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

Annelie Schedin Leiulfsrud, OTR, PhD, Associate Professor
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).
Conclussion 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".