Lucile Packard Foundation
for Children's Health

Report

Putting Children First

Scenarios for the Future of Children's Health and Well Being in the U.S.

April 2013

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Lucile Packard Foundation for Children's Health

400 Hamilton Avenue, Suite 340, Palo Alto, CA 94301 (650) 497-8365
www.lpfch.org

This report was commissioned by the Lucile Packard Foundation for Children's Health and prepared by Stratus Inc. and writer Jenny Johnston.

Executive Summary

In early 2012, the Aspen Institute and the Woodmark Group — an association of 25 leading children's hospital foundations from the U.S. and Canada — conceived a project designed to spur new actions and strategies for transforming the future of children's health and well being. Together, they organized the *Aspen Children's Forum: Investing in Children's Health and Well Being* — a first-of-its-kind gathering of philanthropists and children's health experts that took place in July 2012.

"We need to stop being surprised that children aren't being put first in this country and do something about it."
— Aspen Workshop participant

The "centerpiece" of the Forum was a set of provocative scenarios about the future of children's health and well being, created specifically for the event. Scenario planning is a strategic process designed to help organizations and individuals imagine, influence, and plan for a better future. The Aspen scenarios postulated a range of future economic and social conditions that might occur, all framed around the question: *What role can we play in facilitating the transformation of the health and well being of children in North America over the next 20 years?* The Lucile Packard Foundation for Children's Health funded and participated in the development of these scenarios.

By the end of the forum, the participants had concluded that they needed to launch a national children's advocacy movement unlike any that has been attempted before.

Creating the Aspen Scenarios

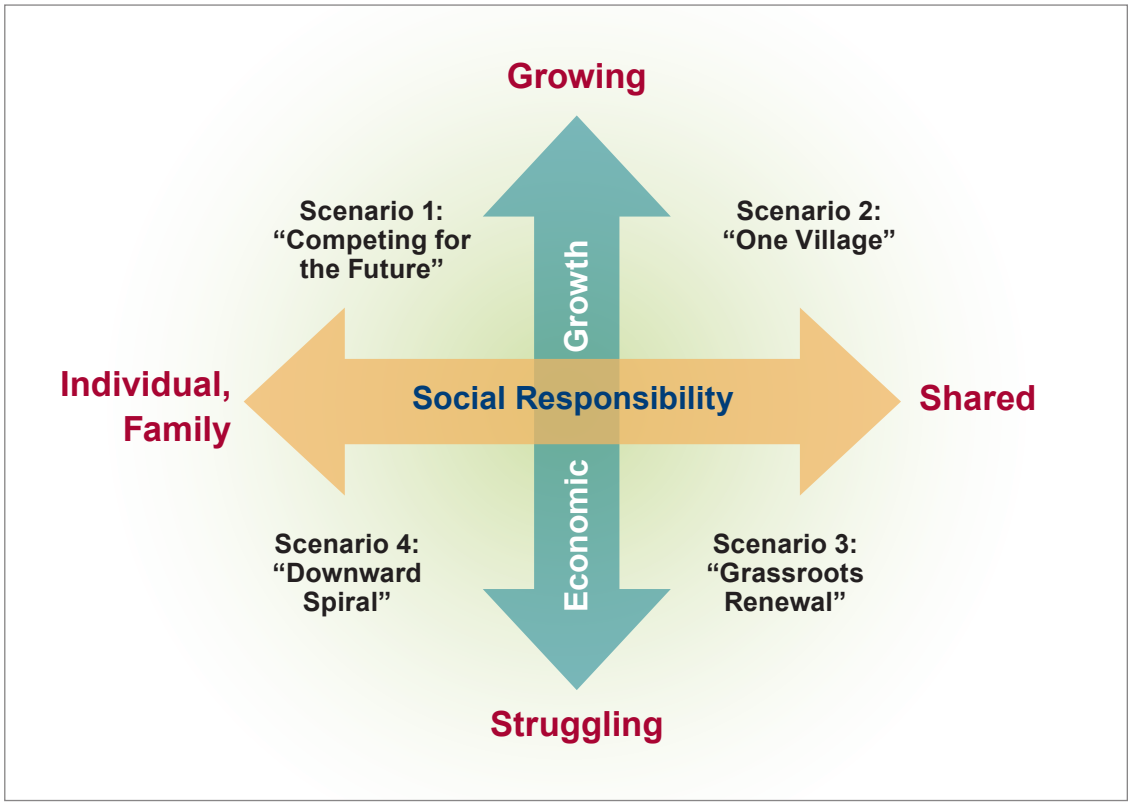
The scenario planning process kicked off in early 2012 with a series of in-depth interviews with prominent thought leaders in children's health, including heads of government health agencies, public policy experts, practitioners and professors of pediatric medicine, major philanthropists, and leaders of large foundations. The goal of these interviews was to generate a wide range of perspectives and insights on not only the current state of children's health and well being but also how it might evolve, and what factors — societal, economic, political, technological, etc. — might be most responsible for determining the direction of that evolution.

The themes raised during these interviews then became fodder for the next phase: the scenario development workshop, held in Washington, DC, in April 2012. Roughly a dozen representatives from leading children's hospitals, foundations, nonprofits, and government agencies attended the workshop, during which participants worked through the various scenario creation steps. A critical part of that process was generating a list of critical uncertainties — driving forces that are both highly important to the focal issue being considered and highly uncertain in terms of how they will play out.

Critical uncertainties are, in essence, the building blocks of scenarios. Ultimately, the group chose two critical uncertainties as the "scaffolding" for the scenario framework:

- **Economic growth.** This uncertainty refers to the various economic conditions under which governments, corporations, hospitals, and families alike could be operating in the coming decades. On one end of the axis, the overall U.S. economy is once again strengthening, with resources becoming more easily available. At the other axis endpoint, the U.S. economy continues to be challenged, descending into greater difficulty.

- **Social responsibility.** This uncertainty reflects a range of possibilities about who, in the coming decades, will be primarily accountable for the health, safety, and happiness of our children. Will society take responsibility for all children through government, or community organizations — or will this responsibility lie fully in the hands of individual families? More than the economic axis, this axis focuses on a variable over which Americans have more discretion. What might we choose, and why?



Once crossed to form a matrix, these critical uncertainties frame out four very different futures:

- **Competing for the Future:** *A world in which a booming U.S. economy ushers in a new era of innovation, economic growth, and better health for the majority of Americans — but not for the poor or the unemployed.*
- **One Village:** *A world in which a dangerous decline in the wellness of American children causes children's health to become reprioritized as a leading national issue, inspiring significant health-care advances.*

- **Downward Spiral:** *A world in which America's safety net starts to disappear, its middle class shrinks, and more and more families are left without help in supporting themselves and their children.*
- **Grassroots Renewal:** *A world in which the U.S. economy falters, leading communities turn inward and create local approaches and solutions to their own essential healthcare and well being needs.*

The Aspen Children's Forum

In July 2012, about 350 people congregated in Aspen, CO, for the anchor event of this process: the Aspen Institute Children's Forum. Nearly half of Aspen participants were "transformational philanthropists," that is, individuals or families who make significant financial contributions to children's hospitals. These philanthropists were joined by dozens of representatives from children's hospitals across North America, as well as a host of leaders in various key aspects of pediatric health, health policy, education, athletics, digital games, and garden and playground design.

The unprecedented event was organized around two key questions: What would the world look like if children were truly put first? And how might we get there? The scenarios served as a platform for exploring these questions. In several of the Forum's breakout sessions, participants discussed the strategic implications of the four scenarios: what would need to be done in each — or in any — future to ensure that the health and well being of children becomes a top priority? Within each breakout, participants divided themselves into small groups to explore the scenarios along three tracks:

"We don't need 'fix it' incremental strategies. We need to be thinking in terms of transformation."

— Neal Halfon, MD, Director, UCLA Center for Healthier Children, Families, and Communities

1. **Diagnostics and the delivery of care.** What would a children-first approach to diagnostics and the delivery of care look like in each scenario?
2. **The research agenda.** What are the key challenges and opportunities for children's research in each scenario, and what might a children-first research agenda look like?
3. **Healthy living for children.** What happens to popular culture — and how is "healthy living for children" defined — in these very different futures we may inhabit?

Participants began by considering the strategic implications of each individual scenario. They then looked *across* the scenarios to identify strategic implications that would hold true in all four future worlds, not just one or two. Ultimately, the groups identified several systemic changes that would either *naturally happen* or *need to happen* in order for a children-first agenda to be achievable, no matter which world — or combination of worlds — were to unfold:

- In every scenario, we'll see more **community-level/ambulatory healthcare models**. This means that more care will be delivered in a range of alternative settings throughout a child's community. Instead of being "siloed" in hospitals and doctors' offices, care will be delivered in a more cohesive fashion.
- **Innovation and invention** focused on children will be critical no matter which future unfolds.

- **Strong families and strong communities** that rally around the support of children will be required under every scenario.
- The **definition of children's health** must be expanded to take into account the whole child. Understanding the whole ecosystem of influences on a child's overall wellness needs to become a standard component of assessing a child's health and well being.
- In any future scenario, many philanthropists will practice **philanthropy** that is much more proactive and participatory than their previous activities. Elevating the health and well being of children will require an entirely new kind of **cooperation and collective action.**
- Children's hospitals will need to be **aligned around research,** with integrated data systems, analytics, and metrics for pediatric research, as well as nationwide data repositories accessible to all physicians and researchers.
- The question of **leadership** — who leads a children-first agenda? — will be an issue whether resources are abundant or scarce.

A Call to Action

Throughout the Forum, participants and panelists had talked primarily about "creating a children-first agenda." During the closing plenary session, that language shifted — importantly — to "starting a national advocacy movement." This change in terminology reflected the heightened sense of urgency — and the expanding sense of possibility — that emerged during the course of the gathering, and strongly signaled the true scope of the group's ambition. Participant and philanthropist Anne Bass may have captured it best with these words:

> "*We need to take our collective wisdom, excitement, and dedication toward children's health and focus it more broadly into some kind of national movement… that would [put] the voice of children first. It would need to have the power and commitment of entities like the National Rifle Association (NRA), in terms of their reach toward legislatures, and the AARP, which is another very effective organization. I think we need to create something that is so effective that lawmakers would ignore us at their peril…. We need to take the collective ideas from this conference and move out aggressively and actively to promote children to the best of our ability and in the best way we can*."

It was also clear to participants that (1) transformational philanthropists are uniquely positioned to lead this movement and (2) children's hospitals could also play a significant leadership role.

Since the Aspen Children's Forum concluded, a number of steps have been taken to capitalize on the meeting's momentum and advance the work that began in Colorado. Those involved in this process look forward to the work ahead — and to further broadening and deepening the collective conversation about the future of all children. To learn more about this process — and how to participate — contact David Alexander, MD, president and CEO of the Lucile Packard Foundation for Children's Health (david.alexander@lpfch.org).

Introduction

Year after year in the United States our investments in children continue to decline. Yet year after year, children's needs grow steadily greater. More than a third of U.S. children and teens are now overweight and obese, and that number is climbing. Nearly 15 million U.S. children, or 21 percent of all American kids, live in poverty — that's the highest rate of child poverty in the developed world. Among 30 industrialized countries, the U.S. has the third-worst rate of infant mortality and the second-highest rate of teen pregnancy. Meanwhile, children's literacy rates are falling. Collectively, these statistics reveal a sharp and shameful truth: we are failing our children.

In early 2012, the Aspen Institute and the Woodmark Group — an association of 25 prominent children's hospitals and independent foundations that support children's hospitals in the U.S. and Canada — conceived a project designed to address this underinvestment problem not by tinkering at its edges but by finding ways to transform it from the roots upward. Together, they organized the *Aspen Institute Children's Forum: Investing in Children's Health and Well Being* — a first-of-its-kind gathering of philanthropists and children's health experts that took place in July 2012.

"Children's hospitals are operating by the old system but looking to help create the new system. We just need the tools to make it happen."

— Kurt Newman, MD
President and CEO
Children's National Medical Center

The goal of the meeting was daunting but simple: to find a way to turn the platitude "putting children first" into a platform for change that inspires real and immediate action. While the Forum featured a range of talks, plenaries, and interactive breakouts, the "centerpiece" of these sessions was a set of provocative scenarios about the future of children's health and well being, created specifically for the event. These scenarios postulated a range of future economic and social conditions that might occur, all framed around the question: *What role can we play in facilitating the transformation of the health and well being of children in North America over the next 20 years?* The Lucile Packard Foundation for Children's Health funded and participated in the development of these scenarios.

Why Scenarios?

Scenario planning is a strategic process designed to help organizations and individuals imagine, influence, and plan for a better future. The process begins by identifying the many forces of change in the world that have particularly strong influence on the difficult issues groups or individuals are trying to resolve. Those forces are then combined in different ways to create a set of scenarios that tell very different yet equally plausible stories about how the future could play out.

Scenarios are designed not to reinforce what people know or assume, but to challenge their thinking and make visible what they might *not* be seeing — or what they have never before considered because it lies outside the status quo or their sense of what is possible. Importantly, scenarios are not predictions. Rather, they are thoughtful hypotheses that allow people to imagine and rehearse different strategies for how to shape the future in better directions.

About This Report

This report begins with a quick overview of the process by which the Aspen scenarios were created — from the initial expert interviews conducted in January 2012 through the scenario creation workshop held in Washington, DC, in April 2012. Next, it shares the scenarios themselves, which paint four very different portraits of how the state of children's health and well being could evolve over the next few decades. Finally, it shares many of the critical insights and implications that emerged from participants' interaction with the scenarios at the Aspen Children's Forum — as well as how they might be used to empower new actions and strategies for transforming the future of children's health and well being.

The Scenario Creation Process

The scenario planning process kicked off in early 2012 with a series of in-depth interviews with prominent thought leaders in children's health, including heads of government health agencies, public policy experts, practitioners and professors of pediatric medicine, major philanthropists, and leaders of large foundations (see Appendix for a full list of interviewees). The goal of these interviews was to generate a wide range of perspectives and insights on not only the current state of children's health and well being in the U.S. but also how it might evolve, and what factors — societal, economic, political, technological, etc. — might be most responsible for determining the direction of that evolution.

Among the questions posed to each expert: What concerns you most about children's health and well being? If society succeeded in transforming children's health and well being beyond anyone's wildest imagination, what would that success look like, and what would be its milestones? What erroneous or unchallenged assumptions could lead to the blockage or failure of such a transformation?

"The issues that we deal with daily will not get solved until they have the vitality to get seen."

— Diane Bernstein
Emeritus Board Member
Children's National Medical Center

From these critical interviews, nine key themes emerged, each highlighting an issue or area that interviewees felt needed to be addressed and/or resolved for a better future for all U.S. children to be possible. These themes then became the foundation for all of the scenario planning conversations that would follow.

Key Themes in Child Health and Well Being

1. Creating the case for putting children first. *"Why is focusing on children important rhetorically, but not important in terms of budget allocation?"* asked one interviewee. The notion of "putting children first" is a familiar platitude — and a sentiment that no politician or voter would dare object to, at least in theory. So what would give "teeth" to this message, elevating it to the level of national priority, a true societal platform? As one interviewee put it: *"We need to create something that allows people to move from individual or sector concerns to something bigger."* Several said that highlighting the connection between children's health on the one hand and long-term, sustained economic growth and societal progress on the other will be critical to any such effort. *"Investing in young people is the best investment government could make."*

2. Finding the right metrics. *"How do we measure progress to show which investments in children's health and well being work — and which do not?"* Currently, there are few shared or universal metrics for measuring a child's overall health — let alone measuring well being, which is even more difficult to assess. (A few interviewees pointed to the Early Development Instrument [EDI] as one example of a good metric for measuring both). Moreover, the costs and benefits of investments are difficult to analyze because, as one interviewee said, *"the long-term benefits of investing in children do not*

surface until 20 years or more in the future" — a problem he called the *"tyranny of timeframes."* Finding ways to measure and track outcomes over time will bolster everyone's understanding of what works and what doesn't.

3. Population-level healthcare. *"We're good at dealing with the health issues of children who are sick, but lousy at promoting children's health and well being for the whole population,"* said one interviewee. Shifting the strategic focus from taking care of sick children to looking out for all children will require a much wider view of "health and well being." As one person put it: *"If we're looking to address the system, we need to look beyond what we traditionally mean by health."* An expanded definition would include factors such as mental and emotional health, readiness to learn, nutrition, environmental safety, and more, many said. They also noted that this expanded definition would mean that children's hospitals would need to take on an even larger role in their communities. *"Pediatric hospitals should not just focus on children in the emergency room. Instead, they should be the champions of children, as an authoritative and respected member of the community,"* said one interviewee, while noting that hospitals still must care for high acuity patients.

"Independent of the circumstances of their birth, all children have the right to health and well being."

— Alan Guttmacher, MD
Director, National Institute of Child Health and Human Development

4. The need for new economic and social models. *"How do we get through this major transition of our economic and social institutions to end up stronger on the other side?"* Interviewees expressed considerable concern about the impact that the economic downturn has had on children and families — and deep uncertainty regarding how, when, and if the U.S. might make the transition to a new economic model, as well as what it would look like. Among the top issues they cited: structural unemployment, the inability for college graduates to secure jobs, the disappearance of the middle class, and increased poverty in the U.S. (15 percent of Americans now fall below the poverty threshold — 21 percent of children). Also, several interviewees talked about how the current economic environment is exposing a widespread ideological belief that children are the responsibility of families — not of society at large. *"Individual kids are valued in families. But we don't value children in general as a society."* The question is: will that — or can that — shift?

5. Intergenerational tensions. *"There is growing [resource] tension between the elderly and children/young families."* Interviewees agreed that the needs of seniors are being addressed far more effectively — and vocally — than the needs of children and young families, even as both groups' needs are becoming greater. Whereas Medicare, Social Security, and pensions are steadily in the public spotlight, drawing strong political and media attention, children's issues attract relatively little focus. *"The biggest cultural shift of the 20th century was the invention of old age, moving life expectance from 45 to 85,"* said one interviewee. *"A huge chunk of our investments go toward the scaffolding we need to support growing numbers of old people."* This often creates an *"us versus them"* mentality when it comes to investment and spending: *"Golf courses or daycare centers? That's a real tension."* Several interviewees attribute the greater focus on issues affecting older generations to their sheer voting power. *"It's a ludicrous idea, but imagine the difference it would make if children could vote. It would change the world. Social Security would not just be for those over 65."*

6. Role of philanthropists. Interviewees felt that in general, children in Africa, Asia, and elsewhere in the world receive far more philanthropic funding and attention than U.S. children — in part because the perceived need is greater; they also felt that the vast majority of U.S. philanthropic contributions were directed toward non-health issues, like climate change. Most philanthropic support for children's health issues in the U.S., they said, comes from *"people with a vested interest in children's health"* — such as those who are raising a sick child. *"Philanthropists are rarely interested broadly in the topic of children's health."* Some suggested that this was a perception issue, as well as a messaging challenge. As one person put it: *"The key is getting philanthropists to understand that this is a topic that affects them personally."*

7. Popular culture and technology. *"What is the true impact of popular culture on children's health and well being?"* Much has been said about the negative effects of pervasive media, video games, etc., on kids. But several interviewees asked: how might popular culture's power and influence be used to influence the choices and behaviors of children and their families in positive ways? Some saw a role for technology — now the chief means through which popular culture is communicated and shared — in helping to spread positive memes and behaviors. *"Even little kids are incredibly adept with IT. How can innovation in technology usage help with healthy behaviors and choices?"* But the potential downsides of technology also need to be explored: *"We need to gain a better understanding of how new technology (social technology in particular) affects kids. The number of kids who have media and TV addictions is rising; is that setting them up for other addictions? Does it rewire their brains?"*

8. The changing American family. *"Our traditional views of family are changing; we're in the painful middle of a very significant transition."* The profile of American families continues to evolve, as the traditional nuclear family takes on different forms and dynamics. An increasing number of children (21.2 million, or 26 percent of American children under 21 in the U.S. today) are being raised by single parents, many of whom struggle to balance work and family responsibilities. Meanwhile, almost one child in 20 lives in a household headed by a grandparent, with no parent present. *"It's clear that we're going to be seeing some very different family forms moving forward,"* one interviewee said. "*It's a huge uncertainty in my mind. What is a family going to look like in 30 years?"*

How can innovation in technology usage help with healthy behaviors and choices?

9. Nutrition. *"We need a fuller understanding of children's nutrition."* Several interviewees raised the issue of childhood nutrition and its complexity as an issue. While initiatives to improve the nutritional profile of school meals, for example, are important, nutrition requires a systemic approach to improving the kinds of foods available to children at every stage of growth and development and in every environment. Nutritional education, for children and families, is another critical piece. So is access. *"We think about food from the standpoint of first foods, school food, and community food,"* one person said. *"With community food we want to change the kinds of food readily available or change people's choices. Access around community food has to happen first before you can change institutional food choices."* Nutritional issues are also closely tied to children's activity levels — which is another area of children's health that needs to be further explored.

In addition to illuminating the broad landscape of issues that the Aspen scenarios would need to address, the interview output also led to the creation of the scenario project's focal question — a broad yet strategic query that would serve as an orienting device throughout the scenario process: ***What role can we play in facilitating the transformation of the health and well being of children in North America over the next 20 years?***

The Scenario Framework

In April 2012, about 20 representatives from leading children's hospitals, foundations, nonprofits, and government agencies gathered in Washington, DC, to develop a set of scenarios about the future of children's health and well being that would address this question. The group began the scenario development process by reviewing, refining, and expanding on the key themes that emerged from the interviews. They then used that expanding list of themes to generate a more detailed list of **critical uncertainties** — driving forces that are both highly important to the focal issue being considered *and* highly uncertain in terms of how they will play out. Critical uncertainties are, in essence, the building blocks of scenarios. Understanding how these important social, technological, economic, environmental, and/or political forces might evolve not just individually but in combination is the crux of any scenario set.

After generating an ample list of critical uncertainties, participants then further refined the list and, finally, prioritized the uncertainties in terms of relevance and importance. Below are the top tier of uncertainties that the group considered, in priority order.

Critical Uncertainties for the Future of Children's Health and Well Being

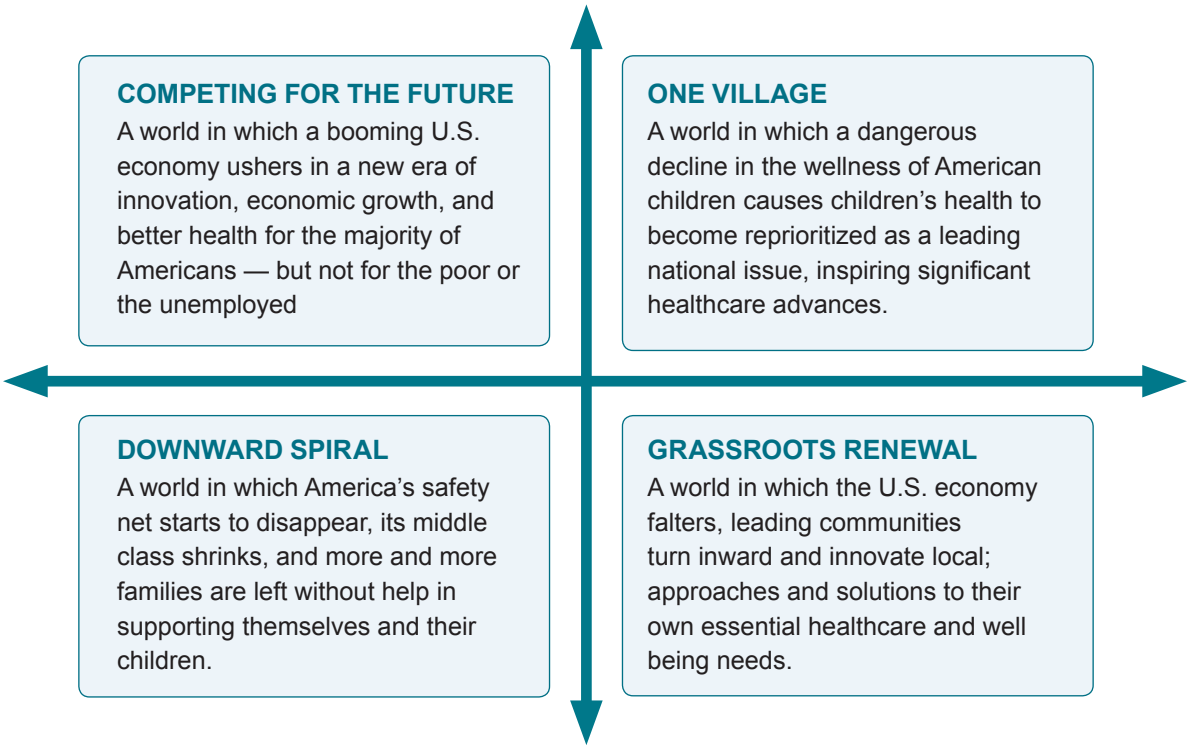
1. Social values around children
2. Policy economics around children
3. Evolution of the healthcare delivery system for children and their parents
4. Overall U.S. economic climate
5. Access to healthcare and health education
6. Impact of environmental conditions on children's health
7. Advances in genomics
8. Changing characteristics of the family
9. Resource tension between elderly and children
10. Impact of popular culture on children
11. Warfare vs. welfare system
12. Immigration policy and treatment of "other people's" children
13. The ability to influence children's behaviors and choices
14. Challenges of adapting to changing technology
15. Understanding of lifelong health (disease and health profiling)
16. Policies and perspectives on end-of-life care and the impact on kids
17. Changes in disease prevalence

Participants then tested how various pairings of these uncertainties might come together to create a scenario framework — essentially, a 2x2 matrix defined by two axes, each of which represents one critical uncertainty. The goal was to choose two uncertainties that, when crossed, would create the most divergent, plausible, useful, and provocative set of scenarios. Below are the two critical uncertainties that participants ultimately selected to serve as "scaffolding" for the scenarios:

Economic growth. This uncertainty refers to the various economic conditions under which governments, corporations, hospitals, and families alike could be operating in the coming decades. On one end of the axis, the overall U.S. economy is once again strengthening, with resources becoming more easily available (although choices about how to allocate those resources remains complex). At the other axis endpoint, the U.S. economy continues to be challenged, descending into greater difficulty. In such a world of scarcity, resources would be difficult to obtain. In either environment, the economic *choices* in terms of what dollars are allocated to children would be critically important, no matter what resources were available.

Social responsibility. This uncertainty reflects a range of possibilities about who, in the coming decades, will be accountable for the health, safety, and happiness of U.S. children. Will society take responsibility for all children — or will this responsibility lie fully in the hands of individual families? More than the economic axis, this axis focuses on a variable that Americans have more discretion over. What might we choose, and why?

Once crossed, these critical uncertainties frame out four very different futures:



Once the matrix was established, participants spent time deepening the logic underlying each scenario and developed outlines for how each story might unfold. Ultimately, the workshop yielded a draft set of scenarios about how the world — and with it, the future of children's health and well being — could evolve over the next two decades. These drafts were further refined in the weeks that followed, and finalized in advance of the Aspen Children's Forum.

The Scenario Narratives

Each of the scenarios that follows tells a brief story about how one of the four different futures defined by the scenario matrix might develop. These stories are not meant to be exhaustive — indeed, much more will be happening in these worlds that just what is on the page. Rather, they are designed to inspire more imaginative — and more strategic — thinking about what the evolution of such a world might mean for our organizations, our culture, and most importantly, our children. Accompanying each scenario are two additional features designed to further illuminate each scenario and the world it would create: a box summarizing that scenario's key features, and short sketches of five fictional characters who find themselves living in that future environment.

Finally, a note about how to read these scenarios. In order to fully engage with them, it's important to fight the desire to choose a favorite scenario, and also to suspend disbelief concerning the possibilities. Keep in mind that **elements of *all* the scenarios will be components of the future,** which is why it's important to consider the scenarios as a complete set. While nobody can control which elements of which scenario will come to pass, actions can be taken to exert critical influence on which direction the future takes and how upward or downward its trajectory bends.

Scenario 1: Competing for the Future

This is a world in which the health status of many American children improves dramatically as a result of the U.S. successfully stimulating a new era of innovation and economic growth that improves employment opportunities, quality of life, and healthcare opportunities for an increasing number of families. Healthcare becomes a bustling marketplace characterized by individual choice. Cures are discovered for many chronic and thought-to-be incurable diseases. However, infrastructure to support the poor and the unemployed is weak or nonexistent.

How this world unfolds: In 2013, the U.S. government begins taking stronger measures to both rein in its spending and jumpstart the nation's economy. Congress passes significant fiscal reforms and new legislation designed to stimulate job growth — including a series of tax overhauls that favor business and stimulate innovation and entrepreneurism. New benefits and incentives are put in place that support employers taking more initiative in providing health coverage and health savings plans for employees. In 2014, U.S. GDP kicks upward to 3.5 percent and doesn't slow down for the next seven years. By 2015, unemployment has slid to 6 percent. The Dow hits 14,000 again — and keeps climbing. The U.S. economy is on a path to strong recovery.

Key Features of *Competing for the Future*

- Increased individual accountability and choice in healthcare
- Children remain the responsibility of families, but families have increased support from employers
- Social safety nets are no longer deemed necessary
- Growing upper and middle class and shrinking lower class; lower class truly becomes the silent and forgotten
- Population, overall, becomes healthier, with the exclusion of the poor
- Philanthropists cover what industry does not; disenfranchised individuals and research on health issues are not considered attractive from a business standpoint

The nation's renewed focus on business increases its global competitiveness to pre-recession levels. The U.S. job market expands once again; so does the size of its middle class, as fewer and fewer Americans fall behind. Employers scramble to attract qualified workers, showing an increased interest in the quality of their employees' lives. In highly competitive and booming industries like tech and biotech, employers compete to offer prospective employees the best possible benefit packages, which include health savings accounts with varying levels of employer participation; a range of private health insurance options; professional training; and support services such as daycare and education funding for employees' children. Eager to ensure a continued pipeline of high-quality workers for years to come, many companies also invest directly and proactively in the workforce of the future by funding and supporting a range of programs and institutions that provide quality education, healthcare, and necessary services to U.S.

children. As employers take on more and more of the costs of employee benefits, federal and state safety nets become less and less relevant — and public funding for healthcare, social services, and research declines markedly. By 2016, the Affordable Care Act is repealed.

In this environment, alternative types of health insurance plans and approaches that cater to this new employer-driven market start to flourish. As healthcare costs rise, many employers find ways to lower the price of the insurance provided to employees; some try to incentivize their workers to choose lower-cost plans. Healthcare savings accounts continue to grow in number. Prevention efforts thrive. Traditional insurance plans are on the decline. For their part, insurers exploit new data mining software to tap into the rich personal data generated by prospective customers to help them distinguish between good and bad risks.

"It's about mobilizing a community of scientists and practitioners to work in a certain way — and that's about more than just money."

— Norman Rosenblum, MD, Professor
The University of Toronto

Meanwhile, the pace of medical advancement accelerates, thanks in large part to the influence of an increasingly innovative economy, market dynamics, and the willingness of the expanding middle class to pay out of pocket for cutting-edge treatments. Breakthroughs in stem-cell therapies, personalized medicine, and genomics lead to new treatments for obesity and a host of diseases related to aging, including Alzheimer's. Boutique medical practices catering to individuals who want more attention and guidance on everything from nutrition to anti-aging strategies proliferate. By supplementing insurance-covered care with their own dollars, the affluent are becoming healthier and living longer. Meanwhile, an increasing number of chronic or incurable diseases are being successfully managed or diminished; some employers even pay for the treatment of conditions that improve the well being and performance potential of working-age Americans.

Given the widespread absence of federal dollars, research institutions — including children's hospitals — turn to private companies, foundations, and philanthropists for funding. Large corporations become key backers of research and wellness programs that they think are "market attractive" and have the potential to elevate their brand image among consumers. Meanwhile, medical research for which the "returns" are considered low — such as research into rare children's diseases — is not widely pursued. Philanthropists become the lead funders of such research.

Philanthropists play another key role as well. With social safety nets gone, poor families truly struggle — particularly when it comes to getting the help they need for their children. While many more Americans are now living more comfortably, those still jobless or barely scraping by experience high rates of obesity, chronic illness, and poor nutrition. Without income or insurance, these families and children are "locked out" of the system and their care options are limited; indeed, there is no longer any formal infrastructure in place to support or look after them. As a consequence, many philanthropies shift their focus toward addressing the needs of the disenfranchised so that the poor — and especially poor children — are not totally forgotten.

Competing for the Future: A Day in the Life….

*Read about what life in **Competing for the Future** looks like for a few select "characters": Jason, a 10-year-old with spina bifida; Natalie, a 7-year-old from a disadvantaged family; Acme Children's Hospital, a 300-bed facility; José, a researcher specializing in juvenile diabetes; and Nora and Herb Smith, husband and wife philanthropists. Then, see how these characters' lives and their circumstances shift from scenario to scenario by reading the snippets about them at the end of each scenario story.*

- **JASON** — Jason gets a new sensor-embedded wheelchair, which, along with his part-time therapist and afterschool tutor, is paid for by the family's health savings account (HSA). Offered through his dad's new high-salary tech job, the HSA gives the family more choice when it comes to Jason's care. While Jason's treatment path is full of strong support, it is not characterized with new advances, as the ROI on rare-disease research is considered too low in this world to justify deep investment. The family is saving up HSA funds for a trip to Tokyo, where an advanced medical facility doing pioneering research on spina bifida is a big draw for families willing to pay out of pocket for pioneering care.
- **NATALIE** — Her single dad's part-time warehouse job brings in very little cash and virtually no benefits. Meanwhile, the outside supports that the family has always relied on — including food stamps, free school lunches, and Natalie's after-school program — disappear. While Natalie is relatively healthy compared to the rest of her family, her nutrition is poor and unbalanced, and she's often hungry. With no discretionary income, the family can't afford to buy her new clothes or books. Surrounded by people and peers who have more, Natalie withdraws, feeling forgotten.
- **ACME CHILDREN'S HOSPITAL** — Acme sees a significant change in its patient profile. A majority of its patients are now covered through HSAs or other employer-provided plans (which, in general, are increasingly unwilling to cost shift). This segment of "consumers" is also more price sensitive; families shop around for the best prices on MRIs or surgeries, making their own personal decisions based on value. While Acme now treats fewer Medicaid patients (and there are fewer people on Medicaid more broadly), it incurs significantly higher losses on those patients. Worried about cost containment and its flat revenues, Acme looks to further reduce its exposure to Medicaid patients while also spending money on marketing and advertising designed to attract plan-covered patients.
- **JOSÉ** — A large media conglomerate known for its blockbuster kids movies becomes the lead funder of José's juvenile diabetes research lab. Nearly all medical research now has some form of private backing, so it makes sense that a company enjoying record profits would get in on the action (and enjoy the associated positive PR). Given the company's considerable audience reach, linking its brand with this disease will do more to raise awareness of juvenile diabetes than any public service campaign ever could. Freed from having to worry where his next grant might come from, José can now focus fully on the science — and hopefully push forward toward a breakthrough.
- **NORA and HERBERT SMITH** — The Smiths provide financial support for a new free children's healthcare clinic in their hometown. The clinic is one of an increasing number of privately funded free healthcare facilities popping up across the country to address a rising paradox: in a nation of growing and visible wealth, those without money or means are worse off than ever. On their first visit to the clinic after it opens, the Smiths see hundreds of families waiting in the blazing sun for their turn at free care.

Scenario 2: One Village

This is a world in which continued declines in key health indicators and a devastating pandemic that disproportionately affects children jolt the U.S. government and its people into taking broader, collective responsibility for the health and well being of all American kids. Improving the lives and livelihoods of children — and of everyone — becomes a strong and more prominent national priority, inspiring inclusive and universal health coverage, new investments in research and technology, and more focused and coordinated action.

How this world unfolds: In the early years of this scenario, recurring economic shocks deepen and intensify economic uncertainty and instability. While the rollercoaster economy continues to dominate the headlines, an increasing number of articles about the problems facing U.S. children also begin to make front-page news. In 2013, a flurry of new research reports and surveys on the state of America's kids reveal shocking statistics on just how bad the U.S. is doing globally in terms of health and education metrics among children; literacy rates are dropping precipitously, and new projections suggest that 50 percent of U.S. children will be obese by 2030. Indeed, every important indicator for children's health is sliding downward. The situation becomes dramatically worse in 2014, when a novel strain of avian flu originating in Asia travels at lightning speed around the globe. The devastating virus hits children particularly hard: among the millions of Americans who lose their lives, at least half are under age 12.

As the pandemic recedes, a broad and deep reassessment begins. The stark realization that children are no longer getting the supports they need — and that the U.S. is, in essence, setting up its future generations to fail — suggests that a new approach to improving children's health and well being is needed. In 2016, a new administration starts realigning the country's economic and social priorities from the ground up, beginning with significant tax reform. New tax dollars streaming in from corporations and individuals help fund vital new programs designed to help improve not only the financial but also the physical health of all Americans — with an increased focus on children. Providing universal access to quality healthcare becomes a widely supported national leadership priority. By 2018, universal healthcare is fully in place.

At the same time that policies and priorities are shifting — and the notion of shared accountability becomes increasingly foundational to the way that individuals, businesses,

Key Features of *One Village*

- Society has a shared responsibility for all children; children are a priority and understood to be the future
- Universal healthcare and access for every child and family
- Family and children's health is improving
- Significant high-tech medical and wellness advances
- Increased understanding of the impact of environmental factors and behavioral choices
- Philanthropists fund cutting-edge research focused on rare children's diseases and changing detrimental behaviors among kids

nonprofits, and government operate — the U.S. economy finally moves from recessionary to recovering. The uncertainty and fear that characterized the period from 2008 to 2016 get replaced by more coordinated effort and a determination to "get it right for our kids" this time. Innovation becomes the fuel that pushes this promise forward, much of which is funded through government grants. A greater focus on improving childhood health and well being — and preventing poor health in the first place — opens the doors to new experiments and insights. In 2017, the U.S. establishes the National Innovation Lab for Children's Health (NILCH). Elsewhere, research into the root causes of diseases gets significant federal funding and leads to big advances. New collaborations between employers, schools, and insurance companies focus on preventive care, family education, and reducing sick days — and prove highly successful.

"Lots of people are trying to put kids on the agenda. We've got many decades of experience, but that experience hasn't led to a solution."

— Olivia Golden
Fellow, Urban Institute

As research becomes more sophisticated, the ability to pinpoint susceptibility and risk also greatly improves; so does knowledge of the impacts of environmental factors and behavioral choices on well being and disease development. Personalized medicine increasingly becomes the norm, with low-cost genomic profiling (just $50 per genome) becoming widely available — leading to all children being routinely screened for genetic diseases. Meanwhile, individuals of all ages are able to more actively manage their own health through increasingly sophisticated healthcare-related apps; mobile technology-based games designed to reward healthy behavior also abound.

By the 2020s, many chronic diseases, including diabetes and asthma, are being successfully treated — and increasing numbers of cases are being prevented altogether, particularly among children. Although rare childhood diseases are still not a high priority, national programs on nutrition and health, now built into universal care coverage, have an unprecedented impact on children, adults, and the elderly. Children's hospitals increasingly focus on a broader, preventive platform for enhancing children's health, nutrition, and education. Indeed, the U.S. is no longer dangling low on the list of the world's healthiest countries but is steadily climbing into the top tier — thanks in large part to sharp declines in obesity and new capabilities to address genetically detectable diseases in children before these diseases develop.

One Village: A Day in the Life….

*What would it be like to live in this world? Below, get a glimpse of what life in **One Village** looks like for our five "characters."*

- **JASON** — Rapid advances in the medical understanding and treatment of all childhood diseases, including spina bifida, radically improve Jason's previously constrained life. His medical care is more genome-specific and personalized. He is practicing walking with braces that are loaded with data-gathering capabilities, enabling his care team to adjust their approaches in real-time. Jason is also happier — not because of all the attention on his illness but because of all the attention on *him* — and on all kids, no matter their health status. Jason feels like a priority in this world — like his health and happiness really matter to more than just his circle of friends and family.
- **NATALIE** — Before universal healthcare came into place, Natalie's family had no coverage and couldn't afford basic checkups or care in any form. Her dad still doesn't make much money, but both he and Natalie are now fully covered. As a consequence, Natalie now regularly visits a pediatrician. Her new pediatrician updates her vaccines and gives her a colorful, government-issued chart on which she can track things like her height and weight and whether she's happy or sad; every time she plays outside, she gets a sticker. Natalie's afterschool program gets new funding, and the run-down park in her neighborhood gets a total makeover.
- **ACME CHILDREN'S HOSPITAL** — With primary care for children more widely available, Acme — along with most other children's hospitals — becomes a complex care center focusing on sick children with complex needs. Federal funding and support has made a huge difference to its delivery and care options. Universal coverage and enhanced benefit plans that provide medically necessary care to all offer stability to the hospital's operating budget.
- **JOSÉ** — Within the space of one year, José and his team publish five major articles on juvenile diabetes in leading research journals. With ample funding available from the government, NGOs, and industry alike, José spends half his time doing research and the other half hiring more scientists to add to his team. It's not money that José lacks in this world — it's researchers, who are being wooed left and right by labs and hospitals that do research on children's diseases.
- **NORA and HERBERT SMITH** — The Smiths help found a new rare-disease research lab as a way to bolster coordination among the disparate assortment of researchers working to find treatments and cures for "outlier" diseases among children. With the government now driving — and funding — the research agenda for most common diseases, the Smiths believe that philanthropy and the private sector can apply the same drive and focus to *uncommon* ailments, including those that don't occur in the U.S. The research teams had already made huge breakthroughs, especially in the genetics of rare pediatric ailments.

Scenario 3: Grassroots Renewal

This is a world in which the economic recession marches onward and downward, driving the U.S. into further debt and placing strict limits on federal funding for even the most essential programs. With basic but limited healthcare coverage in place for everyone, communities turn inward, innovating local approaches and solutions to their own essential healthcare and well being needs. While access and outcomes vary by community, the best grassroots innovations spread and scale.

How this world unfolds: The economic recession intensifies, driven in part by the EU's spiraling debt crisis and the continued devaluation of global currencies. A cash-strapped U.S. government slides into deeper debt. Meanwhile, growing numbers of American families fall into poverty as jobs remain scarce and government support dwindles. Despite the increased needs of its citizens, the U.S. government has no choice but to start slashing costs in many areas. However, it does make basic coverage for all a priority, and the Affordable Care Act is expanded to create basic (although truly limited) coverage for everyone.

Key Features of *Grassroots Renewal*

- Shared responsibility for children at the community level
- Rudimentary, basic health coverage for everyone
- Local, community-based innovation spreads virally
- Federal, state, and local guidelines are in place, but health and well being vary by location
- Philanthropy works to fill the gaps toward each child receiving the highest quality care

In the absence of adequate funding and support for many programs, local communities have no choice but to find ways to fill in the gaps created by retreating federal dollars — and begin to pave their own path forward. Neighbors help neighbors. Cities (and in some cases, regions) become like miniature nations, with their residents, businesses, and institutions working together to take care of their own. Local hospitals, supported by local philanthropy, take on a more expansive role in community health and well being, providing not just medical care but accessible health education, nutritional counseling, and other offerings designed to improve their communities. In a world in which unemployment and poverty continue to expand, youth crime and violence reach shocking levels in many places; some visionary communities tackle these issues head-on, working within their neighborhoods to address their root causes. Not surprisingly, mayors have a new level of power and oversight in this world, able to implement health-promoting policies, including those related to nutrition, that go far beyond federal recommendations and guidelines. New York Mayor Bloomberg's attempted ban on supersized soft drinks was just the beginning.

Of course, not all communities have the resources and skills to address their own needs, which extend beyond the arena of healthcare into education, public safety, and even infrastructure upkeep. Some communities thrive under their new freedoms and responsibilities; others sink. Different communities have markedly different capacities for supporting the health and well being of their kids — with the result that children thrive in some places but struggle in others. Some communities see an uptick in diseases due to low immunization rates, getting hit especially hard by localized outbreaks. But with increasing frequency, the best local solutions go viral: communities that have "cracked the code" on a particular problem freely share their knowledge and innovations with other communities far and wide, which then replicate these successful models.

"If you want to mobilize, you need something that grabs attention beyond social justice."

— Jennifer Howse
President, March of Dimes

With significant federal funding cuts to the NIH and private labs, medical research becomes the purview of philanthropists, who continue supporting vital research into childhood diseases both common and rare. Philanthropists and private funders also focus on scaling successful healthcare models across North America. Meanwhile, new mobile device-based apps enable innovative collection and analysis of public health data; some communities use these apps to track patterns of birth defects, but most community health efforts focus on basics like immunizations.

In this new grassroots landscape, the ways in which the health system delivers care also change and diversify. Various local models proliferate. In some communities, local schools contract directly with physicians to provide primary care to students. With resources still tight, more and more children's hospitals streamline their spending by investing primarily in their area of specialty and limiting their other offerings. In some places, children's hospitals organize into regional networks, working together to provide numerous specialties to their communities and outsourcing the rest through distance medicine. As time progresses, hospitals and communities alike continue to draw from the multitude of community experiments and innovations happening around them — determined to improve the health and well being of their people, especially those who are most vulnerable.

Grassroots Renewal: A Day in the Life….

*What would it be like to live in this world? Below, get a glimpse of what life in **Grassroots Renewal** looks like for our five "characters."*

- **JASON** — Jason's local medical coverage and quality of care both diminish, as his community fails to become innovative and resourceful when left to its own devices. With less — and less consistent — care, Jason's stamina and coordination suffer. His family makes plans to move across the country, to a city that's become a model for how to take care of special needs children at the community level; the city has created a new kind of seamlessness between medical care and education that never existed anywhere before. It is also on the forefront of population data collection, gathering a new level/depth of data about the needs of all kids in the area that yields far greater insight into who needs what and where.
- **NATALIE** — Times are tough in Natalie's hometown; her dad says that the city has about as much money as they do, and they're barely getting by. Still, Natalie's neighborhood is tight knit; collectively, her neighbors work hard to take control of their circumstances and address local problems. Natalie spends much of her time with her grandmother, who is part of a new neighborhood group called The Elders — which, as far as Natalie can tell, is a whole bunch of grandmas and grandpas who've decided to make things better practically all by themselves. "Not having much in the way of resources," her grandma says, "doesn't mean there isn't still a lot to give."
- **ACME CHILDREN'S HOSPITAL** — While Acme plays a role in various community and private-sector efforts to enhance children's care locally, providing so much primary care to so many has a negative impact on its revenues. As a consequence, the hospital begins to focus almost exclusively on what has long been its leading specialty: pediatric surgery. It also becomes part of a consortium of hospitals that partner, through their alliance, to offer a full range of specialized care to sick children.
- **JOSÉ** — José struggles to secure research grants. With federal funding now slashed, his work is increasingly funded by local community foundations and private donors, which have more specific outreach and applied missions. As a result, José moves to a new community where a philanthropist has established a research center focused on diabetes.
- **NORA and HERBERT SMITH** — The Smiths join the mayor's new Community Council — an assemblage of local businesspeople, philanthropists, teachers, physicians, nonprofit leaders, and even teenagers who have stepped up and stepped in to help their community thrive in the face of lean times. Some of the city's unique approaches to addressing local issues prove highly successful and start catching on elsewhere. For their part, the Smiths have found creative ways to fund and maintain specialty pediatric clinics at a time when similar clinics are closing around the country; other cities learn from what they have done.

Scenario 4: Downward Spiral

This is a world in which attempts to jumpstart the U.S. economy fail, forcing the federal government to make deep slashes to vital social supports — including basic healthcare coverage. America's safety net starts to disappear, its middle class shrinks, and more and more families are left without help in supporting their children. In this "every man for himself" environment, philanthropy and civil society step in to help stave off further declines.

How this world unfolds: As the global economic recession continues, a seemingly unending series of shocks foil all efforts at recovery. By 2013, the recession has taken on the characteristics of quicksand: the more we struggle to get out of it, the further down we sink. As interventions fail, frustration intensifies. Plagued by indecision about how best to move forward, the U.S. government has no choice but to deepen its cutbacks and strip away funding from even its most basic, longstanding programs. In 2013, the Affordable Care Act is repealed. In 2014, Medicaid gets converted to a block grant and federal funding for the program is cut by 20 percent. The NIH sees its budget slashed by 50 percent.

No collective response kicks in — no communal sense that "we're all in this together." Instead, individuals and families are largely left to fend for themselves. Local and state safety nets start to loosen and in some places disintegrate. With governments, companies, and individuals furiously treading water to keep themselves afloat, families and children get bumped down the priority list — in some places falling off the list altogether. Insurance premiums skyrocket and more families opt out — or are forced out — of coverage. With nowhere else to go, people flood emergency rooms with common and highly treatable illnesses. Rising unemployment and depleted savings accounts leave more and more Americans without the ability to pay for even basic care. Environmental conditions worsen in many places, with higher incidences of waterborne diseases reported. Not surprisingly, dysfunction starts to flourish. Crime, family abuse and neglect, and violence-related ER cases are all on the rise. Across America's cities, storefronts empty and streets grow more dangerous.

The big story in this world is the precipitous decline of America's once-thriving middle class. Across the country and across all age groups, significant numbers of middle-class families slide further down the economic ladder to join the swelling ranks of America's "have-nots." With far more families losing their asset base than gaining it, many fear that the country's middle class will disappear entirely. Moreover,

Key Features of *Downward Spiral*

- America's middle class shrinks
- Individuals and families remain responsible for their children, but without support
- No government discretionary budget
- The health of the U.S. population, on the whole, is in decline
- Employer health coverage diminishes and the social safety net is underfunded
- Basic healthcare is not accessible to all
- Philanthropy plays a crucial role in funding basic programs

healthcare access and information remain dangerously limited among the "have-nots." (Meanwhile, the affluent can buy anything they want, including advanced medical care.) Across the U.S., the health status of already-poor families and children begins a rapid downward slide. Behavioral choices worsen. Fast food companies make record profits as cheap food beckons. Among the poor, obesity and a suite of common, preventable diseases increase and spread at accelerated rates. Some of these diseases affect everybody, regardless of income. In 2020, a measles outbreak closes 20 percent of all schools in the U.S., due largely to lack of funding for immunizations and a resultant general population decrease in immunity.

Underfunded hospitals also struggle. Many hospitals (including children's hospitals) close, while others accept only a limited number of Medicaid patients. With little discretionary budget spending at the federal level, government support for medical education and training gets cut by 50 percent. As a result, there are fewer doctors in general — and many fewer pediatric specialists. Most of the public hospitals that remain open expand their ER facilities, which now run 24/7 triage at overflow capacity. Medical technology advances continue, but access to their benefits is limited to those who can afford such care.

There are bright spots. Churches and other identity-based organizations step up in their communities to help where they can, pooling and redistributing the financial generosity of members with means — and the volunteer hours of those either with means or without. Indeed, volunteerism is on the rise in this world, with the unemployed and elderly taking a leadership role in helping where they can. Philanthropy and civil society also work feverishly to help out where families, the state, and the market cannot. For all, the battle to help Americans stay healthy and well runs straight uphill. By the mid-2020s, life expectancy and birthrates in the U.S. have decreased, and infant mortality is on the rise. By 2032, the private sector is the home of innovation and research; with no discretionary budget left, the NIH closes its doors.

Downward Spiral: A Day in the Life….

*What would it be like to live in this world? Below, get a glimpse of what life in **Downward Spiral** looks like for our five "characters."*

- **JASON** — Jason needs a new wheelchair, but there's little chance that he'll get one. His family has become part of the "middle class slide." After being out of work for six months, his dad finds a new job that is stable but comes with a much lower salary and far fewer benefits. As a result, the family can't afford specialized care and education of any kind for Jason. His mom now stays home with him full-time, becoming Jason's therapist, tutor, and care coordinator. Jason lies awake at night listening to his parents talk out their worry and stress. The toll of constant care — and navigating complex systems to try to find answers to questions about Jason's health and best options — is weighing them all down.
- **NATALIE** — Natalie's family situation deteriorates even further; so does the health status of most of her family members — including, for the first time, Natalie herself. She develops a deep, hacking cough that she tries very hard to keep from her dad and her grandma, because she knows they can't afford to take her to the doctor. Her father's heart problems also worsen, and he is unemployed. Natalie is worried and fearful of what will happen to both herself and her father.
- **ACME CHILDREN'S HOSPITAL** — Every department struggles to care for the steady stream of patients coming through the doors — but with increasingly limited resources. Continual funding cuts have forced the closure of the hospital's east wing, as well as its two community outreach clinics. Services like Child Life and chaplaincy are eliminated. With every dollar funneled into basic medical care, it's hard to imagine how the hospital can operate at anything but a loss.
- **JOSÉ** — José spends more time searching for new sources of funding than working on research in his lab. With virtually no government funding for basic science available — and with the NIH, once his lead funder, no longer offering any grants at all — José finds himself competing instead with thousands of researchers working to secure grants from private donors and funders. He also observes, with growing alarm, that the pace of basic science research has slowed down appreciably.
- **NORA and HERBERT SMITH** — The Smiths' email inboxes fill up daily with dozens (sometimes hundreds) of new and urgent requests for funding from hospitals, researchers, and health clinics. The Smiths used to fund some of the most cutting-edge medical research and treatment in the world. Now they fund emergencies, not innovation. Their philanthropy is focused on doing what they can to help their local hospital and research facility keep its doors open.

The Aspen Children's Forum: Exploring the Strategic Implications of the Scenarios

In July 2012, about 350 people congregated in Aspen, CO, for the anchor event of this process: the *Aspen Children's Forum: Investing in Children's Health and Well Being.* Sponsored by the Aspen Institute and the Woodmark Group, the event was organized around two key questions: What would the world look like if children were truly put first? And how might we get there? The scenarios served as a platform for exploring — and beginning to answer — these questions.

One factor making this gathering unique was the composition of its audience. Nearly half of Aspen participants were "transformational philanthropists," that is, individuals or families who make significant financial contributions to children's hospitals, by far the largest block of philanthropic dollars invested in children's health. These philanthropists were joined by dozens of representatives from children's hospitals across North America, as well as a host of leaders in various key aspects of pediatric health, education, athletics, digital games, and garden and playground design. Each member of this highly diverse group brought considerable knowledge and expertise to bear on the Aspen conversation.

Over the course of two and a half days, participants were asked to imagine ways in which healthcare delivery, research, technology, public policy, and popular culture could be harnessed — perhaps even in completely new ways — to achieve the goal of advancing the health and well being of children. Plenary panels and breakout sessions were led by philanthropists, scientists, policymakers, and healthcare practitioners alike, which served to ground the conversations in the day-to-day decision-making of those who might ultimately implement a children-first agenda.

The Forum's dozen or so breakout sessions were designed to help participants engage with the issues at a deeper level and to generate fresh thinking about what the future of children's health and well being might look like. Session topics ranged from recent clinical breakthroughs and the promise of genomics to next-generation pediatric training and the benefits and risks of sports and play. Three of the breakouts were scenario-based working sessions in which participants explored the scenarios' strategic implications: what would need to be done in each — or in any — future to ensure that the health and well being of children becomes a top priority? Each breakout session focused on one of three tracks:

- **Diagnostics and the delivery of care**. What would a children-first approach to diagnostics and the delivery of care look like in each scenario?
- **The research agenda**. What are the key challenges and opportunities for children's research in each scenario, and what might a children-first research agenda look like?
- **Healthy living for children.** What happens to popular culture — and how is "healthy living for children" defined — in these very different futures we may inhabit?

Within each breakout, participants divided themselves into four small groups — one for each scenario — to explore the scenarios along each of these tracks. What are the challenges and opportunities facing families and key players in each scenario? What would a children-first approach look like in one future versus another? What would our philanthropic, public, and private investments look like, and how would we collaborate across sectors toward a common goal? And where and how might philanthropists, children's hospitals, policymakers, and others have a significant impact on moving society toward a children-first world?

Strategic Implications *Per Scenario*

Participants in the Aspen breakout sessions began by considering the strategic implications of and for each individual scenario. Below is a summary of the scenario-specific implications that emerged from these sessions.

Competing for the Future

- The provision of healthcare would be **market driven** and **outcome oriented**. Specialized care in regional hubs would become the most fiscally effective approach, but this would also increase regional disparities. Non-hospital partners would pick up the role of general care.
- We'd see more **"venture philanthropy,"** where the core tenets of finance and business management get applied toward philanthropic goals. Philanthropists would look for opportunities to leverage their resources, knowledge, and influence; they'd also provide entrepreneurial seed money — investing it where it might have the greatest impact — and be a nonprofit-motivated voice helping people make better choices.
- The healthcare research agenda would become **more corporatized**, as brands align themselves with chosen wellness campaigns. (For example, Pixar might sponsor an anti-obesity campaign, giving 30 percent of its ticket revenue to obesity prevention and research.) Companies might also invest back in communities in different ways, playing a bigger role in local decision-making: "What type of children's hospital do we want in our community?"
- Diseases **that affect the most people** would attract the most research money.
- The problems of **the disenfranchised** would increase. Interestingly, the self-employed would become a new group of the disenfranchised in this scenario. With health savings accounts (HSAs) as the dominant form of "insurance," a catastrophic disease diagnosis could spark instant bankruptcy.
- Basic research would continue to be a hard sell. But without basic discovery, real innovation and breakthroughs would lag. A more community approach to basic research might kick in. **Public-private partnerships** would form around research, which would require a broader net and focus to bring in more players and content.
- Who would drive the market? **Mothers or primary caregivers** — no matter their socioeconomic status. Amid an onslaught of choices and information, services that help caregivers navigate the healthcare marketplace and make the best and healthiest choices for their children would thrive.

One Village

- We'd see a tremendous **national culture change** — and the emergence of a nationwide, high-level strategy for navigating everyone toward the new priorities. A flurry of new kinds of child-focused care and services would emerge along the whole spectrum of care, from hospital to home. There would also be great emphasis on prevention — specifically, stopping childhood health issues from becoming problems into adulthood.
- With vast new resources focused on prevention, there would be less need to create expensive new acute care facilities. While children's hospitals would offer a greater range of services, they might also find they have **too many beds** because fewer children require hospitalization.
- A sense of **civic responsibility** would still be important; an environment of ample government funding wouldn't preclude that. But grassroots initiatives would be less necessary in this scenario and possibly difficult to get off the ground.
- Previously standalone services for children — health, nutrition, education, etc. — would become **integrated**, and roles and responsibilities would shift and blur across once-formal boundaries. Community-based programs and activities — including after-school programs — would join in the integration, becoming key venues for health and wellness education.
- There would be opportunity (and funding) to **study what has never been studied before**. We'd see new research into how social, biological, economic, environmental, and other factors impact children's health and wellness; new explorations into treatment options for children with special needs; and more opportunities to focus on global challenges for children, e.g., in developing countries.
- Philanthropists would be **innovators rather than fixers**. Private philanthropy could take a leading role in shaping the direction of the children's health agenda and funding the dissemination of good research.
- Policymakers would be free to **"think big"** and create programs with broad and long-term impact. They would also be instrumental in setting national parameters and ensuring that children's health and well being remain the country's top priorities.

Grassroots Renewal

- **Philanthropists** would primarily back initiatives that had broad-based support and real energy behind them; some may even make the existence of networks and coalitions a precondition of funding. Philanthropists would also become deeper partners, playing multiple roles (funder, advocate, policy influencer, etc.). They may even help create intellectual capital markets — "markets of ideas" — that help mitigate the risks of these investments.
- Local and regional grassroots organizations and movements would mobilize a broad spectrum of citizens — parents, elders, teachers, doctors, youth, the unemployed, among others — to address vital needs. Community participation could become a larger part of people's lives, resulting in **a more engaged civic society**. Some localities might create "community dashboards" to hold themselves collectively accountable.
- How would nonprofits and companies stop competing for scarce resources? For many, by forming **collaborative networks**. Leaders at all levels and in all sectors (government, hospitals, towns, nonprofits, etc.) would need to act as connectors of ideas, people, and organizations in order

to maximize impact and learning. Local government could serve as a connecting mechanism, working to share and scale successful projects and best practices.

- The overall **learning cycle** — for foundations, universities, hospitals, etc. — would need to become shorter and quicker, especially given the fragmentation of the research agenda at the national level. (Basic research would be underfunded and minimized, which in turn would force regionalization and consolidation.) Rapid evaluation, iteration, and dissemination of clinical outcomes and research would be critical. Even without funds, government could take a lead role in helping to set national agendas for research.
- **Children's hospitals** would think globally but act very locally. Most would specialize, becoming focused nodes in larger regional networks. Depending on the strength of the networks they belonged to, some would find strong funding, while others would struggle. Other hospitals might become "hospitals without walls," serving as central community health nodes and offering not just care but education, school nutrition curricula, etc.
- Why do we assume that health is dependent on a growth economy? Why can't we have a health **model that *isn't* dependent on growth?**

Downward Spiral

- This world would feel like **a return to the 1930s**. Families and communities would be forced to develop greater self-reliance, prompting increased volunteerism and self-help. Food banks, churches, and local organizations would become critical community anchors. Backyard gardens would pop up, so that families could feed themselves. We'd see a return of localized barter systems as well as more reliance on midwives and nurse practitioners. Small, localized "villages" might even develop.
- **Children's hospitals would be inundated** but still wouldn't turn people away (though some might consider changing their policy of "serving all"). Their services would become less centralized, moving out into communities in order to deal more effectively with escalating demand. Basic services would be increasingly available in communities through mobile clinics.
- Philanthropic giving would become more **strategic, targeted, and creative**, focused primarily on addressing immediate and short-term needs. Philanthropists would also play a larger role in setting the healthcare agenda, becoming leaders in rallying crisis funding and encouraging corporations to give more, especially at the clinic level.
- There would be more opportunities for **small businesses** to innovate cheap, scalable solutions. More low-cost products would come to market — and create new markets. Drug development could move away from big pharma and toward creative boutique startups.
- The intense focus on cost savings could create opportunities to develop more efficient systems, as well as to **de-fund legacy programs**, services, and research that haven't shown strong results. However, such de-funding could also cause public backlash, even giving rise to an "Occupy Healthcare" movement.

Strategic Implications *Across All Scenarios*

The breakout groups then spent time looking across the scenarios for key themes: what strategic implications would hold true in all four future worlds, not just one or two? During these conversations, some clear patterns emerged. Ultimately, the groups identified several systemic changes that would either naturally *happen* or *need to happen* in order for a children-first agenda to be achievable, no matter which world — or combination of worlds — were to unfold. One of the most important implications that emerged across all scenarios was the need for a coordinated, comprehensive effort to elevate the priority of children.

- In every scenario, we'll see more **community-level and ambulatory healthcare models**. This means more health care being provided in clinics, schools, storefronts, and homes, and through mobile outreach. The health system will also move toward a more virtual system with less and less physicality, as the practice of telemedicine spreads. Eventually, only costly or complex treatments will take place in hospital settings. We need to decide what these new models should look like, and proactively design, experiment with, and implement the most promising.
- **Innovation and invention** will be critical no matter what future unfolds. Similarly, the future will be information-rich no matter what — although how that information gets distributed and used will vary across scenarios. In each scenario, innovation is not an option, it's a necessity — though the nature and direction of that innovation will differ. Our opportunity to influence that direction begins now.
- **Strong families and strong communities that rally around the support of children** will be required under every scenario. This means that both levels of responsibility will need to be evoked and inspired through the children-first agenda that we establish. For such an agenda to ever take hold, a major cultural shift will need to take place, nationwide. As one participant put it, "There has to be a fundamental change in the way our society values our kids."
- The **definition of children's health** must be expanded to take into account the whole child. Understanding the whole ecosystem of influences on a child's overall wellness — including their socioeconomic status, the quality of their learning and play, their support systems, etc. — needs to become a standard component of pediatric assessment and treatment. In order to make this happen, our vertically integrated system need to become more *horizontally* and more *longitudinally* integrated as well.
- In any future scenario, philanthropists will practice a **different form of philanthropy** — one that is much more proactive and participatory — than in the past. They'll play a critical role in advancing cross-sector partnerships to fill gaps in the healthcare system. Their funding choices (especially the choice to fund networks and collaborations over single institutions) will have the capacity to shift the children-first agenda forward.
- Elevating the health and well being of children across the U.S. — and for all generations to come — will require an entirely new kind of **cooperation and collective action.** We'll need new kinds of cross-boundary collaboration — not just between children's hospitals but among hospitals, researchers, philanthropists, corporations, foundations, educational institutions, government, venture capital funders, and others. The responsibility for promoting and enforcing that agenda must be shared across sectors and silos.

- Children's hospitals will need to be **aligned around research.** We need integrated data systems, analytics, and metrics for pediatric research, as well as nationwide data repositories accessible to all physicians and researchers. We need smart maps that show us which diseases are occurring where, and genome-wide association studies targeting children's illnesses — and all those data need to be shared. We also need to invent learning systems that allow all parts of these networks to learn very rapidly from one another. And we need to make rigorous evaluations a requirement; otherwise, we won't learn what works and why.
- The question of **leadership** — who leads the kids-first agenda? — will be an issue whether resources are abundant or scarce. In different scenarios, different actors would pop up to serve as strong guiding voices — mothers, philanthropists, government, free enterprise. But if we're setting a children-first agenda proactively, we need to create that leadership in advance — right now — rather than wait to see how children may or may not get prioritized.

A Call to Action — Starting a National Movement

At Aspen, it quickly became evident that the appetite for transforming the shape and state of children's health and well being among the individuals engaged in this process was enormous. As the Forum drew to a close, one big question loomed: how might this group capitalize on the collective insights arrived at through the scenario process — and convert their shared energy and enthusiasm into a movement to put children first?

Throughout the Forum, participants and panelists had talked primarily about "creating a children-first agenda." During the closing plenary session, that language shifted — importantly — to "starting a national advocacy movement." This change in terminology reflected the heightened sense of urgency — and the expanding sense of possibility — that emerged during the course of the gathering, and strongly signaled the true scope of the group's ambition. Participant and philanthropist Anne Bass may have captured it best with these words:

> *"We need to take our collective wisdom, excitement, and dedication toward children's health and focus it more broadly into some kind of national movement…that would [put] the voice of children first. It would need to have the power and commitment of entities like the National Rifle Association (NRA), in terms of their reach toward legislatures, and the AARP, which is another very effective organization. I think we need to create something that is so effective that lawmakers would ignore us at their peril…. We need to take the collective ideas from this conference and move out aggressively and actively to promote children to the best of our ability and in the best way we can."*

While it was not the primary focus of this gathering, participants and panelists alike began to talk through some of the key elements of such a movement, based on the insights gleaned from the scenario process.

- **Transformational philanthropists are uniquely positioned to lead this movement.** This was one of the key strategic implications that emerged from the scenario breakout sessions. In addition to financial contributions, philanthropists also bring to the table considerable entrepreneurial spirit, experience, and influence over our government and society. As panelist Susan Packard Orr, trustee of the Lucile Packard Children's Hospital and the Lucile Packard Foundation for Children's Health, put it: "When philanthropists step up into leadership roles, we have a much broader impact on our colleagues in the sector and beyond. We need to come together with our collective power on this issue; we need to step up as leaders and make something happen, because we really are the ones who can put children first." Added philanthropist and panelist Cindy McCain: "Philanthropists have an incredible voice. Collectively, philanthropy as a whole could change policy."

- **Children's hospitals could play a strong leadership role.** Children's hospitals, panelists pointed out, are more networked than general hospitals — and pediatrics is significantly less siloed than other medical specialties. Plus, these hospitals already enjoy both high visibility and broad reach within their communities. "Children's hospitals are deeply valued in their communities and serve as learning laboratories for how to really engage in the health of the community," said panelist Philip Pizzo, MD, dean of Stanford School of Medicine. Panelist Alan Guttmacher, MD, director of the National Institute of Child Health and Human Development, added: "Children's hospitals are trusted, valued members of the community that bring along with them the wisdom, the energy, the creativity of their trustees and the philanthropists who support their work. That kind of energy — that kind of ability — is something we can really galvanize."

"Philanthropists have an incredible voice. Collectively, philanthropy as a whole could change policy."
— Cindy McCain, Philanthropist

- **The movement needs a simple, clear story.** "We need to tell our story in a meaningful way that can influence policy," said Orr, adding that children's causes and campaigns are often high on sentiment but low on the ability to convert that sentiment into real dollars, decisions, and policy actions. Guttmacher added that the movement's core tenets needed to be specific — not broad: "We need to get very granular, then build messages against that." The movement would also need to have one unifying voice — a "collective voice," as Pizzo put it — as well as a shared plan and a shared sense of prioritization.

Since the Aspen Children's Forum concluded, a number of steps have been taken to capitalize on the meeting's momentum and advance the work that began in Colorado. Those united in these efforts continue to strive toward the same, audacious goal: to catalyze a movement that will bring about a world in which political leaders consider the implications for children of every one of their policy choices; in which children's hospitals, philanthropists, and other stakeholders use their collective wisdom and power to ensure that no child is denied the opportunity to be healthy and well; and in which all children come to sit at the center of our culture and its systems — and never again at the periphery.

"When philanthropists step up into leadership roles, we have a much broader impact on our colleagues in the sector and beyond."
— Susan Packard Orr, Philanthropist

In the meantime, the scenarios shared in this document continue to generate and inspire fresh insights into both what is necessary and what is possible for children to truly come first. Those involved in this process look forward to the work ahead — and to further broadening and deepening the collective conversation about the future of all children.

Those interested in learning more about this process — and how they might participate — can contact David Alexander, MD, president and CEO of the Lucile Packard Foundation for Children's Health (david.alexander@lpfch.org).

Appendix

Interviewees

- **David Alexander**, MD, President and CEO, Lucile Packard Foundation for Children's Health
- **Alan Guttmacher**, MD, Director, National Institute of Child Health and Human Development
- **Neal Halfon, MD**, Director, Center for Healthier Children, Families, and Communities; Professor, UCLA, departments of pediatrics, health sciences, and policy studies
- **Paul Kershaw**, Associate Professor, University of British Colombia, Human Early Learning Partnership
- **Arlene Leibowitz**, Professor of Public Policy, UCLA School of Public Affairs
- **James Mandell**, MD, CEO, Children's Hospital Boston
- **Patrick McCarthy**, President and CEO, Annie E. Casey Foundation
- **Susan Orr**, Trustee of the Lucile Packard Children's Hospital and the Lucile Packard Foundation for Children's Health
- **Sara Rosenbaum**, Professor of Health Law and Policy, School of Public Health and Health Services; Director, Center for Health Services Research and Policy, George Washington University
- **Sterling Speirn**, President and CEO, W.K. Kellogg Foundation

Scenario Development Workshop Participants

- **David Alexander**, MD, President and CEO, Lucile Packard Foundation for Children's Health
- **Diane Bernstein**, Emeritus Board Member, Children's National Medical Center
- **Diana Goldberg**, Board Member, Children's National Medical Center
- **Olivia Golden**, Fellow, Urban Institute
- **Alan Guttmacher**, MD, Director, National Institute of Child Health and Human Development
- **Neal Halfon**, MD, Director, UCLA departments of pediatrics, health sciences, and policy studies
- **Jennifer Howse**, President, March of Dimes
- **David Karshmer**, Special Advisor, Collective Invention Inc.
- **Michael Lu**, MD, Associate Administrator, Maternal and Child Health, HRSA, Department of Health and Human Services
- **Kurt Newman**, MD, President and CEO, Children's National Medical Center
- **Ashlee Rea**, Program Officer, Aspen Philanthropy Group and Global Philanthropy Forum
- **Norman Rosenblum**, MD, Professor, departments of pediatrics, physiology, laboratory medicine, and pathology, the University of Toronto
- **Pam King Sams**, Executive VP and Chief Development Officer, Children's Hospital Foundation, Children's National Medical Center
- **Peter Schwartz**, VP of Global Relations and Strategic Planning, Salesforce; Cofounder, Global Business Network
- **Jane Wales**, VP of Philanthropy and Society, Aspen Institute; Founder and CEO, Global Philanthropy Forum
- **Eileen Walsh**, VP of Programs and Partnerships, Lucile Packard Foundation for Children's Health
- **Mark Wietecha**, President and CEO, Children's Hospital Association