

Modular care: Down syndrome care that focuses on patients

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For every patient coordinated and personal care is a must. When several professionals and/or organizations are involved in providing care to a

patient, mutual coordination and collaboration is crucial. But in practice coordination is not always up to par. In his doctoral research Vincent Peters shows how cooperation can be at its best when care is provided by a modular care organization. This he illustrates using the provision of health care to children with Down syndrome. On Wednesday, December 9, 2020, he defends his doctoral thesis *Turning modularity upside down: Patient-centered Down syndrome care from a service modularity perspective* at Tilburg University.

Down [syndrome](#) is a complex congenital medical condition that results in developmental delay. Children with Down syndrome often need simultaneous treatment for a variety of medical conditions, and this requires adequate collaboration and coordination between a range of care professionals (such as pediatricians, physiotherapists, and family doctors) and organizations (hospitals, allied care providers, and healthcare institutions for mentally impaired people). In the Netherlands, the care provided to children with Down syndrome is organized on a multidisciplinary footing (Down teams). However, patients and their parents indicate that in practice this [multidisciplinary approach](#) does not yet fully meet their needs and concerns.

Focus on the patient

In his doctoral thesis, Peters addresses how the care provided to these children is organized, and why. Currently, every hospital organizes its care differently and that is not always conducive to high-quality care. Parents of children with Down syndrome often do not understand why care is organized differently, nor where they should go for care. Peters also explores the potential for improvements, with the ultimate goal of arranging collaboration and connections across disciplines and organizational boundaries in such a way that the focus is on the patient.

"Vincent Peters' doctoral research contributes to the outpatient clinics

for people with Down syndrome evolving into even higher-performance specialized clinics. His research also helps secure greater recognition and firmer ground for these outpatient clinics in the Dutch healthcare system. This is important, because it means our children with Down syndrome are given even better care, and that certainly adds to both their quality of life and to that of their support circle," said one parent of a child with Down syndrome.

Collaboration with hospitals

In doing his doctoral research, Peters collaborated with the Jeroen Bosch Hospital, the Elisabeth-TweeSteden Hospital, the Máxima MC, and the Spaarne Gasthuis. The combined medical and organizational knowledge of the two supervisors Prof. Dr. Bert Meijboom (Endowed Professor "Organization of Chain Care" at Tilburg University) and Prof. Dr. Esther de Vries (Endowed Professor "Chain Care" at Tilburg University and Coordinator Data Science in the JBZ) has been experienced as very valuable because it provides insights from different angles.

He examined the care provided to children with Down syndrome from a modular perspective. Modular organization of healthcare entails dissecting the care provided into components and modules. Rather than routinely providing the full care package, care professionals deliver these components based on their patients' specific wishes and needs. The aim of this modular approach is to match as closely as possible the care available and the individual patient's need for care.

Multiple applications

The findings reported in Peters' [doctoral thesis](#) are not only relevant to [children](#) with Down syndrome, but can also be applied to the delivery of care to people with other complex medical conditions, such as cancer

and multiple sclerosis, because patients with these diseases, too, rely on care provided by a wide range of professionals and organizations.

Provided by Tilburg University

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