

Family Well-Being in Massachusetts:

State analysis of the National Survey of Children with Special Health Care Needs

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In collaboration with the MA Consortium of CSHCN Family
Participation Workgroup

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Goals and Objectives

- To better understand the needs of families of CSHCN in MA
- To provide policy relevant state-specific information to consumers and advocates in Massachusetts
- To produce two consumer friendly analyses of the policy relevant data regarding CSHCN and their families

National Survey of CSHCN

- Phone survey conducted from 10/2000-4/2002
- Nationally representative and state representative sample
- 744 CSHCN in MA; 38,886 in US
- Repeat survey currently in the field

Process & Analysis Plan

1. Meetings with Family Participation Workgroup
2. Workgroup interested in looking at unmet need among CSHCN in MA
3. Also interested in looking at unmet need among children with more severe conditions

Unmet Need
Analysis of all CSHCN
Massachusetts Data

Types of Needs

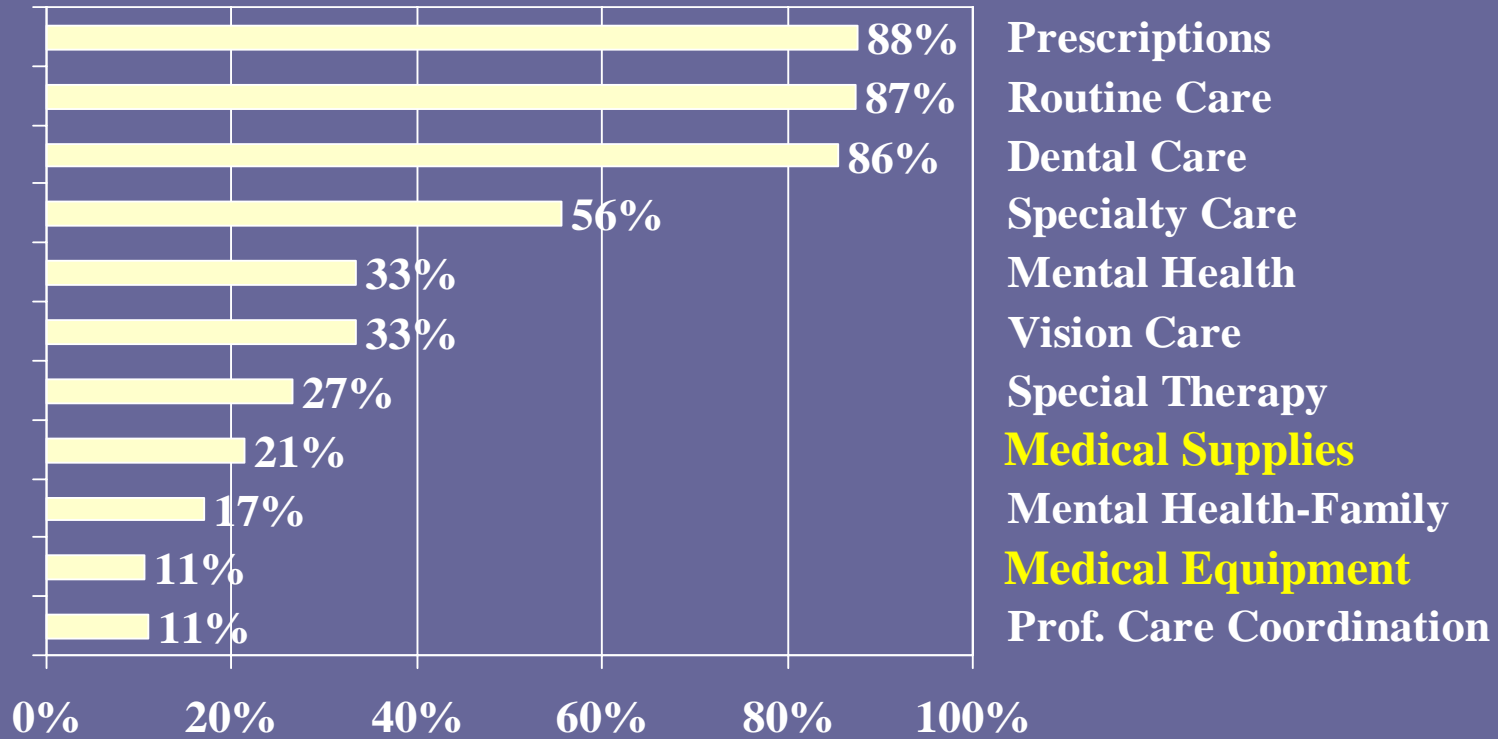
Health Care Services

- Routine Care
- Specialty Care
- Dental Care
- Prescription medication
- Special therapy
- Mental health services
- Substance abuse treatment (age 8+)
- Vision/Hearing Care and Devices
- Home health care
- Medical supplies and equipment
- Mobility aids (age 3+)
- Communication aids (age 3+)

Family Support Services

- Professional care coordination
- Mental health care/ counseling for family member(s)
- Respite care
- Genetic counseling

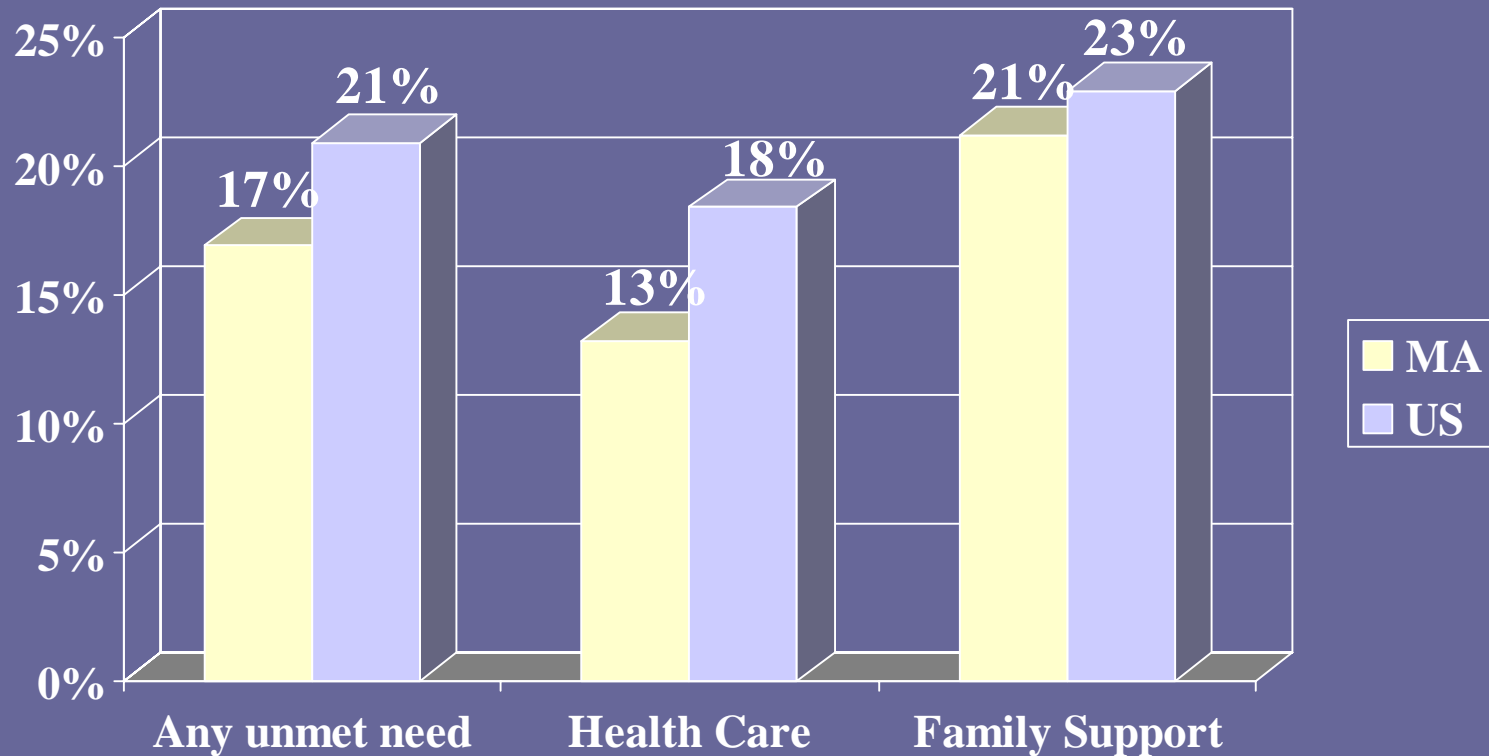
Need for Services, MA



Communication aids, Mobility aids, Home health care, Substance abuse treatment, Hearing care/devices, Respite care and Genetic counseling all less than 10%

Data from the State and Local Area Integrated Telephone Survey National Survey of Children with Special Health Care Needs, 2001. Centers for Disease Control and Prevention, National Center for Health Statistics.

Unmet Need – MA & US



Percentages are of those reporting a need

Data from the State and Local Area Integrated Telephone Survey National Survey of Children with Special Health Care Needs, 2001. Centers for Disease Control and Prevention, National Center for Health Statistics.

Other MA Data Available

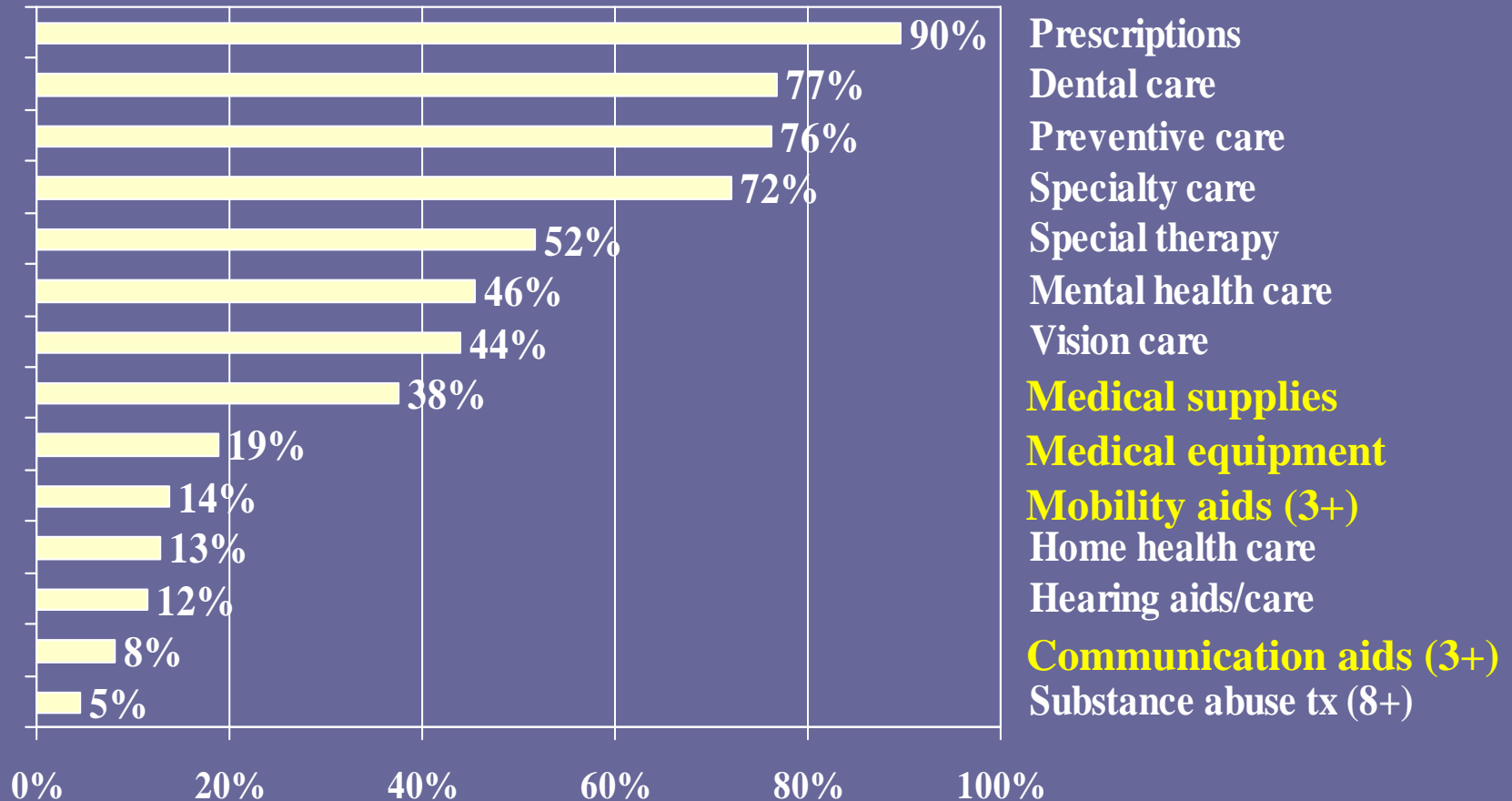
- Unmet need:
 - How child/family characteristics relate to unmet need
 - How service systems relate to unmet need
- Financial burden among MA families
 - Percent of MA families reporting financial problems b/c of child's health
 - How child/family characteristics and service systems relate to financial impact

Unmet Need
Analysis of CSHCN
with More Severe Condition
US Data

Severity Sub-sample

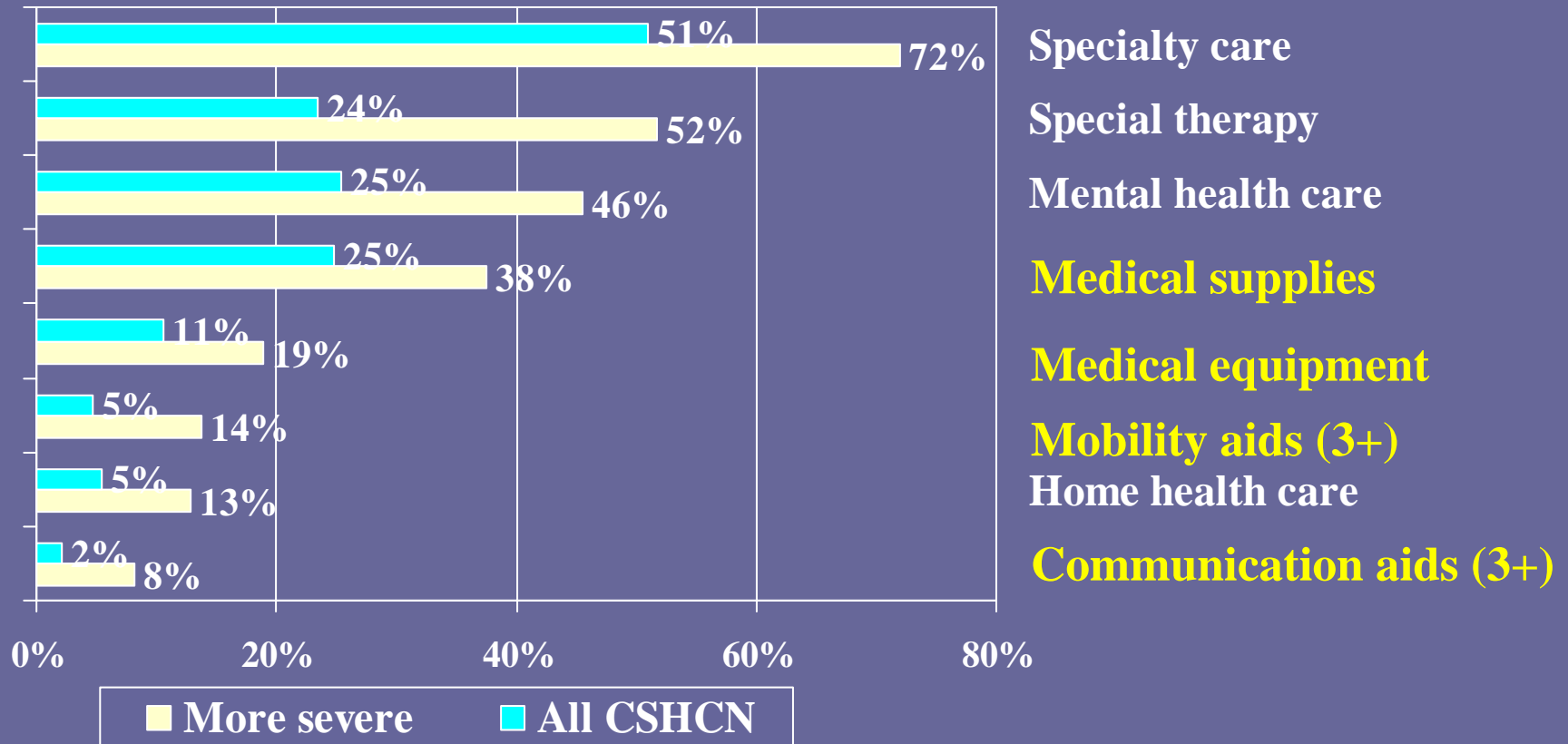
- US analyses for adequate sample size
- Includes 5,203 (13%) CSHCN in US
- Selected if:
 - Positive for 2 or more CSHCN Screener items
AND either:
 - Condition affects ability ‘a great deal’
 - Parent Rank of severity 8+ (on scale of 0-10)

Need for Health Care Services – CSHCN with More Severe Condition, US



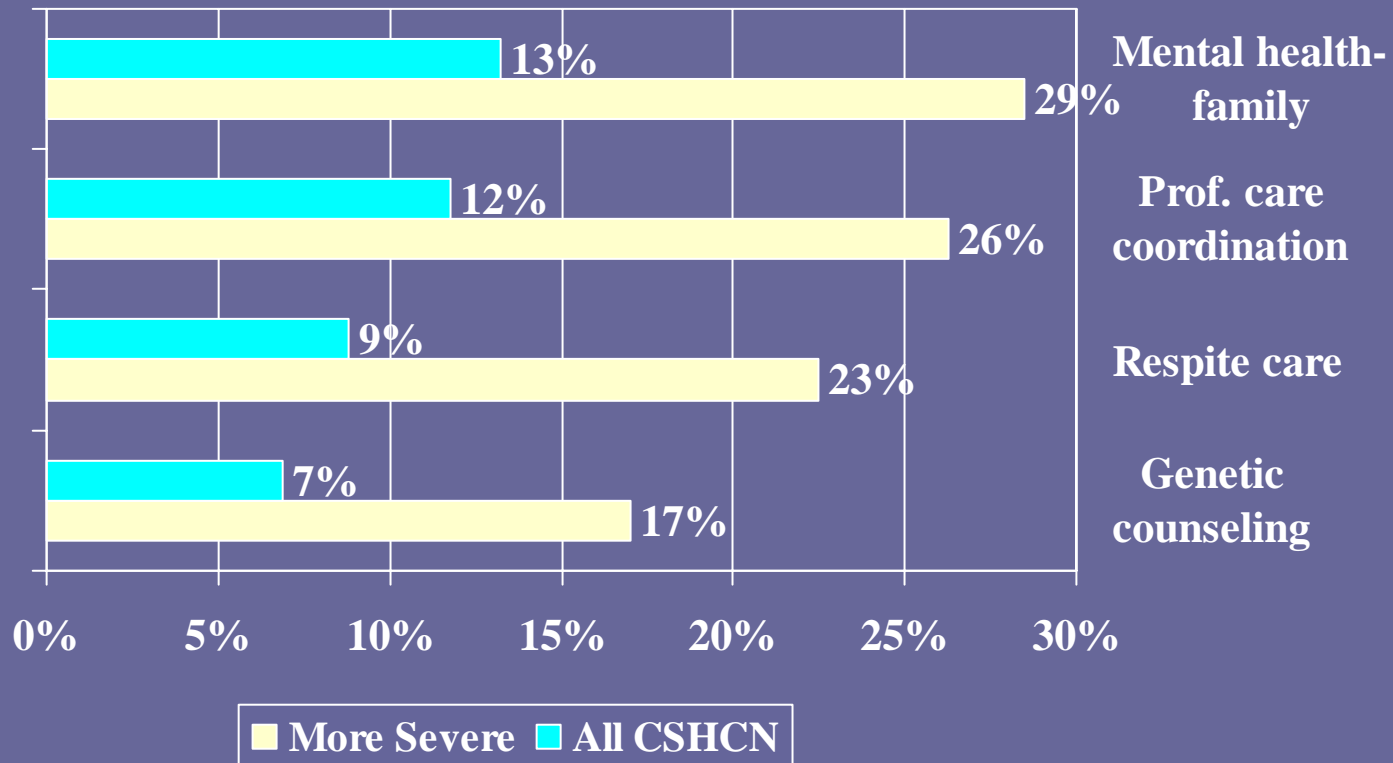
Data from the State and Local Area Integrated Telephone Survey National Survey of Children with Special Health Care Needs, 2001. Centers for Disease Control and Prevention, National Center for Health Statistics.

Need for Health Care Services – All CSHCN and with More Severe Condition, US



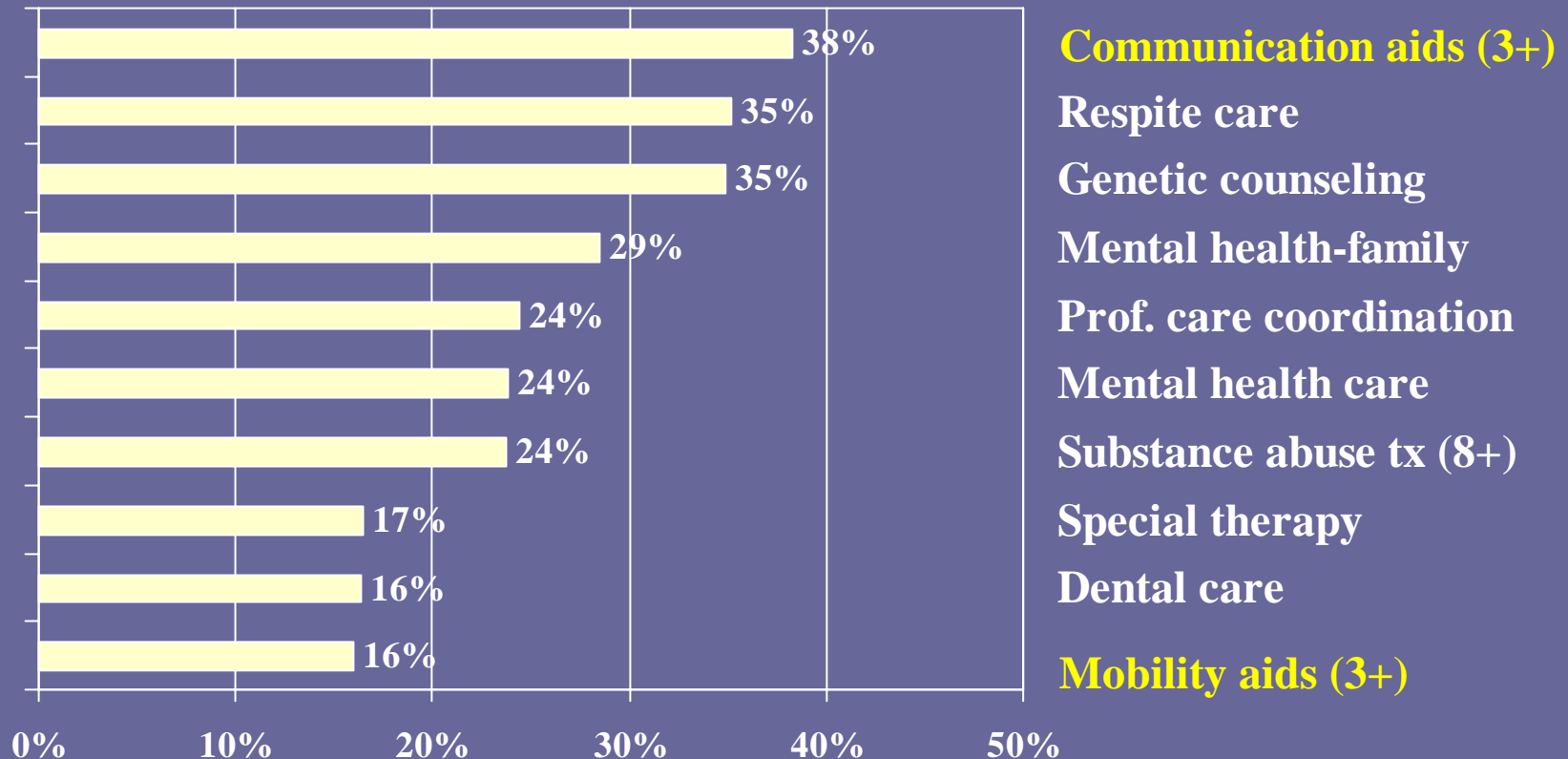
Data from the State and Local Area Integrated Telephone Survey National Survey of Children with Special Health Care Needs, 2001. Centers for Disease Control and Prevention, National Center for Health Statistics.

Need for Family Support Services – All CSHCN and with More Severe Condition, US



Data from the State and Local Area Integrated Telephone Survey National Survey of Children with Special Health Care Needs, 2001. Centers for Disease Control and Prevention, National Center for Health Statistics.

Top 10 Unmet Needs – CSHCN with More Severe Condition, US



Data from the State and Local Area Integrated Telephone Survey National Survey of Children with Special Health Care Needs, 2001. Centers for Disease Control and Prevention, National Center for Health Statistics.

Unmet Need CSHCN with More Severe Condition, US

- Non-whites were more likely than whites to have an unmet Preventative Care need
- Hispanics more likely to have unmet Rx med and vision care need
- Poor and near poor families were more likely to have unmet Preventative, Dental, Rx med, and vision care need

Data from the State and Local Area Integrated Telephone Survey National Survey of Children with Special Health Care Needs, 2001. Centers for Disease Control and Prevention, National Center for Health Statistics.

Summary

- Select NSCSHCN MA data will be available for advocacy purposes at www.massgeneral.org/children/ccahp
- More data available at www.cshcndata.org
- Repeat survey currently in field
 - Repeat unmet need analysis
 - What would help advocacy purposes?

References/Contacts

State and Local Area Integrated Telephone Survey National Survey of Children with Special Health Care Needs, 2001.
<http://www.cdc.gov/nchs/about/major/slaits/cshcn.htm>

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www.massgeneral.org/children/ccahp