



**Charles Homer MD, MPH, Keynote Speech at the  
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Thrive. Honestly, it is a pretty ironic theme for us to have chosen in 2009. We choose our themes a year or so ahead...and if you look at where we were a year ago, and where we are now, the change is breathtaking....

When I turn on the radio or check the Times online these days, “thriving”—prospering, succeeding—is not what I am hearing. Rather, it is surviving—getting through. Avoiding bankruptcy, staying out of foreclosure.

Keeping alive and viable until these tough times turn around is what I hear and what I read.

Even we in this room are not immune from these fears—yes, these are fears, and they are very real. Leading up to this meeting, I asked many of you, and many like you who traditionally attend this conference, what was on your mind. The first, second, and third thing on all of your minds was not prospering, not succeeding, not your dreams of a better future, but surviving...will I still have a job?, will I still have a program?, will the activities and services I’ve created be sustained. For a few, it was will my patients still have housing or enough food to eat.

And of course, we at NICHQ are not immune, either. We, too, have been affected by the turbulence in the economy, reflected here by the many of our colleagues who could not attend due to strict travel restrictions.

Now Newsweek magazine and others may tell us that some level of stress is not a bad thing—it keeps us focused, keeps us motivated, helps us respond and learn. But pervasive, recurrent high levels of toxic stress are harmful to the developing brain, and are harmful to all of us. Early on, shortly after starting NICHQ, I wrote a note to myself about lessons on leadership—and one of the messages to my self was “ More action (less fear)—what is the worst that can happen?” Because fear narrows our focus, restricts our possibilities, it creates tunnel vision. That’s what Roosevelt meant when he said the only thing we have to fear is fear itself...it is that fear lowers that sense of possibility.

Even when I asked many of you about your hopes, even then I could detect fear creeping around the edges and restricting possibilities. So despite our having

a new Child Health Insurance Bill with significant resources for quality measurement and demonstration programs....rather than a hallelujah, I hear “is it enough—and will they forget kids in health reform”? Even though we now have billions of dollars for health IT—more money than anybody working could really have imagined even a few months ago, I hear not hosanna’s but, “will it work”?

This reminds me of how it used to be in Boston when the Red Sox were in first place in July—you could take no joy, because you knew they would be behind the Yankees by Labor Day; even worse, if the Sox were beating the Yankees in the 8<sup>th</sup> inning of Game 6 of the playoffs there was no joy, because you knew Derek Jeter would be celebrating soon with champagne. But –thankfully—those painful days of fear are now gone!

We can’t imagine success, prospering—never mind the second, the true definition of thrive that we are seeking—vigorously flourishing—while wearing the narrow blinders of fear. No. Our task is to acknowledge fear, but then to move

beyond it, reject it, remove the blinders. These are tough times and our timelines for change may alter, but our ultimate vision and destination are no different now than they were a year ago. We must stay alive to possibility because we are committing ourselves to helping our children thrive.

So, how?

Recently, one of my dearest friends lost both of her elderly parents within ten days of each other. When I spent a few hours visiting with her, she showed me pictures gathered over nearly a century—pictures that tell a story, that give us hope, that point the way forward.

Her father, Rafael, a Jew, was drafted in the Polish Army.

He fought against the Russians, was captured and shipped to do hard labor in Siberia. Eventually he travelled back through central Asia and—after finding no survivors of his own family—ended up in a displaced persons camp.

Her mother, Ada, was captured by the Nazis and spent much time in the death camps. She survived—unlike the rest of her family—only because she worked in Schindler’s factories. After liberation, she, too, went to the displaced persons camp...where she met Rafael and they married.

Talk about tough times, about times when hope might well be abandoned and fear certainly should have restricted possibilities for a long, long time. In the scrap book that Ada prepared for Rafael for their fiftieth anniversary there was a sequence of pictures that riveted my attention.

The pictures of a steamship coming past the Statue of Liberty, of survivors embracing on the ship, and most moving to me, of them looking out at what awaited them.

And what awaited them—embodying the hope and opportunity of America in 1948--was embodied in words written on the margin of the snapshot “and they welcomed us with music.”

And they welcomed us with music.

It is not just celebration that the music represented, but that through music, “they” and “us” were joined TOGETHER. As the definition says, into or in one gathering. Into or in unity. Ada and Rafael, *together*, supported by their fellow survivors, *together*, in their new community, *together*, --aided, no doubt by a healthy dose of resiliency—were able to sustain their hope, to prosper, and to enable their daughter to thrive and to see their grandson Jeremy—now 16—also thrive, now, amazingly, on a high school robotics team. And, to bring the story full circle, Jeremy’s team coach says about the Robotics work, “The whole thing is about sharing and working *together*.” He gets it. That’s how we will overcome fear.

Our goal—the goal of our conference and of all the work that the National Initiative for Children’s Healthcare Quality does—is to help children thrive...our mission is that we improve child health and well being-- by improving the systems

of children's health care. Our vision is a world in which all children receive the health care they need – to lead lives that will enable them to flourish vigorously.

And it is our being together, and our working together, that will get us there.

Much has indeed changed since last year .

Last year, in order to put you in the frame of mind that America could be the best place for children in the world, I had to ask you to imagine travelling forward a dozen years into the future and looking back on what it took. ] And I articulated what I imagined it would take to get the political will to accomplish this---

- an economic crisis that would motivate middle class America to act to expand health insurance coverage (check),

- a growing awareness of the obesity epidemic that would spur investment in prevention (check), and
- a president willing to expend political capital to make changes in our health system and advance the health of our children (check).

That in itself is a lot of change—good change, positive change, opportunity out of crisis change—to take place in one year.

Last year I talked about the good ideas for what a better health system would look like—the key components—and the key supports we would need to accomplish them. In the 12 months since, others have issued their reports and recommendations, adding their voices, creating a groundswell that is striking in its consistency, reinforcing the major themes I mentioned a year ago, themes now echoing in the senior levels of government. If you look at the Priorities articulated by the National Priorities Partnership, or the Roadmap issued by the Commonwealth Commission on High Performing Health Care, the major

conclusions from the Mayo Clinic, the vision articulated by Governor Kitzhaber at the IHI Forum and the Triple Aim framework of the IHI and the Blue Sky vision from Neal Halfon and Helen Duplessis, there are great, great similarities— together: Into or in unity, In cooperation-

What are the common elements of these approaches?

- First, provide universal health insurance coverage. Not nearly universal. Universal.
- Second, strengthen our system of primary care, adopting the framework of the medical home, the healthcare home, the child and family health home—you choose the term.
- Third, emphasize prevention more than we do now—both clinical prevention, such as effective counseling and use of immunization--and community prevention-- using health impact assessments analogous to

environmental impact assessments, incentives for greater availability of healthy foods, tobacco taxes, public transportation, safe parks.

- Fourth, make care safer—our systems in hospitals and other health care settings must be redesigned to reduce and ultimately eliminate medical harm.

The key building blocks to get to these aims are also clear.

Achieving these four elements will require us to:

- Reform our payment system to reward improved population health and better clinical care. Payment should also be guided by the evidence about what works and what doesn't—subject to the important limitations in the quality of evidence now available for many pediatric decisions.

- Engage deeply with families. The goal of all the system changes must be to support the capabilities of families to provide care and to make informed choices. And families must be involved in making all of the changes.
- Use effective health information technology and
- Create widespread capability in quality improvement

NICHQ has a strong record of accomplishment in all of these areas.

Our two national Medical Home learning collaboratives helped transform practices and build state systems in more than 22 states.

Our obesity work spans both clinical prevention—helping you counsel more effectively—and community change—giving you the tools and skills to change your communities.

Our helping organize and then work with the pediatric affinity group in support of the 100K and 5 million lives campaigns together with the strong safety component of our annual Forum, has made children in our country safer.

Our Health Affairs report on the business case for quality—building on work from our Bergman award winner Paul Kurtin—highlighted the lack of a consistent business case for quality for providers making such investments under our current system.

Parents are faculty in all of our work; we have created for the first time a family partner committee to advise this Forum, and we have expanded both the numbers of parents and offerings for them throughout this event.

We just published the papers from our conference on the potential for Health Information Technology to improve the quality and efficiency of children's health care.

Our work with the federal Maternal and Child Health Bureau and State Title V—Special Needs Programs has built quality improvement capacity in over twenty state public health departments—often working with their state AAP chapters—to undertake improvement in support of medical home, specialty access, and other elements of an improved system of care. Our new work with the Autism Treatment Network is helping to create a system with similar capabilities to the CF foundation to improve care and outcomes. Our work with state Medicaid systems in Ohio and NY to improve perinatal care is directly addressing the capabilities of state Medicaid agencies, in concert with CMS, to support improvement, and our collaboration with the Vermont Child Health Improvement Program’s improvement partnership as reflected in their holding their annual meeting in conjunction with ours is another way that we are building widespread improvement capacity.

But let me add that I have a personal reason to be passionate about creating medical homes. let me tell you a story, not a pediatric story, but a story about my now very old 85-year old father.

My dad grew up in Philadelphia. After residency, and a stint in the Army, he started a primary care practice of internal medicine in small town New Jersey...not a prestigious career track for a top student in an Ivy League med school, even then, but my Dad loved his work. He worked hard—up before six to round at the local community hospital; staying in the office through the evening hours they had most weeknights and on Saturday, too.

We lived above the office—Dad called upstairs whenever the light fixtures shook too much from his three boys jumping on the bed above the waiting room. His diagnostic skills were legendary—his reputation cemented when he flew out from NJ to Hawaii and diagnosed my uncle with a dissecting aortic aneurysm, saving his life.

And my father balanced his life with hobbies—renowned as a gardener, appreciated as a fisherman.

My first job was filing X rays in the basement. A little later I worked in his lab, taking EKG's with that goeey cold jelly and the suction cups on the chest, spinning hematocrits and doing manual white blood counts. In the morning, I'd hear him take X rays—"take a deep breath, hold it, let it out." In the evening, I'd sit in his office and listen to him calling back his patients with test results and consultant information.

When I first went into the work I do now, my parents didn't get it...health care was good enough, they said—look at what your father did his whole life; I was just contributing to the cost of overhead, I heard my Dad once say. But that has changed.

We don't know, really, what my father's diagnosis is, what is causing him the chronic pain, smooth muscle dysfunction affecting bowel and bladder, autonomic

instability, mood problems that now limit the quality of his life so drastically. It's no small irony that even with his three sons being doctors, we don't really know.

What a perfect situation for a good, comprehensive, multidisciplinary medical home team—where the team can prioritize needs . Where they can coordinate specialty care and provide support and guidance during hospital stays. Where they can recommend when and how to involve other family members. Where they can arrange for home assessments and develop treatment plans that help reduce the anxiety and uncertainty of living with an uncertain chronic condition.

**This is the model of care that Cal Sia first designed when he came up with the concept of medical homes for children with special health care needs.**

But you know that this is not the health care system for most of us, including my father. His many specialists don't speak with each other, his primary care provider does no care coordination, there are no common treatment plans...creating an enormous burden on his caretaker—my mother. **Doesn't this**

**sound all to familiar to those of you caring for children with special health care needs?**

Now my parents rate doctors not by their diagnostic skill—as they did before-- but by whether they return phone calls or at least briefly discuss their treatment plans.. They chafe about the long waits in doctor’s offices, the brusque responses, the failure to follow up, the medications omitted when they transition from home to hospital or back. And while they don’t quite understand when I describe what we mean by medical home and integrated care, they know that I’m trying to fix the system that has failed them so miserably—and even if they don’t quite get what I do, they know and value what I’m trying to accomplish, because they know the health care system needs to change.

This is the story of one adult with special health care needs—one with insurance, one with three kids—all doctors-- who know something about

navigating our health care system. It should be as good as it gets, but instead it illustrates the need for high performing medical homes for all of us.

It is because my dad's experience is echoed by so many children that NICHQ has taken the adoption of a high quality medical home for every child as our single, overarching strategy goal for the next three to five years. In every program we do—whether it's improving care for children with epilepsy or follow up from abnormal newborn hearing, whether it is addressing the obesity epidemic or tackling the challenge of intergenerational poverty in Tulsa, Oklahoma, we will seek to promote the establishment of high quality medical homes that work in the context of an integrated care system—with close links to both community resources and specialty care. These program provide us the opportunity to develop and share best practices.

We don't have to create the best practices for us to help advance their widespread adoption. Since NICHQ's founding, we have helped identify better

practices so that you and others can adapt and adopt them. We have worked over this past year, with support from the California Endowment, to identify innovative practices across the state of California. We also learn about such programs through our call for abstracts for this meeting. You will see at this Forum example after example of health care delivery organizations that have developed better practices that you can emulate and learn from, and we will be highlighting such practices in our new e newsletter that you have been receiving.

As a result of what you learn here, you can:

- Reduce catheter associated blood stream infections in your neonatal intensive care unit
- Provide better palliative care for children at the end of life or for whom care and comfort is the goal
- Address obesity not only in mainstream, majority communities but in ethnically diverse and economically disadvantaged communities as well

- Better provide effective care coordination—so its not just an abstraction, but a real process that helps families.
- Establish and improve your medical home
- Create medical homes that address children’s mental health (B1)
- Improve access for children with uncommon medical problems—such as epilepsy—so they can get both technically expert and holistic care
- Engage families more effectively in improvement to achieve better results.
- Become more effective in sustaining and spreading your innovations – a topic that our national innovation advisory group thought was the most important of topic in the entire field of health care innovation to address.

These are practices that you can adopt when you go home and make care and outcomes better for children starting on Monday. I am asking you now—as I do most every year-- for a commitment: to identify a better practice here at this

meeting, to learn about that practice here at the conference and to find one other person here who can be your coach or partner, to take that thing home and to apply it in your setting, and to let us know how that worked. Please don't forget to find your coach or partner—it may be somebody else in the workshop or even the speaker—because remember, the way that we help children thrive, and we ourselves thrive, is to do it together.

As we have reflected on what we have accomplished at NICHQ and how we have gone about trying to improve the system of health care for children, we have realized that highlighting best practices and building system capacity are two critically important means to promote change. But we also believe these approaches of themselves are not enough to assure their widespread adoption and achieve the broad system change that is needed. We first learned this through our work in childhood obesity. Our initial work focused on demonstrating

what clinicians can do in their practices—how they can communicate more effectively and address obesity in the context of the medical home. Yet we found time and again our efforts to promote change in practice stymied by policies and practices that inhibited payment of clinicians for doing what we asked them to do—recognizing that providing health care being both a business and a calling.

So, with support initially from the Robert Wood Johnson Foundation and later from Nemours, we undertook policy analysis to identify current reimbursement policies and articulated a policy framework. Now we are working with AAP, NACHRI, and the Alliance for a Healthier Generation to identify the experiences of providers. And we will partner with these groups to advance the policies, together.

Moving to a broader stage, under the leadership of Lisa Simpson as our National Director of Child Health Policy, we convened in 2005 a conference on Medicaid and quality supported by AHRQ, and, when the SCHIP reauthorization

was coming near, with support from the Commonwealth Fund, extended and refined the analyses to they would apply to SCHIP. This work positioned us so that we were invited through the good offices of the MOD to participate in the child health quality work group with them, AAP and NACH.

Through our participation in that effort, we were part of a broad coalition that TOGETHER managed to include a significant focus on quality in what became the final Child Health Insurance bill.

And, although I stated earlier that there is broad agreement on what is needed in transforming our health care system, we also know that without concerted effort, the voice of children will not be at the table when the major policy changes around health reform are considered. We saw this in the negotiations around the stimulus bill, how at the first sign of pressure, many elements that were important to children—non-controversial items like building schools and family nutrition—were jettisoned in the face of minimal pressure. So,

NICHQ is committed to staying in and expanding our role in policy and advocacy. We won't do it alone—there are many professional groups—AAP and NACH, policy groups—National Partnership for Women and Families, First Focus, Consumer groups—Family Voices, March of Dimes, and advocacy groups--Voices for America's Children, New England Alliance for Child Health—with whom we will work TOGETHER. But our voice, the voice for children and families, the voice for a health care system that can and will give children the health care they need, will be heard. And to do this, we will need your help, in joining together with us as a strong and clear voice for better health care for children.(KEY message)

So, as you go forward from this talk and this conference in these hard and troubled times, I ask you to remember how Ada and Rafael together overcame far harder and more terrible times; together with each other, together with friends and community, together with a country that supported them, they were able to nurture children and grandchildren who flourished. I ask you to

remember my father, who committed his professional life to medicine and his patients, but who was failed by that very system because it is fragmented and oriented towards piece work. I ask you to use that memory to drive yourselves to build a system that cares for us as whole persons.

Let me also ask you to keep in mind another remarkable person, Sandra Clancy, who I just met with last week. Sandra is a truly inspiring woman. She told me how she was living the ideal suburban life outside of Boston, happy in her work as a professor of political science and in her home life with a caring husband and two wonderful children. And then, about two years ago, her elder child—Jack—started not to be himself—headache, stomach ache, tired. She brought him to his primary care doctor, but quickly ended up being referred to a tertiary hospital, in this case Massachusetts General Hospital in Boston. And, as is often the case for many children with complex needs, she ended up taking him to many different specialists—neurology and neurosurgery, GI, hematology. She was

struck on the one hand by their remarkable dedication and depth of specialized knowledge, and, on the other hand, by how they didn't speak with each other and nobody was able to put all the pieces together and consider him as a whole person, and how she, alone, was left with the worry and stress and trying to pull everything together. In her words, the doctors would tell her "I do heads, not stomachs." So, she—again in her words—used a sledgehammer—to get them all together, and through a joint conference, they were able, eventually, to come up with a diagnosis. I asked her about her primary care doctor and she said that he seemed afraid and really did not get involved in Jack's care or supporting the family after the illness began.

The story goes on. Unfortunately, despite now knowing what Jack had, the doctors and nurses were unable to save him and a short seven months after his symptoms first began, Jack died. And afterwards, she and her husband wrote a twenty five page letter to the then chairman of the department, both

acknowledging the wonderful caring and technical expertise of the clinicians who looked after Jack, and also detailing the immense challenges of navigating a complex system and the intense isolation of the experience. And the chairman—Alan Ezekowitz—to his credit met with her and then convened a task force to try to come up with a solution. Now they have set up a program that provides coordinated care for children with special health care needs—a type of tertiary care medical home, with a generalist physician, social work, access to psychiatry and special therapies, and, perhaps most importantly, a family advisor—Sandra Clancy herself. When I met with her, she remarked that the advantage she brought was that she was bilingual—she spoke parent and she spoke medicine—and could translate for each. And she described how she was creating educational videos for families, and working on hospital committees to change this massive institution.

And her final words to me, as we closed our discussion, with just a wonderful smile on her face and radiating positive energy, she said, ‘You know, human beings can get through just about anything—any kind of adversity—but they can’t do it, they shouldn’t do it alone.’”

So, In spite of the narrow blinders of fear that are lying in wait everywhere around us and perhaps within us, ready to isolate us with worry and concern, let us pledge today to “welcome each other with music, ” to create the uplift and resilience of community.

The theme of our Forum, Thrive Together, may seem ironic at first glance only when you read it in the order that it is printed. But If you reverse the words and emphasize Together, we thrive, there is no irony, only truth.

