



Empowering Families

of Children with Health or Mental Health Needs to Partner with Schools

NCCRESt Forum: Leadership for Equity and Excellence
February 9, 2007

Chandra Keller-Allen
Research Assistant & Doctoral Candidate, GWU
cka@gwu.edu



Population of Interest

- Children with special health or mental health care needs (CSHCN):
 - Are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition;
 - also require health and related services of a type or amount beyond that required by children generally; and
 - May or may not also have a disability.





The Medical Home




- A set of relationships that families build with the health, mental health, educational, and other providers who take care of their child all of the time, on a regular basis.
- Must be
 - Accessible, family-centered, continuous, comprehensive, **coordinated**, compassionate, and culturally effective (AAP, 2004)
- Coordinated care for CSHCN includes interaction and information sharing with educational providers.
- Why should education be included in the medical home?
 - Children's health and mental health needs must be met to ensure developmental and educational progress.
 - CSHCN will experience better care and outcomes if health and mental health support are consistent and coordinated across settings, including schools.



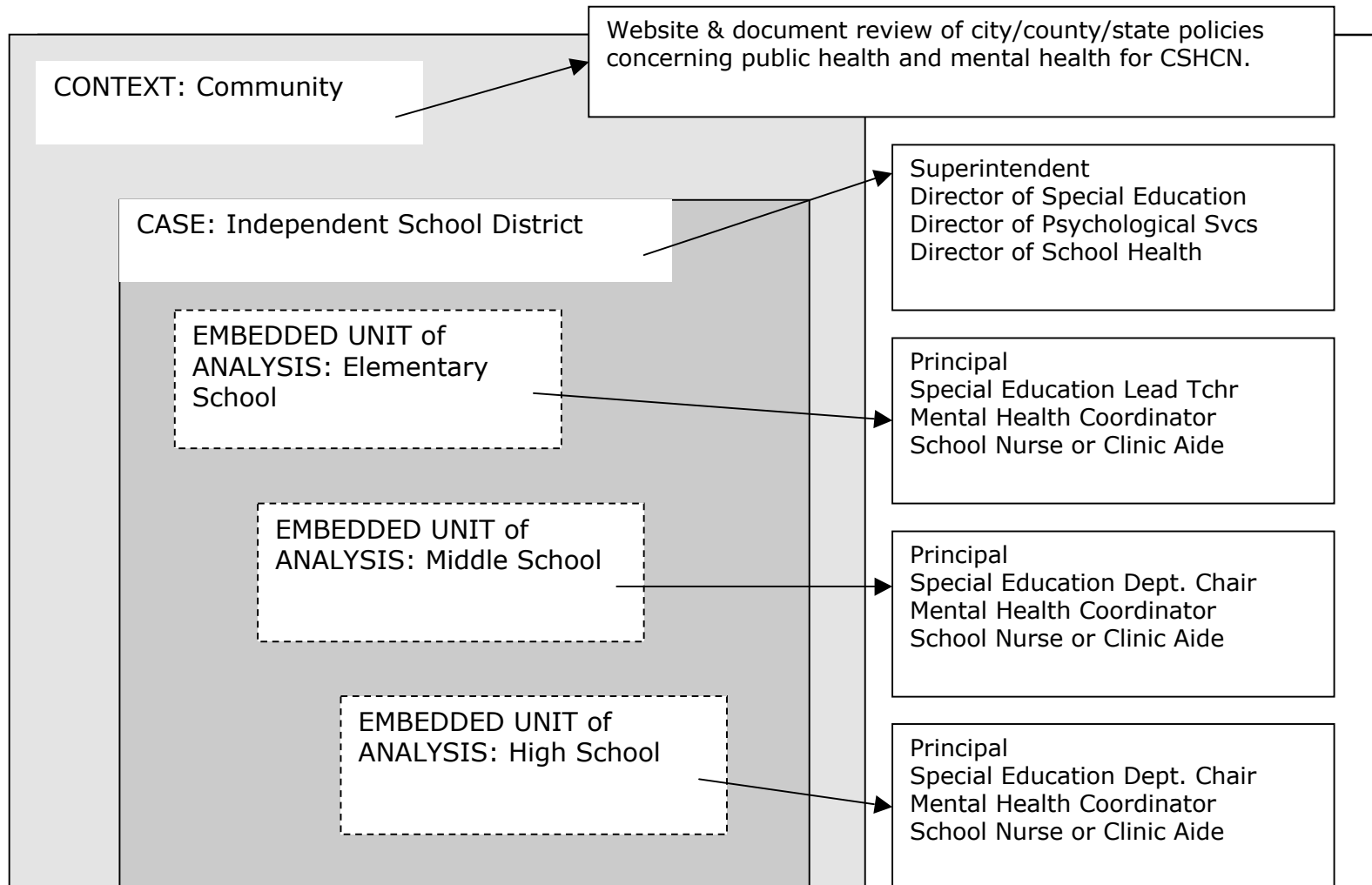
Projects

-  Exploratory multiple case study of a sample of district and school personnel
-  Development of an informational booklet for parents about how to engage school personnel in their child's medical home

Case Study Research Questions

-  How are the three selected school systems meeting the health and mental health needs of CSHCN?
-  To what extent, with whom, and how are the school systems interacting with health and mental health professionals to meet the needs of CSHCN?
-  What challenges do schools face in meeting the needs of CSHCN?

Case Study Design





Case Study Limitations

- Small sample, but representative of large and small school systems
- Self-reported data from district and school employees
- District leadership chose the schools that participated
- Research staff all from education backgrounds; no health or mental health perspective on research team
- No urban core or rural districts represented, but urban demographics represented in two districts



Case Study Findings

- Communication between schools and students' health and mental health providers enhanced care in schools, but occurred for only a fraction of students
- Staffing of school health and mental health professionals varies greatly and impacts support and services provided to students
- Schools use individualized plans for health, behavior, and education to provide a higher level of service to students, but it is unclear how they are integrated.
- Local and state policy has an impact on the ability of school personnel to address the comprehensive health and mental health needs of low-income children and families



Parent Resource Booklet

- The HSC Foundation partnered with GW again to develop a resource for parents to assist them in engaging school professionals in their child's medical home.
- Goal for parents to understand a *Medical Home* is not a place, but a set of relationships that families build with the health, mental health, educational, and other providers who take care of their child all of the time, on a regular basis.



Booklet Content

- Defines population and the medical home concept
- Provides guides and tips for:
 - school professionals they are likely to encounter
 - health and mental health information parents should share with schools to enhance coordination and care for their child
 - typical school-based health and mental health services
 - planning for child's transition to adulthood
 - common school-based individualized plans
 - federal laws that may affect child and services
 - right to free appropriate public education
 - questions to ask schools to ensure needed services
- Includes a resource list for further information

Booklet Validation Process

- Focus groups conducted to discuss content and format
 - 📁👤 Parents of CSHCN
 - 📄👤 Experts in the fields of transition and special education
 - 📄👤 Experts in the fields of health and mental health (has not occurred yet)
- Revision and reformatting of booklet in response to focus group findings



Parent Focus Group

- No other resource with this combination of information
- Some had not heard of the medical home and had trouble understanding concept
- Felt that this booklet should be the middle resource in a series of three
 - What to do if you suspect your child has a health, mental health, or educational problem
 - *Partnering with your child's school*
 - What to do when you don't think your child is getting what he/she needs

Special Education & Transition Expert Focus Group

- Many did not know about the medical home concept and how it might interact with special education and transition services.
- Suggestions to add information re:
 - vocational rehabilitation
 - student self-advocacy
 - school-based disability awareness programs
 - No Child Left Behind
 - 508 plans for technology
 - sharing outside evaluations with school staff
 - diploma options
 - more detailed transition planning and post secondary opportunities



Dissemination Plans

- Release booklet and case study report as part of the HSC Foundation's Family Supports initiative
- Pilot booklet with network of HSCSN parents
- Translate into multiple languages
- Start locally and then distribute nationally
- Line up organizations to be distribution partners
- *Please contact me at cka@gwu.edu if you would like to see the booklet when it is finished.*



Feedback Invited

- Thoughts on usefulness of booklet
- Ideas for dissemination partners
- Training ideas for school staff
- Other ways to engage parents and schools in children's medical home to enhance care