Influence and participation in leisure- and democratic activities for people with intellectual disability.

Introduction to research question
Policy and practice in the welfare society stress that all citizens should be included, but in reality people with ID are often excluded. Research has shown that it is harder for people with ID to be included in democratic and leisure activities, which can affect their own life situation with loss of belonging and exclusion as citizens. Persons with ID do not always vote in the parliament election and are seldom represented in the political democratic system. Their own voices are seldom heard, neither in research nor in the community, which may increase risk of exclusion. The purpose of the study was to examine how to involve and increase influence and participation for persons with ID in a Swedish municipality. The theoretical framework was Arnstein’s ladder of citizen participation with eight levels; manipulation, therapy, informing, consultation, placation, partnership, delegation and citizen control.

Description of Methods Participatory action research where seven adults with intellectual disability, age 17- 30 years, were co-researchers. The study design was performed according to the Action research spiral. The co-researchers took part in two individual interviews, three focus group interviews and three actions. The actions were integrated in the general municipality program and consisted of three events, Influence Cafés, focusing on inclusion in leisure, culture and democracy. The method Talking Mats and photographs were used during the interviews to support dialogue. Data analyses were descriptive- and thematic analysis.

Results Preliminary analyses are reported. In the individual interview, before the actions, three themes became visible: in “more activities”, the co-researchers expressed lack of adaption of activities; “we and the normal” expressed lack of participation in the municipal life compared to other citizens. With the theme “barrier”, the co- researchers expressed a perceived lack of information. According to Arnstein’s ladder the co-researchers did not reach the information level. In the focus groups interviews the theme “additional adjustment” emerged, which included perception about how to do adjustment of the actions. In the individual interviews after the actions, the theme “belonging” emerged. The co-researchers expressed a feeling of belonging and pride, as such the level partnership according to Arnstein’s ladder was reached. After the actions, the co- researchers took part as voters in the Swedish parliament election and felt a higher inclusion in the municipality. In the municipality there has been increased interest and confidence among municipal workers about reaching out to persons with ID and adapting activities that better fit persons with ID.

Brief discussion and implications For persons with ID to be fully included in welfare society and feel that they belong, persons with ID need to know what opportunities that are available and how to get their voices heard. Arranging Influence Cafés in a municipality helped people with ID to get information, to come in direct contact with politicians and officials, and to get their own voices heard about questions that concern them in the community. The actions also influences the municipality in an inclusive direction.

Keyword
Intellectual disability, participation, inclusion