

INCLUSIVE CITIZENSHIP OF PEOPLE WITH MILD INTELLECTUAL DISABILITIES

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Keywords: inclusive citizenship, intellectual disability, participation, stigma, relationships

ABSTRACT

Advisory bodies for Dutch government policy witnessed a growing demand for (long-term) care in the last decade, especially by people with mild intellectual disabilities (MID). This sudden rise is often explained by a so-called 'increasing complexity' of societal structures causing exclusion. But what does this really signify? The question arises; how is inclusion/exclusion experienced by people with MID? Where do fits or misfits occur?

We start off with the premise that everyday life activities offer important indicators for studying citizenship. Hence, we studied the lived experiences of people with MID regarding inclusive citizenship, mainly in the public domain of society. Doing groceries, getting around by public transportation, getting in contact with others or performing sports and hobbies at local initiatives are some examples. Through this scope we explored how disabilities are repressed, conquered, preserved or constructed by societal/social barriers.

Through ethnographic fieldwork 33 persons with MID were followed in a variety of daily activities (in the Netherlands). The study was set up with a co-researcher with MID and in collaboration with People's First group 'LFB Wolvega'. Topics of observations and interviews were related to prevailing definitions of inclusion on three levels: participation, belonging and relationships. Participation was studied through observation and interviewing. Photovoice was applied for reflection on feelings of belonging, the same way drawing and eco-mapping provided insights in relationships and networks. In addition, network members and social professionals were interviewed.

Some main results are:

Participation:

- Although people create diverse and creative ways in participating, a variety of barriers for participation were found confirming the notion that mild intellectual disability is shaped through marginality and experiences of exclusion. Opportunities for participation were frequently found to be daily renegotiated and confirmed.

Belonging:

- Stigma performs an important role in feelings of (not) belonging. Many respondents were not comfortable with the label MID and tried to avoid the use of it because of perceived stigma. Nevertheless, some respondents creatively took advantage of the label.

Relationships:

- Weak ties (neighbors, shop personal etc.) can offer significant meaning to people's daily life.
- Also social professionals regularly have an important role in successful participation as they fulfill multiple roles and deliver diverse forms of support.
- Strong ties (family and friends) on the other hand are sometimes unsteady. Situations of abuse, extortion and patronizing behaviour were encountered.

The ways in which people (with MID) daily give shape to citizenship are dynamic, messy and rather unpredictable. Possibilities for participation, feelings of belonging and relationships are often rapidly altering, mutually intersecting and tied to the experience

of stigma. Therefore, inclusive citizenship is not an outcome which one can easily aim for but should be understood as series of parallel processes of fits and misfits which are frequently renegotiated and confirmed. In order to be more effective in stimulating inclusive citizenship for people with MID, both policies

aiming for inclusion and activation should take in account the dynamic character of these processes. To grasp the messiness of daily life experiences of inclusive citizenship, future research should employ a micro-sociological, relational approach to intellectual disability with attention to intersectionality and diversity.

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