

Embedding Developmental Disabilities into Medical Training

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Until the 19th century, the care of persons with neurodevelopmental disorders/intellectual disabilities (ND/ID), and mental illnesses was largely left to the largesse, or lack thereof, of almshouses and state prisons. In North Carolina, a watershed mark was reached in 1848 when nursing crusader Dorothea Lynne Dix (1802-1887) visited the state. Where Governor Morehead had failed a few years earlier to persuade the legislature to fund the building of an institution for the humane care of individuals with significant mental disabilities, Dix succeeded. The first appropriations of \$17,000 were made for the hospital's construction in 1849, and on February 22, 1856, the first patient was admitted to the new facility.¹

By the beginning of the 20th century, North Carolina had three such facilities in operation, and the resident populations had expanded to include patients, often children, who presented with a wide range of mental, intellectual, and physical disabilities. World War I and the plight of veterans disabled by combat raised social awareness in a broader sense about barriers to access to a host of community, social, and health care privileges.² Continued advances in medical knowledge and systems of care, including the emergence of developmental pediatrics in the 1960s, led to increased life expectancies of children as well as adults with ND/ID. For

example, "In the early 20th century the average life span of a person with Down syndrome was about nine years. A US study published in 2002 found that the median age at death of people with Down syndrome rose from 25 years in 1983 to 49 years in 1997."³

Today it is not unusual for those with significant developmental disabilities to live well into their 60s and beyond. In North Carolina, for example, at the Black Mountain Neuro-Medical Treatment Center the oldest resident is an octogenarian. With continued improvements, the life expectancy of most persons with ND/ID in the 21st century will approach that of the general population and, with appropriate supports that include patient-centered adult medical care, they will live significant and richly rewarding lives.

The deinstitutionalization movement, which began in the 1960s and continues through the present, created mechanisms of support for persons with ND/ID to move from large, state-operated residential institutions to community environments. The social integration model of care, while advantageous in terms of quality of life, has intensified the need for improved training of the health care workforce. The previous institutional model provided medical supervision, often overseen by a physician whose subspecialty was

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psychiatry. However, at the community level, most adult primary care physicians and adult subspecialists have not been clinically trained or operationally prepared to receive persons with significant ND/ID into their practice settings.

A National Challenge

The need for improved clinical training of physicians in the care of persons with ND/ID has been evident since the 1989 Surgeon General's conference *Growing Up and Getting Medical Care: Youth with Special Health Care Needs*.⁴ This initial conference report was followed by the 2001 Surgeon General's report on the need to integrate the mental health and primary care needs of persons with disabilities and by the landmark 2002 report *Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation*.⁵

The 2002 report called for the health care system to "improve the quality of health care for people with mental retardation" and to "train health care providers in the care of adults and children with mental retardation." While these and other advances in the health care system have been considerable, standard medical education has yet to respond in a unified manner.

The office of the US Surgeon General expanded on the topic with yet another challenge five years ago. The 2005 *Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities* asks medical schools to "increase knowledge among health care professionals and provide them with tools to screen, diagnose, and treat the whole person with a disability with dignity."⁶

Indicative of the growing recognition of need, the National Institute of Medicine's 612-page text, *The Future of Disability in America*, was released in 2007.⁷ In May 2009, the North Carolina Institute of Medicine issued its comprehensive report, *Successful Transitions for People with Developmental Disabilities*.⁸ The report includes several recommendations for the legislature to support training of health care providers to work with persons with developmental disabilities. (See sidebar.)

More recently, the *Journal of the American Medical Association* carried a compelling commentary, "Educating Health Care Professionals to Care for Patients with Disabilities."⁹ While not specific to ND/ID patients, the authors provide general guidance and recommendations for medical education to include disability education in medical training, following the six core competencies^a defined by the American College of Graduate Medical Education (ACGME).

Responding to the 2005 Surgeon General's *Call to Action*, the American Academy of Developmental Medicine and Dentistry (AADMD) conducted a survey of all US-based medical schools and dental schools in 2005, with surveys

Successful Transitions for People with Developmental Disabilities: A Report of the NCIOM Task Force on Transitions for People with Developmental Disabilities⁸

Recommendation 6.14: Training for Health Care Professionals

The Area Health Education Centers (AHEC) program, health professional schools, and Division of Mental Health, Developmental Disabilities, and Substance Abuse Services should work collaboratively with health professional associations, self-advocacy groups, parents, or parent advocacy groups to enhance the training provided to health professionals about providing services for people with intellectual and other developmental disabilities. The trainings should include, but not be limited to:

- (1) Education for health care professionals (including physicians, dentists, nurses, allied health, and other health care practitioners) to provide better health care services for persons with intellectual and other developmental disabilities (I/DD).
- (2) Establishing a primary care medical home for people with I/DD.
- (3) Transitioning adolescents with I/DD from pediatric care to adult care and self-management.
- (4) Training of psychiatrists, counselors, and other health care professionals in addressing the needs of individuals with I/DD who need mental health services.
- (5) Education for health care professionals about the developmental disability system and how to coordinate services with the family, case manager, and other direct support workers to assist in providing proper health care for persons with I/DD.
- (6) Internships and residency rotations in settings that routinely provide services to persons with I/DD.
- (7) Support for continuation and expansion of mini-fellowships in developmental medicine.
- (8) The North Carolina General Assembly should appropriate \$150,000 on a recurring basis to the AHEC program to support these efforts.

a. The six core competencies adopted by the ACGME are: (1) Patient Care, (2) Medical Knowledge, (3) Practice-Based Learning and Improvement, (4) Interpersonal and Communication Skills, (5) Professionalism, and (6) Systems-Based Practice.

targeted to medical students, deans, and residency program directors. The report included the following key findings:¹⁰

- 77% of graduate medical education (GME) directors who responded reported no focus on ND/ID in their programs.
- 90% of GME directors reported interest in including ND/ID into residency training.
- 81% of medical students reported they received no ND/ID training.
- 74% of students reported interest in treating ND/ID patients in their future career.
- 100% of school of medicine deans reported interest in including ND/ID in the curricula.

Response in North Carolina

In 2004, the North Carolina Council on Developmental Disabilities issued a call for proposals to improve access and quality of primary care services for persons with developmental disabilities. The Mountain Area Health Education Center (MAHEC) responded and was awarded a three-year grant to conduct a review of the literature, survey stakeholders, identify specific educational needs, and conduct a range of continuing education programs to address them. The initial study indicated the need was greatest with respect to the care of adults with intellectual and developmental disorders. Implicit in the findings was the need for MAHEC to investigate the nascent field of adult developmental medicine.

Recognizing the limitations inherent in traditional continuing medical education activities to address the spectrum of needs identified by the surveys, MAHEC determined a “mini-fellowship” in an expanded, flexible learning format was a more realistic approach to effect change. The original concept was to offer training to faculty from the state’s family medicine GME programs, the idea being that these faculty could serve as champions and mentors in sharing key elements of the training with medical students and residents. The lack of response was indicative of already overwhelming educational demands on the residency programs, and the invitation was extended to physicians in community practice. Ultimately, eight physicians from a variety of disciplines (including family medicine, internal medicine, medicine-pediatrics, and pediatric pulmonology) elected to participate. Among the group were physicians from New Mexico, Ohio, and Massachusetts—family medicine faculty who had learned of the North Carolina endeavor during the year-long curriculum development phase of the project.

The first cohort began in February 2007 with a three-day training orientation and overview of the 12-month experimental educational effort, the first of its kind in the nation. The course content included an immersion experience at the Orange Grove Center in Chattanooga, Tennessee, assigned readings, monthly meetings via live teleconference, self-study, didactic sessions, independent

community learning, and opportunities for performance improvement projects. The goal for the first effort was to create a simple, replicable model that could raise awareness and highlight the collegiality and personal and professional rewards that would attract physicians to this area of work. The learning and fellowship exceeded expectations, concluding at the 2008 annual joint conference of the Developmental Disabilities Nurses’ Association (DDNA) and the American Academy of Developmental Medicine and Dentistry (AADMD). It was at the DDNA/AADMD meeting that the concept of utilizing the MAHEC mini-fellowship to spearhead an effort to begin building a national consensus curriculum in adult developmental medicine emerged.

Prior to completion of the first cohort of the mini-fellowship, MAHEC was asked by the North Carolina Division of Public Health’s Office of Disability and Health to participate in a statewide project to support the transition of youth with special health care needs from pediatric to adult medical home providers at age- and readiness-appropriate times for youth and their families. Three core components of the Carolina Health and Transition (CHAT) project were identified: (1) a health transition curriculum for the youth themselves, to prepare them for transfer of care and increasing self-management, (2) a parallel curriculum for parents and other significant persons in the youth’s support network, and (3) a medical practicum with clinical toolkit to assist the referring and receiving physicians in the youth’s transition to adult providers, as well as to coordinate the transfer of clinical, person-centered information from one provider to the next.

MAHEC, based on its experience in developing the mini-fellowship, agreed to assist the state with this new endeavor. Currently the CHAT project is in the third year of this novel effort, focusing on care coordination and quality improvement processes. MAHEC continues to partner with the state in this work and is also participating in a newly formed national transition research consortium created by Dr. Maria Ferris, a pediatric nephrologist and associate professor of medicine and pediatrics at the University of North Carolina at Chapel Hill School of Medicine.

An Ongoing Challenge

MAHEC continues to build upon the mutually collaborative relationships first forged with colleagues and organizations during the initial cohort of the mini-fellowship. Since that time, the Carolina Institute for Developmental Disabilities (CIDD) has emerged as a new leader in the field of developmental medicine in the state, and discussions on how the mini-fellowship can contribute to the Institute’s mission are underway.

With funding from the Milbank Fund, exploratory work for the second cohort began in early 2009. A number of physician faculty who had already created innovative, effective teaching models in their own training programs and communities expressed interest in participating in MAHEC’s

efforts. A strong desire and eagerness to build a community of peers to advance their shared interests and passion for the work was readily apparent.

The North Carolina mini-fellowship, while unique, is but one in the latest series of attempts to create the foundation for physician training in ND/ID. There are at least a dozen initiatives in medical and community settings around the country attempting to incorporate adult primary care into their training, both for medical students and for residents, primarily through their family medicine departments. It is clear, however, that there will be no meaningful advancement in the care of adults with intellectual and developmental disabilities on a national level without meeting the widespread call to develop not only a consensus curriculum across the learning levels, but also advanced training for those who want to subspecialize in adult developmental medicine.

Knowing curriculum development will require a multi-year, multidisciplinary collaborative effort, the medical course director began to lay the foundation for a national collaborative to continue the curricular work. With the MAHEC mini-fellowship serving as an incubator project for this broader effort, the goals are to address the breadth of relevant issues, identify and review existing resources, and establish recommendations toward a national consensus on the inclusion of ND/ID content in medical education at the premedical, medical, and graduate medical education levels. (For a complete list of the coursework objectives, see sidebar.)

The second cohort, launched in September 2009, includes 20 fellows from 10 states, the District of Columbia, and Canada. Resources under review by the fellows are both comprehensive and international in scope. Utilizing a model developed through a federally funded grant to the Society of Teachers of Family Medicine to enhance education in nontraditional areas of primary care medical education,¹¹ and with the guidance of the project's distinguished advisory committee, the mini-fellowship will, over the next year, focus on answering the Surgeon General's *Call To Action* by developing steps toward the achievement of a national consensus on ND/ID curricular content at the premedical, medical, and graduate medical levels. Funding for 2010 has been provided by the North Carolina Council on Developmental Disabilities. With anticipated future funding from the Council and additional resources, the work will continue through 2012.

By adopting a consensus approach to the education of current and future physicians, the mini-fellowship hopes to serve as a focused, meaningful opportunity that will lead

MAHEC Mini-Fellowship in Adult Developmental Medicine

Learning Objectives

The overarching focus is to effect change that will optimize the availability and quality of care to promote health for this medically underserved and often overlooked population. By the end of the mini-fellowship participants will have created a framework to:


- (1) Build a community of peers to define and advance the field of adult developmental medicine.
- (2) Review selected texts, articles, guidelines, existing educational efforts, and other related resources as appropriate to accomplish the above.
- (3) Develop curricular recommendations with consideration given to scholarship, research, health care advocacy, cultural, economic, and policy interests for peer review, development, and dissemination.
- (4) Define the steps necessary to implement the curricular recommendations across the spectrum of medical education.
- (5) Create a vision and strategic plan for professional and academic relationships that will lead to implementation of these curricular resources.
- (6) Establish a model for mentoring of peer and student learners beyond the mini-fellowship.
- (7) Identify and cultivate steps needed for national sustainability of this curricular project.
- (8) Use a web-based classroom to support this work by creating an enduring product that focuses on the above objectives.

to improved health care, realized potential, and enhanced quality of life for persons with intellectual and developmental disabilities in North Carolina and beyond. **NCMJ**

For further information, contact the medical course director, Bruce Kelly, MD, at bruce.kelly@dhhs.nc.gov or the project director, Irene Jurczyk, at irene.jurczyk@mahec.net.

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Odds of a child becoming a professional athlete: 1 in 16,000

Odds of a child being diagnosed with autism: 1 in 110

Some signs to look for:

No big smiles or other joyful expressions by 6 months.	No babbling by 12 months.	No words by 16 months.
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To learn more of the signs of autism, visit autismspeaks.org

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