
De-institutionalization in Sweden: lights and shadows from the perspective of disability organizations

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Résumé

The principle of independent living and the right to community inclusion is expressed in art. 19 of the UN *Convention on the Rights of Persons with Disabilities* (2006) and reinforced in its *General Comment* n. 5 (UN 2017) which promote/ensure equal opportunities to all persons with disabilities (PwD) to choose *how, where* and *with whom* to live, not limited to the place of residence but including all aspects of person's living arrangements.

The UN intention is reflected in the Swedish disability policy, especially from 1994 in the Act concerning *Support and Service for Persons with Certain Functional Impairments* (the so-called LSS reform) which promote equal/full participation in society and empower PwD to live independently through the fulfillment of intentions for good living conditions (von Granitz et al. 2017). This legal mandate influenced the dissolving of residential institutions for PwD and the establishment of community living support measures (Katoda 2014). Despite this, there are still significant shortcomings in the possibility of participation and self-determination for PwD, especially those with intellectual/multiple disabilities (Jormfeldt&Tideman 2021; Talman et al. 2021).

Starting from a recognition of the Sweden's welfare system/policies, this proposal aims to critically reflect on de-institutionalization underling a double aspect: a. lights/shadows that the right of the PwD to choose their home has taken on in recent decades; b. further changes necessary to make this right real. It utilizes fieldwork data from semi-structured interviews with nine representatives of the main Swedish disability organizations collected during an internship in the Independent Living Institute in Stockholm (ILI). Using a *thematic data analysis* (Green et al. 2008), the work aims at exploring the reality of and the issues on de-institutionalization and community living in Sweden and discussing on today and future's challenges with risks for re-institutionalization as gathered a document-manifest published by ILI.

References

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