The Hows and Whys of Health Services Research and Costs of Birth Defects

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National Birth Defects Prevention Network Annual Meeting
February 28, 2012
Outline

- What is health services research?
- Why is health services research important?
- Why study costs of birth defects?
- Who is collecting health services research data?
Definition of Health Services Research

- Relationship between health service delivery and health needs of the population
- Applied, multidisciplinary research methods
- Includes cost and timeliness of services

Importance of Conducting Health Services Research among Children with Birth Defects

Policy and program development and implementation

Access to care

Diagnosis of condition

Surveillance (e.g., rates, prevalence, incidence)

Referral, treatment and management

Education

Outcomes and Quality of Life
Why Study Costs of Birth Defects?

- Identify problem and resources
  - Conduct research on causes

- Examine attributable costs
  - Health care
  - Special education

- Assess benefits of prevention
  - Lifetime costs
  - Folic acid supplementation

- Develop policy
Methods for Conducting Health Service Research for Birth Defects

- Use of administrative data only
  - Hospital discharge data
  - Health insurance claims data (e.g., MarketScan)

- Use of birth defect registries to identify children and link with administrative data

- Use of parental surveys
  - *National Survey of Children with Special Health Care Needs*
  - Local studies with state birth defects surveillance programs
NBDPN Survey: Preliminary Results

- ~35 operational birth defects surveillance programs
- 45.7% (n=16) have access to cost or charge data during first year of life
- Some states have cost information beyond first year of life
- Some states only link to Medicaid or hospital discharge data for cost or charge information
- Very few states have cost information from a HMO or private insurance
NBDPN Survey: Preliminary Results

- How are cost or charges data used?
  - Economic analysis
    - Cost-benefit
    - Cost-effectiveness
  - Program planning and justification
  - Needs assessment
  - Legislative request
CONCLUDING THOUGHTS
Health Services Research and Birth Defects Registry Data

- Birth defects registry data can be a useful tool in health services research
  - Identification and referral
  - Outcomes
  - Health service needs
  - Policy development and planning
  - Costs
- Definition of ‘cost’ and cost perspectives
- North Carolina Birth Defects Monitoring Program
  - Active surveillance
- Florida Birth Defects Registry
  - Passive surveillance
Other “Costs” to Consider:

- Out-of-pocket costs
- Transportation costs
- Time spent seeking medical care
- Special education and early intervention
- Loss of parental earnings
  — Reduced employment
  — Reduced wages (rarely estimated)
- Loss of personal care, social, and leisure time
Recommendations and Research Needs

- Link with available birth defects registries and administrative data
- Conduct longitudinal studies
- Include all payer types: private and public
- Examine relationship between insurance status and access to care and short- and long-term outcomes
- Determine other types of costs
- Assess factors related to access to care, timeliness of services and cost
Division for Heart Disease and Stroke Prevention

CDC National Heart Disease and Stroke Prevention Program

Five-Part Webcast on Economic Evaluation

Economic evaluation is a process to identify, measure, value, and compare the costs and outcomes of programs and policies.

This webcast series is designed to help you understand the value of economic evaluation and how to incorporate these methods into your programs. The five-part webcast will assist you in choosing the appropriate economic analysis for your heart disease and stroke prevention program or policy.

Click HERE [PDF-68K] to download the Glossary of Terms.
Thank you!

Special Acknowledgments to:
Scott Grosse, Suzanne Gilboa, Margaret Honein, Cara Mai, Cora Peterson, Beth Radcliff, Phoebe Thorpe, Jessica Knight and NBDPN survey respondents

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The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.
References

References (continued)

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