

Research Project

Capacity: An Outdated Concept? An Ethical Investigation of Decisionmaking in Children

Third-party funded project

Project title Capacity: An Outdated Concept? An Ethical Investigation of Decisionmaking in Children

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Organisation / Research unit

Ethik / Institut für Bio- und Medizinethik

Department

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Status Completed

This project is intended to lead to a better understanding of capacity and decision-making in pediatrics. Children are deemed incapable on a daily basis, losing the right to make decisions regarding their own health. Clinicians have difficulties understanding how it can be diagnosed reliably and they do not have a clear idea of what having capacity exactly means. Therefore, the first objective is the philosophical analysis of the concept of capacity in the bioethical literature by mapping its importance within research and health care ethics and by clarifying its conceptual relationship with other key notions in bioethics, such as competence, autonomy, informed consent and vulnerability. Such a clarification is needed due to the lack of philosophical clarity about the concept. The second objective is to show that the concept of capacity is normatively relevant, in the sense that the way in which it is traditionally understood within much of the bioethical literature is too restrictive and places children within a default position. For this purpose, the various assumptions underlying the common reading of capacity will be discussed more in depth. The third objective is to develop a new approach, based on the work of capabilities theorists Sen and Nussbaum, which is able to provide a more nuanced account of children's participation in health care decisions. The hypothesis at the centre of this project is that capacity cannot do justice to the fact that the ability to make decisions is not merely a question of personal (individual) responsibility and performance, but that its development and exercise requires extensive social scaffolding and support. A key thesis of this project is that the capabilities approach can offer a strong basis to develop guidelines to foster the involvement of children in health care decisions. The fourth objective is to improve the quality of ethical discussions of pediatric decision-making, both among the lay public and health care professionals. Moreover, it is hypothesized that the conceptual clarification of capacity, competence and capability will lay the foundation for more pertinent assessment test in pediatrics.

Financed by

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Published results

3659210, Ruhe, KM.; De Clercq, E.; Wangmo T.; Elger BS., Relational Capacity: Broadening the Notion of Decision-Making Capacity in Paediatric Healthcare., The Journal of Bioethical Inquiry, Publication: JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

3868205, De Clercq, E.; Ruhe, K. M.; Rost, M.; Elger, B. S., Is decision-making capacity and "essentially contested" concept in pediatrics?, 1386-7423 ; 1572-8633, Medicine, Health Care and Philosophy, Publication: JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

4514437, De Clercq, Eva; Streuli, Jürg; Ruhe, Katherina; Elger, Bernice S., "Undoing" Capacity: The Capability Approach in Pediatrics, 0031-5982 ; 1529-8795, Perspectives in Biology and Medicine, Publication: JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

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