



Filling a NICH(e)

By Harry Lenhart

Innovative program integrates medical care with behavioral therapy and case management to support at-risk pediatric patients and their families.

Michael Harris, Ph.D., has been a pediatric psychologist for nearly 30 years and has found himself inescapably drawn to the most challenging and difficult cases.

Take one 12-year-old female patient who was diagnosed with type 1 diabetes at age 7*. At various times, she lived in the homes of her stepmother and father, her grandmother and her mother. She was exposed to violence and substance abuse in her mother's home and her father's home and was thought to be a victim of sexual assaults. She didn't inject her insulin on a regular schedule. She was kept out of school for long periods because the school was fearful of her high blood sugars, and there was no school nurse. And in one two-month period, she was hospitalized 22 times with suspected stress-induced insulin resistance.

Patients like her confound the medical system, those with serious and complex medical conditions compounded

by psychosocial and family problems – major league challenges, as Dr. Harris described it. These families frustrate providers when they don't show up at clinic appointments or don't follow treatment regimens.

Subsequently, they fall through the cracks, only to be forced to go back, time after time, to hospital emergency rooms for care. Many are the so-called high-utilizers, or “frequent fliers,” and their reliance on ERs has been a big factor in soaring health care costs.

Dr. Harris envisioned a better way. And so Novel Interventions in Children's Healthcare – NICH – was born.

Filling the cracks

Some 46 percent of NICH families are single-parent households; 48 percent are struggling with unemployment or employment insecurity; 46 percent of the children involved are not in school; 38 percent are either homeless or cope with various forms of housing insecurity; and 76 percent suffer from a variety of psychological and behavioral problems.

NICH interventionists broker the relationship between

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– Dr. Harris

stressed-out families, medical providers and the multiple social systems in which the child and family are embedded, helping families manage the challenges of living and coordinating health care.

Conditions NICH is addressing in its current caseload include: diabetes, cystic fibrosis, chronic pain, cancer, end-stage renal disease, liver transplants, eating disorders, spina bifida, inflammatory bowel disease and common variable immune deficiency.

But NICH will step in to help with any medically complex case that is absorbing a disproportionate amount of health care resources, said Dr. Harris.

“We know that if you aren't meeting the challenges of day-to-day life, it really is impossible to take care of a child with a serious chronic health condition,” he said. “If you're a single parent with four kids, and you're working night shifts and relying on public transportation, how on earth do you meet the needs of a child with a complex medical condition appropriately?”

While there are intervention programs for adults in Oregon (several affiliated with OHSU), NICH is the first to focus on children. There are few, if any, programs like it anywhere else in the country that Dr. Harris knows of.

At four years, NICH is demonstrating success. Hospitalizations for patients are slowing. Outcomes are improving. Costs are falling. It's all evidence of achieving health care reform's “Triple Aim.” Other health systems are calling to emulate it.

Above all, NICH is making a world of difference for individual children. When NICH stepped in for the 12-year-old patient, it negotiated with the Oregon Department of Human



Services to transfer care to her grandmother, collaborated with an endocrinologist and social worker to get her grandmother up-to-speed on the risks of diabetes and began conducting weekly, family-based, problem-solving sessions and daily phone check-ins with 24/7 therapeutic support. Ultimately, the patient went back to school.

Running interference

Interventionists are the key. They are what make NICH unique. Their motto plays off the program's acronym: Nothing I Can't Handle.

Consider 13-year-old Arianah Gilbreath. Her mother, Amber Gilbreath, has her hands full. She's unemployed and a single parent with four children, one of whom is in juvenile detention. Her daughter, Arianah, suffers from pulmonary arterial hypertension (PAH), a rare, life-threatening condition that requires constant vigilance. Amber tries to put a good face on her plight and her daughter's, but she often feels overwhelmed. A winsome girl with sparkling eyes, Arianah is stoic about PAH, for which there is no cure.

Without Harpreet Bahia to run interference, things could easily spin out of control and, occasionally, they have. Bahia is an effervescent, 29-year-old family and child therapist who joined NICH two years ago as an interventionist. She's been managing Arianah's case since July of last year.

Arianah's disease, PAH, causes a narrowing of the blood vessels that connect to the lungs, which makes it harder for the heart to pump blood. So Arianah carries around a canister filled with Remodulin, a vasodilator that is constantly infused intravenously into a vein in her left shoulder. The canister has to be changed every other day without fail. It's what helps keep her alive. She also needs to be in close range of an oxygen tank during the day and be hooked up to it when she sleeps.

Family support

Because of her weakened immune system, the teenager is prone to infections. "If she goes to school three out of five days, that's a good week for us," said Bahia. "I've been trying to use incentives to push Amber into encouraging Arianah

Amber tries to put a good face on her plight and her daughter's, but she often feels overwhelmed.

to go to school even if she was feeling groggy." The latest incentive was a gift card for mother and daughter to get manicure/pedicures. Bahia, working with the school, helped engineer an individualized education plan for Arianah with a truncated school day to conserve her energy.

Bahia meets with the family weekly, is in daily phone contact and is on call 24/7. She makes sure Arianah gets to her cardiologist's appointments at OHSU every month and to her weekly checkups in Salem, where the family lives.

NICH supplied Arianah with an iPad on the condition she send Bahia pictures of her IV site every day to make sure it's clean and not infected. "She has ended up in the emergency room a couple of times because of an unclean medicine line, which posed the risk of infection," said Bahia.

Bahia also got a plastic organizer for the wide array of medications Arianah takes, which had been scattered around her bedroom. For Amber, Bahia acquired a planner to keep all her obligations straight, from medical appointments to school schedules.

"I need NICH," Amber explained. "I do. That's all I have. Arianah has a mean, mean disease."

Ripe for change

Rewind to late 2011. With health care reform on the front burner, particularly in Oregon, Dr. Harris – who joined the OHSU faculty in 2006 – decided to test the waters for an idea that had been percolating in his head.



TEAM CARE What exactly does NICH do? Started by Dr. Michael Harris (pictured, left), NICH deploys interventionists to broker the relationship between families, medical providers and social systems, helping patients and their families manage the challenges of living and coordinating health care. Above, NICH interventionist Harpreet Bahia (center) meets with Arianah Gilbreath (left) and her mother, Amber Gilbreath, prior to accompanying the family on Arianah's medical appointments.

NICH numbers

4 years old

60+ cases

10 interventionists

24/7 help

4 Oregon CCO participants

\$750,000 cost savings

3 requests a day to add more cases



"We are always willing to treat and care and show compassion to those who are struggling a little, but when a patient comes in with a lot of problems that we can't treat medically, the medical community often walks away in defeat," said Dr. Harris.

"Figure out what's going on with the lived experience of the patient and address it in the community, in the home... because, otherwise, the downstream costs, both medically and financially, could be astronomical. We're talking about outcomes for a lifetime."

– Dr. Labby

That bothered him and spurred him to action – both in his research and clinical practice. He poured his energy into studying the social determinants of complex chronic illnesses in children, becoming a national leader on the subject. But more was needed.

To address the challenges – at least for one segment of the pediatric patient population – the context in which families are embedded needed to be addressed in a comprehensive way, Dr. Harris believed.

So he went to David Labby, M.D., Ph.D., then medical director at CareOregon, which, at the time, was the largest managed care organization in Oregon with members mostly in the Portland metropolitan area. There, Dr. Harris found an audience receptive to his idea.

He put together a budget, CareOregon got behind it, and with the critical support of the director of the Institute on Development and Disability at OHSU, Brian Rogers, M.D.*, NICH was launched.



Rapid growth

Dr. Harris assembled an OHSU team that now consists of 10 interventionists, who are available 24/7 to the families they work with, along with two clinical supervisors and three physician consultants.

They currently manage on the order of 60 cases at any one time through contracts with Oregon's CCOs: HealthShare of Oregon, AllCare Health Plan, Willamette Valley Community Health and Intercommunity Health Network, serving patients from Multnomah to Josephine and Coos counties.

National contacts are growing – NICH now has a consulting contract with New York Foundling, a large, child welfare agency that provides community-based services for families in all five New York City boroughs.

And NICH is getting upwards of three requests a day to add more cases. It's expanding as fast as its resources and staff permit.

Of those, preventive cases are becoming the norm. "We have two groups of kids," said Dr. Harris. "One group uses a lot of health care resources. Then we have kids who have all the risk factors but aren't there yet. We're moving away from putting out fires. CCO medical directors are saying they'd rather pay us to see these kids before they cost \$100,000 to \$200,000 to care for."

Arianah is a preventive case. Because of Arianah's fragile condition, the medical team wanted to be certain of a smooth transition.

"They were concerned that things might get worse if



NICH didn't come in," said interventionist Bahia. "Arianah was not a frequent flier. She wasn't one of those making avoidable visits to the ER – although she could have been."

NICH difference

NICH's efforts are paying off across the board. A year after intervention, the data provided to NICH by the CCOs it serves show an average 21 percent decrease in ER admissions. In its initial pilot program for 23 patients, NICH was able to generate \$750,000 in cost savings after a year of services.

"We believe the savings at this point now have grown to the multiple, million-dollar range," said Dr. Harris. "Right now, NICH is shaving the cost curve. But it will bend it for the future."

The genius of NICH is that it reaches out to understand the social dynamics of the family, said Dr. Labby, who has since moved on to become chief medical officer of Health Share of Oregon, an umbrella organization that oversees care for the Medicaid population in Clackamas, Multnomah and Washington counties.

"More and more, as we're doing health care transformation efforts around complex patients, we use exactly the methodology Dr. Harris has identified: Figure out what's going on with the lived experience of the patient and address it in the community, in the home," he said. "These are super-stressed families. And for children, family determinants of health are really significant. Addressing them is hugely important because, otherwise, the downstream costs, both medically and financially, could be astronomical. We're talking about outcomes for a lifetime."

NICH IN ACTION Arianah Gilbreath meets with her medical team at OHSU Doernbecher Children's Hospital. NICH interventionists play a key role in helping patients and their families manage complex diseases.

Award-winning program

NICH was recently selected as one of four recipients of the Association of American Medical Colleges 2014 Clinical Care Innovation Challenge Award. The award recognizes and rewards medical schools for innovative and transformative initiatives in care delivery to advance quality and improve patient outcomes. The other recipients of the award this year were Emory University, Duke Medicine and Children's Hospital at Dartmouth.

The road ahead

Arianah is making plans for the future. She says she wants to be a nurse, something she's known from a young age. Since her diagnosis, she has had plenty of opportunities to watch nurses in action.

Both she and her mother are determined to live as normal a life as they can. Arianah maintains lots of friends and an active social life. She has a Facebook site dedicated to PAH awareness. She babysits. She's not exempt from household chores.

"They say she can't hike and swim," Amber confided, "but as long as her IV site is wrapped, and she's got extra oxygen, we do it all. The house is always full of teenagers. I'm like, 'Live it up, kid!'"

For more information about NICH, contact either Dr. Harris at harrismi@ohsu.edu or Dr. Kim Spiro at spiro@ohsu.edu.



*PARTICULARS

Key details have been altered to protect the patient's privacy.

Dr. Harris is a professor of pediatrics in the OHSU School of Medicine and chief of pediatric psychology in the Institute on Development and Disability at OHSU.

Dr. Rogers is a professor of pediatrics in the OHSU School of Medicine.