Editorial: Social inclusion

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This special issue had its origins in Cambridge, England, at two events hosted by the Social Inclusion Research Group led by Dr. Claudia Schneider and Dr. Adriana Sandu. The workshops we took part in were convened by Prof. Shula Ramon and organized around the theme of citizen involvement in health and social care. The workshops were very lively and involved the sharing of information and ideas from colleagues based in Norway, Finland, Slovenia, Croatia, Italy, and England—all of whom were researching in the broad area of citizen-led issues related to "social inclusion and exclusions." The final workshop focused on issues relating to mental distress and social inclusion, and thus the idea for this volume crystallized. The call for papers was an open one based on the ideas expressed in the workshops, and the final selection of accepted articles reflects accounts predominately from authors currently based in Canada and the United Kingdom. We would like to thank all of the contributors to this volume and also all the participants in the workshops; we particularly extend our thanks to Shula, Claudia, and Adriana, without whom this issue would not have been conceived.

As noted in our call for papers, the concept came to the fore following the focus on social exclusion in the context of poverty and social deprivation in France and was subsequently adopted across the European Union. Within the context of mental health specifically, the key discourse on exclusion and inclusion is a cultural one, where poverty is a reflection of stigma and othering, where deprivation of citizenship rights happens frequently. It can also be perceived as spiritual one, with focus placed on meaning and significance of relationships and finding meaning and purpose in the way we spend our lives. Nonetheless, much like the concept of recovery, much focus was placed on employment as a key "meaningful activity." This is one of many contested aspects of this concept, which wasn't developed as a "top-down" policy priority alone, but from a complex interaction between policy-makers, activists, and theorists (Spandler, 2007).

Despite such complex and multi-faceted origins, it didn't receive much scrutiny and critical analysis on the grassroots level, to infuse it with thoroughly thought out and agreed upon meaning in day-to-day professional practice—similar to many other concepts-come-policy imperatives. It turned into a shorthand void of understanding of its history and complexities embedded within it.

The articles in this special issue offer insights into its grassroots understanding. However, they don't illuminate a path for the implementation of a new and emerging concept. Instead, it can be argued that they offer an archive of the ways it was implemented and lived in practice, as one soon to be replaced with other policy concepts. For example, in the United Kingdom, the local authorities and the NHS trusts are to start implementing the Care Act 2014, with a core focus on *well-being*. Within the Act, its definition presents a cocktail of elements from safeguarding to participation. In parallel, colleagues in Canada propose alternatives within Mad Studies (LeFrancois, Menzies, & Reaume, 2013, p. 17), scrutinizing and abandoning the dualities of "madness" and "normality" to try to offer and implement real alternatives to the mainstream mental health services that nest themselves "in the immediate practicalities of everyday human struggle."

Nonetheless, the core experiential issues expressed in each of the accounts in this issue endure and present a challenge to activists, practitioners, and policy-makers to work toward tackling the power imbalances and structural barriers that impede a more equitable society.

The very purpose of research is to move elements from our background and horizon, the context we live unreflected within, to the centre of our attention. This denotes that these elements have to be transformed into something tangible. At least in this field of study, being tangible means that the elements we want to investigate must be perceptible by means of words. In a naive perspective, words are labels that we need in order to communicate. It is thus no wonder that the Sami language have more snow-related words than the Norwegian and Swedish languages, since snow is more important to the Sami people and their business than to the remaining Scandinavian population.[1]

The ways in which things are framed and understood might also be said of the politics of language used in this field. Each of the contributors has chosen their own way to express their understanding of this field and their experiences within it; consequently we find the terms used to explain this area range from *mental illness* or *mental health* to *mental distress,* and terms for people using services include *consumers*, *service users*, *people with lived experience*, and *citizens*.

In research we find that even though words are understood to be a minor media in general communication (e.g., Mehrabian, 1971), they are crucial to our thinking. For instance Luria (1976) and Hutchins (1995) demonstrated how our cognition is a cultural process whereby language and other means for communication are interwoven in, and shaped by, our surroundings and what we consider as important in them. Ong (1982) even demonstrated how our thinking is shaped differently in oral cultures than in those based upon writing. The words that we use to describe a

[1] One example of these narrow and specific words is "slamkedit," which describes the air space between the snow and the ground, formed when the snow is melting from the ground up, being compressed when one passes over on skis, while the snow itself not is compressed (Ryd & Rassa, 2001).

phenomenon therefore carry cultural connotations that shape our thoughts. There is therefore an important difference between developing categories, concepts, and theories about inanimate objects and developing such constructs about human beings and their actions. While inanimate objects are unaffected by constructs describing them, these constructs easily influence how humans think about themselves (Skjervheim, 1996a, 1996b). This takes place whether the humans learn about the categories, concepts, or theories themselves, or experience the consequences in social interaction with humans who have learnt about them. When the researcher communicates findings (or codes, categories, and preliminary theories for that matter), these can become part of the consciousness and self-understanding of the actors in the investigated field, colouring their past, present, and future (Skjervheim, 1996b). Thus, when we took on the work of this special issue, language was addressed as important, and the editorial board of the journal and the flyer for this issue asked authors to be sure that pathologizing language was not used.

The Editors had, on this basis, long discussions about whether to ask authors to standardize the language being used but ultimately have decided against this, as different terms are also reflective of cultural understandings (both nation states and experiential position) and of the cognition that the researchers have undertaken themselves. We therefore, rather, urge the reader to look at the essence of the articles and the authors' intentions as well as their positionality.

We begin our volume with a powerful experiential narrative by **Joanna Fox,** who presents us with a very personal account of how the different roles and aspects of her identity as service user, senior academic, researcher, and social worker influence and impact on her interactions with mental health professionals. The article pivots on the narration of two key stories which illustrate how professionals responded to her, first as a parent with a diagnosis of schizophrenia and then in her professional roles, highlighting both defensive and responsive practices. The article reflects the arguments developed in our second paper (Kaminskiy) that it is possible for both individuals and collectives of people labelled with psychiatric diagnoses to feel simultaneously power and powerlessness, depending on their personal and professional status and on the value accorded (or otherwise) to their experiential knowledge. Joanna highlights the particular role that narrative research has in capturing "lived experiences" derived from service user expert knowledge as well as the potential of experiential knowledge expressed in stories and narratives to influence professional frameworks of practice and confront the stigma and social exclusion widely encountered by people who have been given a diagnosis of schizophrenia.

The paper by **Emma Kaminskiy** focuses on the theoretical concept of power in the context of shared decision making (SDM) for psychiatric medication management practice. SDM is an important tool for recovery-oriented practice in mental health services. Drawing on the theories of Lukes, Foucault, Archer, and Gaventa the paper highlights the diverse structural components of the UK contemporary mental health system, their intersections, and the resultant opportunities for people using these services to take back control and enact their agency. Central to the rebalancing of power between practitioners and service users,

Emma argues, is the need to equalize the value of service users' experiential knowledge alongside more traditional "medical" forms of knowledge in encounters around medication. To date, the concept of power and how it is enacted and shared has received relatively little attention in the wider SDM literature, yet it is fundamental both to the principles and models of SDM more generally and to the recovery model within mental health services, more specifically. Kaminskiy argues for the acknowledgement of the impact of mental health service users' knowledge and agency and the more nuanced understandings of the intersection of experiential knowledge with dominant biomedical understandings; and she presents a framework for understanding power for collaborative psychiatric medication management practice that depicts power on three intersecting planes at the system (macro), relationship (meso), and interaction (micro) levels.

The next paper by **Coltman, Gapka, Harriott, Koo, Reid, and Zsager** is led by researchers with lived experience who form part of a Lived Experience Caucus linked to the Toronto site of the At Home/Chez Soi project. They present their findings from a project that involved the secondary analysis of data collected from a project based in Toronto related to mental health and homelessness. The Mental Health Commission of Canada At Home/Chez Soi project has taken a housing-first approach, providing approximately half of the project participants with housing as well as services that are tailored to meet their needs, while the other half have access to the regular supports that are available in their community. The caucus informed all aspects of the wider project with their perspectives and advice based on their direct experience of homelessness and use of the mental health system before developing their own research project on which the article is based. The caucus-led project analyzed purposively sampled 18-month follow-up interviews from the At Home/Chez Soi Toronto evaluation in order to explore how the participants discussed and experienced community integration in their day-to-day lives. Their research illuminates the complexity of community integration experienced by participants as a non-linear process that is positively impacted by working toward the self-determination, independence, and empowerment of the project participants.

The powerful intersections between the law and psychiatry and the impact that this has on people with mental distress who are summonsed to the court accused of committing a crime is the topic of the next article by authors **MacDonald and Michaud.** Their study, inspired by institutional ethnographic methods, is based in a mental health court (MHC) situated in Montréal, Canada. The study was multi-method, integrating quantitative and qualitative methods. The authors report on the perceptions and experiences of the primary stakeholders in the court, first and foremost the people who had been accused of a crime (N=20) as well as key actors (N=10) who made up the multidisciplinary team involved in the court, supplementing their findings from participant observation and a quantitative review of court files. The authors argue that MHCs promote a special form of social exclusion that is based on the social profiling of people who have been accused. They target risky behaviours and reward individual mobilization efforts through their promotion of autonomy and self-regulation and their emphasis on psychiatric interventions. These new "socio-medico-juridical practices" bridge two systems of

domination, psychiatry and the law, in an effort to "de-marginalize" people with mental distress who are accused along three axes of intervention—juridical, therapeutic, and individualization and responsibilization.

The article by **Shula Ramon** traverses a number of complex intersectionalities in the lives of women who experience intimate partner domestic violence (IPDV). Drawing on European data Shula highlights the traumatic impact of IPDV on women, the complexity of their responses to it, its impact on their identities, and their resulting social position in Europe. Prevalence statistics indicate the high rate of mental distress among IPDV women victims, and the types such distress takes. The negative social attitudes toward women of IPDV and the distancing that occurs among some workers in mental health and domestic violence services are explored as psychosocial intersectional contexts to highlight understanding for the ways in which "victims" internalize forms of social exclusion and to illuminate the seemingly contradictory behaviour of women experiencing IPDV to disclosure and to living with and leaving the perpetrator, in these contexts. The article concludes with exploring the significance that the new meaning of recovery in mental health could have to women experiencing IPDV and as an approach that has the potential to provide a positive contribution in enabling them to move from being victims to becoming survivors, while taking into account several related intersectional connections.

Our final paper offers us a new model in which to conceptualize the relationship and dynamics between social inclusion and exclusion. Building on many of the themes reflected in the above accounts the joint Anglo-Canadian paper by **Hunting, Grace, and Hankivsky** presents their Intersectionality-Informed Model focusing their example on mental health and use of substances. The thorny definitional issues of "social inclusion" are tackled with the authors arguing that to date—despite the frequent references to social inclusion within research and policy, with inclusion being seen as integral to addressing stigma and discrimination—there is a lack of consensus with respect to the meaning of social inclusion and how this concept can be applied to understand the broader social contexts that influence health and inequity. Their proposed new model addresses what the authors see as key limitations of current conceptualizations of social inclusion and highlights the ways in which their proposed model extends, improves, and complicates understandings of social inclusion, in particular through the addition of understandings of resilience and resistance. They argue that their inquiry-based model is a necessary precursor to better addressing the complexities of stigma, discrimination, and social exclusion, and in so doing, to promoting social inclusion and equity.

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