



# A NEW WAVE OF PROGRESS IN HEALTHCARE IS COMING

*The IDD community is abuzz with enthusiasm about the new clinic model. In the short time that the Lee Specialty Clinic has been open, multiple representatives from other states have inquired as to how this model might be reproduced in their state.*

BY MATT HOLDER, MD, MBA

Imagine a better healthcare delivery system for people with intellectual and developmental disabilities. What would it look like? For years doctors, families, advocates, policy makers and self-advocates have been trying to find a solution to the growing healthcare crisis facing people with intellectual and developmental disabilities (IDD). The end goal imagined by most is for people with IDD to be able to go to any doctor they wish, for that doctor's office to welcome them with open arms AND for that doctor to know about IDD. But we, as a nation, are far from that ideal system of care for people with IDD.

Over the past dozen years myriad reports have surfaced detailing just how far away we are. The Surgeon General wrote a landmark report in 2002 acknowledging that healthcare for people with IDD is far from ideal. Nearly a decade later, the American Medical Association passed a resolution acknowledging that people with IDD are medically underserved. Both cited lack of training of physicians, lack of access to quality healthcare and inadequate healthcare financing as major barriers to care for people with IDD. The result of our current system of care is that people with IDD have some of the highest rates of unmet health needs of any population



**JOYOUS OCCASION:** (Above) Mr. Trey Kramer and Ms. Mimi Kramer; (Opposite page) Dr. Rick Rader, Dr. Matt Holder, Dr. Henry Hood, Dr. Allen Brenzel, Commissioner Mary Begley, Gov. Steven L. Beshear, Rep. Jimmie Lee, Rep. Jeff Donohue, Secretary Audrey Haynes, Ms. Betsy Dunnigan, Deputy Secretary Eric Friedlander at the ribbon cutting ceremony.

on the planet. At any given time, one out of eight people with IDD are in active dental pain, one out of five have low bone density, one out of four need new glasses, one out of three are taking more medications than they actually need and nearly half have had the experience of being turned away from a healthcare provider.

For over a decade, the American Academy of Developmental Medicine and Dentistry (AADMD) has published articles in *EP* magazine discussing the barriers to care that exist. The AADMD is a professional organization that consists primarily of physicians and dentists who focus on caring for people with IDD. At the annual conference of the AADMD, and at other healthcare conferences around the country, experts in this field have described a model of care that, if implemented, would begin to solve these problems. While some nuances of the model differ from expert to expert, most seem to agree on a few premises:

- 1) *A system of clinics should be established that focus primarily on the healthcare needs of people with IDD.*
- 2) *Clinics should serve as teaching sites for medical students, dental students and other healthcare students so that no matter what these students ultimately specialize in, they will have had some training and experience working with*

*people with IDD.*

- 3) *Clinics should conduct clinical outcomes research in an effort to continually improve the quality of care provided.*
- 4) *Clinics should be interdisciplinary in nature, providing coordinated, interdisciplinary care to their patients.*
- 5) *The model of care must be financially viable and reproducible throughout the United States.*

First described in 2003, the model mentioned above has been given various names by experts, advocates and policy makers, but most agree that the development of this model is a key step toward creating the ideal system of care for people with IDD.

For years, experts in this field have struggled to create such a model. A number of doctors have managed to create clinics that focus on people with IDD. Many of them are teaching clinics. A few of them perform clinical outcomes research and fewer still have been interdisciplinary in nature. And while a few of these clinics have accomplished extraordinary things in their own right, none of them have managed to develop a model that is imminently reproducible across the United States.

Until now.

On June 11th, 2014, Governor Steven L. Beshear presided over the ribbon cutting ceremony for the Lee Specialty Clinic in

Louisville, Kentucky. While this ceremony celebrated the opening of just one clinic in one city in the United States, this single event marks one of the most significant developments in healthcare for individuals with intellectual and developmental disabilities in decades.

The Lee Specialty Clinic focuses exclusively on people with intellectual and developmental disabilities. Its core services include primary care medical services, specialty medical services, dental services, psychiatric and behavioral services, physical therapy, occupational therapy, speech therapy, and crisis intervention services. These services are provided in an interdisciplinary fashion, whereby the professionals who provide them communicate with each other for the benefit of the patient. The Lee Specialty Clinic also serves as a teaching and research program where students from any healthcare discipline can learn, intensively, how to care for people with IDD. Finally, and perhaps most important of all, the clinic model is reproducible. Its funding model has been approved at the federal level and is coordinated through the Medicaid system. This means that any state that

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desires to create such a model can do so.

Of almost equal importance, with respect to the financing of this clinic model, the clinic is cost-based. This means that the clinicians within the clinic are not under the same financial pressures as most fee-for-service practices that must see a new patient every few minutes in order to survive financially. Instead, the clinicians at the Lee Specialty Clinic can spend the time necessary to provide the services that an individual with IDD needs. It doesn't matter how medically or behaviorally complex the individual is, or if the person is non-verbal – the clinic was designed to provide the highest quality care possible to any person with IDD, regardless of their level of disability.

## YEARS OF COLLABORATION

The creation of the Lee Specialty Clinic did not occur overnight. In fact, it took years of collaboration between doctors, families, advocates, self-advocates, policy makers and governmental professionals, but its existence stands as a testament to what can be achieved when all of these groups work together for the benefit of people with IDD.

The origin of the Lee Specialty Clinic dates back to 1999 when a dentist, Dr. Henry Hood, a family advocate, Louise Underwood and a state legislator, Representative Jimmie Lee worked diligently to create a pilot dental program. After three years of advocacy, the Underwood and Lee Dental Clinic opened its doors to the public in 2002. At the time, it was estimated that the clinic might serve two or three hundred people with IDD from the Louisville metropolitan area. By 2006, the clinic had received multiple awards for its innovative approach and quality outcomes and it was serving around 700 patients from over 30 counties in Kentucky. Some families drove five hours across the state just to come to the clinic. The success of this pilot

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led the Commonwealth to explore greatly expanding the services offered by this pilot program.

At the same time, the state was continuing to downsize its remaining intermediate care facilities. Of great concern to the families of the individuals still living in the state's institutions was the status of the community healthcare infrastructure. While a lot of attention was being paid to residential options and employment opportunities in the community as part of the social inclusion movement, there was still a glaring void in the community healthcare system for people with IDD. It was already known that the vast majority of people with IDD living in the community had unmet



**A DREAM REALIZED:** EP's Exceptional Governor of the Year Award presented to Kentucky Gov. Steven Beshear by EP magazine Editor in Chief Dr. Rick Rader.

health needs and it was known that the people who continued to live in institutional settings were, in general, more medically and behaviorally complex than most living in the community. The Commonwealth of Kentucky and the families of these individuals asked the question - "If the current community healthcare infrastructure cannot meet the unmet health needs of people with IDD living in the community now, what will happen to the health of the individuals who transition to the community from institutional settings?"

The search for an answer to this question provided additional impetus for the creation of not just one clinic, but a network of clinics around Kentucky that could not only provide the needed healthcare to all people with IDD in the community, but that could help to train the next generation of doctors to provide better care as well. By 2008, Governor Steven L. Beshear and the Kentucky General Assembly made the creation of these clinics a priority. Over the next few years the Commonwealth constructed a new clinic building to house its flagship program.

The Lee Specialty Clinic already has a

patient base of over 1200 Kentuckians from over 55 counties in the Commonwealth and it is ramping up to take on hundreds more over the coming years. Student rotations are available in multiple healthcare disciplines and advanced training programs are available for practicing clinicians from around the world.

The IDD community is abuzz with enthusiasm about this new clinic model. In the short time that the clinic has been open, multiple representatives from other states have inquired as to how this model might

be reproduced in their state. As Mimi Kramer, the mother of Trey Kremer who is a patient at the Lee Specialty Clinic said, "This is what I have been telling people we need for years!"

For Mimi and Trey and thousands of families around the

Commonwealth of Kentucky, something better is just around the corner. A new wave of progress in healthcare is coming. •

### ABOUT THE AUTHOR:

Matt Holder, MD, MBA is the Chief Executive Officer of the Lee Specialty Clinic and the President of the American Academy of Developmental Medicine and Dentistry.



Lee Specialty Clinic provides a variety of health care services, such as primary care, dentistry, psychiatry, clinical psychology, behavioral analysis, crisis intervention and therapeutic services.

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