



COMMENT

Howland Award Address 2018: responding to opportunities to improve child and family health

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I am deeply honored to be the recipient of the 2018 Howland award, and to share with you some observations about the evolution of pediatric medicine as I have experienced its growth over the last five decades. I will also share thoughts about what is needed to further advance health outcomes for children, youth, and their families.

Before I proceed to do so, I would like to thank Dr James Perrin for nominating me for this award. He has been a lifelong champion for children with chronic disease and it has been my privilege to partner with him on several programs that address better outcomes for these individuals and their families.

I would also like to thank my family for sharing this day with me, and for inspiring and informing my work over many years. In particular, I acknowledge the enormous influence that my wife, Dr Barbara Boat, a child psychologist, has had on my thinking and career orientation.

Finally, I wish to thank the many colleagues, collaborators, and contributors to my learning, as a student at the University of Iowa, as a pediatric resident at the University of Minnesota, as a clinical associate at the NIH, as a pulmonary fellow and faculty member at Case Western Reserve University, at the University of North Carolina where I was privileged to lead the Department of Pediatrics, at Cincinnati Children's Hospital Medical Center where I provided leadership for the Department of Pediatrics and the Research Foundation, in my work with various committees of the National Academies of Sciences, Engineering and Medicine, and in my work with many academic pediatricians in various pediatric organizations.

I started pediatric residency in 1966. A 52-year focus on child health has afforded career experiences that I never predicted, often presenting as unplanned opportunities. I initially gravitated toward chronic disease and subspecialty care, targeting the health of individual patients for the first several decades of my career, then realized, perhaps belatedly, that much of what must be done to improve health for children requires the development and continuous improvement of strong research training and health care systems. More recently, population-based attention to behavioral and social determinants of health has captured my attention. A belated epiphany was the recognition that what is needed to improve population-wide child health is also needed to improve outcomes for families of children with chronic disease. I will return to that point.

A brief recap of several personal career experiences will, I hope, provide insights into an ever expanding landscape of opportunities for improvement of child health. I will conclude by sharing what I see as the new frontier for pediatrics.

I had no community practitioner role models early in life, and reflexively followed the pathway of my heroes, the physician scientists who were making discoveries in the laboratory. My research training started during a year of medical student research, a research intensive residency where “experiments of nature” were part of the daily conversation, and 2 years of research training at the National Institutes of Health, where I was an office mate with two future Nobel Laureates. I was not in their league, but I did forge a research plan focused on cystic fibrosis pathophysiology that provided an opportunity to independently build a research program in pulmonary medicine. This experience opened doors to fellowship and faculty posts as a physician scientist. I did not go to the NIH considering a CF or pulmonary-focused career. In fact, pulmonology was a maverick pediatric subspecialty at that time, and was not on my consideration list. Two years of immersion in the world of cystic fibrosis care and research created a passion for improving outcomes for patients with chronic lung disease.

A word to those who are in formative career stages: sometimes choices are part of a plan, but many opportunities are not programmed. Stay open to opportunity, choose thoughtfully, and passionately create a path that can be focused and productive.

My research addressed the chemistry of human respiratory tract mucus and airway secretory biology using explanted human airway epithelium, a novel experimental approach at that time. The first book chapter I wrote was titled “Chemical composition of human tracheobronchial secretions”, in a book gloriously titled “Sputum”.¹ While not attention grabbing in the medical community, I was thereafter viewed as a resource by adult and pediatric pulmonologist alike. My research had good and problematic dimensions: good because very few others were curious about airway mucus, and NIH funding was quite generous. It was less than ideal because the technology was not yet ready to rapidly advance this field, whether at a molecular or a translational level.

Research challenges have flipped today. Technology makes addressing tough questions easier. Funding however, is more challenging to secure. Advancing a research career today demands thoughtful attention to both, as well as strong mentorship, a supportive environment and perseverance. Perhaps most importantly, today there is greater opportunity to address a broad range of research questions, not only in the laboratory but in the clinic. The science of translation has opened the door for investigators who are targeting new or improved diagnostics and therapeutics.

The second phase of my career emerged when I moved to a chairmanship role at the University of North Carolina. I gradually

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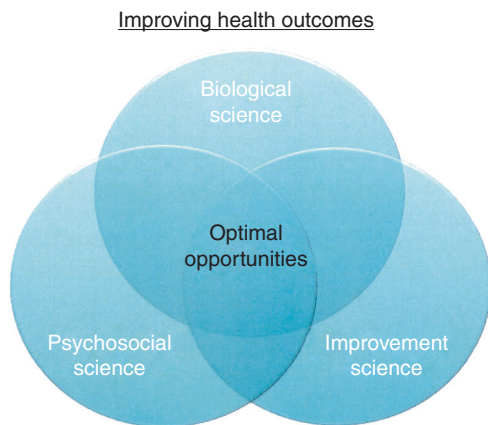


Fig. 1 Synergies among biological, psychosocial and improvement sciences

transitioned to a support and management role, not only for research but also for clinical and training activities. Although active as an investigator, my efforts in laboratory research largely played out in a guidance role for those at the bench. I found satisfaction and joy in helping others succeed in their careers. When I moved to Cincinnati Children's in 1993, my research-related activities by choice were entirely limited to the support of outstanding investigators such as Jeff Whitsett, who had demonstrated the importance of specific proteins for surfactant function and therapy and was unraveling the mysteries of normal and abnormal lung development, also recruiting the next generation of outstanding physician scientists such as Tom Shanley, program chair for this meeting. A key goal was to build the infrastructure needed to facilitate rapid research program progress. We created research divisions that were linked fiscally and programmatically to clinical divisions to accelerate translation. Innovations resulting from robust research drove better clinical outcomes, clinical program growth and the transition of Cincinnati Children's from a community-oriented to a national and international destination medical center.

At that time I also encountered alternative pathways to innovation. In the early 1990s I was asked to join the National Advisory Committee of a Robert Wood Johnson Foundation initiative, the Generalist Physician Faculty Scholar Program. I was a lone specialist on this committee but had previous experience with RWJ Clinical Scholar training, and connections with fellow advisory board members and bright young scholars, convinced me that non-biological dimensions of child health are also critical investigative targets. Some of the young RWJ scholars were engaging health services improvement research. Back home, coached by Dr Uma Kotagal and other quality improvement-focused faculty at Cincinnati Children's, I came to understand that outcomes of pediatric care are determined as much by how care is provided, as by what care is available. They deserve equivalent attention. This focus on continuously improving clinical service and creating family-oriented care also created a magnet for Cincinnati Children's Hospital, attracting families that valued care partnerships with health professionals.

As I reflect on these experiences, no doubt we live in a time of unprecedented opportunity to use biological sciences to advance diagnostic and therapeutic intervention. One only needs to read the current literature on the development of therapeutics for spinal muscular atrophy^{2, 3} or cystic fibrosis^{4, 5} to understand the potential to move from recognition of molecular pathways to molecular interventions. I am never more excited than when I attend a research seminar that recaps work illuminating pathophysiological processes and potential for precision interventions. At the same time, we also have opportunity to synergistically

transform health by more effectively implementing elements of health care improvement, including partnering with patients and families to better understand their needs and preferences. Future opportunities to rapidly improve child health outcomes, in my opinion, lie at the intersection of biological, improvement, and psychosocial sciences (Fig. 1).

It is the psychosocial dimensions of child health that have dominated my most recent reflections and efforts. In 2007, I was invited to co-chair an Institute of Medicine consensus committee that produced a widely read report, "Preventing Mental, Emotional, and Behavioral Disorders among Young People".⁶ I was reminded over and over that at any point in time 15–20% of children and youth are struggling with a clinically diagnosable behavioral disorder, that by 25 years of age 40% will have encountered at least one of these disorders. I learned that childhood behavioral disorders more often than not become lifetime problems. Half of all seriously disabled children whose families receive SSI benefits have a primary mental health diagnosis.⁷ Some have used the term "crisis" to describe the increasing number of children and adolescents currently diagnosed with behavioral disorders, including anxiety, depression, disruptive behaviors, ADHD, and autism spectrum disorders.⁸ Just as we know that adverse childhood experiences (ACES) and toxic stress have concerning neurobehavioral outcomes, we know that a safe, predictable, and nurturing environment in the first years of life foster healthy brain development and positive physical as well as emotional health.⁸ Unfortunately, too many children are disadvantaged by the family and community settings in which they are reared.

With others, I have come to understand that pediatric health care may provide the single best opportunity to promote healthy emotional and behavioral development early in life.⁹ We have always espoused promotion of health and prevention of illness for children. We are beginning to acknowledge that behavioral and physical health are interdependent and should not be segregated in the process of child health care. I view behavioral health as our new frontier, of course partnering with behavioral health specialists, but taking the lead for behavioral health promotion, risk prevention and early intervention for the less complex problem behaviors in childhood.

The American Academy of Pediatrics¹⁰ and more recently the American Board of Pediatrics in their call to action¹¹ have stated that we as pediatricians should take greater responsibility for the behavioral dimensions of child health. A challenge, as most of you know, is that pediatricians are not adequately trained to address behavioral health. Reimbursement for behavioral health care in pediatric practice also is a barrier. Our challenge is to create models of behavioral health care in clinical practice and provide evidence for their effectiveness in practice that compels changes in training and reimbursement.

A number of pediatric practice models address parenting knowledge and skills. One links parenting programs that have shown evidence for benefit in other settings to pediatric practices, a rationale being that enrollment in these programs will improve when participation is suggested by pediatric clinicians.¹² Another is to embed skilled parenting personnel in the clinic and train staff to be more supportive of healthy parenting. An example is the Healthy Steps program¹³ that has now been implemented in child health care sites across the country. A third model is a program in an inner city clinic run by Cincinnati Children's Hospital that provides equal time for the children and parents with a pediatrician and a child psychologist at well child visits, and connects family support to programs internal and external to the practice. Residents whose continuity practice is based in this clinic observe and then take supervised responsibility for the behavioral component of the well child visit. They give this experience high marks.¹⁴ A Stakeholder initiative sponsored by the American Board of Pediatrics and the National Academies has engaged Pediatric Department leadership to consider how behavioral

health training can be implemented beyond current training experiences. The importance of interdisciplinary training and practice for child health care professionals has been noted.¹⁵

Evidence is needed for what works in pediatric practice to promote behavioral health. Much of this work must focus at the family level. The traditional research approach has started with evidence-based program development in a single site, followed by intent to disseminate to other sites. This approach has too often not resulted in broadly implementable programs, and has not advantaged children at a population level. Rapidly growing implementation science offers opportunities for pediatric efforts to design scalable programs and broadly disseminate them.¹⁶

I also suggest that we pay more attention to Learning Networks such as Improved Care Now, spearheaded by Dr Peter Margolis and colleagues, that can drive multi-site care model development and implementation, collectively and continuously improving interventions using real world, real time outcomes data.¹⁷ This strategy has improved outcomes remarkably for patients with inflammatory bowel disease and has been adopted to address more than a dozen other clinically challenging childhood problems. Network learning and program implementation is getting increasing attention from academic centers and federal program and funding agencies.

Let me add that Children's Hospitals and pediatric programs can also catalyze increased levels of school and community support for children and families by providing critical, organizing leadership within the community.

I would like to advance a final consideration. Integrated and family-focused care is as important for subspecialty as for primary child health care. I am increasingly aware that more and more families do not have the resources, the physical and emotional stamina, or support from the health system to deal with the stresses of care for their child with disabling or life-threatening chronic disease. An extreme, but not uncommon example is low birth weight children who graduate from the NICU and eventually go home on a ventilator. There are 250 such families in the Cincinnati area. Parents are often hypervigilant and don't sleep very much or very well.¹⁸ Exhaustion and burnout are common outcomes. We know that these kinds of life stresses for parents provoke telomere shortening,¹⁹ and reduce lifespan,²⁰ promote psychosocial and physical health adversities, and limit parental caregiving capacity.

"As the family goes, so goes the child" is a phrase that is generally accepted, but too often forgotten in the process of rescuing children who have the most challenging disorders. We have expectations for strict adherence to prescribed therapies on the part of family caregivers, but too often do not support these individuals to do this, day in and day out.

My good fortune in stepping out the Dean's Office was being welcomed back to Cincinnati Children's Hospital. I was encouraged to lead a program of the Pulmonary Division that addresses family wellness in the face of a child with cystic fibrosis. We call the program CF WELL, WELL standing for wellness education and learning laboratory. We have assessed CF family needs and begun to implement a more responsive care model. We acknowledge the importance of emotional health and quality of life for families from day one of diagnosis. Improving family sleep, exercise and nutrition are lifestyle goals.

Helping families manage added stress, both general anxiety and situational stress, e.g., at the time their child's health declines, or managing their child's school experience when the school is not fully accommodating of their child's needs, is another goal. We have introduced mindfulness-cognitive therapy to the CF care team and shown that it improves provider empathy and ability to work in the moment with fewer anxious or depressive thoughts. We are poised to offer this intervention to families who sense a need. Will we improve family wellness and ability to meet their children's needs, as well as health outcomes? We intend to obtain

answers to these questions. Will what we learn working with CF families translate to improving quality of life for families of children with other chronic disorders. We think so and welcome efforts by other subspecialties to provide evidence for family benefit in other chronic disease populations.

A concern that is repeatedly shared by parents is that their child with extensive health care needs has benefited from excellent pediatric care, but no one has asked them "How are you doing?" Opening that conversation is a new opportunity for us, one that is being promoted by a current project, the Roadmap Project" that is led by Dr Carole Lannon, sponsored by the American Board of Pediatrics Foundation, and that has invited a spectrum of parents, providers, educators and disorder specific foundations to create guidance within the medical system that will advantage families of children with complex chronic disorders.

There is a perspective that I believe should serve pediatric care, education and research in its quest to continuously improve the health of children and families. The successes of neonatal and pediatric critical care, of better therapies for children with disability and life-threatening chronic disease, have swelled the number of children living with disabling conditions. Dr James Perrin has reminded us that the prevalence of function-limiting chronic disease in childhood has increased four-fold since the 1960s.²¹

Disabling and life threatening chronic disease represents as much as 3–5% of the childhood population.²² Cincinnati Children's Hospital has three times as many beds now as 25 years ago. Similar expansion of beds has occurred in most child health care facilities. Who fills these beds? In large part, it is medically challenging children with chronic disease. Who cares for these children the large majority of the time: it is not us: it is the family, at home.

We celebrate our therapeutic successes, and rightly so. Nevertheless, we need to pose a related question. Will we take responsibility for the unintended consequences of our successes, the added family caregiving burden? I hope the answer is "YES".

Big challenges and even greater opportunities lie in our future. It is my dream, my vision for 2025, that many more children experience healthy physical and behavioral development from the earliest moments in their lives, and that families thrive owing to the contributions of pediatrics across all dimensions of health. I am optimistic that, collectively, we can convert opportunities into healthier and happier children and families. Best wishes to all in within pediatric community in this quest.

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