
Family life with children and personal assistance – a three party perspective.

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Abstract

The introduction of personal assistance in Sweden in 1994 showed an ambition by policymakers to ameliorate the conditions of persons with extensive disabilities. The legislators expressed a vision of autonomy and integrity, and that persons with considerable disabilities should lead a life like others, including having a family and being a parent. Personal assistance has expanded over the years and in 2014 about 16 100 persons were granted personal assistance in average 124 hours per week. Nearly one quarter of the assistance users live with a partner and about 4 percent with one or several children. The study explores a three party perspective on personal assistance; the users', the family members' and the personal assistants' point of view. What does it mean either to live with personal assistance or to work as a personal assistant when there are children in the family?

The study is based on interviews with six women and two men with extensive physical disabilities and their family members. Four female and one male personal assistant with experience of working in families were also interviewed. The personal assistants have no connection to the interviewed families. Simmel's theories about dyad and triad are found to be useful to understand what happens in different constellations with users, family members and personal assistants.

Having personal assistance enhances the possibilities for parents with disabilities to be active parents. It also relieves family members in different ways. The presence of personal assistants may however restrict the privacy of family members'. Working in families means having several parties to consider and it may be difficult to know where to draw the line as to what the tasks of the personal assistants are.

Keywords: Personal assistance, family life, parents with disabilities, personal assistants, dyad, triad.

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