

Family Health Outcomes Project

## Identifying Data Sources for MCAH Needs Assessment, Planning and Evaluation

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Family Health Outcomes Project  
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### Session Objectives

By the end of this session participants will be able to:

- Describe at least one conceptual framework that can guide decisions on what data to use
- Give at least two examples of the advantages and disadvantages of using quantitative data vs. qualitative data
- Identify at least three criteria for evaluating a quantitative data source
- Select an appropriate data source for two sample indicators

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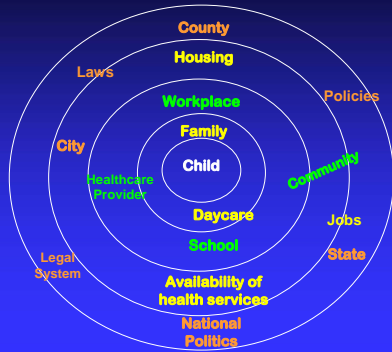
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## Emerging Concepts: Ecological Model




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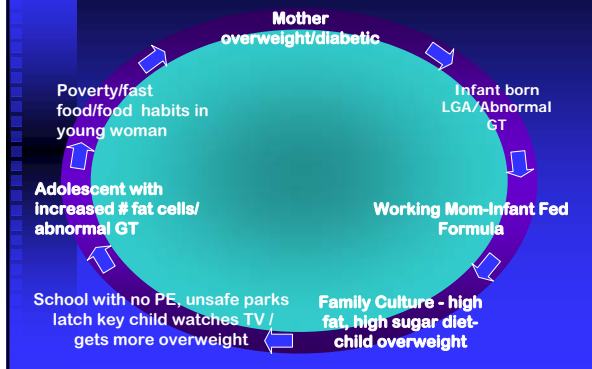
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## Emerging Concepts: Life Course Model




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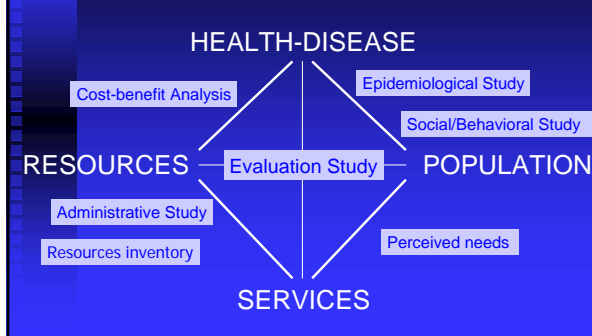
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## Developing a Picture of the Community




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## Types of Data

- **Quantitative Data** – numbers, rates, statistics
  - ◆ Primary- you collect it with structured instruments
  - ◆ Secondary – use an existing data sources
- **Qualitative Data** – words, thoughts, actions, descriptions
  - ◆ Focus groups
  - ◆ Open ended interview questions
  - ◆ Observations



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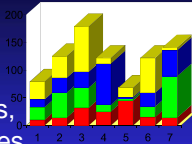
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## Quantitative Data: Advantages

- Quantifies results
- Allows statistical comparisons, multivariate and trend analyses
- Allows comparisons with other groups and over time using standard measures
- Conserves resources if secondary data source available



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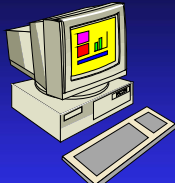
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## Quantitative Data: Disadvantages

- Requires expertise in data analysis
- Limited use in situations where numbers are small
- Collecting primary data is expensive and time-consuming
- Can overlook emerging issues



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### Qualitative Data: Advantages

- Rich data with more details and contextual information
- Can provide new insights
- Can identify emerging issues
- Face-to-face contact allows opportunity to clarify questions
- Can be more timely



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### Quantitative Data: Disadvantages

- Presupposes you to know the significant factors
- Often lacks important variables such as geographic markers or detailed race or ethnicity categories
- May not be timely



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### Qualitative Data: Disadvantages

- Requires expertise in staff and can be time consuming
- Possible inconsistency due to flexibility
- Difficult to make comparisons
- Transcribing and analysis of data costly
- Individuals may alter responses because of group environment



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### Types of the assessment

- **Epidemiology** — answers who, what when where and why of a particular condition of interest
- **Community assessment** – Focuses on what are the needs, perceived problems and capacity
- **Behavioral assessment** – queries individuals about social behavioral and cultural influences
- **Evaluation or monitoring** – explores the impact of a program or policy on a population
- **Health system assessment** – services, utilization, resources/costs

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### Factors to Consider in Choosing the Type of Data You Need

- ? Do I have an evidenced-based hypothesis about the cause of a problem or am I searching for new insights?
- ? Is this a well described and quantifiable problem?
- ? Do I want to compare data with known standards or other population groups?

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### Factors to Consider in Choosing the Type of Data You Need (cont.)

- ? Do I want to understand the perspective of individuals in a community?
- ? Will quantitative data be meaningful? (i.e. adequate numbers)
- ? Are there reliable secondary data sources available?
- ? Are there adequate local resources for a particular method?

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### Factors to consider in selecting a quantitative data set

- Are the demographic variables relevant to my population (s) of interest?
- If I want to calculate population based indicators, is there comparable denominator data available that corresponds to my population of interest?
- Is data collected over time at regular intervals?
- Is the data timely?

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### Selecting an appropriate data source: Exercise

- Preterm births
- Methamphetamine use in reproductive age women
- Teen clubs promoting pregnancy
- Adequacy of primary care
- Access to primary care

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### Preterm births- Issues to consider

- How many cases are there?
- Are there enough numbers to do an epidemiological analysis?
- Am I interested in a description or do I want to know the why?
- Do I have any ideas about what is causing the problem or the increase in the problem?

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**Methamphetamine use in reproductive age women – Issues to consider**

- Are there any data sources that exist?
- At what level do I want to intervene?
- Would it be feasible to collect primary data?
- What resources can I utilize to help?

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**Teen clubs promoting pregnancy: Issues to consider**

- Is this a rumor or is there data to support this?
- What kind of numbers do I expect to find?
- What are my questions?
- Who are my potential partners in looking at this?

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**Access to and adequacy of primary care: Issues to consider**

- Is there a data source that generates enough local data to give quantitative significance?
- At what level do I want to intervene?
- Do I want to look at county resources/capacity or patient behavior?
- Do I need to get input from patients, providers, health care organizations?

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## Secondary Data Sources Useful for MCAH Needs Assessment

- State and nationally collected population based health data sets
  - ◆ Vital records –Birth, death and fetal death, marriage certificates
  - ◆ Birth-death cohort files
  - ◆ Census data
  - ◆ Hospital discharge abstracts
  - ◆ Reportable communicable disease data
  - ◆ Disease specific registries
  - ◆ Genetic disease lab results

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## Benefits of These Data Sets

- Uses standard definitions and methods so local and state data are comparable to national data
- Provides enough data for local health jurisdictions to look at small area patterns
- Useful for epidemiological studies
- Some utility in looking at patterns of service utilization and behavior

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## Secondary Survey Data Sets - National

- National Health Interview Survey (NHIS)
- National Health & Nutrition Examination Survey (HANES), Hispanic HANES
- National Survey of Family Growth
- National Medical Care Utilization & Expenditure Survey
- PRAMS –Perinatal Risk Assessment Survey
- Youth Risk Behavioral Survey (YRBS)
- Behavioral Risk Factor Survey (BRFS)
- Pediatric Nutrition Surveillance System (PedNSS)

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## Utility and Limitations of National Survey Data Sets

- ★ Standard definitions and methods
- ★ Allows for generation of synthetic estimates for states and local health jurisdictions
- ★ Provides data for epidemiological, community assessment and behavioral, and evaluation
- ⓪ Not available in a timely manor
- ⓪ Statistical analysis requires high level analysts and use of particular software

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## Secondary Survey Data Sets: California

- California Health Interview Survey (CHIS)
- Healthy Kids Survey
- MIHA – Maternal and Infant Health Assessments
- California Women's Health Survey

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## Benefits and Limitations of California Survey Data

- ★ Collected regularly and published in a more timely manner than national surveys
- ★ All ask many of the same questions as national surveys so they are comparable
- ★ CHIS allows LHJs to pay for oversampling
- ⓪ Sample sizes can limit statistical utility of data
- ⓪ Parents can opt out of the school survey so sample may not be representative

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### Administrative Data sources

Both State and National Program Data

- ◆ Child Welfare – TANF, Foster Care, child abuse
- ◆ Mental Health – service utilization, estimates of need
- ◆ Drug and alcohol – surveys of prevalence, statistics on utilization
- ◆ Education – dropouts, academic achievement, physical fitness, overweight
- ◆ Criminal justice – crime rates, domestic violence
- ◆ Medicaid/MediCal – utilization data, diagnoses and lab results, costs
- ◆ State licensing data

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### Problems with administrative data sets

- Purpose of data collection is often only for reporting productivity or billing so quality of health data suspect
- Measures conditions in those already in the system so not representative of the conditions in the general population

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### Other government collected health related data

- Environmental surveillance data
  - ◆ Air
  - ◆ Water
  - ◆ Soil
  - ◆ Food
- Injury/Safety
  - ◆ Death and hospital summaries
  - ◆ California Highway patrol /National Highway Traffic Safety Admin.
  - ◆ Consumer Safety Commission - National Electronic Injury Surveillance System

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## Data collected by private and non-profit agencies

- Foundations (e.g. Kaiser, Casey, RWJ, California Wellness, Lucile Packard)
- Advocacy Groups (e.g. Children's Now, Children's Defense Fund, March of Dimes)
- Private Insurance Companies
- Healthcare facilities (e.g. hospitals, HMOs)

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## Criteria for Assessing a Secondary Quantitative Data Source

- Data Quality
  - ◆ Complete and accurate
  - ◆ Valid
- Consistency over time
- Adequacy for local use
  - ◆ Sample size for local community
  - ◆ Contains the specificity for local needs
- Timeliness
- Accessibility
  - ◆ Cost
  - ◆ Confidentiality
  - ◆ Availability over time



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## Data Accessibility



**MCAH  
DIRECTOR**



**COMMISSAR  
OF VITAL RECORDS**

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### Considerations for Primary Quantitative Data Collection

- Existence of a validated instrument or set of questions for area(s) of interest
- Potential sample size
- Potential for random sample
- Resource availability - \$ and expertise

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### Considerations for Primary Data Collection

- Potential partners
- Possibility of using web based surveys
  - ◆ Free or low cost
  - ◆ Generates summaries
  - ◆ Access and receptivity of target population to web

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### Choosing a Qualitative Method

- Determining the objectives for the study and identifying the type of information needed
- Identifying local expertise in both conducting the data collection and analyzing the data collected
- Identifying resources

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## California Title V CSHCN Needs Assessment 2010: A Case Study

### Reviewed Quantitative Secondary Data sources

- CMS net for administrative data: #s of cases, dxs, dates of steps of application and approval process,
- MediCal Paid Claims data
- Secondary Data from Statewide ( and LA) surveys
  - ◆ The National Survey of Children with Special Health Care Needs
  - ◆ *Children with Special Health Care Needs Chartbook 2005–2006*
  - ◆ Children's Specialty Care Coalition's Survey
  - ◆ *Your Voice Counts!!™ Survey done by Family Voices*
  - ◆ *Specialty Health Care for Children in the Los Angeles California Children's Services Program (CCS) Report*

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## California Title V CSHCN Needs Assessment 2010: A Case Study

### Limitations of secondary data

- Not valid at county level except for LA
- No clear definition of medical home
- No data on perceptions of medical providers or local CCS programs
- Limited data on family attitudes
- No data on DME providers
- No data on perceptions of other state agencies e.g. mental health, DD, DSS

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## California Title V CSHCN Needs Assessment 2010: A Case Study

### Decision to collect primary quantitative and qualitative data

- Used an iterative process
  - ◆ Discussions with CCS Stakeholders
  - ◆ Key Informant Interviews
  - ◆ Focus groups
  - ◆ Online surveys

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## Using an iterative process

- Conversations with stakeholders to develop initial list of CCS strengths and weaknesses and issues to explore
- In-depth Key informant interviews using a SWOT framework (strengths, weaknesses, opportunities, threats)
- Focus groups with specific constituencies to learn more about strengths/weakness and strategies for improvement
- Online surveys developed using findings from Key informant interviews and focus groups to quantify issues/strategies using larger sample

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## Example: Access to Durable Medical Equipment (DME)

- Stakeholders mentioned problems regarding access to DME, including delayed hospital discharges
- In key informant interviews, asked doctors, hospital administrators, health plans, and representative of DME providers – very few DME providers in state, reimbursements low, complex cases, paper work, hospitals buying equipment because need beds
- Focus groups – delays in discharges, waiting so long equipment no longer correct size when finally gotten

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## Physician Survey - DME

Physicians reporting the following are FREQUENTLY a problem:

Too few DME providers being available due to low reimbursement rates.	71% (44)
DME providers refusing to provide certain kinds of equipment due to low reimbursement rates for that equipment.	69% (41)
Client discharges being delayed because of delays in getting DME (e.g. ventilators, apnea monitors, wheel chairs)	58% (42)

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## DME Provider Survey

Top barriers to DME Supplier participation in CCS

Low reimbursement rates	53.8% (7)
Delays in payments for the services provided to CCS children	53.8% (7)
Time consuming and difficult paper work to complete to get reimbursed	92.3% (12)

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## Family Survey - DME

Delays in child being discharged because of lack of timely access to DME	12% (22)
Any delays in child getting mobility aids or devices, such as canes, crutches, wheelchairs, or scooters in last 24 months	42% (84)
If delayed, delayed result in mobility aids being in correct size when arrived	43% (32)

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## Family Survey - DME

"It has taken over 9 maybe 10 months for a car seat to be ordered and we still haven't received it. By the time the equipment comes he has grown so much I don't know if it will fit. Same w/ bathchairs and wheelchairs. His wheelchair is 4 almost 5 years old and I feel we need to order one now so when it takes a year to year and half to get we will at least have one on order. Very frustrating as a parent and all we deal with to have to continually call and check up on so many things; there has to be a better way."

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### Mini-Exercise: What are the Best Data Sources for these Indicators?

1. Infant mortality rate
2. Risk factors for poor maternal and birth outcomes
3. Use of infant car seats
4. Prevalence of childhood obesity

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### Corresponding Links for Exercise

1. <http://www.cdph.ca.gov/data/statistics/Pages/default.aspx>
2. [http://www.cdph.ca.gov/data/surveys/Pages/StatewideTablesfromthe2006MaternalandInfantHealthAssessment\(MIHA\)survey.aspx](http://www.cdph.ca.gov/data/surveys/Pages/StatewideTablesfromthe2006MaternalandInfantHealthAssessment(MIHA)survey.aspx)
3. <http://www.chp.ca.gov/switrs/#section4>  
<http://www.nhtsa.dot.gov/portal/site/nhtsa/menuitem.6a6eaf83cf719ad24ec86e10dba046a0/>
4. <http://www.dhcs.ca.gov/services/chdp/Pages/PedNSS2007.aspx>

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### FHOP Data resources

- County pages
  - ◆ Data spreadsheets,
  - ◆ Title V indicator summaries
- California MCAH Resources : topic specific links to many data sources
- Software for analyzing Birth and Hospital discharge data
- Survey Instruments for collecting primary data

<http://familymedicine.medschool.ucsf.edu/fhop/index.htm>

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## Take Home Points

- Collect data that is meaningful for your jurisdiction/population
- Use quantitative data and qualitative data where feasible to tell your story
- Be aware of the limitations of your data sets



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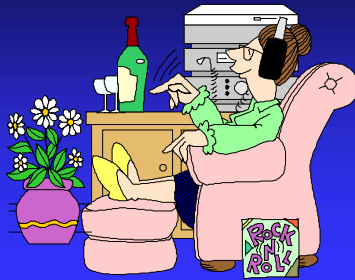
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**RELAX !!!**



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