



Learning from Families about Health and Wellness: Strategies, Tips, and Barriers Family Survey Summary

The IMPACT project has been listening to families in focus groups about health and wellness over the last three years (2011-2014) to learn about the ways families live healthy lives; barriers; and creative ways families overcome these barriers. The Family Survey is an extension of the focus groups to gather additional information from a larger group of families. Over 200 people responded to the Family Survey in June 2014. The following represents a sampling of responses from those 200 surveys.

INTRODUCTION

What do you think are the biggest health concerns that children face today?

- Mental Health/Anxiety/Stress—59.8% of responses
- Lack of Physical Activity—58.1%
- Nutrition—46.9%

DEMOGRAPHICS

How many children do you have and how old are they?

Respondents have between 0 and 6 children; 39% have 2 children; 23.4% have 3; 19.8% have 1 child. Children's ages ranged from infants to age 21, with 18 respondents having adult children. (Some respondents were grandparents.)

Do you have any children with special health care needs or disabilities? If so, how many of your children have special needs?

85.1% of respondents had at least one child with special health care needs. 68.5% had one child with special needs; 23.8% had 2; a few had between 3 and 6 children with special needs.

The types of special needs varied widely, from severe disabilities to mild special needs; from physical to intellectual/emotional needs.

What is your race or ethnic background?

88.9% of respondents were Caucasian, with 2-4% African American, Asian/Pacific Islander, Native American, Hispanic/Latino, Other.

What kind of community do you live in?

44.9% live in a suburban area; 29.9% urban; and 22.8% rural.

CREATIVE HEALTH PROMOTION

What do you do to keep your children healthy day-to-day?

This question generated a wide range of responses. Many 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.

Many 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.

Quotable Quote:

“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.”

Think about the things you do to keep your child with special health care needs healthy? Please give an example of what you do DIFFERENTLY with your child or youth with special health care needs. What do you do the SAME for all of your children?

Quotable Quotes:

“We have open dialogues with them to help them and we have as much information and understanding as possible. We stress that they aren't strange or bad because of their disabilities. We talk about their disabilities as just ways that their bodies function, such as a person with diabetes or a person who needs glasses. It's just the way they were born and there's nothing to be ashamed of.”

“We encourage them all to try their best no matter their ability. We require them all to help out at home with things such as feeding the pets and folding laundry according to their ability. We expect them all to treat each other with respect and kindness.”

“We give them all a chance to be involved with family events, from daily meals to regular family celebrations & activities. They also have the choice to not be involved at this time. (They learn something by not being involved.)”

Families with children with special health care needs or disabilities often find creative ways to adapt healthy activities for their children. What suggestions do you have that might help other parents with children and youth with special health care needs or disabilities improve their health and wellness?

Quotable Quotes:

“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.”

“I have changed my expectations. My dreams of what my children could have been or will be have drastically changed. We live "out of the box." Now I look for how I can support them in their strengths and I bolster them in their weaknesses when, and only when a mistake will lead to drastic failure or something unsafe. Families learn about health in many ways. We want to hear about where you get your health information.”

“We have a disability perspective in place. We give him developmental age-appropriate supervision and a 50-year plan. Our expectations are changes not lowered. We expect excellence; however the time in which he accomplishes this is different.”

“The best thing I do is to observe my children closely to learn who they are and how they react to the world. Then, I work with that child's preferences to involve him in activities he enjoys, not the ones that I think he should enjoy.”

SOURCES OF HEALTH CARE/INFORMATION ON HEALTH AND WELLNESS

Where does your child or youth get most of his or her health care?

- Pediatrician: 60.9%
- Family Doctor: 38.3%
- Sub-Specialty Care Doctor: 26.3%
- Health Clinics/WIC Clinics: 7.6%

Where do you get information on health and wellness for yourself and/or your children?

Top 6 responses:

- Health Care Provider: 27.2%
- Internet: 26.2%
- Friends/Family: 21.5%
- Library/books/magazines/newspapers: 7.3%
- Family-to-Family Health Information Centers (F2Fs): 4.5%
- Health Clinics/WIC/nutritionist: 3.8%

What have you heard from your child's health care providers, like pediatricians and school nurses, about eating healthy food and getting enough physical activity?

- A lot: 30.0%
- A little: 39.3%
- Not much: 30.7%

Is the information you get from the health care providers helpful to you?

- Yes and we follow their suggestions: 63.2%
- Yes, but the suggestions just don't seem to work for our family: 20.6%
- No: 16.2%

Quotable Quotes:

“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.)”

“Sometimes. A lot of the time though it just seems like their 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.”

“We apply whatever we can. We can't use all of it due to our kids' special emotional circumstances and our family situation but we attempt to use as much as possible.”

“We already know much of the information they tell us.”

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

“We follow most suggestions but do ask a lot of questions and have on rare occasions chosen NOT to follow specific recommendations.”

“The suggestions are usually hurried and 'canned' in nature, not tailored to our needs. I get the feeling that everyone is running against the clock and the almighty dollar.”

“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.”

BARRIERS TO HEALTH & WELLNESS

What makes it hard to keep you and your family healthy?

Top 7 responses:

- Time/energy constraints for parents: 26.4%
- Healthy food expensive/hard to find: 23.6%
- Health care expensive: 13.0%
- Specialists far away/lack of options: 13.0%
- Not enough time for active play: 6.7%
- Lack of safe places to play: 5.1%
- Insurance doesn't cover life skills, naturopathic care, therapies, equipment, specialists: 3.1%

Quotable Quotes:

“Having special needs kids is expensive (medical, transportation, time away from work, etc. It doesn't leave a lot of room in the budget for high-quality foods, or a lot of time to cook healthy meals.”

“Most doctors and specialists don't have time or don't really care. Our son is really difficult, and most doctors rely on me to tell them what I think is wrong with him rather than actually trying to figure out what is going on with him.”

“The challenge to manage physical health is made infinitely harder by behavioral health needs that take precedence. If Mom and Dad are frazzled, stress reduces all other function, including meal planning and preparing.”

“Even with double coverage insurance, we still get a bill... Both parents working full time to provide a standard of living that used to allow one parent to be home raising kids. Now kids are raised by the school and babysitter till they are old enough to be home alone and then they raise themselves from 3 pm-6pm when parents get home from work. No mom or dad greeting them at the door with guidance and structure. Some teens are responsible and do chores and school work. Some do not. It is a huge burden to be at work knowing you should be there for your teen, especially when they are struggling. That is the biggest hurdle in keeping my family healthy.”

“Daycare. Special needs daycare is lacking in Oregon and has made my family’s financial wellness very difficult to achieve. Very few trusting caregivers who are willing to learn that are priced well.”

You may have ways that you have learned to help make your family healthier, even when it is hard to do. Maybe your family has a fun way of exercising. Or maybe you have a good idea for how to get children to eat more fruits and vegetables. Or maybe you know a way to get children to brush their teeth every day. What is ONE thing you do to make it easier for your family to be healthy?

Quotable quotes:

“I try to maintain a choice of healthy snacks and limit the "junk" foods in our house. We never buy soda, cookies or candy at the store and only limited (healthier) chips. I engage my children in these choices while shopping, so they have learned to read labels and figure out which choices are healthier. This makes it less of a "mandate" and more a process of learning to choose foods that both taste good and are not detrimental to their health. When they have free choice in other settings, they now choose the healthier versions on their own.”

“I nag. I have to or sloth will win. Reluctance to work or make an effort. Laziness. So I nag. But I give ample warning and time to accomplish before I nag. But yes. I nag them to brush teeth. I nag them to shower and wear deodorant. I nag them about this or that assignment or grade. I nag them about chores. I nag them about moving around. I nag them about eating a vegetable every day. I nag them about helping others. I nag them. I am a nag. I accept that. Though the terms guide, helper, and parent also fit.”

“Long ago, we made a commitment to having one green food on the table nightly. Now we've got our own garden and eat a wide variety of vegetable that we wouldn't have touched when we decided to change our diet. Growing and picking and preserving our own food also gives us a sense of ownership and delight when we eat it, so it's good for our emotional and mental health as well as for our bodies.”

“Smoothies are a great way for kids to take in nut butters, fruit, veggies. Modeling. If I pick up a piece of fruit or carrot to snack on I notice my girls will do the same. If I reach for crackers so will they. The same goes with brushing teeth and flossing. I also make my own popsicles with Greek yogurt (make sure to get a brand with lower sugar and higher protein!) and blend with fruit and sometimes a piece or two of kale and a couple of dates. We are on a tight budget. I buy organic fruit mostly, very little to no processed food and meat. Parents need to be shown how easy it can be to eat better without breaking the budget.”

“I network, apply for grants, and find ways to save money to be able to afford the special equipment my disabled child needs to engage in our community and work and be productive and valued by others. Make people pay attention and want to be a part of my son's life.”

“Teeth brushing. Problem-my daughter wasn't brushing well enough in the back of her mouth. Her dentist told her that I needed more practice so she should let me practice on her mouth when she was done. This worked famously.”

TAKING POSITIVE STEPS TOWARDS HEALTH & WELLNESS

Think about all of the positive steps towards healthier lifestyles that you are familiar with. There may be some that you aren't doing right now. What would help you take those positive steps?

Top 6 responses:

- Support from the community as a whole: 29.3%
- Support from other families: 16.2%
- Support from local government: 16.2%
- Support from health care providers: 16.2%
- More information: 10.0%
- More time: 2.2%

What would you like more information on to help you take those steps?

- Mental Health/Emotional Well-being: 62.0%
- Healthy Food and Eating/Nutrition: 41.1%
- Physical Activity: 39.5%
- Child Development: 31.0%
- Healthy Sexual Development and Sexuality: 28.7%
- Safety and Injury Prevention: 24.0%
- Healthy Weight: 21.7%
- Oral Health: 14.7%

What other thoughts do you have about how to improve the health and wellness of families?

Quotable Quotes:

“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

These quotes and statistics represent a small percentage of the information received from 200 survey respondents. The information 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 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. The conclusion of the IMPACT project is a strong recommendation that more families will be invited to share their wisdom and concerns with the health professionals who support them. Our children and communities will be better for it.

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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.