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Building on Family Strengths  
Portland, OR  
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# Health and Wellness for Children with Special Needs: Families are Ready!!!



# The *New Yorker* view

“Remember when we had to fatten the kids up first?”



# Outline

- Overview of Family Voices' (many) initiatives to support families' efforts to promote and protect the health of their children with special health care needs (SHCN)
- What we're learning from parents of SHCN about helping children develop healthier lifestyles
- Strategies and Resources from our Toolkit





## *Health and wellness projects are:*

- Family Voices IMPACT
  - Funded by the MCHB (2005-2010)
  
- Family Matters: Using Bright Futures to Promote Health & Wellness for Children with Special Health Care Needs
  - Funded by the CDC (2003-2007)



# Bright Futures

American Academy of Pediatrics (AAP)

Bright Futures: a set of principles, strategies and tools to improve the health of all children

<http://brightfutures.aap.org>

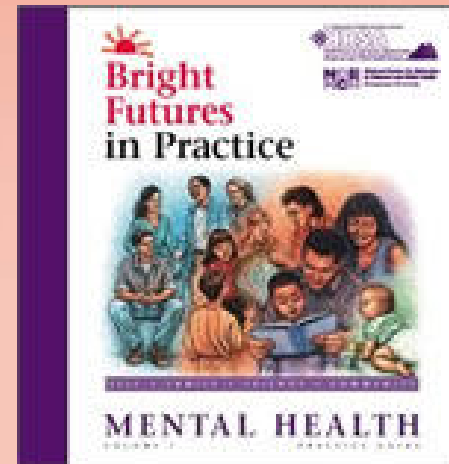


# Bright Futures

## Bright Futures Georgetown

[www.brightfutures.org](http://www.brightfutures.org)

- BF Mental Health
- BF Mental Health Toolkit



# FV IMPACT:

## Bright Futures Initiatives

- Develop and disseminate:
  - *Bright Futures: Family Matters* - electronic newsletter for families and professionals
  - *Bright Futures Family Pocket Guide* - new update will mesh with AAP materials
- Website [www.brightfuturesforfamilies.org](http://www.brightfuturesforfamilies.org)



FAMILY VOICES

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Resources for Children's Good Health

Formerly PICTURE THIS

## Bright Futures: Family Matters

### Teasing and Bullying

While everyone expects to be teased once in a while, bullying has become a problem that children of all ages may be subject to in school, at home or in the community. Only recently has this issue been recognized and taken seriously by parents and other adults. Children who experience bullying are more likely to have feelings of depression, anxiety, are more likely to engage in violent activities and have suicidal thoughts or tendencies. In 2001 the National Institute of Child Health and Human Development conducted a survey that found "16% of United States school children are bullied during the school term. Ten percent reported being bullied but not bullying others, and six percent admitted bullying and being bullied." (Pappano, L "No quick fix where bullies sit" 2003)

**What is bullying???**

- Repeated negative or hurtful behavior—emotional, physical or verbal. Typically there is unequal power— the child bullying has more power than the child being bullied.


**Suggestions for your children if they're being bullied....**

1. Stay in a safe place
2. Stick with groups
3. Be confident (or act confident)
4. Ask me, a teacher or someone else you trust for help when you need it.

**What can you do to prevent bullying??**

1. Talk openly with your child about bullying behavior they've seen or experienced and encourage them to tell you or others about it.
2. Take bullying seriously
3. Get involved with your child's school or start an anti bullying program

This information was adopted from the Stop Bullying Now Organization: [www.stopbullyingnow.net](http://www.stopbullyingnow.net)



### Band-aids and Blackboards

is a resource for children and adolescents with special needs to share personal experiences. In addition to helpful information, resources and suggestions about living with special needs, this site features a section dedicated to teasing and how to deal with bullies. There are also several helpful links to other sites about teasing and bullying. This is a very family friendly site with great information for children with special needs! Go to: [www.faculty.fairfield.edu/leltas/contents.html](http://www.faculty.fairfield.edu/leltas/contents.html)

### Resource for Children, Adolescents and Adults

If your child is being bullied or has been bullied in the past there is an international web site for children to share feelings and emotions. There are separate sections for children, adolescents and adults and there are varied ways to submit materials to help express feelings and frustrations and get support from others (i.e. drawings, music, poems, stories, and multimedia). Go to: [www.bullying.org](http://www.bullying.org)

Family Voices is a national grassroots network of families and friends speaking on behalf of children with special health needs. Our children are also part of the wider world of children. With a Partners in Information and Communication (PIC) Cooperative Agreement from the MCH Bureau - DHHS, Family Voices works to encourage partnerships between families and professionals for children's good health. *Bright Futures: Family Matters* is a digest of articles and news clips to share with families, family organizations, and our professional partners to offer a flavor of activities in the maternal and child health community. We hope to encourage flourishing partnerships!

Check out our Family Voices web sites at: [www.brightfuturesforfamilies.org](http://www.brightfuturesforfamilies.org) and [www.familyvoices.org](http://www.familyvoices.org)

Family Voices at the Federation for Children with Special Needs • 1135 Tremont Street, 4<sup>th</sup> Floor, Boston, MA 02120 • Tel (617) 236-7210 / Fax (617) 572-2094

# Bright Futures Guía para las familias



Sugerencias para los bebés, niños, y adolescentes crezcan sanos

FAMILY VOICES®

# Bright Futures Family Pocket Guide:

Raising Healthy Infants,  
Children, and Adolescents



FAMILY VOICES®

# Family Matters ...



## Title:

Family Matters: Using *Bright Futures* to Promote Health and Wellness for Children with Special Health Care Needs or Disabilities

## Goal:

Design and evaluate methods to support families of children with special health care needs in their efforts to promote their children's health and wellness through family-based activities

## Phases:

- Formative research – focus groups with families in 5 states (05)
- Controlled behavioral intervention study in 4 states (06-07)
  - Evaluating effect of mentor peer support
- Survey research
  - Nationwide online survey of families (06-07)
  - Interviews w/families in Louisiana post-Katrina (06)

# Background



- ❖ Research Partnership between Family Voices (FV) & Tufts University School of Medicine
- ❖ Expands view of health from “health services” to include day-to-day activities and influence consistent with families’ typical roles
- ❖ Utilizes health advice from *Bright Futures Guidelines for Health Supervision* to create practical ideas to use at home

# Project Goals adapted from *Bright Futures*

## Healthy Eating

- Encourage your child's healthy eating habits
- Serve your child three nutritious meals a day and include a variety of healthy foods
- Serve your child nutritious snacks
- Share family meals together on a regular basis
- Make meal times pleasant

## Physical Activity

- Balance the food your child eats with physical activity
- Encourage family participation in regular physical activity
- Promote a safe environment for physical activity

## Screen Time

- Limit your child's TV/video time
- Limit your child's time spent playing video games
- Limit your child's (recreational) computer time

# Project adopts Family Voices' approach



- ❖ Families are the focus and leaders
- ❖ Activities are family-centered
- ❖ Research Partnership
  - Changed protocol to respect Family Voices' family support culture
  - Parent leaders assumed research roles
    - Completed research ethics training
    - Facilitated focus groups
    - Provided behavioral intervention – mentor peer support

# Focus Group Themes:

What families told us about  
health & wellness ...



- ❖ Health and wellness was an important issue for parents of children with special health care needs (CSHCN)
- ❖ Parents see:
  - link with child's overall health status
  - special relevance to children with special health care needs
- ❖ Parents like the universality/"normality" -- their kids are like other kids

# Some issues resonate with families more than others



## *On radar screens:*

Healthy eating-balanced, nutritious meals

Physical activity

Family routines & rules

Supervising screen content

Taking good care of teeth

-----*more complex*-----

Sedentary behavior limits vs. screen time benefits

Avoiding risks re: alcohol, drugs, sex

## *Less on radar screens:*

Well-child visit schedule

Second hand smoke

## *Other issues:*

Gun safety

Self-advocacy skills for children

Self-protection skills for children

Non-traditional approaches

# Survey of parents



- ❖ Over 895 parents participated nationwide
  - 49 states and D.C. represented
  - 840 on-line; 55 in-person interviews, Louisiana
- ❖ Children ages 6 - 18
- ❖ Questions included:
  - children's medical conditions and usual sources of health care
  - parents' sources of information
  - nutrition issues for CSHCN
  - physical activity issues for CSHCN
  - screen time dilemmas
  - attitudes and “roadblocks”
- ❖ Promoting healthy lifestyles is a challenge for all families; families of children with SHCN face additional challenges

# Challenges all families face



*“Schools send great message about healthy lifestyles, then contradict themselves in the lunches they serve and the overabundance of treats. It is also difficult to regulate healthy eating in America as every child’s activity seems to include junk food.”*

*“Although I had more control over my son’s eating habits when he was younger, he now has a part-time job and a car and frequently picks up junk and fast food on his own.”*

# Mental Health Cohort



## Definitions

- Attention Deficit Disorder /Attention Deficit Hyperactivity Disorder (ADD/ADHD)
- Autism, including autism spectrum disorders, such as Asperger's Syndrome
- Mental Health Issues such as anxiety or depression

# Listing any Mental Health Condition



Whole sample (895) - listing **any** of the three mental health conditions

- ADD/ADHD - 353 40%
- Autism - 337 38%
- Mental Health - 310 35%
  - depression
  - anxiety
  
- Listing any of above - 597 67%

# Mental Health: Main Condition



Parents reported 359 children having mental health as a “main condition

## MHM

*Listing as a “main condition”*

- *ADD/ADHD*
- *Autism*
- *Mental Health (depression, anxiety)*

# MHM: Profile of children w/mental health conditions (1)



- Average age 11 years
- Largely male 79%
- Severity of condition:  
1-10 (most severe) 6
- Child's overall health  
good/very good/excellent 92%

# MHM: Profile of children w/mental health conditions (2)



- ❖ Majority white, but sizable minority representation:
  - White 82%
  - Multi-racial 8%
  - Black 5%
  - Hispanic 3%
  - Asian 2%
  
- ❖ 95% have health insurance
- ❖ 94% have a primary care provider

# MHM: Profile of parents



## ❖ Education:

- some college or more 86%

## ❖ Family income

- >less than \$20K 8%
- \$20-40,000. 16%
- \$40-70K 29%
- higher than \$70K 46%

# MHM: Parents knowledge and beliefs about health & wellness



## Dietary guidelines

- % parents agreeing:
  - *I am fairly knowledgeable about dietary guidelines for children – 90%*
  - I feel comfortable deciding what dietary advice to follow – 76%
  - These guidelines are relevant to my child with SHCN – 73%

## Physical activity guidelines

- % parents agreeing:
  - *I am fairly knowledgeable about physical activity recommendations for children – 83%*
  - These guidelines are relevant to my child with SHCN – 75%

# MHM: Parents' sources of information on health & wellness



- Internet 89%
- Print media 72%
- Advocacy & disability-specific groups 72%
- Child's medical specialists 60%
- Parent support groups 60%
- Child's primary care provider 55%
- TV/Radio media 37%

# MHM: Talking about health & wellness with primary care providers



## Well-child visits -

% Parents reporting “a great deal” or at “almost all” visits, time spent discussing:

- Healthy eating 49%
- Physical activity 44%
- Screen time 26%  
(eg. TV, videos, computers)

# MHM: Influence Parents Have Over What Children Eat



## Influence - much or a great deal

	<u>Typical Children</u>	<u>CYSHCN</u>
• Ages 6 – 10	90%	81%
• Ages 11- 14	60%	66%
• Ages 15 – 18	24%	52%

# MHM: Nutrition – Food and Eating



- My child's special needs affect food 75%
- Concern with child's weight 45%
  - underweight 18%
  - overweight 27%

# MHM: Nutrition Food and Family Life



75% of parents report that their child's special needs affect food choices and eating habits

% parents reporting. . .

- I often prepare a different meal for my child 49%
- My child eats the same foods every day 49%
- My child's feeding issues make it hard to provide healthy diet 43%
- Making sure my child's diet is healthy is very time-consuming for me 42%
- My child's emotional issues make it hard for me to provide a healthy diet 41%
- Using food as a reward is useful 26%

# MHM: Children's diets and eating habits (I)



...how many servings of ---- does your child eat on a typical weekday?

## ❖ fruits

- 3.2 servings on average
  - 88% eat 2 servings or more/day

## ❖ vegetables

- 2.7 servings on average
  - 47% eat 3 servings or more/day

Current daily dietary guidelines for children over 2 have evolved:

- Fruits: 4 servings (up from 2)
- Vegetables: 5 servings (up from 3)

# MHM: Children's diets and eating habits (2)



...how many servings of ---- does your child eat on a typical weekday?

## ❖ **dairy products**

- 3.4 servings on average
- 69% consume 3 or more servings/day

## ❖ **Whole grains**

- 3.2 servings on average
- 63% eat 3 or more servings/day or more

## ❖ **Lean meats, eggs, beans, nuts**

- 3.3 servings on average
- 92% eat 2 servings/day or more

Current daily dietary guidelines (2005) for children over 2:

- Dairy: children ages 2 – 8: 2 servings; age 9 and over: 3 servings
- Whole grain: 3 or more servings
- Protein: no clear guidelines at present

# MHM: Children's diets and eating habits (3)



❖ % children eating “junk food” (foods high in calories/low in nutritional values):

- On typical weekday 63%
- On typical weekend day 73%

# MHM: Family eating practices during a typ wk



- How many evening meals do you eat together as a family?
  - None 4%
  - 1-2 16%
  - 3-4 19%
  - 5-6 27%
  - 7 34%
- % children eating a meal in room with the TV turned on “often” or “almost all the time” 21%

# Challenges that some families of children with SHCN face



*“My son struggles with weight because of a medication he was on. It is an additional concern to diet and exercise that a lot of anti-psychotic meds that children with mental illness cause significant weight gain, regardless of ‘lifestyle.’”*

*“Although we have always made healthy foods available to our child, he has an aversion to many foods. . .Because of his social/ emotional issues his physician agrees we need to pick our battles.”*

*“Since he entered adolescence, food and tv have been two areas where, quite honestly, we have given up. All our energy is funneled into other areas (keeping him safe, keeping him in school, keeping him out of the juvenile justice system, etc.)”*

# MHM: Physical Activity and Exercise



- ❖ 27% of parents report that their child's special needs affect their ability to exercise and be physically active
  
- ❖ Children's levels of activity
  - ❖ Always or frequently active: 56%
  - ❖ Sometimes active: 31%
  - ❖ Rarely or never active: 14%

# MHM: Children's level of exercise and activity



- ❖ During the past week, on how many days did your child exercise or participate in **moderate** or **vigorous** physical activity for at least 20 minutes?
  - **Moderate:** 51% exercised 5 or > days
  - **Vigorous:** 20% exercised 5 or > days

## Healthy People 2010 Goals for Physical Activity

- Increase % of adolescence engaging in moderate PA for least 30 minutes, 5 days/week from 20% to 30%

# MHM: Roadblocks to Physical Activity & Exercise



- As parents, we're not physically active 20%
- Adults do not make my child feel welcome 20%
- Adults lack skill to include my child 32%
- Other children do not make my child feel welcome 35%
- Needs more supervision than is available 40%
- Lacks interest/motivation in phys activity/exercise 51%
- Doesn't have friends to play with 59%

# Physical activity may be a special challenge



*“It is very frustrating as a parent of a child who looks perfectly normal, but isn’t. Other parents, coaches, instructors, etc. do not understand the challenges. In a community like we live in, the pressure to compete athletically is incredible. When you have a child that doesn’t excel in sports and is the target of ridicule, it is very difficult to find activities that are successful.”*

# MHM: Children's Screen Time



## *How much time does your child typically spend:*

- ❖ Watching TV
  - ❖ On weekdays: 1.3 hrs a day
  - ❖ On weekends: 2.5 hrs a day
  
- ❖ Watching videos or DVDs
  - ❖ On weekdays: < 1 hr a day
  - ❖ On weekends: 2 hrs a day
  
- ❖ On computer, excluding video games
  - ❖ On weekdays: < 1 hr a day
  - ❖ On weekends: 1.3 hrs a day

# MHM: Children's TV Time



- % Children viewing TV 2 or fewer hours a day
  - On a typical weekday: 84%
  - On a typical weekend: 57%

## *Healthy People 2010 Goals for Screen Time*

❖ *Increase % of children & adolescents who view TV 2 or fewer hours a day from 60% to 75%*

# MHM: Screen time is a complex issue



*“A lot of my child’s TV watching after school is as a down time. Listening is extremely difficult and they need quiet time without responses needed. Play time with others is limited to weekends because of the energy/emotional/focus toll of making through a school day. We’ve tried lots of things, but the quiet, non-demanding down time is critical.”*

*‘I know my child watches a lot of TV. We are trying to cut back. He is so active that this is the only time we get to get other things done; he needs constant supervision...’*

# Parents say:



- Dietary guidelines are not relevant for my child **11%**  
- **73% disagree**
- I encourage my child to eat healthful meals **57%**
- I encourage my child to eat healthful snacks **61%**
- I encourage my child to exercise regularly **58%**
- I am able to limit my child's screen time **73%**

***PARENTS ARE READY to ADDRESS HEALTH  
& WELLNESS for THEIR CHILDREN!***

# Thoughts and Recommendations



- Provide information and reinforcement to families
- Seek out resources, referrals, ideas about adaptations to meet recommendations
- Add to agendas, include information in newsletters
- Carry out more research, especially with nationally representative samples

Identify this as an important topic for discussion!

# Strategies and Resources



## Strategies – from discussions with families

- Set goals
- Determine child and families' interests and resources
- Examples from discussions with families. . .
- Family Organizations – put on agendas, in newsletters, etc.

## Resources

Family Matters, see [www.brightfuturesforfamilies.org](http://www.brightfuturesforfamilies.org)

- Resources for all kids/families – use or adapt
- Seek support for efforts

# For further information



## ❖ Tufts Medical School

- Paula Minihan – [Paula.minihan@tufts.edu](mailto:Paula.minihan@tufts.edu)
- Aviva Must – [Aviva.must@tufts.edu](mailto:Aviva.must@tufts.edu)

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