case.
- NPM#3 Percent of children on CSH with a medical home. This standard will be calculated from the data system which was obtained from the information on CSH-1. Problems will be addressed systematically or on a case-by-case basis.
- NPM#11 Percent of children on CSH with a source of insurance for primary and specialty care. This standard will be calculated from the data system with the information obtained from the CSH-3. Problems will be addressed systematically or case-by-case.
- NPM #12 Percentages of children without health insurance. For the children on CSH, this standard will be calculated from the data system from the information obtained from the CSH-3.
- NPM#14 The degree to which the state assures parent participation in programs and policy activities. In the MCH Section, a parent consultant assists the program managers in understanding the impact of decisions and language on families and consumers. Locally, PHN serves as a representative on Local Interagency Coordinating Councils. The state Early Intervention Council expects local ICC's to have actively participating parents. The CSH Program Manager and PHN MCH Consultant will serve on the EIC.

The Federal government has come up with six (6) outcome measures for Children with Special Healthcare Needs. The outcome measures encompass the philosophy of a community-based, family-centered, culturally competent, coordinated system for these children and their families.

The six (6) outcomes are:

- All children with special healthcare needs will receive ongoing comprehensive care within a medical home;
- All families of children with special healthcare needs will have adequate private and/or public insurance to pay for the services they need;
- All children will be screened early and continuously for special healthcare needs;
- Services for children with special healthcare needs and their families will be organized in ways that families can use them easily;
- Families of children with special healthcare needs will participate in decision making at all levels and will be satisfied with the services they receive;
- All youth with special healthcare needs will receive the services necessary to make

appropriate transitions to all aspects of adult life, including adult healthcare, work, and independence.

III. STATE PROGRAM STANDARDS

The state care coordination standards have been discussed in Chapters Three (3) and Four (4). The coordination of care will be assessed by utilizing the Family Care Coordination Record Evaluation/Teaching Tool (Appendix F). Below is an explanation of some of the terms that are on the evaluation form:

- The PHNs providing care coordination services are: a registered nurse and will have been oriented to the CSH program by state staff.
- Client referred to the PHN Office had an initial contact within ten (10) working days.
- Applications will be completed by the PHN Care Coordinator and sent to the State CSH Office within 30 days.
- The State CSH Office will notify the PHN Care Coordinator of eligibility of the client within 30 days of receiving the application.
- Visits have been made according to the frequency required by the Tier assignment.

IV. CSH CARE COORDINATION EVALUATION/TEACHING TOOL

Different methods of conducting ongoing evaluations of the Care Coordination Project will be utilized. Site visits, chart audits, client and provider surveys, barrier logs, case studies and data collection are some of the methods.

V. SYSTEM/DATA COLLECTION OF LOCAL PROGRAM

Site visits will be done every two years to each county by the State CSH Program Manager or the Nurse Consultant. Mail in record audits will be done every year utilizing the Family Care Coordination Record Evaluation/Teaching Tool (Appendix F)

State CSH personnel will meet with the PHN Care Coordinator(s) and their supervisor to discuss how the program is being implemented at the local level, review caseload data, and assure compliance with program performance standards. This will also be a time to discuss difficult or medically complex cases and provide support and teaching to the members of the team.

A written report of the evaluation will be given to the County Manager and a copy to State Public Health Nursing. The State CSH and PHN Staff plus the local supervisor will make plans on how to address any gaps found in the system. This may be done by sharing the unique ways other county PHN's have solved Care Coordination problems. Or it may involve directing state funds into areas where the deficiency in services has been determined.

Using the Family Care Coordination Record Evaluation/Teaching Tool which is based on the

outcomes which with care coordination the CSH program strives to attain. The records will be assessed in the following areas to determine if nursing process was followed:

Basic Record Information:

- All forms have all basic information/identification completed
- Relevant data are recorded in a standardized, systematic format
- All entries have a signature, title and date
- Referral source to the PHN is stated using the Referral Intake Form (PHN-11, Appendix E)

In the 'Assessed' column a "0" or "1" is used to designate if there is documentation of the statement stated under the Parameter column. As in the first item on the evaluation form, "Evidence that the client has been assessed for a Primary Care Provider (PCP/ Medical Home) and how that PCP is utilized". Under the Assessed column if no documentation is in the chart about a primary care provider then it would be a "0" and the problem section may be noted as a "potential" or "active" problem. Under interventions it would be noted that the Care Coordinator needs to obtain this information. If it is stated that there is a primary care provider, but there is no indication of how the client utilizes the primary care provider then it would be marked a "1" as assessed. Then in the intervention/follow-up column, it would be marked further follow-up needs to be done to assess the utilization of the PCP. Again in the problem section depending upon the client, the problem may be marked "potential" or "active".

In the 'Problems' column, a check is needed to indicate if the statement asked is a problem to the client. Using the above example of having a primary provider, if the child had a PCP whom they utilized for regular well and ill care, then 'None' would be checked as there is no problem. If there is provider, but the PCP is not being utilized for well care this would be marked as an active problem. Potential could be marked if the family has a change in finances or transportation and may not be able to continue seeing their PCP on a regular basis. Further follow-up would indicate if the potential problem turned into an active problem or no problem.

In the 'Intervention/Follow-up needed' it would be noted what further intervention or follow-up is needed as seen by the auditing person.

The 'Comments' column may be used for any comments for the benefit of the care coordinator who is being audited and other staff who may have access to the tool.

The first Outcome Measure is: All children with special healthcare needs will receive regular ongoing comprehensive care within a medical home. A medical home is a source of routine healthcare in the community that assists in early identification, provides ongoing primary care, and coordinates with a broad range of other specialty, ancillary, and related services. The four areas that are evaluated in this area are:

1. PCP provider who provides ongoing comprehensive care. This means the client receives well care following the American Academy of Pediatrics periodicity schedule and is seen when ill.
2. The coordination by the PCP with a broad range of other specialty, ancillary, and related services covers many professionals. The PHN promotes the coordination between the PCP and the other services by encouraging the families to release information to the PCP and other specialists. This may entail asking the PCP to attend an IEP meeting or assisting the ISC for the Children's Waiver to plan for the client's increasing medical needs. The PHN functions as person to explain to families the need for exchange of

information amongst the providers helps to promote a seamless care and also that the PCP or specialist may assist in getting the medical needs of the client served in settings outside the hospital or clinic.

3. The medical treatment plan will be indicated in the medical records. If there are future appointments, lab tests, other diagnoses which may be covered by CSH or referrals to other specialists or ancillary services, these should be followed up on and/or the progress documented, or documentation as to why the family is not following the medical plan.

4. Anticipatory guidance in planning for client when change is coming in the medical arenas deals with transition and providing a seamless form of care. This would be indicated when a preemie is coming home from a hospital or an adolescent is changing to an adult provider. Noting if the family is aware of the change and how are they prepared for the change would be documented. Any referrals or efforts to inform of possible resources to the families to adjust to the change should be documented.

The second outcome measure: All families of children with special healthcare needs will have adequate private and/or public insurance to pay for the services they need.

5. Assessment of the family's financial situation and referrals to the necessary services. The areas evaluated here would be does the family qualify for Social Security disability, Children's Waiver, Kid Care, Head Start, LIEAP, WIC, etc. Also, included in this would be assessment if the family has insurance and what does it cover, what the deductible is, & what the premiums are. If the parents are divorced, it would be assessed what parent may have the responsibility of providing insurance for the children.

6. Follow up on referrals and what is the outcome of the referrals would be documented. If the family had been referred to WIC and they went but were deemed over income this should be noted. Or if the family may have not have kept the appointment, this would be documented. The follow-up may be documented on the Community Services sheet or on the narrative of the clinical pathway.

The third outcome measure: All children will be screened early and continuously for special healthcare needs.

7. Client receives an annual well child evaluation by PCP, specialist or PHN. This means the client will have a well child evaluation by someone annually. If the child does not have a regular PCP or the periodicity schedule does not require a visit for two years, the PHN will do an evaluation to see if anything has occurred that may require a visit to a provider.

8. Promotion of preventive care for chronic diseases requires planning and understanding of disease processes and would require collaboration with the PCP. Some examples are the yearly evaluation of a client with Neurofibromatosis for lisch nodules which are cancerous. The client may not have the condition, but needs to have annual screenings to detect it as early as possible. A child with Down's has a higher incidence of leukemia and so if has symptoms a referral to the PCP would be expected. A child with diabetes getting regular HbA1C and eye evaluations would promote early diagnosis and intervention and thus promote better outcomes for these diseases.

9. This information will be taken from the dates noted on the Intake Referral Form, the

CSH application, the time frame for contacts according to the Tier Level (See end of Chapter 4 Page 5 on schedule of visits for new clients and established clients.) and any notes in the progress notes or comments section of the clinical pathway as to why the referral may have been delayed. At the beginning of this chapter time frames for acting upon referrals and getting eligibility determination are stated and will be references for timeliness also.

The fourth outcome is: Services for children with special healthcare needs and their families will be organized ways that families can use them easily.

10. This assessment of the family's special needs, culture, values, etc. may depend upon the tier level of the family how much information is obtained. A Tier 1 family should be asked if they understand the disease, the treatment plan and how this is affecting the family. If there is any concern about the family's ability to comprehend the written materials due to reading level or the primary language of the family, this should be noted. With Tier 2 and 3 families, further assessment of how the family views illness may lead to understanding that they really do not see this disease as a problem and so they will be missing some of the appointments or they may put it as a first priority and the family is breaking up. The Care Coordinator may serve as a referral source to various resources or point out to the PCP that the family does not view that part of the treatment as important and they will not be completing that part.

11. The support system of the family has been assessed as to whom they seek for support and how that support system functions for the family. Many families state they have a support system, but that system is not available to them in times of need. The Care Coordinator may note that the family completes on the MCH-1 that they have certain people for support, but on the Family Needs survey they state that the people that they named as support, do not provide support. The Care Coordinator may assist the families at looking at their strengths and what their needs are. Then assist them in getting support in that area. The Care Coordinator does not have to be the support to the family.

12. Recognition or assistance has been given to the areas that the family has stated they need help. This does not mean that the public health nurse has to fulfill all the needs of the families. Referrals to community resources are expected and areas with no resource should be brought to the attention of the state office. In looking how common is the noted gaps or problems that have been identified, the CSH program will utilize this data to look at future plans to help bridge those gaps. This documentation may noted on the Family Needs Survey as to how the family views the condition or disease affecting the family or it can be noted in the Progress Notes from telephone calls, office/home visits with the family or from comments in the medical records. If there are areas where the Care Coordinator can refer the family this should be noted on the Community Resource Sheet or on the clinical pathways or the progress notes.

13. An assessment of the how the child's condition affects the family may be indicated in the progress notes on the clinical pathway. This can be by direct quotes or paraphrasing what the family states. An example would be "I need more information on what they have diagnosed." It can also be a statement in the medical records, i.e. "whole family's sleep patterns were being disrupted." The Family Needs Survey would also be an area where the family shows how the condition is influencing them. It has one area, "needing more time", marked by many people. With further questioning, this may be an indication of how the child's condition affects the family. Or there is a section marked "needs more information on child's condition." The PHN may be able to supply the information or a

referral may be made to a community or state resource.

14. The evidence that the family was informed of their rights and responsibilities will be the signed sheet on rights and responsibilities. The proper documentation made for authorization of services will be the signed Financial Sheet agreeing to the CSH services and properly completed and signed releases of information. Sometimes, this may include discussing who is the proper person to be signing the papers for this information, as the person who is signing needs to be the legal guardian, custodial parent or step parent. Families may need help in knowing their rights and responsibilities in other programs such as Medicaid, the school IEP, or the Social Security Disability Program. Again, the Care Coordinator does not have to know about all these programs as the client/family can be referred to a knowledgeable resource and follow up done to make sure the family got their concerns or rights explained adequately.

15. The evidence of the collaboration between the care coordinator and the client/family about outcomes or goals may be seen on the clinical pathways where individual goals may be written. On a Tier 1 family this may be as simple as stating a goal that the family will call the Care Coordinator if a problem, such as a billing problem or a change in the client's medical condition, occurs in the following year. A Tier 2 or 3 family may have a goal of the Care Coordinator and the client/family will be in contact once a month to discuss the client's medical treatment plan. Both of these goals do have a time frame attached to let both the client/family and the Care Coordinator know what is expected. The clinical pathway has a place for date of next visit which would establish a time line. If the family continues to meet with the Care Coordinator this is taken as the family is participating in this decision. Another goal may be that the client/family will establish one provider as a primary care provider (medical home) within the next 6 months. If the family does not establish a provider and it is shown in the documentation that the Care Coordinator worked with the family in providing names, transportation, etc and it was to no avail, this is not seen as a failure. It would be audited as the problem was 1-assessed, checked "Active" on the Problems and the interventions done would be noted. The goal may be changed to client/family will obtain one well child screening this year by someone.

The sixth outcome is that all children with special healthcare needs will receive the services necessary to make appropriate transitions to all aspects of adult life, including adult healthcare, work, and independence. (This section should only be completed on clients 14 years and older.)

16. The documentation on this section can be noted on the clinical pathway or progress notes. There may be notes about discussion with client/family that the current pediatric provider only sees clients up to age 21 and has the family thought about what they are going to do. It may be a client who will be graduating and going to school in another area and will need a healthcare provider in that area. There may be problems or gaps in this area as at this time there may not be adult providers who will take a client with CF as they may not have the background to deal with that disease process. This should be reported to state as the lack of providers and the current needs of the client. It may be inquiring of the client/family if certain tertiary care clinics will continue to see the client or are they able to recommend someone else. Transition planning may occur as early as the application process. This may be the referral of a teenage client for services to an adult provider to set up a system for continuity of care.

17. If a child with special healthcare needs has an "Individualized Education Plan" (IEP)

at school, there should be a plan starting at age 14 for the transition into adult life. Some parents are not aware that educational services can continue until the client reaches 21 years of age. The Care Coordinator can document on the clinical pathway or progress notes contacts with the school or with the family about the IEP. The Care Coordinator may agree to reinforce to the family specific points of the IEP or help them understand their rights in the school system or she may refer them to a parent support group who can assist the family in getting the IEP to meet their needs.

18. The Care Coordinator would document referrals to parent support groups or to a legal service in helping the families establish guardianship of a client who is unable to understand their rights or be independently responsible for themselves. Helping the family allow the client more independence may be the first step documented towards working as an adult. Again referrals to the Governor's Council on Developmental Disabilities or the Social Security Administration may be seen as the Care Coordinator planning and assisting the family in this area. The stages of development may include information on sexually transmitted diseases or birth control. Or they may be discussing with the client/family the use of a tool such as "Packaging Wisdom" for the client to take to a provider without the parent accompanying the client. This would be shown in the clinical pathway or the progress notes or as a referral on the Community Resource.