



Using the CSHCN Data

for fun and profit

MA Consortium for CSHCN
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How can the data be used

- Needs assessment
 - Program planning
 - Grants and contracts
- Training
 - Unique documentation of family perspective
 - Sensitize professional and preprofessional students to family experience
- Advocacy
 - Distinctive picture of strengths and weaknesses of system of care
 - Given thoughtful interpretation

Thinking about the MA profile

<http://cshcndata.org/anonymous/stPrevalence.aspx?geo=Massachusetts>

- More kids with special needs than other states
 - Slightly fewer experience major impact of special health need
- Significant system strengths
 - Insurance coverage
 - Access to services
 - Especially medical care
- But important unmet needs
 - Family supports
- With important family consequences

A few points to note

- Difference in prevalence of SHN
 - Not due to high EI enrollment
 - More evident in school-aged children
 - Very high prevalence of special health needs among Hispanic children
 - Possible causes
 - Real difference in prevalence
 - Difference in culture that affects perception
 - Difference in culture that affects reporting
 - Difference in services
 - Especially between MA and states with high Hispanic population

A few points to note (cont.)

- Major areas of unmet need
 - Family supports
 - Family-centered care
- With major consequence for families
 - Financial burden
 - Workload
 - Impact on parent employment

Caveats and conclusions

- Recognize limitations in data
 - Parent report
 - Expectations and experiences not comparable across states
- Recognize strength of data
 - Parent report
 - Tells the story from a family perspective
- Suggests need to better understand Hispanic experience
- Directs attention to family supports
 - Not a story of unmet medical need