

Possibilities and dilemmas of independence: life stories of people living with intellectual or mental health disability

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Background: Although Swedish disability policy and legislation have been based on citizenship and the rights to live and participate as members of society for more than 20 years, people with disabilities still encounter barriers to independence in everyday life. This paper, based on a study designed in collaboration with disability organizations, explores possibilities and dilemmas of independence in the life course of people living with intellectual or mental health disability.

Methods: 20 in-depth interviews with persons with intellectual or mental health disability were conducted, using either a semi-structured topic guide or pictograms. The interviews covered several areas in life, such as; housing, parents, friends, work, spare-time, economy and health. A thematic analysis revealed recurring themes in the interviews.

Results: Discrepancies between political discourse and the obstacles to independence that permeates everyday life constituted dilemmas throughout the life course. This was particularly evident in accounts of work and relationships. Having an employment and an income was described as central for living independently. However, some aspects of employment such as going in and out of temporary employment schemes, contributed to feelings of powerlessness. Friends, partners and parents could be a support when striving for an independent future, but some relationships also contained aspects of control and limitations. In response to these dilemmas, some informants developed empowering strategies; but, others yielded due to a sense of hopelessness and lack of control.

Conclusions: Informants experienced lack of independence in important areas in life, however, what was perceived as most problematic varied between individuals and during the life course. These findings point to the importance of developing forms of support that departs from individual wishes and visions for the future, and not, as currently, from a predefined idea of what independence is.