Birth Defects Surveillance Program Evaluation

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Why we’re here today

- Basics of evaluation
- CDC-funded state birth defects surveillance programs
- Experiences from Michigan and Colorado programs in implementing the evaluation plan and tools
Evaluation

- Systematic collection of information about a program that enables stakeholders to better understand the program, improve its effectiveness and/or make decisions about future efforts.

WHAT!!!  Conduct an Evaluation?

Is it painful?  
YES  NO

Is it useful?  
YES  NO

Is it necessary?  
YES  NO
Recent news article
OMB would toughen how agencies measure program value

- Agencies can expect changes in how they evaluate the effectiveness of their major programs and recommendations in the fiscal 2010 budget proposal to eliminate some programs, said Peter Orszag, President Barack Obama's nominee to be director of the Office of Management and Budget.

- "The president will release his budget policy outline in February, and it will contain some program eliminations in it," Orszag told the Senate Homeland Security and Government Affairs Committee Jan. 14.

- "We should be focusing our metrics on results and outcomes, not what we're doing to get there, and let agencies focus on how to get there," Orszag said. "It's hard to do anything if you don't measure it because you don't know what to change and where you're going. It's crucially important."

Source: Written by Mary Mosquera, January 21, 2009

Which way?

One day, Alice came to a fork in the road and saw the Cheshire cat in a tree.

"Which road do I take?", she asked.

His response was a question:

"Where do you want to go?"

"I don’t know," Alice answered.

"Then," said the cat, “it doesn’t matter.”

Lewis Carroll, Alice's Adventures in Wonderland
• **WHY conduct evaluation activities?**
  Evaluation helps to understand where the program is working as intended, and the areas in need of improvement.
• **WHEN do we do evaluation activities?**
  Effective evaluation is on-going, not an event that occurs at the end of the project.
• **WHO are the users of evaluation info?**
  Determine each stakeholders’ information needs, for what purposes and how often.

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**Evaluation in a nutshell**

• Determine the purpose of the evaluation.
• What do you need to know?
• How will it be measured, by whom & when?
• Who needs this information?
• How will the evaluation information be shared and used?
Build effective programs through:

Thoughtful planning (logic models)

And IMPROVE programs through:

Focused evaluation

Background: CDC-funded State Birth Defects Surveillance

- Funding for state-based birth defects surveillance since 1995
- Evaluation required as part of RFA, but no formal guidance provided to states
**CONCEPTUAL MODEL**

**State Birth Defects Surveillance Cooperative Agreements**

**IF**
We do...

**THEN**
Changes in knowledge, attitudes, behaviors, practices & policies within systems & individuals can be produced

**ACTIVITIES**
- Surveillance: To strengthen state birth defects surveillance systems
- Capacity Development: For public health action
- Prevention & Referral: For improved outcomes
- Evaluation: For on-going improvement

**OUTCOMES**
- Improved birth outcomes
- Improved quality of life
- Improved birth defects surveillance

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**ACTIVITIES**
- Measurable, sustainable, improved birth defects surveillance methodology
- Effective transfer of surveillance information for intervention uses
- Outreach campaigns with prevention messages & activities
- Coordinated intervention channels to link affected children & families to services
- Continuous quality improvement

**OUTCOMES**

- Improved birth defects surveillance
- Improved birth outcomes
- Improved quality of life
- Informed agencies, organizations & individuals
- Early identification & linkage to services
- Early utilization of services
- Data driven strategies integrated

**CONCEPTUAL MODEL**

- Data collection
- Data analysis
- Database linkages
- Data dissemination
- Identify & engage key internal & external partners
- Prevention & referral plans
- Continuous quality improvement
- On-going evaluation of activities, processes & outputs for improvement

**What next?**

- Conceptual model - good overview
- Need a more detailed roadmap for grantees and others interested in birth defects program evaluation
Resources

- Resource Guide – Logic Models for Planning and Evaluation
- Evaluation Plan Template
- Evaluation Checklist
- Capacity Development Worksheet
- Matrix Listing of Projects/Activities With an Evaluation Component
Evaluation Guide – Developing Logic Models

- Step-by-step guide to help reader:
  - Identify major components of a logic model
  - Develop state-level birth defects surveillance and data utilization activities with build upon indicators
  - Understand basic components of evaluation development

Resources – Evaluation Matrix

<table>
<thead>
<tr>
<th>Evaluation Questions</th>
<th>Indicators</th>
<th>Data Sources</th>
<th>Data Collection Timeframe</th>
<th>Data Analysis</th>
<th>Communication Plan</th>
<th>Staff Responsible</th>
</tr>
</thead>
<tbody>
<tr>
<td>What do you need to know?</td>
<td>Measurable signs of progress that reflect objectives</td>
<td>Data from state birth defects surveillance systems</td>
<td>Where will you get the data?</td>
<td>When will you collect the data?</td>
<td>What will you do with the data?</td>
<td>When &amp; how will you share results?</td>
</tr>
<tr>
<td>Have strategies to reach at-risk populations been developed?</td>
<td>Data-driven list of at-risk populations is developed.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have the prevention plan activities been implemented?</td>
<td>Data-driven list of at-risk populations is developed.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>To what extent are the surveillance systems sufficiently reaching the target audiences?</td>
<td>Changes in numbers for the target audience</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Evaluation Checklist

**Evaluation Plan**: Identify questions to answer.
1. **What will you measure?**
2. **What is key program input or output that is associated with the program?**
3. **What do you need to know to evaluate the program?**

### Step 1: **Select Interventions/Program Goal**

Define the program’s purpose.

- **What will you evaluate?**
- **How will you collect data?**
- **How do you interpret data?**

### Step 2: **Identify Data Collection Methods**

- **Identify data sources (e.g., surveys, interviews).**
- **Identify data collection methods (e.g., interviews, focus groups).**

### Step 3: **Plan for Data Analysis and Interpretation**

- **Assign responsibilities to appropriate staff.**
- **Analyze data.**

### Step 4: **Summarize Findings**

- **Summarize key data.**
- **Provide a summary of evaluation activities.**

### Step 5: **Plan for Reporting**

- **Prepare a report.**

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### Resource - Worksheet For Capacity Development

<table>
<thead>
<tr>
<th>Partner List</th>
<th>Surveillance</th>
<th>Referral</th>
<th>Prevention</th>
<th>Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>March of Dimes</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>Advocacy for birth defects surveillance infrastructure; prevention &amp; outreach; health messaging</td>
</tr>
<tr>
<td>Title V MCH</td>
<td>X</td>
<td>X</td>
<td>National &amp; local resource</td>
<td></td>
</tr>
<tr>
<td>Community Health Centers (coordinate through State Primary Care Association)</td>
<td>X</td>
<td>X</td>
<td>Service provider / medical home for underserved/uninsured; CHC operate under state Primary Care Association (this is a separate group from the Office of Primary Care) – PCA can help with data &amp; access issues &amp; culturally appropriate channels for prevention strategies</td>
<td></td>
</tr>
<tr>
<td>State Office of Ethnic Health</td>
<td>X</td>
<td>X</td>
<td>Conduit to ethnic populations</td>
<td></td>
</tr>
<tr>
<td>County Health Departments</td>
<td>X</td>
<td>X</td>
<td>Data source; conduit to audiences for referral &amp; prevention</td>
<td></td>
</tr>
<tr>
<td>Spina Bifida Association</td>
<td>X</td>
<td></td>
<td>Advocacy for birth defects surveillance infrastructure; prevention &amp; outreach; health messaging</td>
<td></td>
</tr>
<tr>
<td>Medicaid</td>
<td></td>
<td></td>
<td>Data source: claims data on plan enrollees who receive services</td>
<td></td>
</tr>
<tr>
<td>State health agency programs, e.g., WIC, family planning, chronic disease/nutrition</td>
<td>X</td>
<td>X</td>
<td>Data source: partners working to strengthen/enhance data foundation – test linkage accuracy; vehicle for dissemination of prevention messages</td>
<td></td>
</tr>
<tr>
<td>Part C Early Intervention</td>
<td></td>
<td></td>
<td>Health outcome data source</td>
<td></td>
</tr>
<tr>
<td>Health care providers, e.g., pediatricians, obstetricians, nurses</td>
<td>X</td>
<td>X</td>
<td>Prevention &amp; outreach; focus group to identify provider/patient preconception/early pregnancy information needs</td>
<td></td>
</tr>
<tr>
<td>Infrastructure &amp; partner health communication units</td>
<td></td>
<td></td>
<td>Engage in plan/evaluate prevention messages that resonate with a range of appropriate audiences (women of childbearing age, parents of children with BD, underserved &amp; vulnerable – higher risk audiences, etc.)</td>
<td></td>
</tr>
<tr>
<td>Hospitals &amp; if applicable, hospital associations</td>
<td>X</td>
<td></td>
<td>N/A</td>
<td>Data source</td>
</tr>
</tbody>
</table>
## Resource – Evaluated Activities

### Matrix Listing

<table>
<thead>
<tr>
<th>Target Population</th>
<th>Topic Area</th>
<th>Project (Abstract)</th>
<th>Evidence Base</th>
<th>Specific Program Activities</th>
<th>Evaluation Methods</th>
<th>Costs</th>
<th>Outcome</th>
<th>Lessons Learned</th>
</tr>
</thead>
<tbody>
<tr>
<td>Water and sanitation - Y2K</td>
<td>Rural and urban</td>
<td>Role of campaign managers in multi-country pilot projects: 1995-1999 (moved to national project in 1997)</td>
<td>1,000,000 people served in 7 countries</td>
<td>Training of campaign managers; use of toolkits; workshops; support materials.</td>
<td>Pre/Post campaigns, contained case studies, impact evaluations, impact reports, and policy papers.</td>
<td>High</td>
<td>Improved</td>
<td>Successful intervention, increased awareness, and improved sanitation practices.</td>
</tr>
<tr>
<td>Aids awareness</td>
<td>Rural and urban</td>
<td>Role of healthcare providers in HIV/AIDS education and prevention</td>
<td>500,000 people served</td>
<td>Training of healthcare providers; educational materials; support services.</td>
<td>Pre/Post campaigns, contained case studies, impact evaluations, impact reports, and policy papers.</td>
<td>High</td>
<td>Improved</td>
<td>Successful intervention, increased awareness, and improved outcomes.</td>
</tr>
<tr>
<td>Magnesium reserves</td>
<td>Urban and rural</td>
<td>Role of local government in magnesium reserves management</td>
<td>500,000 people served</td>
<td>Training of local government officials; educational materials; support services.</td>
<td>Pre/Post campaigns, contained case studies, impact evaluations, impact reports, and policy papers.</td>
<td>High</td>
<td>Improved</td>
<td>Successful intervention, increased awareness, and improved outcomes.</td>
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</table>