Pioneers in Pediatric Psychology: Technology, Mentors, Collaborations, and Life Experiences in an Evolving Pediatric Psychologist

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Though I hardly think of myself as a “pioneer,” I suppose I need to admit to being an older and hopefully wiser member of the Pediatric Psychology family. As proof of the “older” part, I will recount a few observations related to the impact of technology on our practice, scholarship, and communications. Transitions from traditional medical models to interdisciplinary health care systems that integrate psychosocial care and family empowerment are highlighted to underscore how we all may have grown a little wiser. My most significant observations are also my most personal. The invitation to submit this piece has provided a precious opportunity to review the role that mentors and collaborative relationships have played in the development of pediatric psychology and in my life. I will also share personal observations from challenging chapters in our family’s life that defined my perspectives and priorities about health care, psychosocial interventions, trauma, and resilience. The net impact of my professional and personal experiences has been to be open to change—in perceptions, in practices, and in professional roles—and to feel some urgency about making our individual and collective efforts count.

Technology

As proof of my place among the dinosaurs, I date myself by sharing that one of my first psychology-related jobs as Dr. Al Finch’s research assistant in 1979 involved carrying our punched data and command cards six blocks from the Virginia Treatment Center for Children (VTCC) to the one building at the Medical College of Virginia, which held the one computer in the entire state-of-the-art medical complex. There I would pass our cards through the glass window’s small opening to the one team of men authorized to feed cards to the carefully guarded computer. If we really had priority and a good rapport with the gents behind the glass, we might get to see the printout from our run within a few hours. Otherwise we would come back the next day. If the printout showed an error in the run I would go back down to the bowels of the building to punch more cards and repeat the process.

I think of this not-so-long-ago era as I hear my graduate and undergraduate research collaborators sighing with frustration that their analyses on their portable laptops are taking “forever” (seconds and seconds), as we communicate with hundreds of partner parents of youth with special needs with the stroke of a key, and as I watch colleagues pulling up electronic records of a child’s full assessment and treatment history in an instant. The awesome capacity of this technology comes with greater need for ethical reflection and professional vigilance. Protecting confidentiality and other rights of vulnerable populations requires extra attention and concern when huge longitudinal data sets can be carried around in your pocket and “Reply all” is only a millimeter or so from “Reply.” Protecting research data sets and patient records requires a constant attention to detail and investment in security. Still our capacity to creatively apply new technologies to enhance treatment compliance, reach underserved populations, and put “treatments that work” into the hands of those who need them is to me one of the exciting developments in pediatric psychology.

I hope that the present readers will be more open to the potential roles of technological innovation than I was. I publically admit that one of my last acts as President of the
Society of Pediatric Psychology in 1996–1997 was to passionately object to the transition of our journal from Plenum Press, who had faithfully helped us build our print journal, to Oxford University Press, which stood poised to help us transition into the modern era of electronic publishing to include such “high tech” processes as electronic submission, reviewer access, and dissemination. Loyalty and our long professional relationship, I argued, should outweigh the “whistles and bells” of technology. It had worked perfectly well “snail-mailing” three hard copies for review. Right? How much better could electronic publishing be? Fortunately for pediatric psychology, I was outnumbered by people who could see the need for us to move with the times. We needed to harness the best means available to gather, critically review, and rapidly disseminate our scholarship to wide interdisciplinary audiences. You all were so right. You were also right that activating new technology and maintaining “old school” relationships were not mutually exclusive. Even as technology has changed nearly everything in the past 35 years, our personal, professional, and organizational relationships have remained a defining and formative foundation for pediatric psychology.

Professional Mentors and Collaborators

Mentoring and collaboration across generations and disciplines have been central to the identity and development of clinical child and pediatric psychology. At Colorado College from 1973 to 1977, I defected from an education major to a psychology major after witnessing the passion that my professors had for applying empirically validated learning principles to solving significant issues in children and adults. I left with a firm grounding in behavioral psychology and a vision of a future that in some fashion involved helping children and families. As a clinical psychology graduate student at Virginia Tech, I knew I wanted to specialize in work with children, but our child track did not yet exist. On the advice of incoming Virginia Tech clinical child faculty member Dr. Tom Ollendick, I looked up one of his mentors who was a great cognitive-behavioral researcher in my hometown of Richmond, VA. Specifically, I cornered Dr. Al Finch at a Southeastern Psychological Association meeting and boldly asked whether I could volunteer in his research program in the coming summer. He agreed to let me visit and interview based on the faint strand of an academic connection to Dr. Tom Ollendick, and a personal connection to his former VTCC intern Dr. Edith Ott.

On the appointed day as I sat in the VTCC lobby in my best professional attire, Dr. Finch came flying down the hall with his 3-year-old throwing up over his back. As he ducked into the men’s room he hollered his apologies and instructions: sick kid; wife with an exam; intern Tony Spirito would tour me around and take my questions; if he thought I was OK I could start in June. In the context of a world where few men played regular roles in childcare, especially on the gnarly days of sickness, I was totally bowled over. “Wow!” I thought to myself, “this is a man I want to work with.” I got my wish, following Dr. Finch to the Medical University of South Carolina (MUSC) in 1982 and to The Citadel in 1991. To this day I am proud to work with Dr. Al Finch and to claim him along with Dr. Tom Ollendick, Dr. Edith Ott, and Dr. Tony Spirito among the valued colleagues, mentors, and role models on my professional family tree.

As I emerged from graduate school, the fledgling field of pediatric psychology was inherently interesting to me. I was drawn to populations whose psychological needs were secondary to their physical and/or developmental needs. It was not until my 1981–1982 internship at what was then Children’s Memorial Hospital (now Ann and Robert H Lurie Children’s Hospital of Chicago), when mentors Dr. John Lavigne, Dr. Barbara Brandt, and Dr. Suzanne Bachman Ivey invited and guided me in, that I realized the range of roles a psychologist might play in the systems surrounding pediatric patients and their families.

Soon after, I discovered that generous teachers, advocates, and scholars like Dr. John Lavigne (Lavigne, 2013) were not the exception but the rule in Pediatric Psychology. For young people who can connect electronically to experts all over the world, it may be hard to fathom what it was like to go to my first pediatric psychology gathering at the American Psychological Association meeting and see the welcoming unpretentious faces of the great names of the field whose books and journal articles I was becoming immersed in—Dr. Michael Roberts, Dr. Lizette Peterson, Dr. Gerry Koocher, Dr. Logan Wright, Dr. Donald Routh, Dr. Annette La Greca, Dr. Debra Bendell, Dr. Jan Culbertson, Dr. Diane Willis, and Dr. Dennis Russo, to name a few. Their professional contributions are well known to these readers, but the extraordinary approachability and encouragement of these distinguished leaders, famous names humbly hidden behind bow ties and running shoes and cowboy boots, made me realize I was on my way to a professional home full of “good folks.”

One of the most significant developments in pediatric psychology to me has been the further extension of our networks, collaborations, and mentor relationships across disciplines. My contemporaries and I entered a world
where a traditional medical model was the guiding force in the composition of children’s health care teams, the conceptualization and treatment of problems in children and youth with special health care needs (CYSHCN), reimbursement, and leadership hierarchies. Psychologists were invited guests in many medical settings, and were often relegated to assessment or specific minimally reimbursed intervention roles, primarily with other psychologists. While our scholarship and legislative advocacy certainly played a role in pediatric psychologists’ increased status and involvement in children’s health care, I contend that it was the person-to-person and on-the-ground team collaborations that helped chip away at the traditional roles and barriers.

When I arrived at MUSC in 1982, I was tasked with building bridges to pediatric programs. I sought out and was blessed with great pediatric mentors and listened attentively to their perspectives. We threw ourselves into shared missions like supporting cancer patients and their families, tracking and properly referring graduates of our neonatal intensive care unit, and documenting/responding to the needs of families. In these quests, we were too busy working together to trip over MD-PhD or hierarchy issues. The passion of MUSC’s Dr. Abner Levkoff, one of the first neonatologists to build neonatal intensive-care unit inpatient care programs and follow-up in our region, inspired me to use my emerging skills to translate his far-sighted visions into viable programs. His network connected me to great names like Dr. T. Berry Brazelton and to new young faculty and fellows who would go on to grow and sustain the services well beyond our times on the faculty.

Dr. Levkoff told me one day, among other more mundane things, that he had seen a posting by Utah psychologist Dr. Glen Casto, who was looking for collaborators in a multisite grant study. He asked whether I could follow up and see what it was about. This small transaction between two mutually respectful colleagues led to our 10+ years of involvement in the Early Intervention Research Institute’s longitudinal study of early intervention effectiveness (Saylor, Casto, & Huntington, 1996). If at any point we had sold each other short, brought egos or disciplinary “turf” politics into the interaction, overanalyzed the gap between my very junior status and his very senior status, or taken our eyes off of the children and families we were committed to serving, none of this would have happened.

After witnessing what psychologists could do to enrich neonatal follow-up programs, the Director of MUSC’s Pediatrics’ Genetics and Child Development Division asked whether I could work with his new young developmental pediatrics faculty to integrate publishable scholarship into their practice. I began to mentor, among others, a new young rising star named Dr. Michelle Macias. As many of you know, Dr. Macias has gone on to be a tremendous pioneer, leader, and contributor in the field of developmental and behavioral pediatrics. Our relationship has spanned decades and expanded to include friendship, research and grant collaboration, and mentoring of one another’s trainees (Clifford, Saylor, Macias, & Kreh, 2001; DeOcampo, Macias, Saylor, & Katikaneni, 2003; Doig, Macias, Saylor, Craver, & Ingram, 2000; Fussell, Macias, & Saylor, 2005; Macias, Roberts, Saylor, & Fussell, 2006; Macias, Saylor, Haire, & Bell, 2007; Macias, Saylor, Kreh, and & Romanczuk, 2000; Montgomery et al., 1999; Wohlfeiler, Macias, & Saylor, 2008). Simultaneously at an organizational level, psychologists like Dr. Dennis Drotar, Dr. Glen Aylward, Dr. Sue Berger, and Dr. Terry Stancin kept psychologists in active collaborative relationships and leadership roles in key interdisciplinary networks, especially the Society of Developmental and Behavioral Pediatrics.

I cannot emphasize strongly enough the importance of networking, joining, and finding mentors, especially for those of you in the front end of your careers. Many of you have found your way to Pediatric Psychology as “direct descendants” in the academic family trees that link back to pediatric psychology pioneers. Others of you, like me, will be “out there” trying to muster up the courage to wander in and introduce yourselves. Please know that what motivated all of us to form a Society of Pediatric Psychology and later an APA Division for Pediatric Psychology was the sure knowledge that we are better together than in silos, and that we have a lot to learn.
from those who came before us and those coming up behind us. We have a shared passion and mission, and all potential contributors to that mission are welcome. We are eager to meet you, electronically or in person, and help you find the place where you might best develop and contribute. Let us help you connect to your colleagues in a field that is still collaborating on the “cutting edge.”

Families and Youth With Special Needs as Mentors and Collaborators

Another significant shift from the traditional medical model has been the empowerment and engagement of families in their children’s health care. The movement toward considering the parents as collaborators and vital members of a system (vs. individual) coping with stress was interdisciplinary. I first recall reading about it in nursing and education journals in the 1980s. Many of the enduring models and practices of family-centered and system-based care were articulated and validated in the late 1980s and 1990s under the leadership of pediatric psychologists such as Dr. Anne Kazak, who highlighted system issues in populations coping with pediatric illness (Kazak, Segal-Andrews, & Johnson, 1995) and Dr. Terri Shelton, who addressed these issues in populations “needing specialized health and developmental services” (Shelton, 1999; Shelton, Jeppson, & Johnson, 1987; Shelton & Stepanek, 1995). The movement spread to pediatrics and continues to undergird empirically validated, funded “best practice” in the past decade (Dunst, Trivet, & Hamby, 2007; Perrin et al., 2007).

Embracing a model of family engagement and collaboration also led to some of the most important attitude shifts of my career. Of all the great mentors I have had, I believe I learned the most from the parents of children with special needs and the young adults with special needs I once considered the potential “patients.” In the late 1980s and early 1990s, I witnessed families growing more empowered. Their informed voices were more widely acknowledged in legislative, medical, and educational practices. Soon they were essential team members in treatment planning, task forces, and committees steering policy and practice in my interest area of CYSHCN.

The unanticipated impact of sitting with families on committees and collaborating on advocacy initiatives was that my world view began to shift—I might have a PhD, but it was the parent who was most expert in his/her child and in many cases his/her psychosocial and systemic needs. When I really started listening to the parents and their CYSHCN with a mindset that they had much to teach me, I finally began to “get it.” Because I was open to this change in perspective, I not only developed as an interventionist but also found new directions for my professional efforts in the community.

Like many pediatric psychology colleagues and perhaps the field itself, I have “grown up” with and been educated by a generation of world-changing parents and CYSHCN. For example, I met several parents of children with Down syndrome nearly 30 years ago, often in inpatient consultations when their children were having heart surgeries and they needed additional support. Our Caring Connection grant funded parent networking and support initiatives eventually grew into self-sustaining advocacy groups. Listening to the Caring Connection parents helped us realize that their experiences could help inform and educate psychology and health care professionals to be more effective in family-centered health care delivery. Our subsequent parent-driven Parent and Professional Alliance (PAPA) grant project engaged parents with health care trainees at all levels and developed training materials from parent narratives. As we (really) listened to our PAPA parents talk about their then school-aged children being left out of “typical” arts and sports activities, we became inspired to propose, implement, and evaluate the Peer EXPRESS program, which networked school, recreation, medical, and nonprofit advocacy programs to enhance CYSHCN participation in fully inclusive sports, arts, camp, and community service clubs.

By 2005, the youth with Down syndrome we had met as infants were now adolescents finding their own voices, and one of the disheartening stories they told us was of the bullying and ostracism they encountered now that they were more regularly among their middle school peers. Thus began our studies of bullying and ostracism in CYSHCN, which continues to this day (Saylor et al.,
The Peer EXPRESS project was a driving force behind my shift in professional emphasis to community-level interventions, interagency collaboration, and now service learning and civic engagement. In 1991 I moved to an academic setting (The Citadel). Since then I have been witnessing the tremendous impact that the now young adults with Down syndrome were having on my college student volunteers and interns. In my current position as Director of Service Learning and Civic Engagement, I regularly see these adults with Down syndrome changing the perceptions of future health care practitioners and college students of all majors. Recent data suggest that the most impactful service experience of the dozens of options our 2000+ college students engage in each year was service that brought our students face-to-face with adults who have disabilities (Hernandez & Saylor, 2014). This generation of “trailblazers” raised the bar for both opportunity and expectations for CYSHCN. Several are making their way through innovative college programs, jobs and careers, and leadership in advocacy initiatives such as Special Olympics, Best Buddies, and End the R Word campaigns. It is they who are now the consultants and my students and trainees who are now the recipients of the service.

My takeaway to younger (and older) readers is to find an issue or population you are passionate about and volunteer yourselves to work side-by-side with those you aspire to serve. Seek out and learn from those individuals and family members who are immersed in the issue personally as well as professionally. Try to make a difference in advocacy for critical needs and progress while learning from those you advocate for. Be open to changes of perspective, shifts in scholarly focus, and even change in career paths that may grow out of these relationships.

Professional and Personal Worlds Intersect: Putting a Face on “The Patient”

The most significant changes in my pediatric psychology perspective came not from my graduate and continuing education but from the unanticipated experiences of sitting hospital vigils with my son and later with my husband, recovering from a hurricane, and seeing the suffering and resilience of children and families through a new lens.

In 1987, when I was 5 years into practicing pediatric psychology, my infant son Paul was admitted to the MUSC with a sudden high fever. The roaring kidney infection that led to his admission that night and the subsequently diagnosed anomalies in his renal, urinary, and digestive tracks were relatively mild compared with those of most pediatric patients I followed through our pediatric inpatient and outpatient consultation services. Our family had many more resources to bring to the crisis. Still, waiting outside while he howled through a lumbar puncture procedure, seeing him with an IV in his bitty head, and (not) sleeping by his crib in the old MUSC Children’s Hospital changed my pediatric psychology training and practice forever.

I still vividly remember my ghastly nights in the old, familiar, children’s hospital, especially the anguished eerie nighttime howls of a youngster down the hall—a child whose sibling had died in a car accident that left her painfully injured. I remember the seemingly endless intervals between the pressing of nurse call buttons and relief for my child’s distress. I wanted to go back and reexamine every pediatric consult in which I had noted, “mother appears depressed” (Gee, do you think??). While diagnosis and treatment of maternal depression might be a vital component of an inpatient or outpatient consult, I could not help but wonder if my clinical/biological/individual diagnosis lens had colored my perception and interpretation of behaviors and appearance that were actually rooted in system-level issues and reactive to acute conditions. In all seriousness, I considered ways I might have every pediatric psychology trainee spend a few nights on a pediatric inpatient unit, grabbing food and showers only in the rare moments a trusted friend or family member could come cover. I still would recommend this immersion in culture and context that are unique to a pediatric inpatient unit if the ethics and logistics could be worked out.

Paul’s kidney surgery at age 5 years further opened my mind and heart to the vital psychosocial services that had mostly seemed academic or ancillary to me until then. Pediatric psychology colleagues had begun to empirically test methods for child pain management in studies I honestly thought of at the time as intellectually interesting studies in “hot topic” areas. How desperate I was for those promising pain management interventions that ultimately emerged in pediatric psychology as I looked at my son’s pale 5-year-old face contorted in wide-eyed pain! During this time, my resolve to find “treatments that work” was intensified and never abated.

Fortunately, Paul was among the first patients to enjoy the beautiful new atrium and “Child Life” program at MUSC’s new Children’s Hospital. When I had seen the early Child Life programs at Children’s Memorial Hospital in Chicago I had a vague sense of them being a positive thing for a hospital to have—nice idea, nice toys, happy place, nice public relations. Again it all took on new significance through the lens of a patient’s mother. I credit the little insight and tolerance my son had for his surgery.
to the Child Life therapist’s preop sessions that exposed him to the steps of the process in relaxed and not-threatening play. More importantly, the atrium space and its activities were the only things powerful enough to lure him into moving with his considerable postsurgical pain. These were not frills. They almost certainly reduced his need for medications and shortened his hospital stay.

A colon issue led to Paul being on homebound instruction for 2 months at the beginning of middle school. As he returned to school 20 pounds thinner and visibly frail, Paul was targeted for severe ostracism and bullying at the hands of previously amicable peers. As chronicled above, I had heard from CYSHCN that bullying was an issue but, until this experience, I somehow did not completely believe that kids would really be so cruel as to target a visibly vulnerable peer (or that teachers and guidance counselors might be so passive in their response or even join in the demeaning of the child who was down). The realization that all of my pediatric knowledge and skill could not adequately protect him from something that was psychologically devastating and directly interfered with his physical and academic recovery humbled me, infuriated me, and strengthened my resolve to invest professional energy into the study of bullying and ostracism in youth with special needs. One of the fruits of this effort was the Bullying and Ostracism Screening Scale (Saylor et al., 2012), illustrated by resilient young adult artist Paul Saylor.

The intersection of professional and personal worlds was by no means just my individual or isolated experience. In 1989, Hurricane Hugo came to the Charleston, SC area and rocked our worlds. There were few people unscathed, and most of us were displaced for months. Still, Al Finch and I gathered our trainees, resolved to apply our training to document what we could about the impact of the event on children, and set out to provide more information to the next community than we ourselves had after Hugo. A year later, our friends and colleagues in southern Florida endured the wrath of Hurricane Andrew and, too soon after, colleagues in Oklahoma City got the call that there had been a bombing at the federal building with more than a hundred fatalities (Irving, 1995).

I suspect few of us studied pediatric stress and trauma with an eye toward having it in our toolkits when disaster struck our families or communities. However, together we were able to pay attention, document, organize, conceptualize, learn from, and share knowledge that might help the next families (and the next, and the next) to rise up and cope effectively (Saylor, 1993). I hate that Miami and Oklahoma City experienced such devastation but I am proud that pediatric psychologists like Dr. Annette La Greca, Dr. Eric Vernberg, Dr. Robin Gurwitch, and others on the scene were open to the change in priorities, harnessed their professional and scholarly training and networks, and made something useful and important emerge from the experience (La Greca, Silverman, Vernberg, & Roberts, 2002).

Lessons Learned—Individual and Collective Openness to Change

The pediatric psychologists sharing their perspectives in the Pioneers in Pediatric Psychology series may all tell the tale of the past 40 years in different voices and with different emphasis. What we all had in common, however, was our desire to invest in an interdisciplinary knowledge-base and network of teachers and practitioners to address the needs of children and families in some of the most complicated and stressful circumstances imaginable. I hope the current and future members of pediatric psychology will demonstrate the resilience and flexibility to change their personal pathways and if needed the organization’s focus to follow where the data and times lead us.

In this commentary, I have reflected on changes in technology as well as advances from the traditional medical model to interdisciplinary collaboration and family-centered care. Through all the changes, the essential and stable ingredient of our forward progress has been our person-to-person mentor and collaborator relationships across professional generations, disciplines, and roles in the family care team. I have been honored to be part of the pediatric psychology family tree and look forward to sprouting a few more leaves and branches in the decade(s) to come.

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