A One-Year Fellowship in the Care of People with Disabilities: A Demonstration Project

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Abstract

Problem:
People living with disabilities have difficulties accessing and obtaining health care, and the care they receive is often inequitable compared to that offered to people without disabilities. This disparity is partly due to insensitivity by health care providers, but lack of provider education in the care of people with disabilities is a persistent and prevalent problem.

Approach:
Starting in July, 2021, Thomas Jefferson University will offer a one-year clinical fellowship in the care of people with disabilities. Available to graduates of Internal Medicine and Family Medicine residency programs and housed in our Department of Rehabilitation Medicine, the fellowship is intended to train physicians to provide medical care to people with a variety of disabilities while preparing them to help institutions offer more accessible and comprehensive care. This manuscript describes the fundamental features of this novel training program, and how the authors reached consensus on its central aims, clinical rotations, curricula, and supporting experiences.

Expected Outcomes:
In the first 3 years of the fellowship, program leaders will track: 1) learners’ knowledge of a variety of secondary effects of disability; 2) learners’ comfort in assessing co-occurring and secondary conditions of disabilities and in providing clinical care to people with disabilities; 3) learners’ academic output, satisfaction with the fellowship, and employability, and; 4) the financial feasibility of sustaining the training program.

Next Steps:
The authors are interested in ensuring that the fellowship provides meaningful educational and leadership opportunities to its trainees. If it is successful, we hope that this model can be replicated by other institutions, and that we can use its curricula to enhance and improve disability-specific education in undergraduate and graduate medical education.

**Keywords:** Medical Education; Graduate Medical Education; Curriculum; Disability

**Introduction**

People living with disabilities frequently have difficulties accessing health care. Facing both structural and attitudinal barriers (Kroll et al., 2006), people with disabilities are often given incomplete health care rather than being appropriately accommodated (Pharr, 2013; Stillman et al., 2017). Though the Americans with Disabilities Act (ADA) was passed 30 years ago and explicitly prohibits discrimination in health care facilities (H.R. 2273, 1990), Frost demonstrated that many medical practice managers are unaware of or uninterested in this law (Frost et al., 2015).

Even when people with disabilities are able to obtain health care, it is frequently inequitable when compared with the care received by able-bodied counterparts. Stillman found that female wheelchair users receive PAP smears at lower rates than do all American women (Stillman et al., 2017), and Chan demonstrated that Medicare beneficiaries with more activities of daily living (ADL) limitations receive fewer preventive interventions than do those with fewer limitations (Chan et al., 1999). In a study of receipt of health care by 432 wheelchair users, two-thirds were routinely examined by their primary care provider (PCP) while seated in their chair and over three-quarters were examined while fully clothed (Stillman et al., 2017). Not surprisingly, 54.1% of respondents felt they had been provided incomplete medical care as a result of their disability.

Part of the discrepancy in health care offered to people with and without disabilities is attitudinal. In a study of the experiences of patients with disabilities, many reported insensitivity to their disability-specific needs by health care providers (Kroll et al., 2006). However, the literature also suggests that health care providers are inadequately educated about how to see to the health care concerns of people living with disabilities. In a study of community-dwelling adults with disabilities, participants spoke of having to teach their physicians how to care for them (Morrison, George and Mosqueda, 2008). In Larson McNeil's survey of 501 PCPs in California (McNeal, Carrothers and Premo, 2002), 20% were unaware of the ADA and nearly three-quarters acknowledged need for additional training in the care of people with disabilities. Only 22.8% and 34.1%, respectively, had received such instruction during medical school and residency.

Lack of equitable and accessible care may lead to physical, interpersonal, financial, and psychological consequences for people with disabilities (Neri and Kroll, 2003). Decades after passage of the ADA, however, a number of barriers to care persist. As 22% of Americans have a disability (Courtney-Long et al., 2015), addressing disability-specific health care disparities is a matter of importance. In response to this challenge, our working group has developed a one-year clinical fellowship in the care of people with disabilities that will be available to graduates of Internal Medicine (IM) and Family Medicine (FM) residency programs and will be housed in the Department of Rehabilitation Medicine of Sidney Kimmel Medical College (SKMC) at Thomas Jefferson University (TJU).

**Methods and Approach**

**Mission:**
We convened a working group of experts in undergraduate and graduate medical education and physical and occupational therapy, all of whom have experience in the medical care of people living with disabilities. All members were faculty or staff at Thomas Jefferson University in Philadelphia, PA, and each was chosen for his/her history of leadership and scholarship in the care of people with disabilities and complex medical needs.

Our first task was to reach consensus about the fellowship’s goals. We agreed that graduates ought to have the knowledge, skills, and confidence to assess and provide care for people with a variety of disabilities, and to be adequately educated in the care of individuals with disabilities to communicate and collaborate with health care providers with greater expertise. We also felt they should be positioned to help health care networks and medical centers become more welcoming and accessible to patients with disabilities. In essence, we wanted our graduates to become physician leaders who will enable health care institutions to provide high quality care to individuals who have historically struggled to receive it.

In considering program development, we identified the following goals:

1) Fellows will rotate through a variety of inpatient and outpatient venues with an eye toward building their ability to help provide care to people with disabilities and to manage common secondary effects of disability;
2) Fellows will read literature that covers central topics in the care of people with disabilities, but should also be challenged to pursue their own reading and scholarship;
3) The fellowship curriculum ought to emphasize inter-professionalism, leadership, transitions of care, community integration, and adaptation to disability;
4) Fellows ought to meaningfully engage with community-based organizations and consumers with disabilities.

Venues of Care and Learning Objectives:
We divided the year into four clinical blocks, each with an attendant set of clinical and cognitive skills. The first is a 6-week inpatient rotation that is evenly split between our inpatient consultation and acute rehabilitation services. Fellows will learn the basics of acute management of stroke, acquired brain injury, and spinal cord injury (SCI) and demonstrate understanding of the rational supporting consultative recommendations for people who have recently sustained injuries and disabilities. The cognitive objectives associated with this block include: 1) principles of appropriate mobilization and of inpatient rehabilitation after acute hospitalization; 2) understanding appropriate and safe disposition; 3) ability to provide patient and family education, and; 4) understanding inpatient quality and safety for people with disabilities and complex care needs.

The second block is a 4-week rotation through two sub-acute care facilities that are affiliated with our institution. Fellows will learn the sub-acute management of individuals with disabilities and the stabilization and simplification of their medical regimens. Cognitive objectives include: 1) understanding the integration of medical treatment with therapies and the role of therapies in restoring and maximizing function; 2) consideration of patient, family, and caregiver education at time of discharge home, and; 3) an appreciation of how best to engage with community organizations and resources.

The third block is a 24-week rotation in outpatient care during which fellows will spend time in a number of clinics, gaining exposure to individuals with congenital and acquired physical and cognitive disabilities including limb loss, spasticity, acquired brain injury, SCI, Cerebral Palsy, Amyotrophic Lateral Sclerosis, and Parkinson's Disease. They will also participate in an inter-professional upper extremity clinic with focus on restoration and maximization of function after SCI. During this block, fellows will learn the basic management of common co-occurring conditions and secondary effects of disability including spasticity, neurogenic bowel and bladder, somatic and neuropathic pain, dysautonomia, and depression and anxiety. They will also become familiar with the preventive care of people with chronic neurological diseases. Associated cognitive objectives include: 1) understanding the broader scopes of
practice of physical, occupational, and speech and language therapists; 2) consideration of the tolerability and efficacy of the medical regimens of patients with multiple co-morbidities; 3) ability to identify significant gaps in the care of people with disabilities, and; 4) developing an enhanced understanding of patients’ experiences with illness and disability.

The fourth and final block is a 4-week rotation that focuses on community engagement and resources. Through formal rotations with community-based organizations including a visiting nurse association and the Centers for Independent Living, fellows will be expected to: 1) understand the availability, funding of, and gaps in community-based resources for people with disabilities; 2) appreciate care needs across the lifespan of people with disabilities; 3) develop an enhanced understanding of adaptive equipment and exercise-based therapies; 4) be able to describe specific laws and principles related to accessibility, and; 5) analyze the utilization of electronic and telemedicine technologies in the health care of people with disabilities.

Each learning objective is "mapped" to an associated experience, be it a meeting with an academic or community leader, a group exercise, a reflective writing piece, completion of "stackable" educational credits, or a longitudinal engagement. For instance, fellows will learn about quality and safety and longitudinal care needs by completing online credits through our university’s Colleges of Population Health and Rehabilitation Sciences, respectively. They will come to better understand principles of accessibility by leading inter-disciplinary (including consumers) walk-through assessments of our medical campus’ outpatient clinics. They will consider the potential utility of telemedicine by co-conducting 3 tele-health visits with attending physicians then interviewing the patients about the interactions' effectiveness and convenience. They will reflect on tolerability and efficacy of medical regimens by reviewing patients’ charts, questioning them about relief of symptoms and side effects, then suggesting alternative treatments, if appropriate, to their attending physicians. They will become familiar with the process of community integration by following 3 patients from inpatient rehabilitation back to the community, with a focus on coordination of care, transition to outpatient care, and availability of resources.

While fellows will be expected to pursue their own learning objectives, the committee also developed a core literature-based syllabus covering: a) health care accessibility for people with disabilities; b) basic management of a variety of disabilities and secondary effects of disability; c) transitions of care; d) patient experiences with illness and disability; e) shared decision making for people with cognitive and intellectual disabilities; f) pain management; g) functional restoration and recovery, and; h) rehabilitation ethics.

**Additional Questions and Expectations:**
For each rotation, the committee developed a series of "questions for consideration" that the fellow ought to pursue on his/her own. They include but are not limited to how best to educate inpatient physicians and staff about the optimal care of patients with disabilities, how to maximize communication between inpatient and outpatient teams caring for people with disabilities, how to improve PCPs’ knowledge of the care of individuals with disabilities, and how to utilize emerging technologies and adaptive equipment to help people maximize their independence and function.

In addition, fellows are expected to present original work minimally at one national conference and to produce an independent scholarly ("capstone") project as a requirement for graduation.

**Outcomes**

The planning committee agreed that the following outcomes ought to be tracked during each year of the fellowship, and that changes to the program may be made based on feedback:
1) Fellows’ comfort and confidence in providing care to persons with a variety of disabilities;
2) Fellows’ perceived knowledge of a variety of co-occurring conditions and secondary effects of disability;
3) Fellows’ evaluation of the quality and relevance of the program’s literature-based curriculum, associated experiences, and mentorship;
4) Departmental leadership’s assessment of the time, cost, and sustainability of the fellowship;
5) Employment opportunities for graduating fellows.

Next Steps

The planning committee’s first step is to advertise the program and select our inaugural fellow. In our unpublished study of 176 house officers in 10 northeastern IM and FM programs, 27% said they would consider completing a one-year clinical fellowship in the care of individuals living with disabilities. We believe, then, that there will be substantial demand for this program, but that we need to disseminate information about and create sustained interest in it.

Second, we are considering ways to utilize our curricula to improve disability-specific education in undergraduate and graduate medical education. Committee members with educational expertise are evaluating opportunities to insert more comprehensive disability-specific materials into existing medical school curricula and to develop educational foci or tracks within residency programs in the care of people with disabilities.

Finally, once this program has begun, we will seek opportunities to have other academic institutions develop similar fellowships. We hope that our efforts will produce a generation of physicians that can provide high-quality care to people living with disabilities while transforming the way the American health care system sees to their complex needs.

Take Home Messages

- Individuals with disabilities have difficulties receiving equitable health care
- Physicians are inadequately trained in the care of individuals with disabilities
- There is substantial potential interest in fellowship level training for generalists in the care of people with disabilities
- This manuscript presents a proposed plan for such a novel fellowship

Notes On Contributors

Michael Stillman is an Associate Professor of Internal Medicine and Rehabilitation Medicine at Sidney Kimmel Medical College. He has an academic and clinical interest in the care of individuals with complex disabilities, and, specifically, with spinal cord injury.

Nethra Ankam is an Associate Professor of Rehabilitation Medicine at Sidney Kimmel Medical College. She is thread director of wellness for the undergraduate medical education curriculum and has expertise in disability and interprofessional care.

Kimberly Heckert is a Clinical Assistant Professor of Rehabilitation Medicine at Sidney Kimmel Medical College. She is board certified in brain injury medicine and is director of the Jefferson Spasticity Care Fellowship program.
Michael Mallow is an Associate Professor of Rehabilitation Medicine at Sidney Kimmel Medical College and director of the residency program in rehabilitation medicine. He has expertise in medical education and in clinical assessment and professional development.

Kristin Gustafson is an Associate Professor of Rehabilitation Medicine at Sidney Kimmel Medical College. She is board certified in both spinal cord and brain injury medicine, and, earlier in her career, was director of the residency program in physical medicine and rehabilitation at Boston University School of Medicine.

Mary Jane Mulcahey is Professor of Occupational Therapy in the Thomas Jefferson University College of Rehabilitation Sciences and director of the college's Center for Outcomes and Measurement. Dr. Mulcahey has extensive clinical and research experience in the neurological upper extremity including studies on outcomes of nerve and tendon transfers and functional electrical stimulation.

Mary Stephens is Associate Professor of Family Medicine at Sidney Kimmel Medical College. She serves as medical director of the Jefferson Continuing Care Program, a medical home for teens and adults with intellectual and developmental disabilities and other complex childhood-onset conditions.

Catherine Verrier Piersol is Professor and Chair of Occupational Therapy in the Thomas Jefferson University College of Rehabilitation Sciences. Her scholarly work has centered on optimizing participation in people living with dementia and building skills in care providers.

Susan Wainwright is Professor and Chair of Physical Therapy in the Thomas Jefferson University College of Rehabilitation Sciences. Her academic foci have included clinical decision making and educational and qualitative research.

Karen Fried is a certified rehabilitation nurse and serves as the outpatient clinic director of the Magee Rehabilitation Hospital physician practice plan.

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Bibliography/References


**Appendices**

None.

**Declarations**

The author has declared that there are no conflicts of interest.

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