

Alternative and Complementary Health Practices for Children with Special Health Care Needs and Disabilities

Patterns of Use and Communication with Physicians

Paula M. Minihan, Aviva Must & Sara Rakaczky, Tufts University
Barbara Popper & Betsy Anderson, Family Voices

2007 APHA Annual Meeting



Children with Special Health Care Needs* (SHCN)

- Federal cross-disability designation initially established to better meet service and policy needs of children with a wide range of health conditions
- 9 million children < age 18 have SHCN
- More children with SHCN now live close to normal life spans making them newly susceptible to common adult-onset chronic diseases as they age
 - HP 2010: *“under-emphasis of health promotion and disease prevention activities targeting people with disabilities has increased the occurrence of secondary conditions”*
- Lack of information about families' perspectives on health and wellness for their children with SHCN limits development of supports and interventions

*term “disability” used by CDC



Policy Support for Children with SHCN & Their Families is Widespread

- Policies support:
 - coordinated, compassionate, family-centered networks of **conventional** health services
 - financial access to health services
 - direct involvement of families
- Policies reflect collaborative efforts of public (federal and state) and private sectors
 - State Title V programs
 - “Medical Homes” initiative
 - “Bright Futures” 2007 recommendations include children with SHCN



Family Matters: Promoting Health & Wellness for Children with SHCN

- Partnership:
 - Family Voices: national family grassroots organization
 - Tufts University: research university

- Aims:
 - Learn what families know about the benefits of healthy behaviors for children with SHCN & if they value these health promotion approaches
 - Find strategies to help parents encourage children to have healthier lifestyles

- With CDC funding we conducted:
 - Qualitative research
 - Controlled intervention study evaluating impact of mentor peer support on parents' efforts to promote healthier behaviors
 - Web-based survey of families nationwide

- Today: Findings on families' use of alternative & complementary health practices from web-based survey

Use of Alternative & Complementary Health Practices (ACHP) in Children

■ Wide variation in prevalence estimates reflects variations in:

- ACHP measures
- sampling frames
- time periods

■ Prevalence estimates:

- 2%: nationally representative sample
- 11%-54%: general pediatric practices
- 34%-74%: specialized pediatric practices

■ This study:

- national sample with cross-disability framework
- sponsored by parent organization and recruited through parent organizations
- focused on current use
- included use of ACH practitioners and "home remedies"

Where are Pediatric Health Care Providers on This Issue?

- No published clinical guidelines regarding use of ACHP in the care of children with chronic illness or disability (AAP, 2001)
- Health providers generally don't know when children use ACHP.
 - Only 44% to 50% of parents using ACHP discussed it with their child's doctor
- Most pediatricians (96%) believed some children in their practices used ACHP
 - 70%: Said discussions were initiated by the family
 - 37%: Asked about ACHP as part of routine medical history
- Child health providers and use of "herbs and dietary supplements" (HDS)
 - 68%: It's important to talk to families about HDS
 - 42%: Felt confident to talk to families about HDS



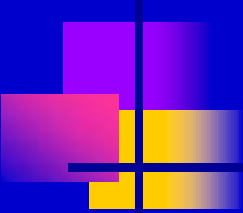
Web-Survey: Methods

- Parents (predominantly mothers) of children with SHCN ages 6 – 18 (self-identified)
- Recruited via a national network of SHCN advocacy and support organizations
 - E-mail list-servs (“please pass along”)
 - Flyers & postcards
 - Displayed within organizations
 - Distributed at workshops & meetings
- On-line anonymous survey (English)
 - Dec. 2006 – Jan. 2007
- Convenience sample (n=893)
- Parents represent 49 states and DC



Survey Instrument

- Emphasis on what families do at home to promote their children's health and wellness
- Total of 219 questions collected data in following content areas:
 - Child's special health care needs & disabilities
 - Interactions with medical professionals
 - ***Use of complementary and alternative health practices***
 - Sources of health and wellness information
 - Nutrition, physical activity and screen time behaviors
 - Roadblocks/barriers
 - Family routines
 - Demographics
- Required 20 – 40 minutes to complete



Characteristics of Children and Parents (n=893)

- 67%: Male
- 11.2: Mean age
- Race/ethnicity:
 - 81% White
 - 6% Multi-racial
 - 6% Black
 - 3% Hispanic
 - 2% Asian
 - 1% American Indian
- Community
 - 24% Urban
 - 54% Suburban
 - 22% Rural
- Mother's education:
 - 54% College degree or plus
- Family's pre-tax income:
 - 20% <40K
 - 27% 40 – 70K
 - 43% >70K
- Top 3: Parents' most useful sources of health & wellness information
 - Internet
 - Advocacy groups
 - Child's medical specialist

Children's Health Profile (n=893)

Conditions

- Many children have >1 condition
- Most prevalent conditions*:
 - 54% Learning disabilities
 - 49% Allergies or sensitivities
 - 40% ADD/ADHD
 - 38% Autism spectrum disorders
 - 36% Mental health issues
 - 26% Mental retardation
 - 22% Orthopedic problems
 - 20% Asthma
 - 18% Epilepsy or seizures
 - 14% Cerebral palsy

Health care access

- 96% have health insurance
- 96% have primary care provider

Health status indicators

- Child's overall health status
 - 62% Very good/excellent
 - 26% Good
 - 12% Fair/poor
- Stability of child's health:
 - 55% Usually stable
 - 29% Changes once in a while
 - 16% Changing all the time
- 6.2 Mean level of severity of disability (1-mild, 10-severe)

**Conditions not mutually-exclusive*

Survey Question

Many families use complementary/alternative medicine as an addition to Western medicine. Within the past 12 months, which of the following practices have you used with your child? (Please check ALL that apply, and also check if you have discussed it with your child's doctor.)

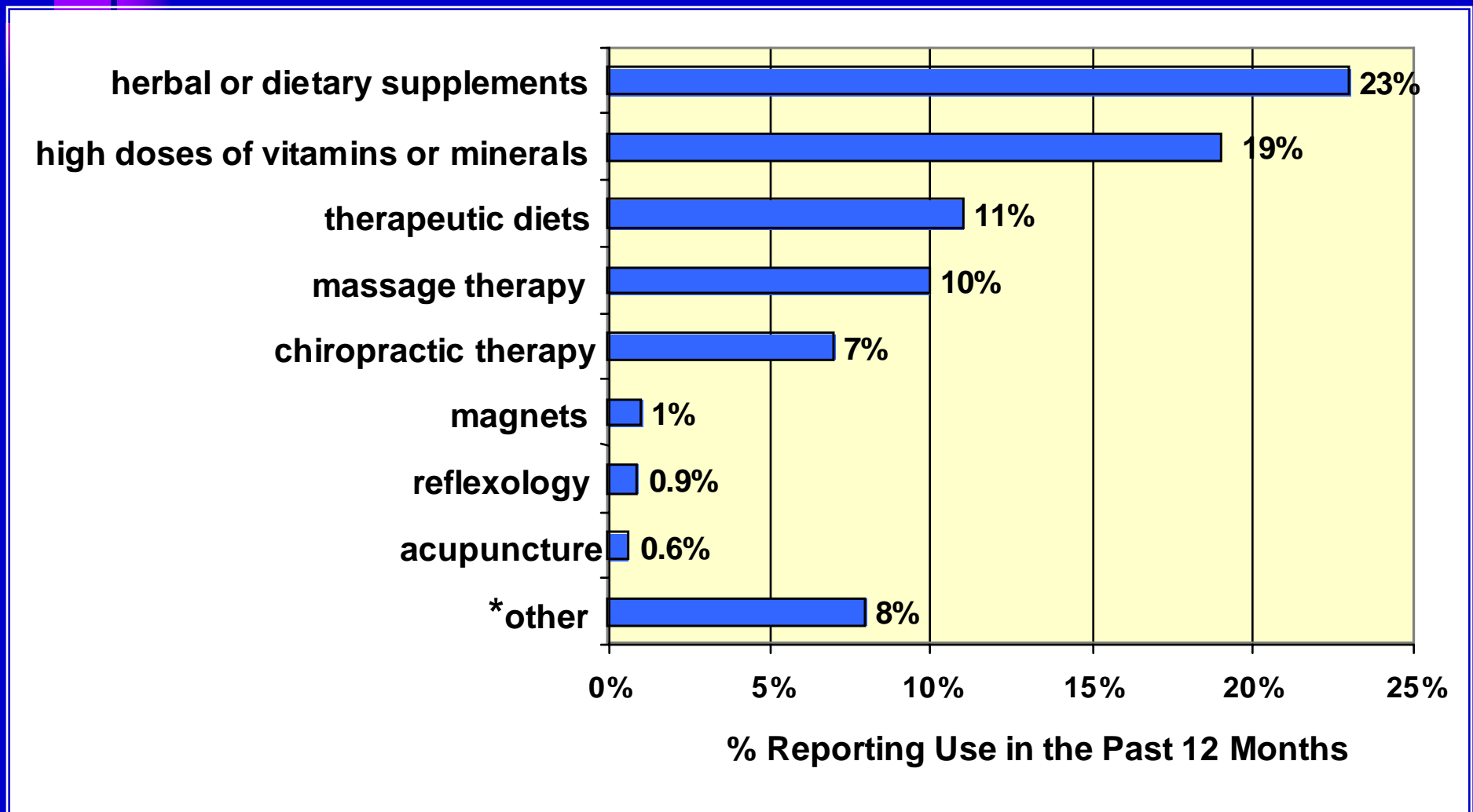
	Practice used in past 12 months	Discussed with child's doctor
B6. Herbal supplements	<input type="checkbox"/>	<input type="checkbox"/>
B7. Specific vitamin supplements in high doses	<input type="checkbox"/>	<input type="checkbox"/>
B8. Chiropractic	<input type="checkbox"/>	<input type="checkbox"/>
B9. Therapeutic diet (like gluten-free and/or casein-free diet for autism)	<input type="checkbox"/>	<input type="checkbox"/>
B10. Massage	<input type="checkbox"/>	<input type="checkbox"/>
B11. Acupuncture	<input type="checkbox"/>	<input type="checkbox"/>
B12. Magnets	<input type="checkbox"/>	<input type="checkbox"/>
B13. Reflexology	<input type="checkbox"/>	<input type="checkbox"/>
B14. a) Other, please specify in B14. b)	<input type="checkbox"/>	<input type="checkbox"/>
B15. a) Other, please specify in B15. b)	<input type="checkbox"/>	<input type="checkbox"/>

Patterns of Use (n=893)



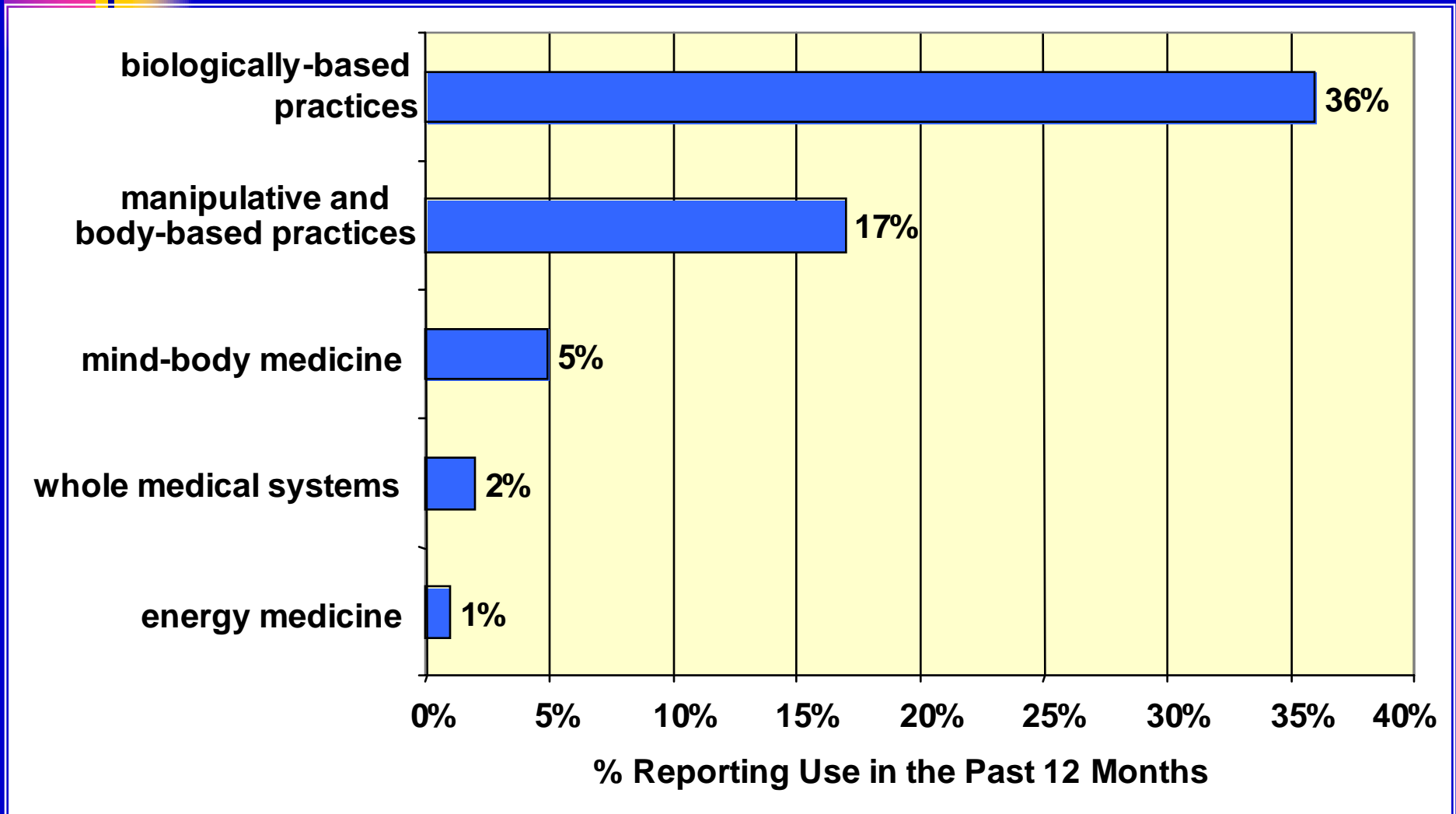
- 44% of children used **at least one** alternative and complementary health practice in past year
- Some children used more than one
 - 23% One
 - 12% Two
 - 5% Three
 - 4% Four or more

Patterns of Use (n=893)



* other (n): experimental behavioral therapies (37), craniosacral therapy (13), chelation therapy (9), homeopathy (8), oxygen therapy (3)

ACHP Use Patterns: NCCAM Typology



Discussing ACHP Use with Child's Doctor (n=893)

ACH Practice	% reporting use	If used,% discussed with MD
Herbal or dietary supplements	23%	38%
High doses - vitamin or mineral supplements	19%	35%
Therapeutic diets	11%	45%
Massage therapy	10%	23%
Chiropractic therapy	7%	23%

Factors Associated with ACHP Use (n=893)

Variable	P-value	Nature of the Relationship
Child's age	.05	Negative, but curvilinear
Child's overall health status	.03	As the child's health declines chances of using increases.
Race/ethnicity	.18	N/A
Type of community	.38	N/A
Mother's level of education	.53	N/A



Limitations of study

- All data parent-reported
- Convenience sample and generalizability is unknown
 - Recruited through advocacy and other networks
 - Parent respondents experienced and confident consumers of health services
 - Parent respondents largely white, well-educated, and financially comfortable
 - "Digital divide"
 - Children with Autism spectrum disorders known to be over-represented
- Lack of consensus and fluidity regarding specific ACH practices
- Complex health status of children limits ability to link use patterns with specific conditions

Conclusions & Future Directions



- Children with SHCN receive care from model networks of coordinated, family-centered and conventional health services.
 - 44% of families had used ACH practices with their child – in addition to conventional health services - in previous year.
- Top 3 ACH practices parents used with their children with SHCN:
 - 23% Herbal or dietary supplements
 - 19% Specific vitamin or mineral supplements in high doses
 - 11% Therapeutic diets
- Only a minority of parents discussed their child's use of ACHP with their child's doctor
 - More parents discussed use of therapeutic diets and vitamin or mineral supplements in high doses with their physicians than other ACH practices

Conclusions & Future Directions

(2)

- Child health providers who don't discuss use of ACH practices with parents of children with SHCN may miss information important to overall quality of care.
 - Discussion of ACH practices should be part of routine history taking
- The reality that many families of children with SHCN use ACH practices in addition to conventional medicine must be added to the policy agenda so supports can be developed to help families and providers respond in ways that promote children's health.
- Family-centered, coordinated systems of health care developed for children with SHCN lend themselves well to promoting discussions of ACHP by families and their children's health care providers.