Organization and impact - self-advocacy in Sweden

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Abstract

Aim: In the last decades young adults with intellectual disability (ID) have begun to self- organize in order to increase power over their own lives and remove barriers to their social participation in society. This study aimed to further understand the new forms of self-advocacy in Sweden by describing and analyzing the characteristics and organization of the movement and its activities and by analyzing the meaning for the members and the influence for identifications, self-determination, relations and daily life. **Method**: A national mapping identified more than 60 self-advocacy groups. Case studies of 4 organizations, selected to reflect organizational diversity, were conducted using interviews, focus-groups, observations and document review. **Findings**: Variability in organizational forms and size, show how self-advocacy groups can be everything from totally independent to be controlled by parents or staff. Despite this the interviews showed that the self-advocacy groups have an important impact on the lives of their members. Participation in self advocacy groups open up for new roles and identities and strengthen control over every-day life. Self-advocates understand self-advocacy primarily in terms of their participation in the self-advocacy group and through the value they experience through achieving independence, control and social connections with each other and outsiders. The most independent groups have in addition to that mounted resistance to society's views and treatment of people with intellectual disability and the traditional ways of delivering services. **Conclusions**: Self-organized activities can be understood in terms of resistance against the society's views and treatment of people with ID and against traditional ways to offer and organize support and service. The self-advocacy movement in Sweden is slowly beginning to influence the way society regards people with intellectual disability, and reshape support services to enable greater service user control.

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