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# EPISTEMIC INJUSTICE AND CONDITIONED EXPERIENCE: THE CASE OF INTELLECTUAL DISABILITY

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**Abstract:**
People with intellectual disabilities are commonly seen as "non-adult others" and as persons of limited credibility, and this view has implications in a number of areas. In this paper, the empirical findings from an interview study focused on lived experience are analyzed in relation to the intersections of intellectual disability and gender. In light of Fricker's (2007) work on epistemic injustice, and in recognition of Anderson's (2012) emphasis on the importance of transactional and structural injustice, a novel aspect of epistemic injustice is provided: as a consequence of conditioned lived space. The social identity of intellectual disability position persons thus identified to belong to a segregated and marginalized group. Although guided by the ambition to care for and protect this vulnerable group, structural transactions provided by the welfare system run the risk of simultaneously depriving individuals of both the experiences and the hermeneutical resources necessary to interpretatively frame and make sense of their limited situation and lack of possibilities – and thus from interacting epistemically in fruitful ways. A key structural feature of the epistemic injustice towards the group is shown to be a lived experience that to a large extent is conditioned by the constructions of disability and gender.

## Introduction

As a group, people with intellectual disabilities are commonly seen as eternal children, as "non-adult others" (Priestley, 2003), and thus as persons of limited credibility (Carlson, 2010). However, the empirical findings of a recent interview study that focused on the lived experience of middle-aged persons with intellectual disability in relation to work, leisure time, and living

conditions (Lövgren, 2013) give us reason to challenge the notion of their limited credibility to be solely the result of their individual impairments. The aim of the present study is to analyze those interviews anew in light of Fricker's (2007) work on epistemic injustice and in recognition of Anderson's (2012) emphasis on the importance of structural and transactional justice.

**Intellectual disability in relation to the social environment**
Intellectual disability (hereafter referred to as ID) is a medical diagnosis that at the same time implies a social categorization with extensive structural and social implications for the individual. According to AAIDD (*American Association of Intellectual and Developmental Disabilities*, 2016), ID is characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This paper discusses IDs from a social-contextual perspective (Shakespeare, 2004; Söder, 2009). This includes taking potential (mis)matches between individuals and their environments into account, that is, the intersection between an individual's capability, situational demands, and the support that is provided to the individual. This means that limitations in personal strengths "may be a result of lack of support and limited opportunities to participation" (Ferguson, Ferguson & Wehmeyer, 2013, p. 253).

In Sweden, support to people with considerable and permanent functional impairments is regulated by the *Act Concerning Support and Service for Persons with Certain Functional Impairments* (the Swedish LSS Act, 1994), which is a powerful piece of legislation that provides rights to extensive services for people with disabilities. The aim of this act is to ensure good living conditions and to promote full participation in community life – in short, to provide for a life similar to ones led by non-disabled people. Examples of support provided by the LSS include residential arrangements with special services for adults, daily activities, personal contact, and personal assistance. Having support according to the LSS is generally regarded as being to the individual's advantage and gives persons with disabilities opportunities to achieve a life they could not manage or achieve by themselves.

However, when institutional arrangements provide support for people with disabilities, these arrangements within the particular setting of ability/disability demarcates "users" as "others" (cf. Gubrium & Holstein, 2001; Järvinen & Mik-Meyer, 2003; Söder, 2000). To receive and use the support of disability services means, according to Sandvin, Söder, Lichtwarck, and Magnussen (1998), taking part in settings where normalization is implicitly embedded in practices and activities. In this arrangement, one group of people – the employed service providers - is seeking to maintain "normal" behavior and life patterns for another group - the residents with intellectual disability (see also Söder, 2000). But, what is considered a "normal life" is a complex question. It is commonly constructed upon common-sense assumptions as a consequence of the service providers' interpretations of how a "normal" life should be accomplished, whereby the support comes to contain aspects of control and disciplining (Sandvin et al., 1998; Söder, 2000). Further, the construction of these social spaces is supported by "an ideology of ability" (Siebers, 2008, p. 88).

There is a close relationship between being identified as "disabled" and being in need of special support. Solvang (2000) describes this relationship in terms of the following three simultaneously existing discourses: *normality/deviance, equality/inequality*, and *us/them*. The first discourse is rooted in a medical perspective where normality and deviance are treated as binary concepts. The second discourse is a material and economic discourse on welfare state efforts to provide democratic participation and access to material goods. The third discourse is a discourse where questions about identity and identification emerge, and this discourse provides possibilities to celebrate differences by embracing what is constructed in the normality/deviance discourse as a stigma (cf. Goffman, 1971/1990; Solvang, 2000), for example, through self-advocacy groups. In similarity with other social movements, protesting against social structures that position them at the margin, a growing number of young adults with ID, in recent decades engage in self-advocacy groups to increase control over their own lives (Tideman & Svensson, 2015; see also Ferguson et al., 2013; Olin & Ringsby Jansson, 2009). However, despite an increasing number of self-advocacy groups, engagement in such

groups is for the majority not as yet an option for a number of reasons. For example, lack of accessibility due to reasons of regionality, generationality and functionality (Mallander, Mineur, & Tideman, September 2014). Further, and of special relevance for this paper, is Skeggs' (1997) argument that as long as people dis-identify with a group that others have assigned them, it is unlikely that they will act politically based on membership in this group.

Thereto, once categorized, the group of people with ID has seldom been, and still is not, seen as "*knowing subjects* in their own right" (Carlson, 2010, p. 15). Paternalistic attitudes towards people with ID have marked them as "eternal children" or non-adults. This has worked against an articulation of their experiences, and further, has encouraged skeptical attitudes concerning their credibility (Atkinson, 2005; Atkinson & Walmsley, 2010; Carlson, 2010). This is also reflected in research, for example, when questions on reliability have been raised in connection to even the possibility of interviewing people with ID. Questioning of such research is then based on a questioning of the credibility of the informants, that is, their credibility is being questioned even when it concerns their own experiences (cf. McNally, 2002).

**Epistemic and hermeneutical injustice**
The ways in which persons with ID are ignored, neglected, and judged as lacking with regard to trustworthiness can be understood in terms of *epistemic injustice* (cf. Fricker, 2007). Fricker argues that beyond a structurally and systematically unfair distribution of information and education, there exists an *epistemic injustice* "consisting, most fundamentally, in a wrong done to someone specifically in their capacity as knowers" (2007, p. 1). Epistemic injustice includes both a lack of *testimonial credibility* and a lack of *hermeneutical resources*. Having ID is a powerful stigmatizing social identity (Beart, Hardy & Buchan, 2005), and because the lack of credibility in this case usually rests on stereotypical generalizations of the group in question (Goffman, 1971/1990; see also Carlson, 2010) it can be understood in terms of *identity prejudice*, that is, a "prejudice against someone because of their social identity" (Anderson, 2012, p. 165; also Goffman, 1971/1990). An

example of lack of testimonial credibility based on identity prejudice might be when staff in disability care settings question what persons with ID report simply because of their ID.

A lack of hermeneutical resources, on the other hand, refers to situations where there is "a gap in collective interpretative resources [which] puts someone at an unfair disadvantage when it comes to making sense of their social experiences" (Fricker, 2007, p. 1). An example might be when one is the victim of a disability-related hate crime in a society where this sort of crime has not (as yet) been conceptualized. When collective interpretative frameworks as hermeneutical resources are not available, some experiences become difficult or impossible to understand and to communicate – even by those experiencing them. Thus the victim might neither identify with being the victim of a disability-related hate crime nor be recognized as such by society.

Further, group segregation along the lines of ability/disability risks creating epistemic injustice through the creation of divided and conditioned social spaces with an uneven distribution of hermeneutical resources. This is in line with what Anderson (2012, p. 171) argues when she regards group segregation along lines of race and class to be the "key structural feature that turns otherwise innocent, if cognitively biased, epistemic transactions into vectors of epistemic injustice".

The consequence of the above is *hermeneutical injustice*, which is always structural as members of a social group "have been prejudicially marginalized in meaning-making activities" (Anderson, 2012, p. 166; cf. Fricker, 2007, pp. 158-159). Furthermore, as Anderson (2012) points out, "the question turns on the mechanism whereby certain knowers [are] unfairly excluded" (p. 166), and how "testimonial exclusion becomes structural when institutions are set up to exclude people without anyone having to decide to do so" (p. 166). One example of such a mechanism is the organization of welfare services by which people with ID are positioned in segregated social spaces and also become socialized in the role as "dependent deviants" (cf. Sauer, 2004; Söder, 2000).

**Method and participants**

The empirical material consists of notes from several field visits at day centers, sheltered workplaces, and group homes along with transcripts from a total of 35 qualitative semi-structured interviews with seven men and six women, median age 52 years (range 38 - 60 years), who are the objects of disability services in Sweden. Nine of the thirteen participants have supported accommodation. Twelve of the participants took part in daily activities, while one man worked for a subsidized wage and had annual contact with disability services. No matter how the daily activity was organized, all participants considered it, and talked about it, in terms of it being their employment.

The interviewees all belong to a generation "betwixt and between", as they have grown up during an era of a transformed welfare/disability service system, the closure of the major institutions, and an emerging welfare market where service users according to present-day political discourse are conceptually defined as being consumers with the individual responsibility to demand services (but with no possibility to choose the content of such services) (Lövgren, 2013; Ringsby Jansson & Olsson, 2006). However, these kinds of transitions are, in relation to everyday life, relatively gradual processes, and earlier traditions still color both the assumptions of people with IDs and the service system that is in place today (cf. Shah & Priestley, 2011; Söder, 2000).

The study was approved by the *Regional Ethical Review Board* in Umeå (reference number 09-060 Ö), and voluntary participation, along with information about the purpose and use of the interviews, was carefully explained before each interview. All participants were individually interviewed two or three times, each time for 30–90 minutes. Themes such as everyday life, work versus leisure, retirement, and ageing were highlighted. The interviewer made an effort to follow the intensity in the interviewees' engagement, and to support the communication through gestures and small sounds. Notes from the field visits were used to contextualize and enhance the understanding of the interviewees' everyday lives.

**Meaning-making: Self, work, and socio-spatial mobility**
We will here discuss three examples from the study that elucidate hermeneutical injustice where the interviewees have

been marginalized in meaning-making activities in understanding themselves, in working life, and with regard to gendered ranges of mobility. All three examples highlight a novel aspect of Fricker's (2007) account of epistemic injustice, by shifting focus to the actors (in this case persons with ID) in relation to a conditioned lived space.

**Understanding oneself in the world – having "been subject to care"**

A striking finding was the way the interviewees framed the support they received without relating this support to disability at all. Even though all but one claimed to not have any disability, they still framed their activities within a discourse of users of support and services. Having a disability was described as having considerable drawbacks and as being in a problematic situation and was in many ways categorized as Other (cf. Järvinen & Mik-Meyer, 2003; Goffman, 1971/1990). In line with this, the interviewees did not see themselves as having (special) rights to support; instead, they displayed somewhat paradoxical apprehensions of losing their present home and work. This is contrary to Swedish studies of younger generations with ID, more often engaged in self-advocacy-groups, that tend to embrace their position as people with ID when it comes to claiming rights (cf. Olin & Ringsby Jansson, 2009; Tideman & Svensson, 2015).

The interviewees had relatively vague notions of their position in the service system and of how and why things are the way they are. They had, to varying extents, long been included in settings such as special schools, group accommodations, and daily activities and had, for as long as they could remember, "*been subject to care*". For Henrik, this was due to chance, almost like fate, while Anna recalled that a psychologist decided that she should go to a special school. Johan assumed that he was put into a special school because he previously asked a sibling for "*too much help*". Barbro defined herself and other persons who live in the group home as "*users*". She used the term mainly to describe a position within the disability service system where some persons are users, i.e. persons who receive support, and some are staff, i.e. persons employed to provide support. In sum, all of the interviewees referred to situations where support is

included without accounting for it or in other ways explaining it in terms of the judicial grounds for receiving support. In fact, the vast majority seemed unaware of having received support due to their intellectual disability. As compared to a younger, well-informed, generation of people with ID who refer to and identify themselves as belonging to this category (cf. Lövgren, 2013, pp. 169-171), this is noteworthy. Our interpretation is that these members of an older generation have to a large degree not been informed of their intellectual disability. This might be an effect of caring for with a wish to create a protective capsule against a possibly hurtful knowledge of belonging to a stigmatized and marginalized category in society (cf. Lövgren, 2013; Todd & Shearn, 1997).

Although the subject position as a user can be interpreted as taken for granted, the main requisites of the position of obtaining support were not included because the participants did not refer to disability as a condition, neither as a requisite for the support they received nor for their rights to receive support (cf. Gustavsson, 1999; Olin & Ringsby Jansson, 2009). People with disabilities were described by the interviewees as people different from themselves, as people with more pervasive problems ("*persons who cannot get dressed*", "*eat by themselves*", etc.), and who were thereby represented as "the Other". Johan explained that he is faster and more capable: "*I'm better, you know, and good at talking, you know*". Another man, Bertil, stated that he does not want to socialize with the other residents in the group home because they "*have a disability*", and unlike him "*cannot be out on a job*". Anna gave another illustration of how disability is understood when she doubts a workmate's statement that he has an intellectual disability:

> Axel is his name, he says he is [intellectually disabled] but it doesn't show, I don't know, maybe he has something but [...] I mean, he eats neat, I mean, some they just sit and spoon it in and it's not pretty, but he eats with knife and fork, he eats so damn fine, you know.

This is quite a struggle for Anna, she really likes Axel and wants to be friendly with him – but not if he has a disability. She prefers

to spend time with "*normal people, those who can talk and behave*". Even if Axel states that he has a disability, Anna doubts it because Axel does not meet her expectations of people with ID.

These narratives illustrate how, through socialization, attitudes about what is considered to be normal or deviant, as well as the hierarchy between these putative binary positions, have been internalized. Seemingly unaware of having been ascribed to be members of this category, and allocating this categorization to "the Others", the interviewees do not see any relationship between their own personal characteristics and the perceived characteristics of people with ID. This is an example of dis-identification, which refers to not seeing oneself as belonging to the category to which one has been allocated (cf. Skeggs, 1997). As a consequence, this dis-identification leaves the person with a lack of adequate hermeneutical resources, for instance to claim one's right for support when needed, such as provision of a group home and daily activities (Lövgren, 2015). Our analysis thus reveals an epistemic injustice in terms of a lack of hermeneutical resources to make sense of and handle their situation in relation to the welfare system.

**Working life: Paradoxical discourses**

The second example of epistemic injustice, of not having access to a discourse that reflects central elements and prerequisites of one's experiences, was given through the interviewees' narratives of their work. The "work" they referred to is daily activity, a welfare service according to the LSS to which people with ID are entitled. The LSS guarantees that individuals who are excluded from the labor market have the opportunity to engage in meaningful occupation, and for their participation they receive a compensation payment of 30–35 SEK/day (which equals the cost of a cup of coffee in the local cafeteria) on top of their disability pension. The LSS does not regulate the individual's performance, nor is it an obligation to attend the daily activity. However, the interviewees referred to obligations and to particular requirements to be fulfilled in order for them to maintain their jobs. They also expressed concerns about being able to retain work in a strained labor market. These concerns of potential unemployment are paradoxical because they do not

adequately reflect their position as rightful users of disability services.

In their narratives, work was portrayed as the hub around which much of their life was organized, structured, and given meaning. Being at work was related to structure, a sense of meaningfulness, and values such as social interaction and identity (cf. Esser, 2005). In their descriptions the interviewees came forth as being competent and self-determined adults, and especially Kalle and the other male participants described their competence in relation to their work: positioning themselves as mechanics, janitors, shop assistants, etc. However, the analysis revealed the participants' uncertainties about their entitlement to work. The interviewees said that they were often worried that their workplace would "be closed" (Leif and Johan), that there would be "layoffs" (Bertil), that "you never know if they have to make cuts" (Mikael), and that "it's very tough in the labor market right now" (Arne). Inga and Barbro stated that they have to take care of their work and fulfill their obligations; otherwise they might "be dismissed". Not fulfilling work duties, such as not attending or not doing it right, was associated with getting fired, unemployment, and the difficulties of finding a new job: "if you are older, it's hard to get any job at all" (Arne) and "when you are 50, 60 years, they will not hire you" (Anna).

We suggest that some of their concerns about and experiences of their duty to meet work requirements can be seen as stemming from an embedded disciplinary dimension of normalization within disability support (cf. Sandvin et al., 1998). The very idea of "normal" everyday life relies on normative beliefs, also such as concerns work: that it is "normal" to go to work every day and that when having a job one should take care of it. Furthermore, these concerns can be seen as an illustration that their work (daily activity) is situated "at a crossroads between the labor market policy and social policy", which creates a "situation with internal contradictions" (Olsen, 2009, p. 216). On the one hand, the participants express obligations to meet the requirements adopted from the labor market, while on the other hand the participants are excluded from the labor market and their work efforts are not acknowledged by society as "real work" (Lövgren, 2013; cf. also Lillestø & Sandvin, 2014).

Another salient illustration is given by Arne's account of the impossibility of being on sick leave. He describes how he, unless very seriously ill, avoids being on sick leave due to the loss of salary. However, because Arne has a disability pension and is working at a daily activity center, he will not lose any salary. On the contrary, despite the loss of compensation payment he would save the greater expense of travelling 60 kilometers round-trip to the activity center. Thus Arne is referring to a part of the social insurance system from which he is excluded. He has been left to make sense of his own situation with a general discourse of working life, which is not adequate for describing or explaining his own situation – positioned as he is in disability services version of work (cf. Olsen, 2009).

These narratives reveal the experiences of taking part in a general discourse of working life – and the societal norms of what one is expected to live up to. However, to try to understand one's own experiences through the use of a general discourse of working life, while at the same time being deprived of any real opportunity to take part in general working life, is to live a contradiction that we argue is psychologically oppressive (cf. Bartky, 1990). Further, the lack of hermeneutical resources to make sense of one's circumscribed and conditioned lived space (cf. Siebers, 2008), also adds to a lack of the testimonial credibility that is generally afforded people with ID because their explanations and narratives tend to not "make sense" (cf. Anderson, 2012).

**Gendered ranges of mobility: Circumscribed experiences**
Access to vehicles and to public spaces is an illustrative example of how the interviewees' lived experiences are conditioned by social constructions of disability and gender. Cars, mopeds, buses, and bicycles are important for the ability to independently take part and interact in the community. However, in our study it was only the men who were independent users of vehicles, thus the possible range of mobility and experiences of social contacts was gendered. For the women, the lack of similar mobility meant circumscribed socio-spatial experiences.

The car is of significant importance for Arne – not only for being able to commute to work, but also to get away from home for a while, maybe to make a stop to have a coffee and interact with others. The bicycle is a symbol of freedom for Johan, Henrik, and Mikael. It facilitates getting to work, getting around, and taking part in what happens in the community. Even riding the bus functions as a tool for contact with the rest of society. Bertil and Mikael are well acquainted with the city buses, both when it concerns timetables and the drivers. Mikael often sits near the driver in order to communicate and offer assistance. But social interactions are not only related to use of vehicles. Johan, Kalle, Henrik, and Bertil all talked of relations and interactions with neighbors, shop owners, and other persons in the neighborhood. Thus they all have the opportunity to develop weak ties in the local community, a kind of social belonging that in studies of inclusion are highlighted as important for creating a sense of participation (Ringsby Jansson, 2004, pp. 59, 61-62).

None of the women own or use bicycles; instead, they walk or take the bus straight to their daily activity. All of them have experiences of riding bicycles as children, but unlike the men they describe it as difficult and dangerous and that the traffic is hard to handle. When asked, the staff of the activity center confirmed that, generally speaking, the female users of disability services seldom use or have access to bicycles, mopeds, or cars.

However, as stated earlier, the use of vehicles is not the only way to get around and make social contacts. But warnings and prescriptions can work as social circumscriptions as well. Several of the women referred to the need to be cautious and be wary of certain situations, such as traffic, being out late at night, or certain groups of people such as drunken men. Some of the women had been bullied on the bus or scared by unknown followers' steps behind them, and these experiences have led them to reduce their range of mobility even further. Even though some of the men described similar threatening situations, this does not seem to have had a similar restricting effect on their use of public space, and this illustrates how gendered notions influence the use of and access to socio-spatial arenas. To ride a bicycle or a bus just for the fun of it gives the men the

opportunity to explore and take part in their local community. Girls and women, however, have not as a rule been encouraged to take part in an extended socio-spatial domain (cf. de Beauvoir, 1949/2006, e.g. her chapters on "Childhood" and "The young girl"). Further, in spite of good intentions to protect, advices and cautioning not to hurt themselves on part of parents and staff, has also worked to discourage the women from using the full potential of their physical abilities (cf. Young, 1990/2005, pp. 32-42).

To sum up, the women had limited access to social arenas outside of disability services, and none of them talked about relations to persons or activities in the local community. The interviewees' range of mobility *and* the adjunct opportunity to acquire experiences and to develop weak ties in the community is thus clearly conditioned by a gendered construction of disability. Especially the conditioning of the women's lived space has led to a more severe lack of resources in the form of experiences and social interactions, and the social knowledge gained in such experiences. This reflects a gendered and uneven distribution of hermeneutical resources, which further adds to the epistemic injustice that people with ID face.

**Discussion**
Despite its stated social-political aim of participation and equal rights, the institution of disability services risks resulting in a segregated context. These normalizing procedures often work through a demarcation of differences accompanied by a devaluation of certain differences. Guided by the ambition to care for and protect vulnerable groups, structural transactions such as the practices of support in disability services run the risk of simultaneously depriving individuals of both experiences and adequate discourses as hermeneutical resources necessary to interpretatively frame and make sense of their situation and (lack of) possibilities (cf. Anderson, 2012).

Our results highlight the consequences of the pervasive segregation and conditioned lived space for people with intellectual disabilities fostered by the disability services, in an era when deinstitutionalization and an empowerment-movement through self-advocacy are supposed to have lessened these practices. In the practices of daily activities, a "normalizing"

discourse of working life and its conditions seems to have been adopted, thereby leaving the interviewees with a mismatch between lived experience and discourse. In the absence of adequate hermeneutical resources they are left to make sense of various situations as best they can with the discourses they have at hand. Furthermore, if, as in this case, one does not identify oneself with the social identity one is given by society, it will make it even harder to make sense of one's limited position.

    We have further shown how a key structural feature of epistemic injustice suffered by people with ID is a lived social space that to a large extent is conditioned by the constructions of disability and gender, through two levels of oppression. Firstly, the mechanisms of exclusion, physical as well as othering, embedded in institutional segregation leads to hermeneutic injustice, in ways that are reinforced by gender. Secondly, the mismatch of social experience within the disability services and the interviewee's adoption of discourses such as the language of a "normal work life" result in a testimonial injustice. Thereby they are partly excluded from the possibility to interact epistemically in fruitful ways, which adds to their lack of testimonial credibility. Further, both levels of oppression harm their testimonial credibility and feeds into an already existing prejudice. Given the lack of credibility accorded their own experiences by the wider community, the psychological oppression which people with ID endure must become a matter of social, political and ethical concern.

**Concluding remarks**
By drawing upon Fricker's (2007) work on epistemic injustice, and in recognition of Anderson's (2012) emphasis on the importance of transactional and structural injustice, we have provided a novel aspect of epistemic injustice; as a consequence of segregated and conditioned lived space. A pattern, which is reinforced by gender. The implications of our theoretical contribution extend to other oppressive social categorizations such as race, ethnicity and class, which limit and condition social space. As Fricker (2007) states, it is essential to have the possibility to articulate one's experiences and to contribute as a producer of knowledge because this is part of what defines personhood. Thus, to promote the possibility of articulating the

experiences of a subjugated group of people and to let these experiences be taken into account, is an important step towards preventing dehumanization. The empowering benefits of having one's experiences acknowledged and accounted for in adequate, non-pejorative, frames have been reported in contemporary research focused on a present generation of young people with ID who engaged in self-advocacy groups.

## Acknowledgements

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