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INTEGRATED CARE FOR CHILDREN WITH DOWN SYNDROME: PERSPECTIVES OF
CAREGIVERS AND HEALTHCARE PROVIDERS ON RESOURCES, GAPS IN CARE,
AND THE VALUE OF DOWN SYNDROME CENTERS

A Dissertation

Presented to the Faculty of
Graduate School of Leadership & Change
Antioch University

In partial fulfillment for the degree of
DOCTOR OF PHILOSOPHY

by

A. Nicole White

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March 2022

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This dissertation, by A. Nicole White, has
been approved by the committee members signed below
who recommend that it be accepted by the faculty of
Graduate School of Leadership & Change
Antioch University
in partial fulfillment of requirements for the degree of

DOCTOR OF PHILOSOPHY

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ABSTRACT

INTEGRATED CARE FOR CHILDREN WITH DOWN SYNDROME: PERSPECTIVES OF CAREGIVERS AND HEALTHCARE PROVIDERS ON RESOURCES, GAPS IN CARE, AND THE VALUE OF DOWN SYNDROME CENTERS

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The facilitation of healthcare for people with Down syndrome offers a unique challenge to healthcare systems. Both caregivers and healthcare providers often need to navigate a complex system of specialties in care, resources, and expertise to optimize treatment and care plans for children with Down syndrome, whose needs vary widely and extend beyond the walls of a hospital. This study identified seven domains of care based on conceptualizations of integrated care in the literature: coordination, communication, continuity, dignity, information, shared decision-making, and resources. Groups of survey items intended to capture these domains were used with a sample of caregivers and healthcare providers to explore the medical and social gaps that limit the facilitation of whole-person care for children with Down syndrome. This study further examines differences in caregiver perceptions of care depending on whether their child has received care in a Down syndrome Center (DSC) or specialized clinic. Finally, the study examines the level of the burden associated with navigating the health care system and critical resources for caregivers while examining the amount of stress healthcare providers experience in facilitating care for people with Down syndrome. Key findings in this study indicate the value of DSCs for both caregivers and healthcare providers about integrated care values and satisfaction in care delivery. Additionally, the study identifies critical gaps in resources and awareness of the challenges caregivers and healthcare providers experience in managing and coordinating care. These findings have implications for future directions in improving healthcare for children with Down syndrome. The full text of this dissertation is embargoed until April 1, 2023.

Keywords: leadership, Down syndrome, integrated care, Down syndrome clinic, Down syndrome center, caregiver, healthcare provider, leadership, centered care, healthcare, specialized care, specialized clinic, healthcare systems, healthcare access, IDD, Ds, intellectual disabilities, burden, social gaps, medical gaps, disability