



# Transition Medicine— From Pediatric to Adult Care: Part 1

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Now more than ever, children with chronic diseases are surviving into adulthood. Whether through innovation in technology and research, collaboration among teams and multidisciplinary care models, or health care delivery at the patient or population level, medical science continues to improve the health of those who are most in need of lifelong care. This has resulted in a tidal wave of adolescents and young adults with complex medical needs who are now entering the offices, emergency departments, and hospitals of “adult” providers. In some cases, they come as no surprise, with well-developed transition goals and plans, and the transfer of care from pediatric to adult providers is relatively smooth. On the contrary, and as is often the case, they arrive with a complication, after a lapse in care, and with no records or limited personal knowledge of the details of their own medical history.

Although there are a growing number of providers who devote their careers to the emerging adult with chronic disease and interest in the field of transition medicine is ever-increasing, education and training of providers on the key elements of transition is lacking. Furthermore, although the subspecialist has a par-

ticular interest in successful transition of adolescents and young adults, the general pediatrician plays just as important a role in this process and this is often underappreciated.

In this two-part *Pediatric Annals* issue, we explore the pillars of transition medicine and learn how they apply to chronic diseases like cystic fibrosis, type 1 diabetes, and HIV, before ending where we started—educating future providers on how to do this well. Next month in part 2 of the issue, we’ll see how two residency programs have incorporated transition consultations into outpatient and inpatient settings and revisit specific diseases where successful transition is critical—autism, congenital heart disease, and allergy and immunology.

The first article, “A Review of Interventions Aimed at Facilitating Successful Transition Planning and Transfer to Adult Care Among Youth with Chronic Illness,” by Dr. Jill Weissberg-Benchell and Jenna B. Shapiro discusses the key pieces of a successful transition process: the transition coordinator, clinic, and program. The authors highlight a theme that is carried on throughout a pediatric patient’s transition to an adult care model—communication is key. Be it at the personal interface with the transition coordinator, an obvi-

ously important relationship, or at the clinic or programmatic level, patients (and their parents) want to know what is happening, with whom and when, and for what reason. In this article, we learn about the interventions of the last decade aimed at improving transition, often by encouraging communication of all stakeholders, with the goal to increase independence and autonomy for the emerging adult with chronic disease.

The second article, “Current Concepts of Transition of Care in Cystic Fibrosis,” by Drs. Ajanta Patel, Maria Dowell, and B. Louise Giles explores the decades-long transition success story of cystic fibrosis (CF) care. The authors acknowledge that despite a most suitable model—specialized providers caring for a well-defined disease that spans the age chasm—there is still much to be learned about, and improved upon, regarding CF transition. Specifically, despite there being over 100 CF centers in the United States in which transition systems are in place or in development, there is still much variability in transition methodology and an unmet need for improving patient benchmarks; perhaps this will occur via a novel digital toolkit launched for CF programs in 2015.<sup>1</sup> The third article, “Models of Care for Adolescents and Young Adults

with Type 1 Diabetes in Transition: Shared Medical Appointments and Telemedicine,” by Dr. Jennifer K. Raymond describes how telemedicine and shared medical appointments, or group visits in which several teens with type 1 diabetes (T1D) see a provider simultaneously, can be used to improve T1D transition. Not only are they effective tools that increase access to care and encourage the development of independence and health responsibility, these two models can be combined in a novel way to teach teens (and providers) about transition. It turns out that web-based video conferencing is cool!

In the fourth article, Dr. Mary Ellen Acree introduces us to the ever-changing field of chronic HIV, in “Transition of Care for Youth with HIV.” In this piece, she describes the social stigma that plagues the life of

an adolescent with HIV and how that affects his or her own transition to an adult care model. She acknowledges that nearly 50% of teens with perinatally acquired HIV have a mental illness and this can clearly affect the transition process. What’s more, people with HIV are more likely to be underinsured and face more economic hardships than their peers.

The final article, “Using Quality Improvement in Resident Education to Improve Transition Care,” by Drs. Sofija D. Volertas and Rita Rossi-Foulkes describes their experience in developing and implementing a quality improvement project that spans multiple patients over many generations in an internal medicine-pediatrics residency program. In their early experience, patients in need of chronic care and a prolonged and thoughtful

transition can still achieve successful transfer of care in a busy, academic medicine-pediatrics practice in which providers frequently come and go during/after training.

From successful transition interventions to implementation in real-world chronic disease and residency training programs, we hope you sit back, think about how transition affects your practice (because it does), and perhaps learn something. Let’s face it—we’re getting older and so are they. Ready or not, here they come!

#### REFERENCE

1. CF R.I.S.E. website. [www.cfrise.com](http://www.cfrise.com). Accessed April 25, 2017.

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## About the Guest Editors

**Jeremy Nicolarsen, MD, FACC**, completed medical school and his Internal Medicine-Pediatrics residency at The University of Chicago. From there, he went to Denver, CO, to complete a combined “Med-Peds” cardiology fellowship in Pediatric Cardiology and Cardiovascular Disease (adult cardiology) while additionally completing 19 months of training in the care of adults with congenital heart disease. He is now the Director of the Providence Adult and Teen Congenital Heart Program in Spokane, WA, and with his team, has created (and always continues to develop) a transition program for adolescents and young adults with congenital heart disease (CHD). Dr. Nicolarsen is passionate about this vulnerable population and has participated in the American College of Cardiology efforts to improve transition for teens with CHD and hopes to continue to work with his colleagues in the adult CHD community to improve the continuous care of these patients.

**Jill Weissberg-Benchell, PhD, CDE**, is a pediatric psychologist and a certified diabetes educator with over 25 years of research experience and clinical work with children, adolescents, and their families. She is a Professor of Psychiatry at Northwestern University’s Feingold School of Medicine. She has published numerous research articles and offered workshops and lectures addressing issues such as improving self-management behaviors, family adaptation and coping, building adolescent resilience, the use of technology (continuous glucose monitor, pumps and the artificial pancreas), and transitioning from pediatric to adult care. Dr. Weissberg-Benchell has co-authored two books, one that focuses on transitioning from pediatric to adult care, and another that centers on working with adolescents with type 1 diabetes.