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Let's tango! Integrating professionals' lived experience in the transformation of mental health services

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Let's tango!

**Integrating professionals' lived experience
in the transformation of mental health services**

Simona Karbouniaris

Let's tango!

Integrating professionals' lived experience in the transformation of mental health services.

Simona Karbouniaris

PhD dissertation, Leiden University Medical Center, the Netherlands

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Let's tango!

Integrating professionals' lived experience in
the transformation of mental health services

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*In memory of Wouter and all others who couldn't sufficiently
profit from care ...*

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Preface

'It's all about the truth of things. What is the truth of illness, what is the truth of addiction? What is the truth of mental health or mental illness? And of course, to deal with something and to help people, you have to know what their truth is. But I just find the truth in itself of value and I must say that my personal development has been the search for truth. I am not saying I have got there.'

'Only in the presence of compassion will people allow themselves to see the truth'
Gabor Maté, 2022

Dr Gabor Maté is a Hungarian-Canadian physician and author who has a background in family practice and a special interest in childhood development and trauma. He is renowned for his compassionate approach towards addiction and mental distress and is one of the few who translated the language of trauma into concepts such as 'truth', 'wounding', and 'healing'.

Although trauma has different faces, Gabor Maté's words legitimise the journey of many who end up in care facilities, either as a professional or on the other side, as a service user. He underlines the essence of subjectivity and at the same time refers to the long-lasting effects of childhood adversity on later health and well-being, and the complex aftermath of trauma manifesting in all sorts of disbalances.

Research in mental health and addiction in the last decades advanced by combining expertise from different scientific fields, including the voice of those with lived experiences with mental illness. It contributes to embracing more diversity and plurality in existing and new facilities. By acknowledging the interplay between biological, psychological, social and spiritual dimensions, the road towards a fully embodied practice is paved.

The collective wisdom of Gabor Maté and many other experts on trauma, therapy, recovery and spirituality have made these pages and my own life and work profoundly richer. Over the years I have written a series of auto-ethnographic reflections, that touched upon my lived experiences with attachment and trauma wounding. These personal insights have been interwoven throughout the entire manuscript as a source of knowledge and hopefully help the reader to consider the different perspectives and layers that I tried to capture in my work. These reflections also reveal my biography, experiences, normative persuasions and frames that inevitably have played a role in the process of sensemaking and interpretation. I want to acknowledge my limitations as a higher educated, European, female, non-clinician, researcher with a strong preference for a non-pathologising framework for all forms of mental disbalances. Researchers are not value-neutral, and these reflections can be read as an attempt to illuminate how all aspects of myself are at play in my research.

My wish is to inspire and invite all wounded healers to step forward and embrace opportunities to engage relationally in encounters with those who are struggling today.

Utrecht, March 2023, Simona Karbouniaris

A note about language

'Let's tango' symbolises the dance of freedom of professionals with lived experiences with mental distress. It also touches upon the ability to use embodied knowledge in existing power dynamics and to be creative and improvise.

Throughout the text, in this dissertation, the terms 'service user', 'user' and 'patient' are used to refer to those making use of (mainly) mental health services. I am aware of certain groups' preferences for alternative terms such as 'client' or 'survivor'. I have tried to adapt to the perspective of those involved in the different studies and have expressed my personal preference in my reflections. More on this matter follows in the dissertation itself. Additionally, the terms expert-by-experience, peer (support) worker and peer expert are interchangeably used for those who work in mental health services without having obtained their credentials in the traditional manner. Obviously, this does not mean that experts-by-experience, peer (support) workers and peer experts don't work in a professional way. On the contrary, many of them have received training.

Given that traditional professionals have started harnessing experiential knowledge in addition to their core profession, i.e. professional knowledge acquired as social worker, nurse, humanistic counsellor, psychologist, or psychiatrist, I append 'lived experience' as an adjective, e.g. 'professional with lived experiences'.

