

To flourish

In search for a good life for people with a severe intellectual disability and serious behavioural problems

Summary

Background

The emergence of the citizenship concept results in an increase of attention for the quality of life of people with an intellectual disability, improvement of their living conditions, and encouraging participation. Discussions on the principles and the implementation of citizenship (inclusion, living in society, self-direction, rights) usually do not refer to people with severe intellectual disabilities and serious behavioural problems. The possibilities and conditions for citizenship for this specific group have only been researched to a limited extent. They mainly stay on institutional grounds under institutionalised care; they live as members of a group and are approached as such. In these types of settings, caregivers are often confronted with various barriers in their attempt to include the citizenship principles into their daily practice.

The capability approach, developed by Nussbaum, links the notion of citizenship to care ethics. This approach implies a broad concept of citizenship: individuality and rights on the one hand, and care and recognition of dependence on the other. Nussbaum advocates a society in which all people are offered the possibility to live their lives in dignity. The capability approach consists of promoting conditions (external capabilities) to enable the best possible development of individual potentials (internal capabilities).

The goal of this study is to investigate whether the capability approach also provides prospects for full-fledged citizenship of people with severe intellectual disabilities and serious behavioural problems.

Research question

The research question addressed in this study is: How can the principles of citizenship in general and the capability approach in particular be applied to people with severe intellectual disabilities and serious behavioural problems? How should care be organized, and how can society make room for the unique character of these people in order to enhance their quality of life and respect their dignity?

Against the background of this general research question, the following sub-questions have been formulated:

- What are the principles of the capability approach and in what sense can they provide a concrete formulation of the citizenship concept and the care ethics approach?
- What is good care for people with severe intellectual disabilities and serious behavioural problems from the perspective of relatives, professional health-care providers and managers, and what are the conditions and strategies required to realise this care in practice?
- How can the capability approach serve as a source of inspiration for the practice of caring for people with severe intellectual disabilities and serious behavioural problems?
- How can this practice be changed in such a way that it will actually contribute to the quality of life and dignity of people with severe intellectual disabilities and serious behavioural problems?

Method

In order to answer the research questions, both a theoretical and a practical study have been conducted. The theoretical part consisted of a literature study in which the relationship between citizenship and care ethics (in particular the capability approach) has been investigated. The empirical part consisted of three sub-studies. The first study is a Grounded Theory analysis of interviews with relatives, caregivers and managers, to gain an understanding of their experiences and views regarding good care for people with severe intellectual disabilities and serious behavioural problems. The second study is a further analysis of the interviews, based on elements of the capability approach. What light do the experiences and views of relatives, caregivers and managers shed on the possibility of realising capabilities in the actual practice of caring for people with severe intellectual disabilities and serious behavioural problems? The third study is an in-depth case study, using an action research approach, elaborating on the process of change of Anja, a person with an severe intellectual disability and serious behavioural problems.

Findings

The theoretical study shows that the citizenship perspective, care ethics and the capability approach are complementary and mutually enriching.

The Grounded Theory analysis of the interviews shows that good care aims at realising the core value of 'flourishing'. Against the background of this fundamental value, caregivers try to find a balance between encouraging enrichment through participation in daily life and providing appropriate safety and security.

The analysis of the interviews from the capability approach perspective shows

that this approach can provide direction to the care for this specific target group. It also shows that the capabilities need further specification. Due to the seriousness of their limitations, people with severe intellectual disabilities and serious behavioural problems are less able to develop their internal capabilities, as a result of which external capabilities are of much greater importance to them than to other people with a disability.

The case study shows that the focus of caregivers changed from control to support of activities in everyday life. Caregivers increasingly provided care based on relational security (connection) instead of technical security (restriction of freedom). The study shows that even within an intramural setting, change can be achieved by facilitating reflection and dialogue.

Recommendations

In the care for people with severe intellectual disabilities and serious behavioural problems as well as in society at large, more attention should be paid to factors that encourage flourishing. Family participation, organisations, care facilities and service providers should facilitate more participation in everyday life. Furthermore, in society, tolerance and respect for difference are important.

In order to encourage flourishing, attention should be paid to: (i) the transition into society, (ii) appropriate housing supply, (iii) facilities in society, (iv) development of the potential of the person with an severe intellectual disability and serious behavioural problems, (v) the role of relatives, (vi) the role of fellow citizens, and (vii) the role of caregivers.

Conclusion

From this study it can be concluded that the principles of citizenship in general and of the capability approach in particular, can be applied to care for people with severe intellectual disabilities and serious behavioural problems. The concept of 'flourishing' can help make the citizenship approach applicable to this group as well.