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Book Review

Lisa I. Iezzoni, *Making Their Days Happen: Paid Personal Assistance Services Supporting People with Disability Living in Their Homes and Communities*. Temple University Press (2021 Dec 15), ISBN-13: 978-1439920763

The release of Dr. Lisa I. Iezzoni's new book, *Making Their Days Happen*, could not have come at a more ideal time. For decades, there has been an impending crisis in the availability of workers who provide personal assistance services (PAS) to individuals with disabilities and older adults in the community. Powerful demographic and societal trends are contributing to the crisis, including an aging population, increased needs for home- and community-based services, and a marginalized workforce primarily consisting of women of color who make poverty wages and have few worker protections and benefits. However, COVID-19 has exacerbated the crisis and as with many equity issues, brought to the forefront longstanding systemic issues. In the book, Dr. Iezzoni delves into these complex issues through a combination of policy analysis and qualitative inquiry to advance our understanding and help inform potential solutions.

What separates this book from the previous work are the voices of people with disabilities receiving supports and direct care workers providing supports. The book draws heavily on the lived experiences and perspectives of 21 consumers receiving paid PAS and 20 PAS workers. Interviews were conducted in 2018, prior to the onset of COVID-19. The majority of consumers interviewed were middle aged with years of experience using PAS from a variety of different workers. Similarly, the majority of PAS workers had

worked in the field for some time with different consumers. Rich stories and quotes are adeptly used throughout the book that bring life to the issues and illustrate the real-world impacts that policies have on the lives of individuals. The level of openness and the sharing of incredibly personal details about the interpersonal relationships between consumers and workers, really attests to Dr. Iezzoni's qualifications as a disabled researcher and trust she established with participants.

The book is organized into five parts. Part I provides relevant policy and social context. Some of this section may seem basic to readers who are more familiar with the independent living movement and disability rights. However, it provides foundational information for a broader audience who might not be as familiar. Key policies related to community living are discussed, including the Rehabilitation Act, Americans with Disabilities Act, and US Supreme Court *Olmstead* decision. A chapter is devoted to payment of PAS, primarily focusing on the primary payer, Medicaid, and structure of home and community-based services. Finally, key workforce and labor policies are discussed, including the Fair Labor Standards Act, state nurse practice acts, and immigration policies.

Part II provides an overview of consumers receiving PAS, the types of supports provided, and workers providing these services and supports. Key demographic information is provided on consumers and workers from national surveys and labor statistics. While somewhat limited to physical activities due to the composition of the sample, narratives from consumers help vividly illustrate common tasks performed. Stories from workers, coupled with previous survey research, highlight motivations for why individuals

become personal care attendants and practical realities they face, including often working multiple jobs, low pay, and few opportunities for advancement. Part III describes the two main approaches to providing PAS: agency-directed and self-directed models where individuals have more control over hiring, firing, and managing their workers. A balanced approach is taken discussing the pros and cons of different models and key policy issues with each model.

Part IV provides incredibly rich insights into the interpersonal complexities of receiving and providing PAS. The juxtaposition of consumer and workers perspectives is unique. Most of the previous work, and policy advocacy for that matter, have tended to focus solely on the perspectives of one group or the other. Moreover, few previous studies have broached the nature of relationships between consumers and workers. As Dr. Iezzoni points out in the book, even some early pioneers of the independent living movement aimed to separate the receipt of assistance with activities of daily living from any feelings of emotion. The book breaks new ground in discussing complicated interpersonal themes related to intimacy, conflict, trust, respect, and physical and emotional safety. A chapter is also devoted to the paid nature of the relationship and systemic policies often out of the control of consumers and workers, such as low-wage reimbursements and electronic visit verification. Valuing similarities and differences in the perspectives of consumers and workers helps us understand just how interrelated the issues and potential policy solutions are.

The book concludes with Part V that examines practical aspects of obtaining PAS today and looks ahead to the future. The challenges in finding workers and strategies in finding a good fit are shared. The story of a 20-year-old college student is used to hit home a multitude of real-life issues he currently faces and how these challenges will likely become even more daunting in the future. Dr. Iezzoni is honest here: there is “no tidy ending.” Yet, she provides a range of thoughtful policy options that advocates have coalesced around that would move us forward in improving access to home and community-based services and a quality workforce. She leaves us with a glimmer of optimism and an incredibly poignant story of hope, that of Michael and Nelita.

Overall, *Making Their Days Happen* is an extraordinary work that I hope reaches a broad audience of policymakers, advocates, providers, scholars and others. It is accessible to those within the field of disability as well as outside. As many advocates and policymakers at the local, state, and federal levels grapple with the workforce crisis, this book advances our knowledge of the issues and the

real-life impacts of policies on the people's lives, hopefully leading us forward.



MAKING THEIR DAYS HAPPEN

Paid Personal Assistance Services
Supporting People with Disability Living
in Their Homes and Communities

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