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# **Social participation in theory and practice: The perspectives of people with a spinal cord injury**

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# Challenges in the research literature on participation

- **Challenge:** How to bring in a perspective of participation in society with a stronger emphasis on human agency, i.e. what people do, how they perceive themselves, and how they are perceived by others as citizens in different roles and societal contexts.

# Aim and research design of study

- **Aim:** To explore the concept of participation in society based on the experiences of people with spinal cord injury (SCI).
- **Data:** 31 in depth interviews in Norway.
- **Analysis:** Qualitative content analysis (MAXQDA).
- **Theoretical framework:** Two narratives of social participation (activity/capability) vs. theory with an emphasis on social recognition.

# Participation in society as it is understood by informants with SCI

- Activity and engagement (23:31)
- Autonomy (19)
- Normality and normal conduct (17)
- Socializing with others (16)
- Work and education (16)
- Contribution to society (13)
- Equality and rights (13)
- Accessibility (9)
- Organisational work (6)
- Active individual role (6)

# Activity and capability

- The conventional view of participation in rehabilitation & ICF is partly supported in the interviews
- Household chores relatively peripheral topic in the interviews.
- The informants understanding of participation in society is mainly regarded as a positive and active process with a focus on being connected to others and socially connected as a person and social citizen.

# Activity and capability

- Most study participants lived active social lives on par with the general Norwegian population.
- The main obstacle is employment after SCI with a substantial share not in employment (60%) but with many potentially willing and capable to work outside the labour market.

# Participation and integration in society with a strong link to social recognition

- **Key narratives:** normality, having a job and not to deviate from "people in general".
- **Strong emphasis on** the importance of social recognition, human rights and the importance of being a productive citizen (current or previous contributions as workers).

# Conclusion and implications of study

As Occupational therapist we need a broader and more complex notion of:

- society than found in static notions and models of participation roles, domains and environment

- how social institutions, norms and structures contributes to or prevent people to live rich and "flourishing lives".