

Disabling Asthma

Practice & Policy Implications of Children's Experience

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Overview

- Background – Disabling Asthma
- Missouri Disabling Asthma Survey
- Results & implications
- Follow-up, interventions
- Collaborative research design
- Findings and policy implications
- Communication of findings

Definition

- Newacheck & Halfon (2000) defined disabling asthma “long-term reduction in the ability to participate in children’s usual activities, such as attending school and engaging in play”. Used National Health Interview Survey data to examine disability among 62,171 children under age 18.

Asthma Disability

- Newacheck & Halfon (2000) reported a 232% increase in disabling asthma from 1960-1998 among school age children. This is far in excess of increases in asthma prevalence (70%) and increases in disability due to other chronic illness in childhood (113%). Why the increase?

Newacheck, P. W., & Halfon, N. (2000). Prevalence, impact, and trends in childhood disability due to asthma. *Archives of Pediatrics & Adolescent Medicine.*, 154(3), 287-293.

Disabling Asthma Among U.S. Children

- Newacheck & Halfon (2000) found that 1.4% of US children experienced some degree of disability due to asthma. Prevalence of disability was higher among black children odds ratio (OR) 1.66, adolescents (OR, 1.64), low income (OR, 1.46), and single parent family (OR, 1.37).

Possible Explanations for Worsening Asthma Disability

- Prescribing & adherence patterns – the most effective Rx (ICS) must be inhaled into the lungs for weeks to reverse obstruction
- Most people do not learn how to correctly breathe asthma medications into their lungs
- Adverse lifestyle changes – lack of physical activity, more time indoors with high exposure to passive smoke, pet dander, dust mite, cockroach; decreased intake of vegetables and fruits, becoming overweight

Questions About Disabling Asthma Among Children?

- What is the rate of disabling asthma among Missouri school children?
- What is the level of health risk perceived by the school nurse?
- How do urban & rural rates compare?
- Does geographic disparity exist?

Inventory of Missouri Students with Special Health Needs 2006 – 2007*

- 466 of 524 (89%) school districts reporting
- Data for 823,293 school children K-12
- 62,898 (11.7) were taking asthma medications at school or home
- 7608 (0.92%) history of life-threatening allergies to foods, insects, or latex
- 41,953 (5.1%) ADD/AHDH diagnosis
- 5185 – seizures, 2317 – diabetes

*Source: Missouri School Nurse Consultant, Department of Health & Senior Service

Disabling Asthma Missouri Survey Design

- Draft version January 2005 (MU)
- Focus group review March 2005 with 45 Missouri School nurses during workshop "Asthma & Learning"
- Addition of a health risk score
- Changed wording for some questions
- Added "likely to know" item

Disabling Asthma Defined

- **Children with disabling asthma meet criteria any ONE of the following criteria:**
- a) school absenteeism rate of **>1 day/month or >10 days annually,**
- b) reduced capacity for physical activity resulting in restrictions in curricular or extracurricular activities such as physical education, field trips, sports, band or choir
- c) serious asthma symptoms that interfere with school participation on a monthly basis
- (cough, wheezing, shortness of breath, or chest tightness)

Survey Items

- 1. Zip code for my school(s)

- *(If you serve schools in multiple zip codes please enter information for each separately)*
- 2. Total number of students for my schools in zip code above _____
- 3. Number of students with disabling asthma for this zip code

Survey Items

- *4. Asthma is negatively impacting these students*

1 2 3 4 5 6
Never, Seldom, Sometimes, Often, Usually, Always

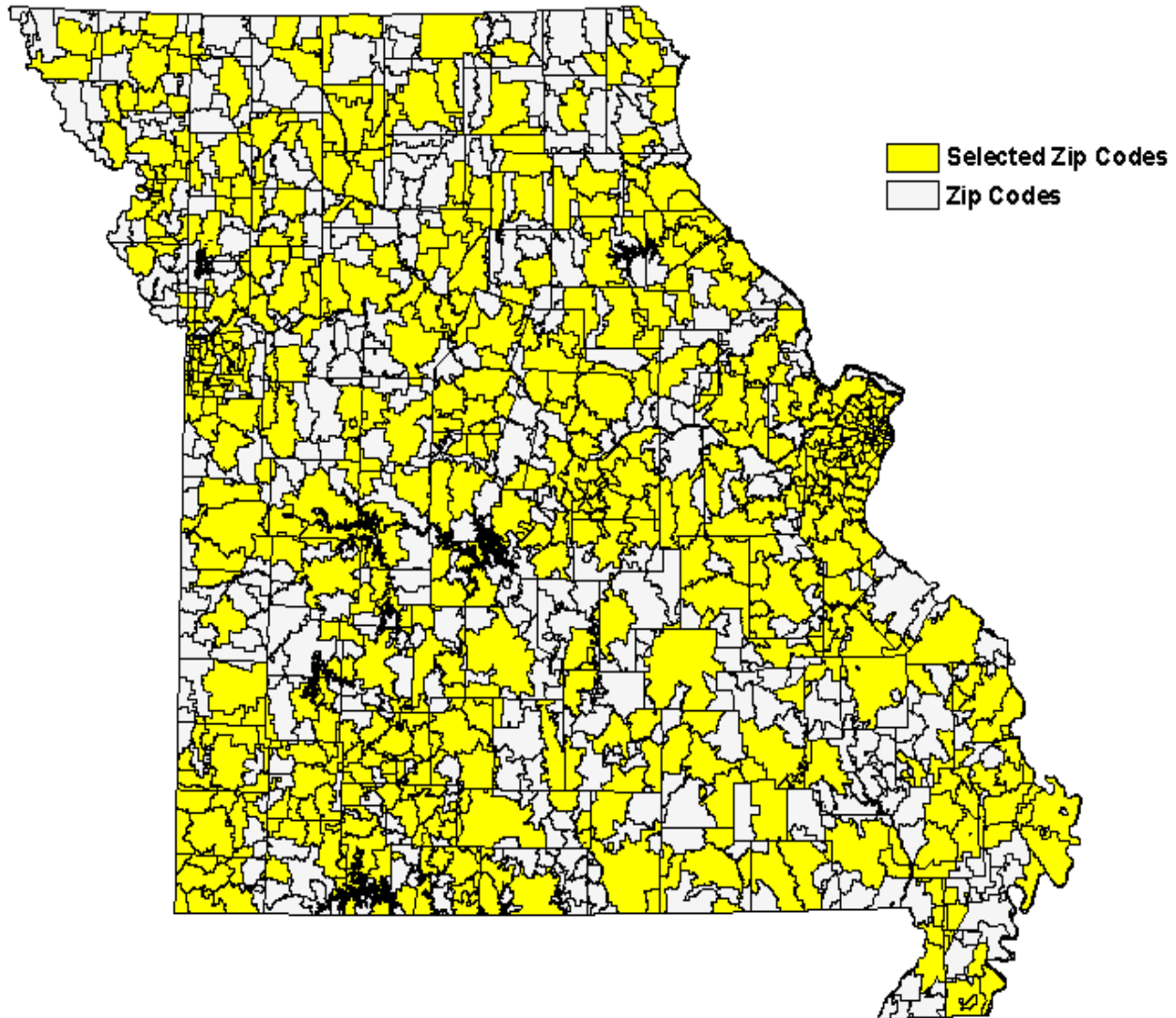
- *5. If a student in my school has disabling asthma I am aware of the problem*

1 2 3 4 5 6
Never, Seldom, Sometimes, Often, Usually, Always

Disabling Asthma Missouri Survey Details

- Disabling Asthma, May 2005 (MU)
- To 1400 Missouri school nurses
- One report per nurse (team) for each zip code
- Responses from 487/669 ZIP codes
- Analyzed 846 school nurse reports for 520,000 of 925,000 students (2005)

Response To Disabling Asthma Survey by School Zip Code



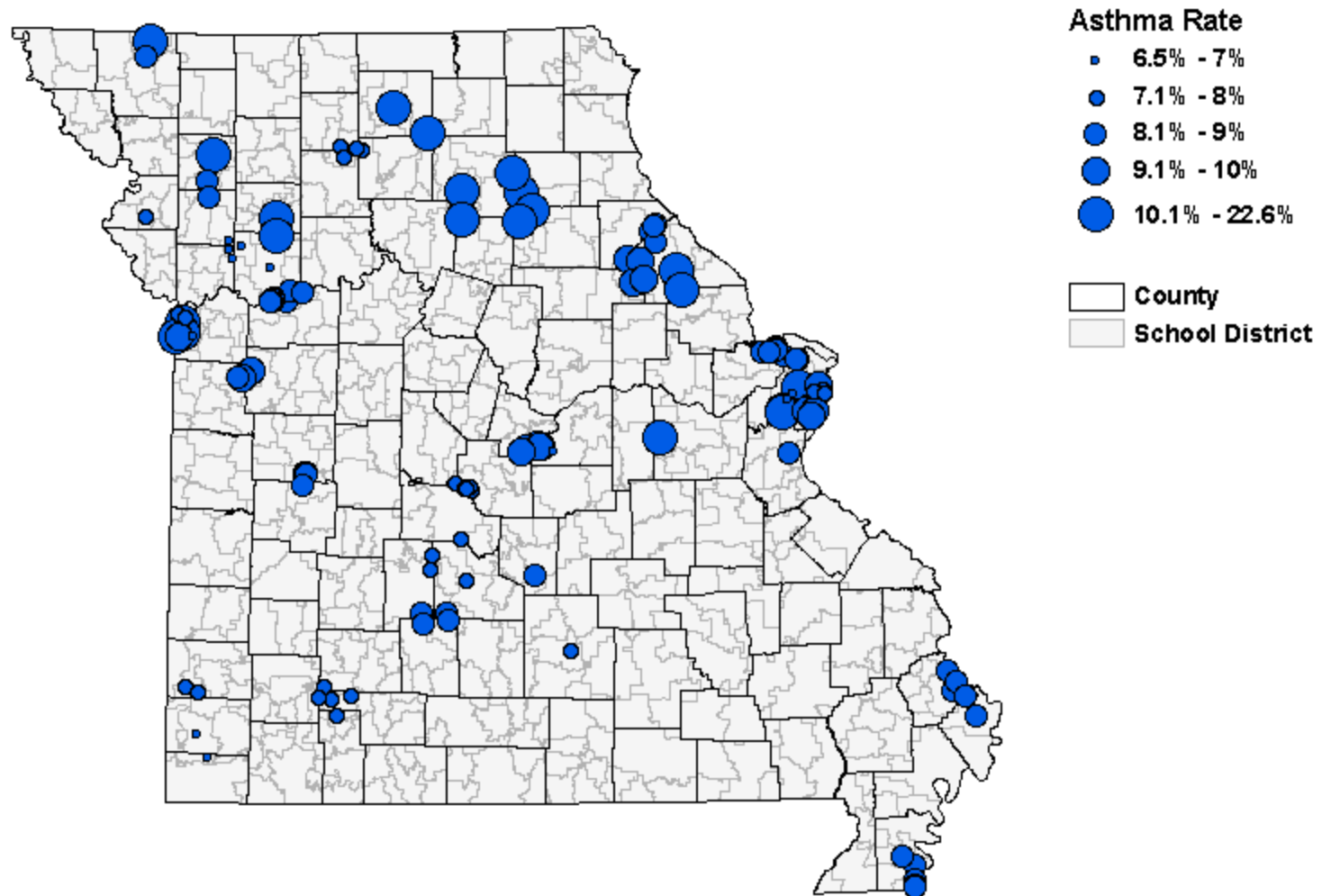
Disabling Asthma Survey Findings

- Large number of high rate zip codes
- Both urban centers demonstrated high rates (St. Louis & Kansas City)
- Missouri median rate was 1.4%
- 50 zip codes reported rates 4-15 times the national rate of 1.4%
- Many rural foci of asthma disability

Geographic Disparity?

There is evidence that public health approaches should be targeted or weighted to address a disparate distribution of asthma disability.

Disabling Asthma Rates Among Missouri Schools (K-12) Highest 50 Urban or Rural Zip Codes, May 2005

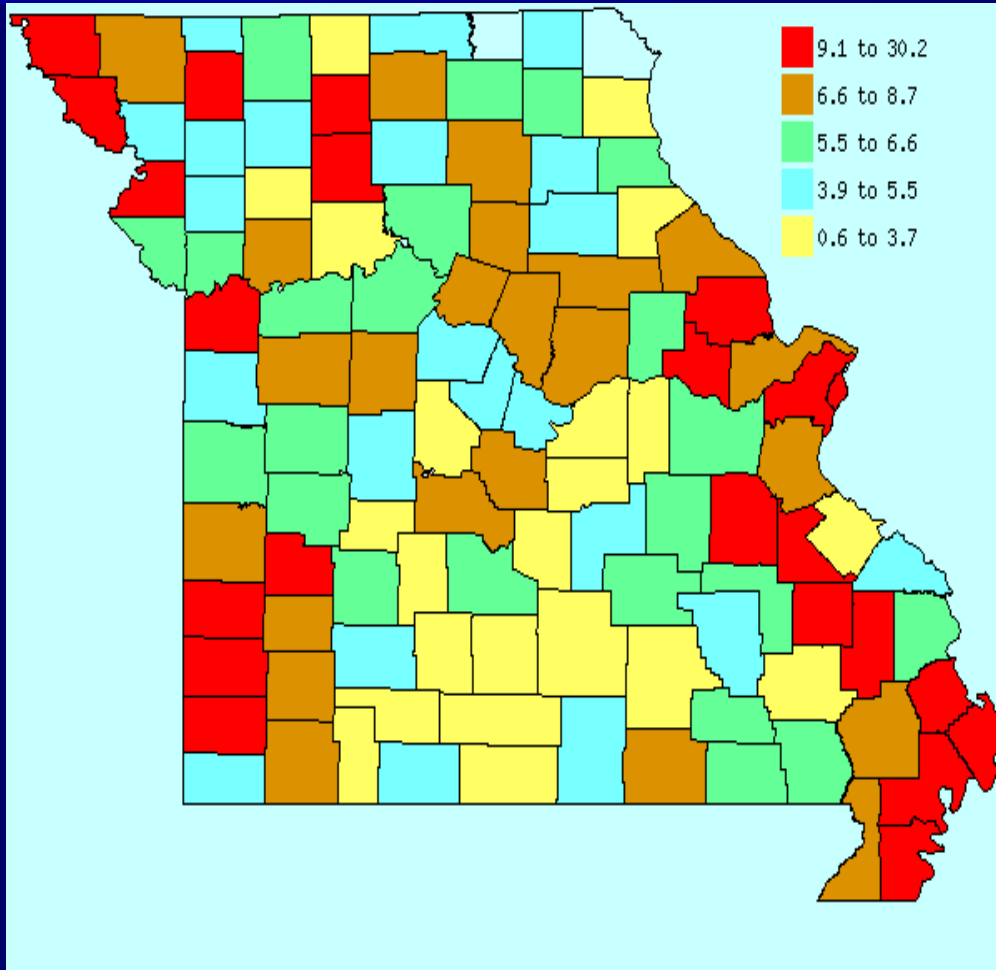


Source: Francisco, B. and Konig, P., 2005. School Nurse Survey of Disabling Asthma in Missouri, Unpublished Data, University of Missouri, Columbia.

ER Visits Cost of Asthma Among Missouri Children

- 2003 15,140 visits <20 years
- 2003 – highest rate among young children, 9220 visits < 10 years
- \$9,781,534 in ER costs for <18 years
- Medicaid costs about 3 times higher (<18)
- Costs for African-Americans 4 times higher

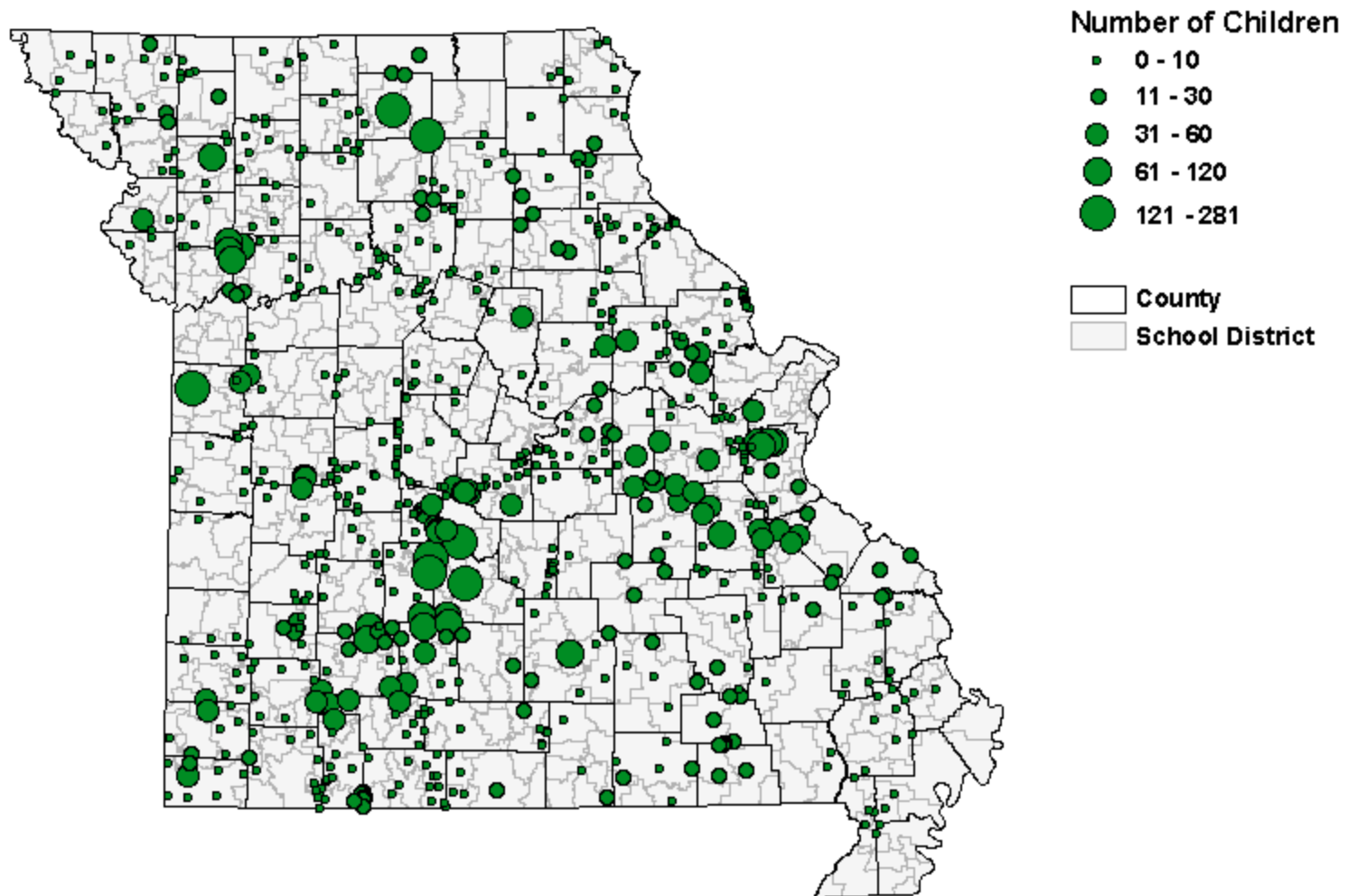
ER Visit Rates <15 years



Follow-up Strategy

- Mapping allowed identification of “high priority” schools ($\#DA \times$ risk score)
- Intervention – support a coordinated school health approach to asthma
- Collaborative research design – aid evaluation of problems & successes

Numbers of Rural School Children in Missouri with Disabling Asthma by School ZIP Code, May 2005



Source: Francisco, B. and Konig, P., 2005. School Nurse Survey of Disabling Asthma in Missouri, Unpublished Data, University of Missouri, Columbia.

Interventions

- Meeting with superintendent – key messages, resources list, web links
- Two training sessions with school nurse, health staff – process of care
- Resources – multi media education for staff, students, parents
- Skills/equipment – In-Check Dial & electronic peak flow meters

Key Messages for Schools

- Human impact of asthma
- Child's need for self-care education
- School financial losses due to asthma
- Resources available
- Asthma Ready™ school program

Statute 167.627

- August 28, 2005
- Revised Self-administration guidelines
- Also, 190.246, Epinephrine auto-injector possession and use

4 Resources For School Asthma

- See "School Governance & Leadership", Spring 2003, American Assoc. of School Administrators
<http://www.aasa.org/publications/sgl/>
- Tools for Schools EPA
<http://www.epa.gov/iaq/schools/>
- "Strategies for Addressing Asthma"
<http://www.cdc.gov/healthyyouth/asthma/strategies.htm>
- Managing Asthma: A Guide for Schools
http://www.nhlbi.nih.gov/health/prof/lung/asthma/asth_sch.htm



Strategies for
Addressing Asthma
Within a Coordinated School Health Program



DEPARTMENT OF HEALTH AND HUMAN SERVICES
CENTERS FOR DISEASE CONTROL AND PREVENTION



<http://www.cdc.gov/healthyyouth/asthma/strategies.htm>

The Experience of Rural Children Whose Daily Lives Are Limited by Asthma

**A Collaborative Research Design
Funded by a Chronic Disease
Fellowship, University of Missouri**

Review of the Literature

- >50,000 scientific articles related to asthma (Medline™, CINAHL™, PsychInfo™)
- >14,000 for childhood asthma
- Only 6 qualitative studies focusing on children's experience of asthma
- Prevailing intervention construct was not based on observational studies of children

Expert Clinical Guidelines

- Large amount of self-care required
- Need for a partnership with children and parents to improve asthma care
- Children's perspectives have not been adequately described
- Little data to describe what children are trying to do in relation to their asthma
- Limited basis for building a partnership

Are We Asking the Right Person?

- By age 11 the child's report alone correlates with clinical findings, parental report does not enhance the predictive value of the clinical history
- Before age 11 parents' report enhances the child's report, strengthening the correlation with clinical findings
(Guyatt, et al, 1999)

Are We Asking the Right Person?

- Children as young as 7 may be dependable, valuable reporters of their own asthma health status.

Olson LM, Radecki, L, Frintner, MP, Weiss, KB, Korfmacher, J, & Siegel, RM, 2007. At What Age Can Children Report Dependably on Their Asthma Health Status, *Pediatrics* 119: p. 93-102.

<http://www.pediatrics.org/cgi/content/full/119/e93>

Why Descriptive Phenomenology?

The paradoxical trend of better treatments and worsening disability might be related to lack of understanding of the day-to-day experiences of children who live with asthma.

Research Aims

- To describe children's intentions related to the experience of disabling asthma
- To examine the varied contexts of their experience at home, at school, in their community, and in the places where they receive health care services
- To compare and contrast the phenomena of children's experience with pertinent theoretical frameworks, concepts, and constructs

Technology

**Health
Care**

Culture

Home



School

Community

Education and the Media

Specific search strategies based on this model yielded >2300 abstracts deemed relevant to the study. These were reviewed and approximately 400 articles were retrieved and incorporated into the final literature review.

Lessons from the Literature

- Rural children were under-represented, urban, inner-city asthma dominated
- Parents were found to under-estimate children's asthma symptoms
- School nurses were leading professionals who assist children with asthma and recognize their disabilities at school

Identifying the Population

- Statewide survey of school nurses
- Selection of 20 rural schools in the 19 counties surrounding Columbia
- Recruitment materials sent home by school nurses for children likely eligible
- Parent initiated contact by mail
- Phone interview to ensure child's rights and evaluate inclusion criteria

Geographically Accessible, Eligible Population

- Zip codes in 19 surrounding counties within a 100 mile radius - accessible
- 20 rural schools w/highest priority scores
- DA rate was 2.8% for these schools
- 271 total children with disabling asthma
- 125 eligible children (age 7-12 years)
(Porter, 1999)

Design

- Cross-sectional
- Rural children
- School age, 7-12 years
- Identified by school nurses
- Goal - 8 participants, at least 3 of each gender, representative of 8% minority population (at least one minority child)

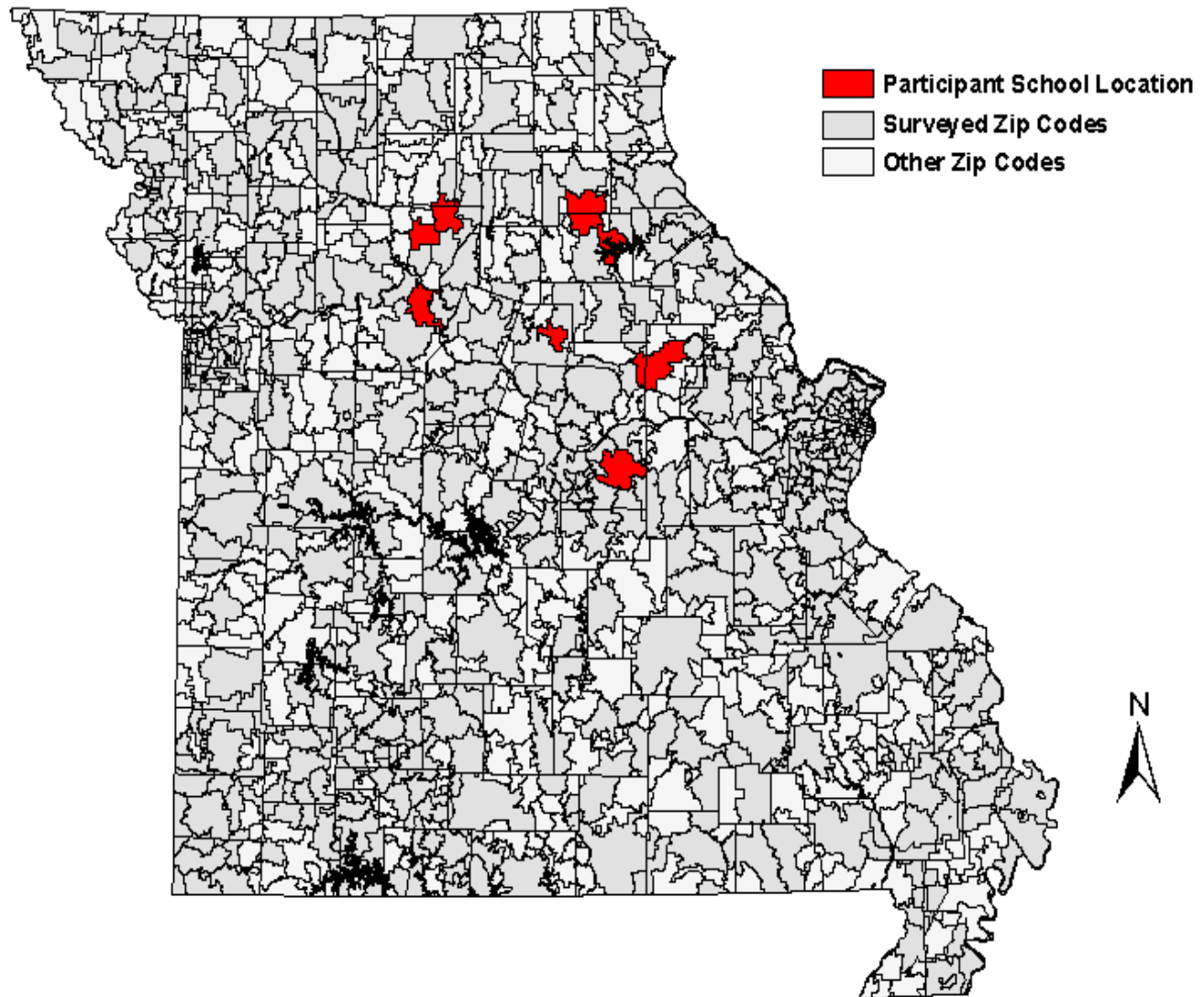
Data Collection

- In home interviews, 3 per child at one week intervals, parent in adjacent room
- Digital recordings, transcriptions, N Vivo™ for coding, analysis, and model building
- Semi-structured interview guide to assure consistency in the interviews
- Child's spontaneous descriptions were encouraged, rather than adherence to the sequence of questions in the guide

Recruitment

- Permission from 19/20 superintendents
- Met with 19 school nurses
- Requested assistance, reviewed materials
- Received 10 responses from families
- Screened and enrolled 8 children
- Parental consent, child assent
- 3 males, 5 females; 2 minority children
- Age range 7-10 years, mean 7.5 years

Location of Participants by School Zip Code



Findings

- Extensive taxonomy of more than 100 intentions and 150 contextual elements
- Very young children provided rich descriptions of their experience
- Young children were aware of numerous environmental factors affecting them
- They were trying to do many things

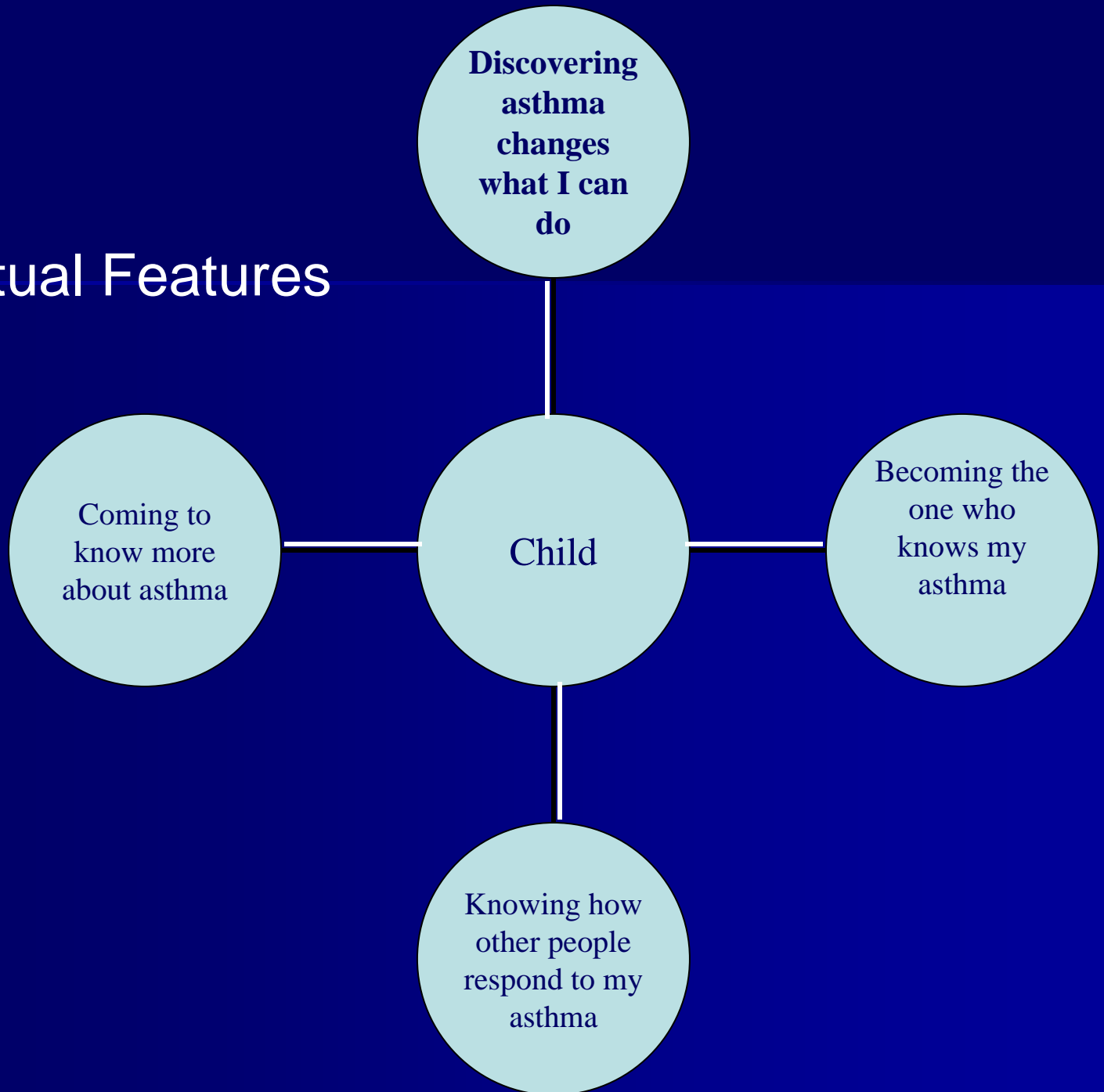
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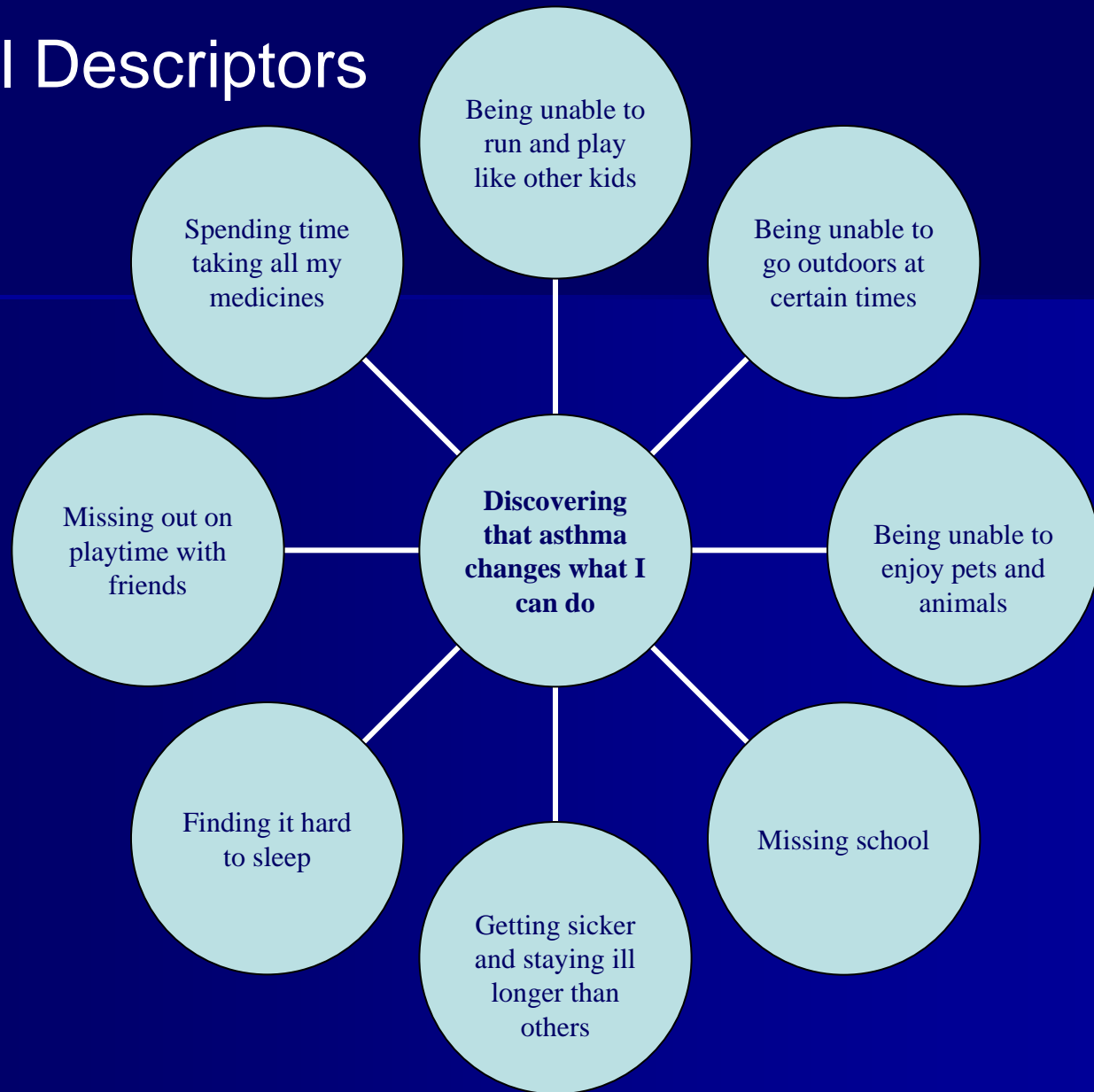
“They don’t believe me.”

10 year old

Contextual Features



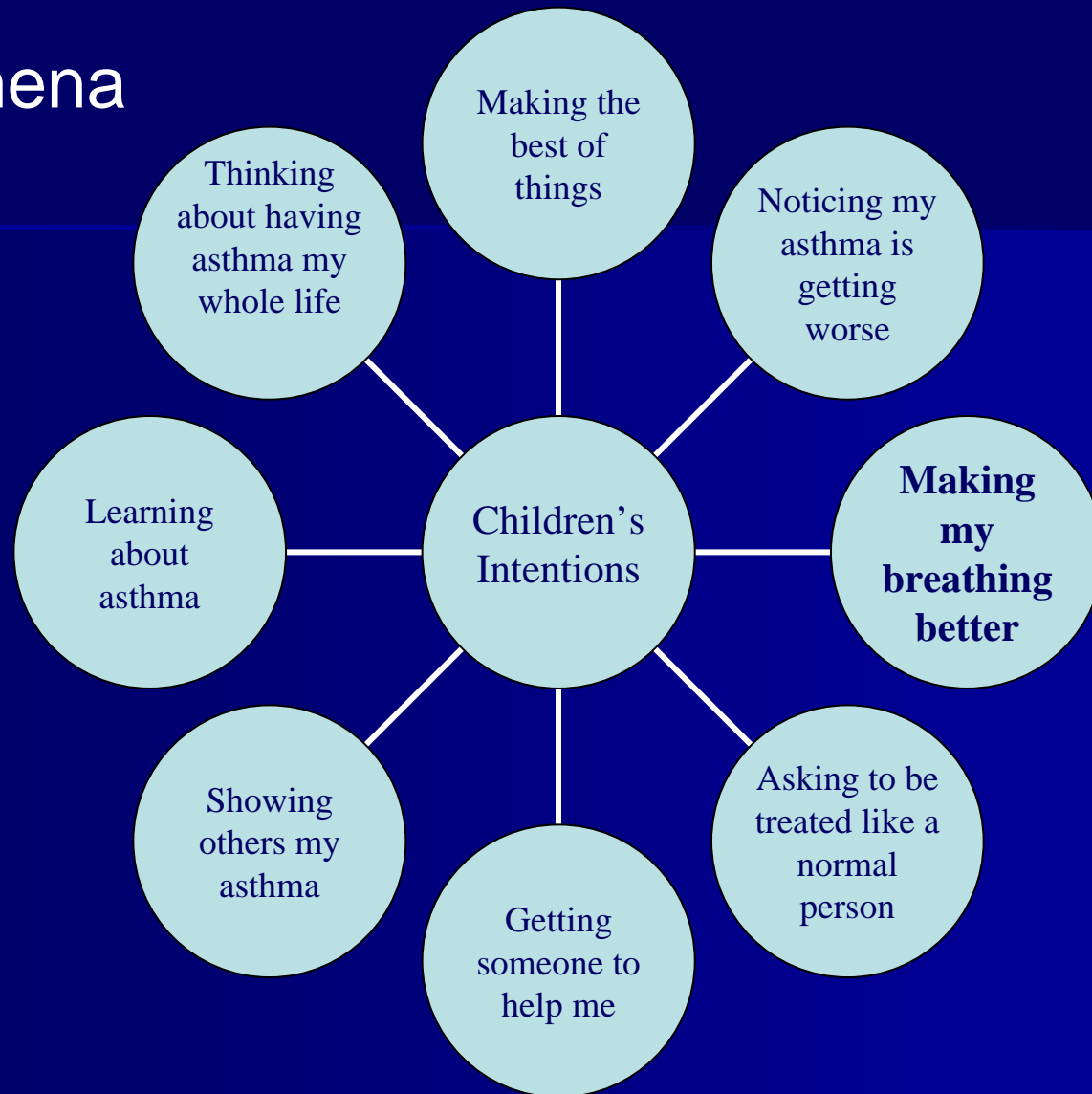
Contextual Descriptors



Knowing What Makes My Asthma Worse

- Breathing certain kinds of air
- Catching a cold or getting sick
- Running, working, or playing hard
- My allergies and my breathing connect
- Problems with my stomach
- Knowing my asthma is worse at night
- Not knowing what causes the trouble

Phenomena



Intentions



Conclusions (School)

- Access to the school nurse was blocked on occasion by adults who doubted children's reports of respiratory difficulty
- Safety concerns and best practices were described in children's accounts of their asthma episodes that occurred at school
- Children described important ways that school nurses helped them with asthma

Conclusions (School-2)

- Children sought support from office staff, teachers, and administrators in the absence of the school nurse
- These people assisted children in the use of their inhaled medication
- Children trusted and depended upon teachers and school staff to help them
- Children use a richer vocabulary to describe their asthma (not just “wheezing”)

How Do We Take On Asthma?

- Promote awareness of the problem
- Evaluate the impact of asthma
- Be prepared for emergencies
- Focus on improving school services
- Use a coordinated approach
- Provide tools, increase staff skills

Results & Implications

- Data suggest geographic disparity
- Schools reporting high level of perceived health impact/risk were motivated to participate in improvement efforts
- Survey served to both quantify the problem and identify level of need
- Policy change resulted – “contracted” nurses (>500) were asked to ID and focus efforts to aid children with disabling asthma
- Foundation funding addressed disability