

The Role of Families in Health Promotion: Family Wisdom about Health and Wellness Knowledge, Strategies, and Barriers

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This summary report is dedicated to the families who participated in the IMPACT Health and Wellness Initiative focus and discussion groups, to those who took the time to answer the summer 2014 survey, and to the family leaders and organizations who contributed so much time and energy to gather the perspectives of culturally diverse families. Thank you!

“When it comes to understanding family wisdom - parents have given us gems. We hope that health providers and policy makers will listen to the wisdom that these families have shared, to better address social determinants of health which create ongoing health disparities.”

“...Parents ...must, and do, prioritize how they will spend their time and energy. They are open to learning from trusted others, and like to share ideas and concerns. There is room for new information and better ways to do things. But it takes time, and it takes trust, and it takes getting good health promotion information that is meaningful and accessible.”

“We need to look at life coaching rather than prescriptions. It is about being a partner in change, not a didactic direction.”

--Family leaders who participated in the Family Voices IMPACT Health and Wellness Initiative.

Introduction

Family Voices believes in the power of research informed directly by families. Such research can lead to enduring practices adopted by both families and health professionals. Over the course of three years (2011-2014), through focus and discussion groups and a health survey, culturally diverse families shared their perspectives and priorities about wellness and prevention. What families want – a holistic approach to health and wellbeing – fits well with the overarching spectrum of health promotion topics found in the Bright Futures Health Promotion recommendations. The Bright Futures health promotion themes include:

- Promoting Family Support
- Promoting Child Development (families wanted to call it *Promoting Healthy Child Development*)
- Promoting Mental Health (families wanted to call it *Promoting Emotional Wellness and Mental Health*)
- Promoting Healthy Weight
- Promoting Healthy Nutrition (families wanted to call it *Promoting Healthy Food and Eating*)

- Promoting Physical Activity
- Promoting Oral Health
- Promoting Healthy Sexual Development and Sexuality
- Promoting Safety and Injury Prevention
- Promoting Community Relationships and Resources

Each Bright Futures health promotion theme has dozens, if not hundreds, of recommendations, and no one person or family can do all of these things all of the time. What recommendations are most important to families? How do families incorporate wellness and health promotion into their daily lives? What tips and strategies do they have for making it easier to accomplish these activities?

IMPACT asked (1) what families know about Bright Futures recommendations for the health of infants, children, and adolescents; (2) strategies families use to promote health and wellness for all of their children, including those with special health care needs; and (3) barriers families face when it comes to health promotion and chronic disease prevention.

This was not a research project, and funding was minimal (only \$3300 per F2F). We based our focus and discussion group scripts on scripts that were developed in a previous research project (Family Voices Family Matters, Tufts/CDC 2008), which we modified to fit the needs of this project. We also used focus group facilitator training methods that were developed for the Tufts/CDC methods. Confidentiality of participants was protected. The focus and discussion groups were peer-led, run by trusted family leaders who were trained in the art of facilitating focus groups.

After the focus and discussion groups, we developed and disseminated a survey, *Learning about Health and Wellness: Strategies, Tips, and Barriers from Families*, to reach a broader base of families, and asked questions similar to the focus group scripts.

Major Overarching Themes found in Focus and Discussion Groups and the Family Survey

Findings from the Focus and Discussion groups and the Family Survey were remarkably similar, and the following themes emerged from both:

- Families desire a holistic approach to health.
- Families desire a strength-based approach to health care, health promotion, and health education.
- Families know a great deal about what healthy behaviors and activities look like. Participants said they try to incorporate healthy habits into their everyday life.
- Families stated that they need and want considerably *more* information and help dealing with emotional and social wellness/mental health and “not just a focus on medications to control behaviors.”
- The themes of food and nutrition were passionately discussed in virtually all of the focus groups, even when the main topic of the focus group was another Bright Futures health promotion theme; food and nutrition is a hot topic, and a source of connection and community building.

- Obstacles to health promotion and wellness were clearly identified by participants. These obstacles are out of families' immediate control. They include lack of infrastructure in their communities for physical activity (no safe streets for walking, no parks, crime and violence in the neighborhood); lack of affordable, healthy food; low income jobs; high stress and fatigue from untreated behavioral and mental health needs of family members; having to work so many hours outside the home in order to make ends meet; cultural and linguistic barriers; and many other issues that create social and health inequities. In short, the social determinants of health were identified by families over and over again as primary barriers.
- Obesity, mental health/anxiety, poor nutrition, lack of physical activity, too much screen time and electronics, and stress were identified as top health problems faced by children today.
- Families had many tips and strategies they willingly shared, and most of them were in line with the Bright Futures evidence informed recommendations.
- Families want more health education, social, and recreational opportunities that are health promoting and that they can afford.

Given the opportunity to spend two or three hours together talking about health promotion and wellness with their peers, momentum was quickly built to seek ways to improve health at the community level. For instance, in one community Spanish-speaking families came together afterwards for a grocery shopping and nutrition class, with a trip to the supermarket to analyze labels; they also started a low cost Zumba class. Thus, the act of convening focus groups run by trained peers can be described as a key venue for opening doors to community conversations and collective action about health and wellness.

Data Sources and Findings

“The discussion group was a wonderful addition to the scope of work of the Oregon Family-to-Family Health Information Center. It helped us launch a presence in a community where we have not been visible and where we were actively recruiting for a Family Liaison. It allowed us to reconnect with our professional partners in the Education Service District and the county Developmental Disabilities Department, and to make a connection with the Klamath Youth Development Center. ... We received the following thank you note from a Service Coordinator from the Community Development Disabilities Program:

... I had really nice feedback. One mom said it felt very productive and was good to make connections with other families in the community. Thanks for the opportunity for our families to participate!

Thank you for the opportunity to participate in Project IMPACT!”

[Quote from final report from the Oregon F2F Project Coordinator.]

Again, this was not intended to be a research project. We were able to collect a wealth of data—most in a qualitative rather than quantitative form. We hope that it can be used to highlight the importance of listening to the families who truly are, as Former U.S. Surgeon General said, “policy makers in their own homes.” This Project should be viewed as a stepping stone for future, more rigorous—and fully-funded research project.

Focus and Discussion Groups in Six States

Families in North Carolina, Utah, New Jersey, Indiana, North Dakota, and Oregon participated in the IMPACT Health and Wellness Initiative and Bright Futures focus and discussion groups between 2011 and 2014. New Jersey and Indiana also piloted Life Course focus groups. In total, 187 families participated in the focus and discussion groups. Groups were sponsored by Family to Family Health Information Centers (F2Fs) funded by the Maternal and Child Health Bureau, HRSA.

Overview of Focus/Discussion Group Characteristics						
Year	State	Total Number of Families	Demographics of Groups	Families with CSHCN or Typically Developing	Bright Futures Health Promotion Theme	Language
1	North Carolina	28	African American, Hispanic, Caucasian	Both	Healthy Food and Eating	Spanish
					Physical Activity	English
					Oral Health	English
	Utah	24	Primarily Caucasian	Both	Emotional Wellness	English
					Child Development	English
					Healthy Sexual Development and Sexuality	English
2	Indiana	66	Hispanic, Spanish-speaking, Caucasian	Both	Emotional Wellness	No Focus Group on these topics
					Child Development	
					Safety and Injury Prevention	2 Focus Groups each topic, one in English, one in Spanish
	Life Course					
	New Jersey	52	Spanish-Speaking Immigrants from Mexico, Uruguay, Venezuela, Columbia, Dominican	CSHCN Diagnoses included: Down Syndrome, Cardiac conditions,	Emotional Wellness	Spanish
					Child Development	English
Oral Health					No Focus Group on this topic	

Overview of Focus/Discussion Group Characteristics						
Year	State	Total Number of Families	Demographics of Groups	Families with CSHCN or Typically Developing	Bright Futures Health Promotion Theme	Language
			Republic, Puerto Rico; African Americans; South Asians; Italian; Irish; Russian	ADHD, Autism, Bipolar, Asthma, Cerebral Palsy	Life Course	2 Focus Groups, one in English, one in Spanish
3	Oregon	11	Grandparents, Primarily Caucasian, Rural location	CSHCN with mental health and behavioral health diagnoses	Emotional Wellbeing	Discussion Group, English
					Child Development	
					Healthy Sexual Development and Sexuality	
	North Dakota*	6 for Focus Group, 41 for Survey	Caucasian, Rural families	Both	Emotional Wellbeing	English
					Child Development	English
					Healthy Sexual Development and Sexuality	No Focus Group on this Topic

*The North Dakota F2F conducted two focus groups. Due to extreme weather conditions in North Dakota and its rural setting, the turnout for the second focus group was very small. In all, 6 families participated in the two focus groups. In lieu of another focus group, North Dakota sent out a survey with similar questions. The responses from those 41 families are not included in this summary.

Overview of Family Survey

Building on the information we gleaned from the focus and discussion groups, we used an online survey to reach additional families, and asked similar questions to those used in the focus groups. Over 200 people responded to our survey, advertised through the F2Fs and other family organizations. Strikingly, although survey respondents were significantly less culturally diverse than the families who participated in the focus and discussion groups, we found that survey results mirrored essentially the same perspectives and overarching themes found in the focus and discussion groups.

Summary Findings from Focus and Discussion Groups and the Family Survey

Biggest health problems facing children today: These seven problems were consistently mentioned across the Groups and the Survey.

- Obesity
- Mental health/anxiety
- Poor nutrition
- Lack of physical activity
- Too much screen time and reliance on electronics
- Diabetes
- Stress

In addition, families frequently mentioned other problems—many of which are variations on the seven themes above, and include high blood pressure, oral health issues, asthma, autism, allergies, limited availability/cost of healthy food options, learning issues, access to care issues, language/cultural barriers, medication/overmedication issues, and lack of community supports for CYSHCN.

What families do to keep their children healthy day-to-day: Despite these on-going challenges, families do their best to build better health futures for their children. The suggestions and ideas they shared ranged from the standard approaches and recommendations seen in *Bright Futures* to creative on-the-ground approaches to encouraging children and youth—and adults—to make healthy choices when possible.

Many suggestions had to do with nutrition—having healthy food, lots of fresh fruits and vegetables on hand; preparing school lunches from home; involving children in gardening, shopping, recipe selection, and cooking of nutritious foods; and avoiding fast food.

In addition, families’ responses had to do with maintaining and improving the emotional health and well-being of the children—encouraging open communication, teaching coping and other life skills, loving unconditionally, monitoring for anxiety, and arranging therapy as needed.

Respondents provide avenues for physical activity and outdoor experiences—from family walks to school sports to getting a good night’s sleep.

Parents (and grandparents) recognized the critical importance of being good role models for their children as well. “Do what I say” is not nearly as effective as “Do what I do.”

Quotable Quote from a Family Member:

“Get them moving around. Take them outside. Hiking. Camping. Shooting. Fishing. Hunting. Swimming in the river. Even just for walks. Or fire pit in backyard. Play Rockband. Provide healthy food choices. Grow blueberries and strawberries in back yard. Ask them if they ate a vegetable today. Ask them if they brushed their teeth. Pay attention to their hygiene and remind them if necessary. Bring them to the grocery store. Teach them to read labels on food. Annual visits to the dentist for cleanings. List a weekly chore around the house that they are responsible for. Talk about what we are grateful for and things we

can do to help others. Keep track of their grades and know some of their friends. Ask who they ate lunch with at school and what they ate. Talk about our days. Talk about what to do if situations like bully behavior, earthquake, etc. To me, healthy is body mind and spirit.”

Tips from Families in Focus and Discussion Groups:

Healthy Food and Eating:

- “It starts with the family setting an example, influencing our friends and changing our patterns.”
- “When you give candy, children want it all the time. Once we make the conscious decision to make better choices, when the children get older they won’t be affected in a negative way.”
- “I make up songs about the fruits and vegetables in order to get my children to try new foods.”
- “I had problems with my kids eating vegetables, then somebody gave me a Mexican recipe that said to cut up vegetables very fine so the pieces are not too big and they can eat it.”

Physical Activity:

- “We have some little chickens that their dad bought for them, so they can run after them. I buy the chicken food, so my children feed the chickens, and spend time out of the house.”
- “Make sure children play for at least an hour each day (outside, in the park, or at mall.) If they don’t get enough activity, they don’t sleep well.”
- “Make sure kids are actually engaged in physical activity on the playground.”
- “Dance with the kids; crawl around on the floor with them.”

Emotional Wellness and Mental Health:

- “Children need and value structure.”
- “We have a manners rule; my children call adults, ‘Mr.’ and ‘Mrs.’ because respecting adults is important.”
- “We teach our children the value of hard work and family.”
- “We are poor but our children feel rich because of the love and sacrifice we make to give them the essentials.”

What families do to keep their child with special health care needs healthy: Most families said they try to promote health in all of their children, including their children with special health care needs, but they admitted it is often a challenge, depending on the child’s diagnosis. A healthy diet and sleep pattern are challenging. Sometimes wellness and health promotion come second, after all of the medical and behavioral needs.

The majority of parents felt that children with special needs require greater care in keeping healthy due to compromised immune systems, limited attention, and physical strength. There are fewer physical and recreational opportunities for children with special needs, and that makes it harder, too.

Time—or lack of it—is a common challenge for parents of CYSHCN. Parents have to wake early and go to bed late to balance out the cooking and care. Everything from bath time to meal time requires maximum attention to ensure safety.

Parents lack adequate supports for their role as caregivers to support the needs of their families when they have more than one child. The parents admitted they just use the “keep the peace” model and pacify the child with things that may not be the best and healthiest choice. The TV is often the motivating tool and families stated that it is on all the time.

One facilitator noted, “The caregivers cried when they pondered their schedules and the amount of time and energy that it takes to accomplish the basic tasks in one day.” Success is often described when the children are sleeping and they can clean up and catch their breath.

Getting needed respite is difficult for families, and even more so for immigrant families.

Quotable Quotes from Families:

“Figure out what each child's love language is so you can be efficient at showing them you care. Model managing emotions, frustrations and challenges by narrating your own so they can hear your thought processes. Use humor as much as possible. It can cut the tension better than anything!”

“Try to keep things ‘normal.’ Our normal life includes much more attention to health issues but try to balance out doing things kids think are ‘fun’ and downplay the effort it takes to keep all of the balls in the air. It IS hard and we don't deny it but expose kids to as much as possible, including others who experience chronic conditions. We talk about what that means to us and to others. Do our best to have experiences for ourselves that allow us to help others and to acknowledge gifts each person has.”

Tips and strategies from families for families about promoting health for CYSHCN:

- Make time for family and relationships; play together.
- Siblings can help with modeling or shadowing for many activities.
- Give reminders/verbal reminders/visual charts.
- Use music to calm child's behavior and provide sensory input.

Emotional Wellness Tips and Strategies: A sampling of the ways families help their children grow and develop in a healthy way.

- Be a role model—parent by example.
- Teach healthy eating and sleep habits.
- Don't let them watch TV, using it as a babysitter.
- Make sure your child(ren) know you love them and are always proud.
- Give them the opportunity to learn and express themselves.
- Have high expectations. Praise them for accomplishments big and small.
- Be there to support them and to catch them if they fall.
- Let them become independent no matter how long it takes.
- Be patient.
- Treat them as an individual not their diagnosis.
- Stay calm and do not raise your voice. Avoid threatening your child verbally; avoid spanking.

Where families get information about healthy habits: Families said they get information from pediatricians, school nurses, and other health providers about exercise and playtime, healthy nutrition, vitamins, vaccines, and oral health. Many but not all families visit the pediatrician, family practitioner, or a clinic. When asked if they had heard about healthy habits from their child's health providers, such as pediatricians and school nurses, approximately 60% said yes, and the rest said no or that the information they received did not fit their lives. This was similar to what we saw in the follow up survey conducted in summer 2014.

With respect to children and youth with special health care needs and their families, more attention to family needs as a whole is desired – families impact each other's life course, and everyone is affected by the health conditions of others in the family.

“It would be great if physicians would consider positive emotions and self-esteem with CYSHCN and their siblings who are impacted by household dynamics.”

Poor provider-patient communication across cultures, especially with immigrant families, was expressed: “The doctors and nurses assume that if we do not ask a question we understand, and we are waiting to be asked questions, so it is a series of missed opportunities.”

Quotable Quotes from Families:

“Very little time is spent on wellness issues. Health providers seem to be pushed for time & usually deal only with the specific issue you came in for (i.e. illness, injury, etc.)”

“A lot of the time though it just seems like the health care provider's solution is, ‘We have a pill for that!’ I don't want my child to have to rely on pills. I would like to have my child learn to develop the skills that he has difficulty developing. However, he does benefit from two medications. What irks me though is that when a problem arises the first approach seems to be to medicate. If I did not know to question that and to ask for more options then he would be on a lot more unnecessary drugs at unnecessary doses and at a much earlier age.”

“They just do not have knowledge of wellness care. They know ‘sick care.’”

“We usually try every idea we're given by doctors who know my daughter's health history. If the ideas don't work then we move on. Sometimes we will re-visit those ideas in another season.”

If not from health care providers, where do families get their health information?

Families said they use peer to peer support, community based organizations, support groups, and they watch television programs. Many said they surf the web and seek out health and disability websites. They also read books, and Spanish speaking families of young children expressed a special fondness for the book, *What to Expect You're Expecting*, in Spanish, because it helps them know the signs of normal development. Spanish speakers replied that information and magazines in the doctor's office are not in Spanish or are not current.

Overarching Barriers to Health Promotion Identified by Families

Families clearly stated that there are economic barriers and societal marketing pressures, and they want info and tips to help them overcome problems they face when trying to promote healthy food, physical activity, and other activities at home.

Quotable Quotes from Families:

“The bad propaganda is everywhere about unhealthy foods: McDonald’s, Burger King, etc. Society doesn’t help us at all, but, we can read and go to libraries or talk to a nutritionist so they can inform us and change our feeding patterns.”

“The economy doesn’t help us, because after we paid the bills what is left, is for eating. We as mothers know how much we have to spend a week to fill up the refrigerator. Sometimes frozen foods are cheaper than fresh foods, and I know that some foods are not healthier, but I have to buy them because they’re less expensive and accessible. It’s my sad reality.”

“Losing your job decreases the income and limits the options to buy healthy foods.”

Behavioral and mental health issues dominate some families’ lives and leave little time or energy for anything else. Parents and grandparents report that behaviors are hard to manage and they are not effectively able to manage challenging behaviors.

Money—or lack of it—is a problem for many families, especially those with CYSHCN. Although there may be a number of community organizations and private recreational options, they are too expensive and out of reach for many families. Healthy food is expensive, and often not available.

Immigrants face additional challenges: “We are not made to feel welcome in this society that calls immigrants ‘Aliens, Illegals and Undocumented.’”

Society and the media often have a negative impact on families. “Society is not a welcoming place for disabilities.” Society and the media often promote ideas and lifestyles before parents have had a chance to address them and teach their children how to handle them. Family values begin at home, often outsider views and society put unhealthy pressure and demands for children about image, beauty and popularity. Characters that are considered popular are not good role models, and very few people with disabilities are honored and shown in a positive way.

Family Tips for Counteract Barriers:

- We do not buy magazines and I hang images of my children on the walls of our home.
- We limit our TV and computer time, and watch things together to address questions.
- We promote family and cultural values because we want our children to view their heritage positively.
- We are the role models and try to teach from an honest and positive place.

Oral Health Promotion Theme-Specific Barriers—and Tips from Families for Overcoming Them: Oral health issues for families with CYSHCN often involve practical issues of day-to-day oral health care (brushing and flossing). In addition, access-to-care issues of finding dentists who are willing and able to treat CYSHCN create an ongoing concern.

When asked if they have difficulty finding oral health care for your children, including any with special needs, many focus group participants responded with a resounding “Yes.”

- Medicaid reimbursement rates and/or withdrawal of coverage decreases availability.
- Waiting in the office and lack of empathy from staff shapes a bad experience for CYSHCN and the child will not want to return.
- Pediatricians do not always offer the best information about dental care.
- Not having one dentist who can see everybody in the family means additional time and energy spent getting needed care.

Tips from Families about Oral Health

- When it comes to oral health, family recommendations included: brush long enough, use the right toothbrush, brush the tongue, use a reward system to encourage one extra minute of brushing, use an electric toothbrush, use floss picks.
- One family said they make it a routine that everyone in the family brushes their teeth at the same time. This makes it easier for the child to learn and makes it feel like part of belonging to the family.
- One mother stated that she speaks directly with the practice office manager, explaining the needs her child has, and strategies that she has found to be successful. She said anxiety is a major issue with one of her children so if the dentist or hygienist is running behind schedule, the child will be unable to appropriately wait in the waiting room.
- Make sure there is communication between providers, especially dentists and doctors, to make sure there are few/no complications.

Quotable Quote from a Family Member:

“The problem: my daughter wasn't brushing well enough in the back of her mouth. Her dentist told her that her mom needed more practice so she (daughter) should let me (mom) practice on her (daughter) mouth when she was done. This worked famously.”

Oral health resources requested

- More local services and pediatric dentists trained to provide services to CYSYCN are needed. Encourage dental students to take training in reference to CYSHCN.
- Provide dental scholarships and incentives to specialize in treating CYSHCN – and then go to rural areas to provide services.
- Pediatricians need to be able to give good referrals.

Safety and Injury Prevention Suggestions from Families:

- If the schools were stricter it would be better.
- I would like children, the youth, and adults with a mental health problem to have an identity and give them the necessary help before an accident occurs.

- I would like there to be more educational programs in Spanish at a lower cost.
- It would be incredible if there were parks and recreation centers for children with disabilities so that they can interact with others, because all children like to play, interact, and have fun.
- I would like the community to be educated, so that they don't see children with disabilities and diseases in a weird way.
- The schools should integrate children with disabilities with those that do not have any as a way to develop interaction, patience, and tolerance.

Resources Requested by Families as of Particular Interest

Families were asked to suggest areas where they could use more ideas or support to improve their child's wellbeing. These include:

- Resources that are geared toward kids and adults that celebrate the abilities in those with disabilities, and that promote healthy self-image or self-esteem different from magazines.
- Resources on healthy food and healthy eating that also complement traditional foods from other countries.
- Education on nutrition for children and teens.
- Resources for parenting and understanding the trends because many of us are still assimilating. It is hard to understand many new traditions and programs if you are an immigrant.
- Resources for working parents who often feel guilty because we are working to provide and missing so much.
- "Disabilities is a topic that has many taboos, so please help to create resources for family members who can make holidays and visits a very draining experience."
- Caregivers need support and information on maintaining their mental health and emotional wellbeing.
- Parents try to limit their child's engagement in things that they consider unhealthy, like too much TV/using TV like a babysitter, and the child has special health care needs such as ADHD or ASD or other behavioral conditions. There are few supports to help the parent replace that activity if the parent needs time to provide care for siblings, cook, take care of the home, or go to work.
- Learn parenting skills so you can lead your household. YouTube has parenting videos.
- Free activities for families, because programs are not available.
- Faith based locations for learning about parenting and getting resources (immigrants).

Healthy Sexuality Theme-Specific Resources/Information Requested:

- "How to learn about teenage slang; becoming aware so you can talk about it."
- "I am nervous about when my CSHCN son wants to date. He physically looks different. I need tools to help him deal with those differences. What if he gets turned down by a girl because of his appearance? Cognitively will he understand what is going on?"
- "I have questions about my typically developing daughter and dating."

- “My son has disabilities but is cognitively able to understand social issues. I worry about him when he gets older. How do I tell him it’s okay?”

Final Thoughts—and Next Steps

Quotable Quotes from Families:

“Parents, with and without special needs children, are often stressed with juggling work and family obligations. Our communities and governments could do more to help with the financial and emotional burdens of this process.”

“Quit making excuses and get moving or eat better. Don't let kids sit around all day playing on electronics.”

“I believe the best way to help families is through family support, such a peer mentors, consumer voice, and education programs.”

“Families need time to be together, and do things together. Physical health comes easier if your mental well-being is strong, meaning you feel safe and loved and that someone cares about you, in a long term healthy way.“

“Maybe, providing more community outreach classes on shopping and cooking. In our community, they're just starting a program (with our local farms) to provide "excess" fresh fruits and vegetables to go to our local food banks. Our community (Parks and Recreation) has a wealth of outdoor activities that are advertised each quarter. Our community has miles and miles of bike paths and parks with lots of community sponsored fun runs/walks, farmers markets, kids' activities/classes, etc., etc., all at low or no cost fees.”

The Tip Of The Iceberg

Throughout the course of the IMPACT Health and Wellness Initiative, Family Voices heard from hundreds of families in our focus/discussion groups and family survey, and collected anecdotal data—family wisdom—around families’ determination to improve their children’s health, both now and into the future. The quotes and statistics in this report represent a small percentage of the information we received from the participants in the groups and survey. The information gleaned is compelling evidence that families want to take an active role in promoting health and wellness for their families and communities. They find creative ways to accomplish this despite significant barriers to overcome. Families need help in identifying physical and human resources in the community, adequate and flexible financing, culturally responsive providers, and the means necessary to partner with health care professionals. Families have great potential as contributors to solutions.

There is an obvious untapped potential for learning more from families—families who are excited to be a part of the discussion. Further investigation and research is warranted to study the best ways to ensure that families, working in partnership with health care professionals and others, achieve the healthy lifestyles they seek. It is our hope that more families will be invited to share their wisdom and concerns with the health professionals who support them, and that our children and communities will be better for it.

Footnotes

Family Voices has put together a guidebook designed especially for families; The Bright Futures Family Pocket Guide: Raising Healthy Infants, Children, and Adolescents, 2nd Ed, available in both English and Spanish. It includes top priority well visit and routine at home health promotion recommendations ages 0-21.

In addition, the Family Voices IMPACT website, www.fv-impact.org, contains a wealth of health and wellness information and resources for families.

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National Family Voices Mission and Vision

National Family Voices' mission is to achieve family-centered care for all children and youth with special health care needs and/or disabilities. Through its national grassroots network, Family Voices provides families with resources and support to make informed decisions; advocates for improved public and private policies; builds partnerships among families and professionals; and serves as a trusted resource on health care. The agency's vision is that every child and youth with special health care needs and/or disabilities receives family-centered care.