SEKEHE

letters on
‘Experiential knowledge’

Co-funded by
the European Union

Dear reader or writer,

On 9 December 2022 we had the pleasure to kick-off the SEKEHE project in Ostrava. During that meeting we concluded that we need to clarify what we mean with 'experiential knowledge'. We opted to create a chain letter and give each partner a month to write.

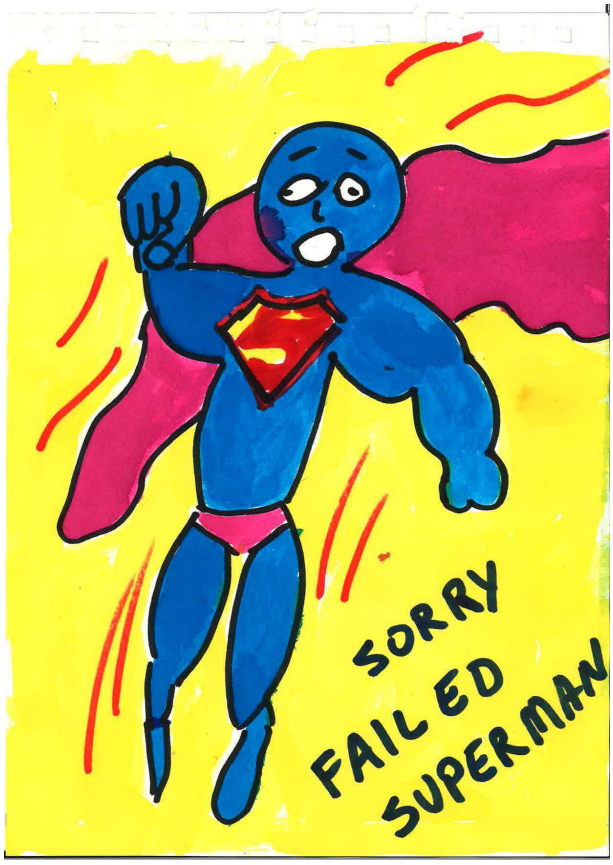
So, these letters are starting points for each partner to share their ideas on experiential knowledge. The goal is to get to know each other while at the same time build a common framework. There are no 'rules' on what you can write and how to write it.

These first letters are an open invitation to engage. You can write your own letter, react on what you've read or pick your favourite colour and write through the existing texts.

Perspectives from EQUALITY//ResearchCollective – Belgium

Dear experience knowledge,

Actually, I don't know if you are doing so well. Officially, you ‘should’ be. You’re expected to be recovered, you ‘must be’ stable, you ‘should be’ able to transcend your individual story and translate a collective of lived experiences into a valuable contribution to society. So that it would become more inclusive and a warm place for all people. Something like that?



I wish you good luck experiential knowledge. Put on your blue superman suit already.

Your knowledge by experience must also stay up to date, stay in touch with what is going on with people in a socially vulnerable position (in this case "the mentally vulnerable"), but don't go so far as to get yourself a ticket for the HIC (cf. High Intensity Care). I said something about stable and balanced. Finding a meaningful way of living with your vulnerability.

Ok, admittedly, at my work, where I am paid to be a ‘Madwoman’ and represent or at least raise the voice of ‘all the crazies’, they don't mind a riot or flipping out. Because they are fine people and probably also have their own moments of mental rioting or flipping outside of the office hours.

But I digress. That's what you have with those ‘Crazies’.

I got to know you when I was on long-term admission and noticed that both patients and caregivers were usually trying very hard to make it work and yet the water was often far too deep. It resulted in frustration, mutual misunderstanding, and irritation. So, I started talking to my fellow patients. About what helped them and what didn't. About what they thought about engaging with an expert by experience (a term I didn't know either and had plucked from a trendy website).

There, I heard many stories of loneliness, not being allowed to talk about the difficult things you have been through and are struggling with. I was staying in a ward where DGT (dialectic behaviour therapy) was the treatment, and we were forbidden to talk about traumas with each other but also with the supervisors. This was because we first had to learn enough skills to deal with it. Unfortunately, just about no one was ever skilled enough to take that step towards trauma treatment.

I asked my fellow patients what they would think about having someone working on the ward who had experienced severe psychological suffering themselves. Almost everyone said that that would help, to feel really understood, but also to experience recognition and acknowledgement, that it might give hope. After having about five such conversations, I was forbidden to have more conversations like this with my fellow patients. For the sake of privacy, they said.

Anyway, when I was supposedly skilled enough and got out, I looked for peer groups in the region. And I ended up in Ghent via Poco Loco with ‘Het Cliëntbureau’ (cf. an organisation that works on recovery and experiential knowledge, run though by and for people with psychological vulnerabilities). It was like coming home. There I met people who were also finding their way in dealing with their difficulties, where you could also make black jokes about us and our situation, where we just saw each other as human beings and not as diagnoses.

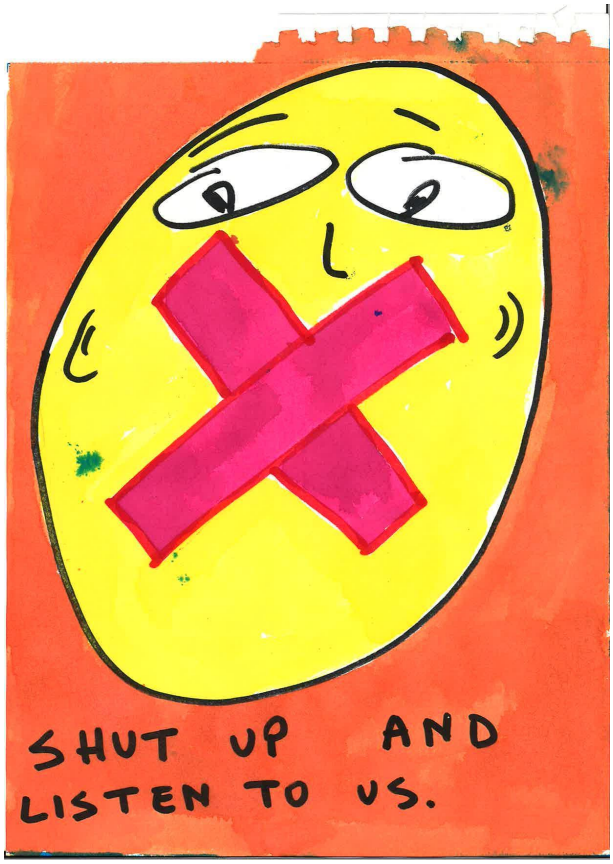
I grew as an expert by experience by sharing a lot, giving trainings, leading a recovery working group together with another fellow sufferer, becoming a Wrap facilitator, volunteering in a mobile team, becoming a patient representative in the ‘PAKT’ (cf. a professional mental health network). I felt I was really growing into that. At the same time, my crazy head did not leave me feeling comfortable and I ended up back in psychiatry much more than I liked, including several times in the closed ward.

Which makes it very clear that they don't have superman suits in my size.

After 10 years, I still wanted to move into paid work, and get back to work as a ‘practice lecturer’. That went wrong after about 2 months, I flipped out, ended up in admissions, I felt so deeply ashamed….

Meanwhile, in the academic workplace, I met Jessica, our boss. She gave me the opportunity to work as an ‘expert by experience’ in Equality//ResearchCollective. Something for which I will be eternally (or at least for a long time anyway) grateful

to her. So far, she doesn't freak out when I freak out, treats me like a human being, gives me confidence... I just have a good boss.



But this little story should not be about my own experience, after all, I need to come to being able to use collective experiential knowledge. I think I can do that, in the sense that I know and can empathise with what mental suffering can mean, what consequences that can have on someone's quality of life, where societal choices (such as particularly low commitment to mental health care) can lead to...

The deinstitutionalisation of care cannot work if the MCT (cf. Mobile Crisis Team) has a registration freeze, that a mental health problem must be solved in a maximum of 18 sessions, ...

Signals and insights that I share at the University of Applied Sciences and in meetings all the time.

It also means that I have absolutely no idea what it is like to have no social network, or a bad roof over your head, no money to pay for private care/ counselling... Coincidence or perhaps other things, I don't know, make that I haven't lived through that, for which I am grateful to my surroundings. Through many admissions, I did see very often in other people the impact that living in poverty can have on your quality of life in general and on your mental health in particular. These are so many elements in a person's life that are too often ignored in healthcare. A

diagnosis might be easier, the individual debt model and all that. Then we don't have to rethink our social structuring. Then we won't start thinking out loud (that's politically incorrect) that it's their own fault. And at Christmas we donate to 'Warmest Week' (cf. a solidary action during the holidays). Hip hip hurrah

That continues to piss me off.

I know I am not representative of the man who stood peeing in my room on the closed ward, not realising that was not really the place. But I do want to let it be known that he exists, that he has as much right to a nice life as anyone else, that he has a very sweet smile. That he is not going to kill you (on the other hand, he is more likely to be killed).

I also get upset that my colleagues find it very difficult to get a real status at this progressive University of Applied Sciences in Ghent because, although extremely intelligent, they do not have a bachelor's degree.

But I am also happy that I can express my anger here, that I can think about alternatives to healthcare, that I work at the only University of Applied Sciences in this country where they are serious about using experiential knowledge equally in teaching and research, and that they are consistent in doing so and seek and find real paths, new paths.

Enough sucking up and praising. I’ve had the honour and pleasure of standing along both sides of counselling, you don't have to convince me what a bridging role an expert by experience can have, how that sum can "translate" things, that it can be fascinating for anyone to employ practice, theory and experience at the same time. I realise that it is a process with many different speeds and that I am often far too impatient. By the way, that has nothing to do with all my diagnoses but everything to do with being Ielde.

Anyway, dear experience knowledge, that's how I've been thinking about it for the last few minutes. Obviously not neatly structured and without ‘Mastertalks’ (cf. ‘highly educated language’). Chances are that I will think differently later on and no one will dare to call me on it. Being crazy has its advantages too.

Maybe until the next one!

Ielde Vermeir

Experiential knowledge, and what it means to me: hereby a stream of consciousness, with the likelihood of that stream being rather meandering.

I find the English term 'Expert by experience' vague, although it slightly strokes my ego if I get to call myself 'expert' in anything. Okay, I am an expert because of my years of experience. But experience in what?

Is it to see suffering first hand, in order to be able to see afterwards? What distinguishes experts by experience from non-experts by experience? Do experts by experience allow clients to see how not to give up hope yet, as a subtle mirror image for courage?

To some extent, I think so. Does that require me to prove and emphasise extra how hard my suffering was, or just the contrary? Am I a shining example if someone thinks: wow, she has had it much harder than that, and she is happy to be alive/ it does mean something/ she has left 'it' behind/ so... I can do that too!'

Or is someone then more likely to think: 'your story is much worse, so I'm acting out.' What conclusion does someone draw? When is it relevant to share your story, in other words when does it give hope and when does it become something purely self-centred?

It peaks when someone (still) completely coincides with his identity as a patient and calls himself an expert by experience. As if that makes my own role suddenly more meaningless, and the concept of experiential knowledge much more hollow. Okay, it is necessary to acknowledge, accept your story and the renunciation in the process, I think then. Decline, re-recovery: moving on, more than being sick. But if that person presents himself as an expert by experience with the main aim of getting recognition for all that suffering, it irritates me. Then you are 'not ready yet', whatever that means. Probably that would be 'being able to distance yourself sufficiently from your own story'. I wonder if I do that and see it especially when, in

my eyes, someone else doesn't. I notice that there is often a kind of suffering hierarchy between expert by experience.

Flashback to training: the lessons around communication to better use your experience. Ever since primary school, this should be compulsory. Still, I got a somewhat uneasy feeling during those lessons: the classics Let-oma-home (advice, judgements, opinions) and Nivea (don't fill in for someone else) are definitely useful to dwell on as awareness-raising. But can we please not take those as hard no-goes and stay a little bit ourselves? Sometimes you only get deeper when you do just smear some level of ‘nivea’ or drag your grandma into it. Depends of course on your gut feeling and bond towards the person you’re working with.

I believe that my experiential knowledge implies that I don't studiously avoid that level, because I want to transcend the 'how do you feel about it', and thus the predictability of the average counsellor. I become insecure when I censor myself from those communication theories, a parrot, as if I were a transparent textbook. When I interpret something, I do so with a question mark after it, or at least with multiple choice questions, including e) other answer. I know from experience (ha) that the best questions are the ones you don't immediately know the answer to. I like to pretend that, in terms of interpreting/filling in for another person, as an expert by experience, I can afford to be just a bit more than the average counsellor. That I just want to distinguish myself by not being crammed into that straitjacket.

So: experiential knowledge means knowing how to use your experience. I notice that in meetings and more policy-oriented meetings, I have a drive to prove myself. When I say something, I deliberately throw in some expensive words, as if I want to prove that I am smart, hoping to be taken seriously and seen as equal (which, of course, mainly shows that I somehow don't experience myself that way). In addition, I phrase my point or reflection in human language, because in doing so I hope to make it as tangible as possible that they are human beings. And so I myself do what I find frustrating with other people: building an ivory tower myself, when I don't even know if there is one. Perhaps words like 'Master Talks' and 'jargon' just

emphasise how non-different we are trying to be, and thus achieve the opposite. Conclusion: I should not use experiential knowledge as an excuse for prejudice.

So, there are still a few words that are spoken in the same breath with the role of experience workers.

‘Bridge builders’. Experts by experience seem to be bridge builders. I find that an oppressive image. Who are those sides, are they social workers, policymakers, or teachers versus clients? As an expert by experience, do you then have to crawl or sprint back and forth, and is there a risk of slipping and falling too quickly to one side? How bitter are you, how realistic are you, can and should you choose? Standing in the middle doesn't build bridges. I'd rather be a road worker.

‘Louse in the fur’. Experts by experience seem to have a louse-in-the-fur function. Brrr. Nobody likes vermin, so it sounds as if experiential knowledge is something you should go to the dermatologist with. ‘Whistle blowers’, it is also sometimes said. Being able to point out what is going wrong, putting your finger on the wound. The latter is effectively easier if you have experience with auto-mutilation.

But it is so easy to criticise with no alternative. On several occasions, I have found that experts by experience have been too militant and become extra bittered and drop out. Mental health care is like a zoo that we, all animals together, want to make more animal-friendly. This is sometimes forgotten; I myself too often indulge in bashing social workers and the system plain and simple. Cynicism pushes away good will, a shame. Experiential knowledge is about patience. It's not about wanting too much, but about wanting too fast.

‘Destigmatising and breaking taboos’ is also what experts by experience seem to do. And I can do that well. Voila. I do not argue, am not inclined to react defensively, but I am. Of course, I am afraid of reactions, but the importance of this being open about my psychic muddle and opening my mouth at appropriate times transcends

that fear. It sounds incredibly conceited to say about myself that I inspire people, but I sincerely believe it when I hear it. And knowing that I can inspire people by throwing myself to the lions is much more exciting than staying scared in my cage.

Though there's still the working point of unlearning the ‘proud nicknames’. Because I'm crazy, I was in the madhouse, I'm from the asylum. You can say that about yourself, because then it's a nickname. I do like a bit of self-mockery to lighten things up, but the line with self-stigma feels too thin these days. Often people don't know how to respond to it either, and breaking taboos with unaccustomed people doesn't work. A fair amount of self-reflection is inherent in experiential knowledge. That too.

I am aware that this stream-of-consciousness is full of contradictions, and effectively meanders as it pleases. Moreover, it became a self-indulgent write-up, which still has very little to do with the original question. They are more reflections than real opinions. I know very little for sure, and I'm quite proud of that. The more I think about it, the more I believe that just this is experiential knowledge for me: questioning everything, first and foremost yourself. Not knowing something and being aware of it is perhaps the most important form of basic knowledge.

Perhaps experiential knowledge means being humble in an arrogant way, and from there engaging in the hope of making other people's lives just a little more bearable. I want to share my knowing and not-knowing with others because I can make others more thoughtful. Ignorance is bliss until someone points it out to you: that's why perspective exists. I want to contribute a piece of perspective, and that is my experiential knowledge.

Evelien Mommerency

Dear knowledge by experience,

I too met you many years ago. Not yet as coordinator of a research centre, but as a driven trainee full of ideals and principles, who had the good fortune to be assisted on her learning path by a number of experience workers avant la lettre, who quickly taught me to regularly colour outside the lines and question professional logics before just implementing them blindly. I think that's where the foundations were laid to continue to meet you regularly in the years that followed; through contacts with client organisations, carrying out practice-oriented research projects, maintaining a number of informal contacts with people who were once part of a number of research projects to keep abreast of how life was going for them and how they were coping with all the adventures and challenges that came their way.

But fair is fair, it all remained rather casual, at times when it worked out, without too many big commitments. And don't get me wrong, these actions too are important, and can be of great significance at times, but it could be more structural.

Two years ago, after conducting a practice-based study on embedding experiential knowledge in the broad social domain, we took a look at ourselves and took a close look at our own research centre. As a collective, we launched in 2020 and from the beginning, experiential knowledge and, in a broader sense, the inclusion of the perspectives and experiences of people who are not heard is strongly intertwined in our DNA.

So now was the time to officially welcome you to our collective! And for real! And then came the questions: Who are we looking for? What kind of knowledge are we looking for? Experience with what? Experience in social exclusion? Don't you stigmatise by sticking people with a certain type of experience? Surely it is about knowledge and not experience?

In short, our choice to explicitly bring in experiential knowledge brings a lot of questions, where we are searching. In the meantime, we found a number of

experience workers who dared to take the plunge with us to embark on this quest together.

So dear knowledge by experience, you are putting me to the test. After all, I am impatient by nature, I tend to want things to move forward, and you force me to slow down. Above all, I am learning from you that it is ok to sometimes not know (without wanting to minimise your expertise) and to express and acknowledge this together. One of the experience workers gave me this wisdom: It is ok to be in a knot instead of wanting to solve it immediately. Perhaps here we transcend the futility of knowledge and collective wisdom begins?

Jessica De Maeyer

Dear experiential knowledge,

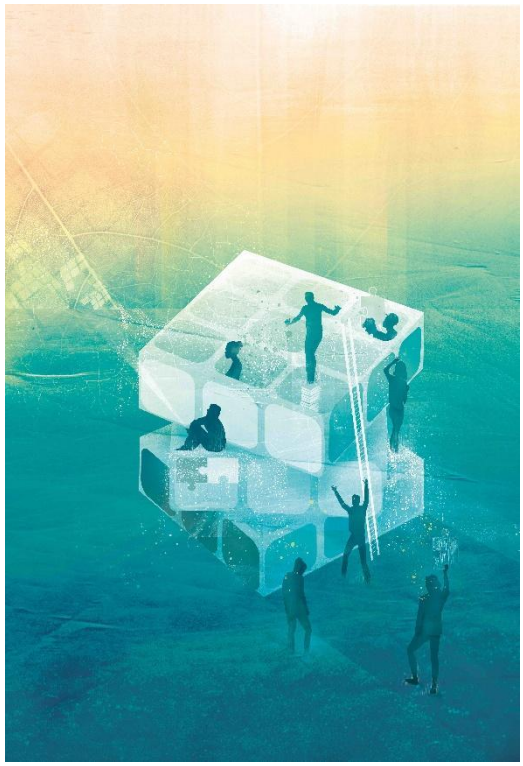
I do remember when we really got to know each other. I met you at HOGENT, the University of Applied Sciences in Ghent. It was one project in particular; the project was called: “Co-creation in focus: A meeting between professionals and experts by experience in three social care sectors.” The baseline of the project originated from the Academic Workplace on deinstitutionalization in Ghent. Practitioners from different settings addressed the growing group of experts by experience. It was an evolution which they encouraged but at the same time they had many questions.

It was a challenge to work with experiential knowledge or truly work together with experts by experience. There were conflicts, experts by experience felt isolated, there was a high drop-out rate, professionals felt unsafe, …

We made it our goal of to understand how experts by experience and professionals can work together and learn from each other to create qualitative and equitable care and support.

It’s from the start of this research that I really got to know you, that I needed some years to truly understand what you’re about. It often crossed my mind and my lips: what is experiential knowledge? It was a question that led to so many more. What

kind of experiences are we talking about? And when does something become knowledge?



Experiential knowledge is being discussed in various fields of health and well-being. Thus, experts by experience go to work in hospitals, government services, education, psychiatric centres, therapeutic communities, living groups, sheltered housing, … It contributes to the fact that knowledge by experience has become a broad concept that conceals various approaches and interpretations.

The statement that will follow on 'knowledge by experience' is based on earlier work from the EQUALITY//ResearchCollective. From here on I will talk about we, acknowledging the shared authorship. In earlier work we tried to make a very clear choice. We situate the development of experiential knowledge in relation to experiences where human rights/quality of life is not being realised or where people themselves don't experience a life that is worth living. These experiences are often 'characterised' by suffering, social exclusion, stigma, trauma, vulnerability, … But, what we do often forget is that these experience are also shaped by surviving skills, resilience, hope, creativity, strengths, …

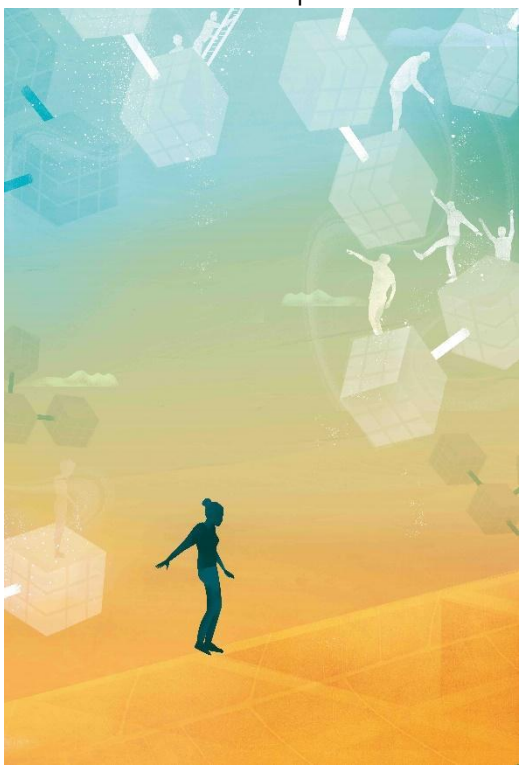
Another discussion that often recurs is about the difference between experience and experiential knowledge. For this, we address the distinction between experiences, individual experiential knowledge and collective experiential knowledge.

The experience itself refer to the concrete, physical, personal and emotional aspects. It is about what one experiences as a human being with mind and body in such situations. The starting point is recognising that people have unique and

embodied experiences and insight of what it means to live a life (not) worth living. When people share experiences, they share their life stories, influential moments, the impact of what life does with them, ...

The starting point for all forms of experiential knowledge is these experiences. When people think about, reflect on or analyse their own experiences it becomes possible deepen the understanding of one's own story. It's here we start talking about individual experiential knowledge. It shows a process where there is a growing insight into one's own situation and the person in question knows or understands what it means to experience a particular problem and how best to deal with it. It may then be about knowing when you need support. Or you may have developed some skills in dealing with challenges of your living situation.

Individual experiential knowledge is about your own personal and social living situation. However, the person in question does not yet know what it means for other people to be in similar situations. Therein lies a difference between individual and collective experiential knowledge. To develop collective experiential knowledge, is to engage once more in a a process of deepening and reflection. That reflection and deepening can be guided by professional, academic, and lay literature. But it can also be enriching to hear and connect with other stories to discover similarities and differences.



Collective experiential knowledge is about more than one's own story and often connects to knowledge about other stories. The extent to which connection to other stories contributes to understanding one's own story or framing other stories determines its collective nature. It is often argued that

collective experiential knowledge only arises when you can transcend your own story.

Collective experiential knowledge is then about situating one's own story and that of others in relation to human rights/quality of life, social exclusion, discrimination, and stigma. In other words, you can read various stories in relation to social problems. Your own story is then no longer central. You can then also frame and understand other stories that are therefore not always applicable to your own story.

To conclude, the development of experiential knowledge is not free of value or a frame of reference. Each sector or topic within the social domain often has specific frameworks. As such, experiential knowledge is always connected to certain 'lenses' that give meaning to all these experiences and at the same time shape them. The mental health domain in Belgium for example is being shaped by the framework of recovery but in poverty practice we see that a different framework that guides the development of experiential knowledge.

It's often within those frameworks that people can find common ground. But it has also been fascinating to see how sensitive the topic of 'professionality' or 'expertise' is. Working with experts by experience challenges professional practice. At the same time, I hear that some experts by experience don't want to be addressed as an expert. Because being an expert implies being distanced, authoritarian and/or disconnected from emotions. But then again, other experts by experience embrace their titles as experts, as they want to be seen as equal to their 'professional' peers. Another layer in this discussion refers to the idea that: 'the people themselves are the real experts by experience.' So what's going on here?

This last idea starts from the recognition that people know what really matters through what they experience. Of course, it is also true that many people develop knowledge and skills through dealing with their challenging situations. Herein lies

a strength-based approach. By extension, ‘expert by experience’ then means that everyone is an 'expert' in his or her own life.

The use of the term experiential knowledge here can mainly be understood as situated language within professional systems of care. It is a backlash against experiences of professional dominance where the plurality of voices of people themselves are either not heard or not heard enough. Underlying such use of the term refers to the importance of recognising and valuing the citizenship and lifeworld perspectives of people in precarious situations.

A second interpretation of ‘expert by experience’ refers to the ‘professional’ use of one's experiential knowledge. In a broad sense, this is about the necessary knowledge and expertise to work with (individual and collective) knowledge by experience in the social domain. In this interpretation, we only talk about ‘expert by experience’ when people can transcend their own story, have knowledge by experience and can systematically or professionally use that in supporting other people. In other words, ‘expert by experience’ is not separate from developing knowledge by experience and is not separate from deploying that knowledge effectively in concrete practices in the social domain.

Sometimes I’m not sure where we are going on our shared road. The idea of experiential knowledge is often based on the same categories, identities, or problems that in first place are part of the problem. The violence that is being performed in systems of care is being shaped by dynamics of exclusion or reducing humans to their problems or identities. But at the same time, people develop their knowledge and expertise from their experiences, and they are ‘allowed’ back in the

system as experts by experiences, based on those same categories. It just doesn't feel right. But in the end, I keep hoping that embracing experiential knowledge help us transform into the direction of more social justice.

Tijs Van Steenberghe

Perspectives from the cold north of Norway – KBT Vocational College

Hello knowledge by experience.
(**Disclaimer!** My entry eventually evolves into being a semi-essay about experts by knowledge and/or peer supports)

You've known me for a long time, whereas I have known you only for a short while. It was not that long ago since I first got to know you, but that isn't to say that I've never seen you before. You've always been there I suppose, I just didn't know what to call you. Much like a song that you know well, but don't know the name of – much like that is how I would describe my prior relationship to you. I guess what I'm trying to say that before, I had only scratched the surface of the world called "knowledge by experience".

I first got to know you (by name) when I started working at KBT Vocational School. Our first meeting was filled with both **wonder** and **amazement**, but also a small feeling of **anxiety** – how could I help teach in this field where I've just met the leading role, the main actor, the star: knowledge by experience. I was going to teach people who have lived lives far longer, tougher, and different than mine. What possibly could I say, that would help people, having revelations and help channel their experience into something valuable, knowledge by experience. (Not to say that experience is not valuable by itself). To make a long story short, I eventually realized that I didn't have to share the exact same experiences as my students to teach experiential knowledge. I also realized, and this is something I remain steadfast on, that my job is not necessarily that centred on my doings. Instead of being a converter of experience to knowledge – I can give them (the students) the tools to do this themselves. My role is to facilitate and be of help in whatever way that I can. It is the students, the experts by experience. who truly are the experts. It is they who hold the answers, their own definitions, I am only here to help. Much like a gardener can help flowers grow, but in many cases, the flowers would have

grown by themselves. Okay, I will try to lay off the metaphors now. I have explained why knowledge by experience made me feel a tiny bit anxious, but I also said that knowledge by experience filled me with wonder and amazement. What do I mean by that? I will stop teasing and start telling you.

What is knowledge by experience for me? (Spoiler warning, I am heavily influenced by my background as a lecturer at KBT Vocational School… but I think that is okay.) I said I was going to lay off the metaphors and It seems like I will only be able to that for a couple of sentences. Imagine a bar of steel, it has limitless potential, it can become anything. Imagine your haircut in the morning… It is probably messed, possibly dirty and curled, or a beautiful, polished vertex/dome if that is your style.

As with the bar of steel your hair has potential, but unlike the bar of steel your haircut is always with you, and you choose what to do with it. You don't always have to do anything with your haircut, but your haircut will always be a part of you. And much in the same way I view experience (and in turn knowledge by experience). Our experiences will always be with us, and maybe we don't use all of them, all the time, we still use them. We can choose to, and we can choose not to. Have I lost you dear reader? I hope not. I guess what I'm trying to say is that we all have experience and can choose to use it for so many things.

Knowledge by experience is something valuable and uniquely our own for each of us. We all have our own experiences, and they differ vastly. But **Experts by experience** perhaps have a certain kind of experience that most of us do not. An experience that is dear bought, an experience that takes years to obtain. They hold valuable knowledge, a type of knowledge you can only obtain by living through it, by experiencing it . I guess I'm going off track a bit, I was meant to tell you why knowledge by experience fills me with wonder and amazement.

The first part, wonder, that is quite easy to explain. I guess you can say that it is a bit taken for granted that we all use our experience to form our daily lives, work, relations and so on. But what fills me with wonder is this specific way of applying

one's knowledge by experience. In a way that I never quite thought of before. I think I'm quite used to, or familiar with using one's knowledge and experience to convey information in the classroom. "Here's something (knowledge) I know, I have learned, I'm going to help you learn it, understand it" But I was not that used to experiential knowledge; "Here's what I have experienced and learned, I have something unique to offer. I'm going to tell you about it, maybe it can help you, maybe it will provide new insights".

What amazes the most with knowledge by experience, and also humbles me is the nobility in it. One may joke and jest, saying: "By helping others with my knowledge of experience, there is at least something good that came out of my experiences". That is true, it is nice to have a utility approach to it. But I don't think it should (or neither does it) undermine the **noble choice of wanting to help others.** There you are, sitting on knowledge that cost dearly, but at the same time this knowledge by experience may be valuable to others. And you choose to share, to open yourself, to support, to listen and to accept the other. I think that takes great courage, care, and compassion. Through my job I've been able to meet so many impressive people, such strong stories and all having this burning passion to help others. Maybe their (experts by experience) experiences is what makes them into beautiful compassionate fellow human beings. They know what adversity is, how painful it can be… and maybe this knowledge is what turns them into helping others through their own experiences.

Concluding remarks

I think I've drone on long enough now. I am looking forward to working with SEKEHE. I hope that through SEKEHE we can promote experiential knowledge in the academic areas, but hopefully at large as well.

So my dear friend experiential knowledge… Stay safe and keep expanding experiential knowledge!

Best wishes Vebjørn Ørsjødal

Dear SEKEHES,

When I started teaching at university many years ago, in subjects within health and social work, experiential knowledge was present through students who had long experience and could contribute with examples and context in the teaching. We had small classes, and it was a close relation between teachers and students.

Over the years, this has changed in the direction that younger students without experience in the field dominates the classes. The consequences have been that practical experience has been less present in teaching.

Gradually users and user organizations have to be included in teaching, but an ideal form has not yet been found. Users and patients often add sad stories about how poorly the services work, or how lucky they have been to meet some understanding therapists or managers. The connection to subject's goals and content are often questionable. The role of users and patients' participation in teaching have not been systematically developed, they often end up in a victim role, instead of a role as an expert with user knowledge.

I see a considerable potential, and I hope and expect that the SEKEHE project can provide experience with good designs for co-teaching, and further develop the teaching together with experiential experts.

“Information is not knowledge. The only source of knowledge is experience. You need experience to gain wisdom” (Albert Einstein).

By testing, sharing and collaborate, we can contribute to building new knowledge, which can benefit us all.

Karl Johan

Perspectives from Our New Future – Belgium

Dear reader,

We are Danny and Evelien from Our New Future.
Together we wrote this letter about experiential knowledge
and what it means for our organization.

We received help for this contribution from several self-advocates.
Together with us, they thought about experiential knowledge.

We met three times.
The first time was with the large group,
at our monthly group meeting.
Then we met two more times with a smaller group.
In this working paper you can read what we discussed.

To ensure that you can understand everything properly,
we will start with a little history.
How did Our New Future come into being?
This may help to understand how we think about experiential knowledge today.

Enjoy reading!

Danny Van de Perre (secretary)
and Evelien De Maesschalck (coach and project assistant)
on behalf of Our New Future.

Once upon a time…

Our New Future exists for more than 25 years.

In our book "One for all, all for one" (Our New Future, 2002), founder Patrick tells how it all began:

"I couldn't do anything with my degree.

If I went to work in an ordinary factory,

then they would have taken away my disability benefits.

So I had to work in a sheltered workplace.

There I came into contact with people with disabilities,

who had it even worse than me.

A lot of people were fooled there.

That's why I joined the union!

I tried to work with the union to ensure that people in the workplace were treated equally.

There were six of us in the union.

Only half were really in it for the union.

The others were more in it for the meeting,

because they got a cup of coffee.

Then I already had the itch to start a movement.

But then came the Turin convention.

It was an European conference.

The Netherlands had prepared the conference together with Germany.

And I was brought in from Belgium.

It was driven by parents' associations.

The self-advocacy groups made their voices heard.

There I saw how people could stand up for themselves!

There I saw how groups of people come together because they want to change something.

And I wanted to see that in Flanders too.

There was another conference of a training service for people with intellectual disabilities.

And there I was woken up,

to start a group together with other people.

I've had a push in my back from a lot of people.

I gathered people and sent a letter,

to set up an association together.

And then Lieve joined it.

I became the first chairman.

And the name of our association became Our New Future

After the first congress, I took the initiative.

All those people were locked up in institutions.

We wanted to change that together!

I wanted to continue working on that!

On the first weekend we met again,

we chose the name of Our New Future."

Patrick dreamed,

along with the other founding members of the organization,

about a new future.

They dreamed of a future in which the rights of people with (intellectual) disabilities were respected.

They wanted to be seen as equals.

They also wanted that future to be theirs.

It is OUR New Future.

Persons with (intellectual) disabilities are central to this.

Self-advocates

"I used to be in my 'shell'. I did not know the organization. Step by step I got to know the organization and myself. I talked about disabilities, but now I prefer to talk about talents. Our New Future taught me to share my own story and to listen to the stories of others." (Didier, April 17, 2023)

Our New Future is an organization of, for and by people with (intellectual) disabilities.

They call themselves self-advocates.

And not experts by experience.

How exactly is that? What is a self-advocate?

Our New Future believes there are six steps if you want to be an advocate for yourself.

The first three steps are about fighting for yourself.

The last three steps are about fighting together.

Step 1

For some things I am completely stuck in myself.

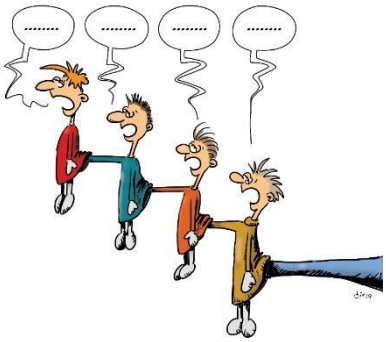
I have grown into myself.

I crawl into my shell.

I am afraid to show myself.

I cannot come out and say something is wrong.

"Having that confidence again is very difficult. I have great trust in other people here in Our New Future. You've been through so much in the long run that you do not trust a single person anymore. I've been through some things sometimes! I have to grit my teeth hard sometimes." (a self-advocate in Our New Future, 2002)



Step 2

I am a ventriloquist doll.

I do everything that others tell me to do.

In my gut, I know what I want.

But I dare not say it.

Because the others are bossing me around.

"Our New Future is an important association. Because we stand up for the interests of people with disabilities. Because we try to help people the best we can. We need help from the coaches to organize something. But the fact that we do it is important. We do not want to be treated like little kids. We say it ourselves here." (Michel in Our New Future, 2002)

Step 3

I think very deeply about myself.

That is my apple.

I reflect under the tree.

I talk about it with people I can trust.

This is how I see for myself what I want different in my life.

I see it completely different.

I want something new in my life.

I want to fight for that now!

"I think the word 'disabled' is so ugly. Then you are labeled as not being able to do something. I do not like that. I think that is a stamp, something that stays." (Patrick in Our New Future, 2002)

Step 4

Together we will think about what is important to all of us.

How are we going to pick apples together?

How are we going to do things together?

We want to solve our problems.

Together we want to change something in our own lives and in society.

"Sometimes they do not really know who we are. They have to be in our shoes before they know who we actually are. Most people think we can do less. I used to have that in school, that they challenged me. They said, "We can do everything and you cannot do anything! I can honestly say that my parents never thought I could get this far. You do not say, 'We will lock them up in an institution.' You can listen to us with attention. It is wrong to treat us like a little child." (a self-advocate in Our New Future, 2002)

Step 5

We work together on a plan.

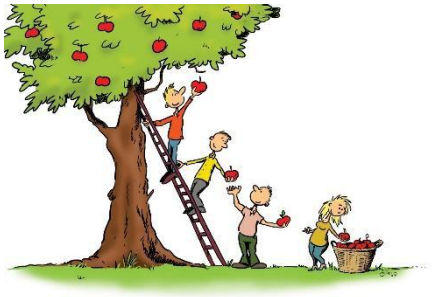
We all pull out a ladder together.

We want to do something about it together.

We do not work alone.

Because together we are strong.

"Disabled should be replaced. In life they speak to you like that. They always say 'Disabled people cannot do much!' That is not true. That is why I came to Our New Future. Having our own abilities, that means something. That means: we belong in this society. You cannot just push us aside." (Geert in Our New Future, 2002)



Step 6

We take action together.

We pick all our apples from the tree.

We do something together to solve our problems.

There is really strong action being taken.

This is how we change something in our own lives and in society.

"We fight against being treated unfairly as human beings. We do not feel good about that. With us, everyone gets a chance. And that attracts people." (a self-advocate in Our New Future, 2002)

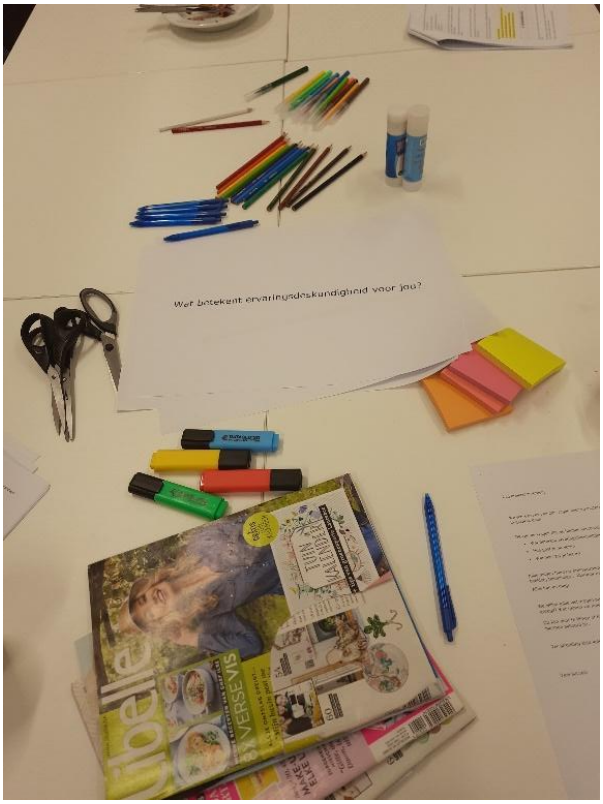
Experiential knowledge in Our New Future

We wanted to understand the role of experiential knowledge in Our New Future properly.

We reflected on this topic during three meetings.

We started from the question: 'What does experiential knowledge mean to us?'

Gradually, other issues demanded our attention.



What do we mean by 'experiential knowledge'?

"We share our stories and grow stronger. Stories are the common thread. We have learned to think and feel for ourselves." (Didier, 17 April, 2023)'

Experiential knowledge is a long and difficult word (in Dutch it is one word).

In order to make this word more accessible,

we split it up.

The word consists of the words 'experience' and 'knowledge'.

This breakdown helps us to think it through.

Our experiences are the starting point.

By reflecting on our experiences,

we get to know ourselves well.

As people with a(n intellectual) disability,

we know what our disability entails.

We know our strengths and weaknesses.

We know what we are talking about.

We share our own experiences with people who have similar experiences.

We also listen to their experiences.

We recognize and respect the differences and similarities in these experiences.

These experiences inspire us and make us stronger.

This is how experiential knowledge connects people.

We also share our own experiences with people who do not have these experiences.

We want people to put on "our glasses" so they can see through our eyes.

We do not share all our experiences:

some experiences we prefer to keep to ourselves.

This is the difference between a public and a private story.

A public story is safe:

we can share this story with everyone.

It consists of experiences that have been important to us.

These experiences have had a great impact,

that is why listeners often remember them.

A private story is and remains ours.

It consists of experiences that we would rather not share with everyone.

It consists of experiences that seem less important.

A public story contains fragments of a private story.

“Sometimes people ask me about wheelchair accessibility, but I cannot tell you anything about it: I have never been in a wheelchair. Of course you can imagine something about it.” (Mieke, 28 March, 2023)

Sometimes we also share the experiences of others.

These experiences often bear injustice.

These are situations that we believe need to change.

Therefore we think they are worth mentioning.

At the same time,

we cannot speak in someone else's place.

It sounds easy to share these experiences,

but we prepare it very well.

We must know well what message we want to give.

This message must be clear.

We must know well which of our own experiences we want to share.

What is a private or a public story?

We must know well what experiences of others we are allowed to share.

"Within Our New Future I share my experiences. I want to break down the walls around us. I do not like the walls that stand between people. They need to stop thinking in boxes. This [experiential knowledge] is a way for me to connect." (Geert, April 17, 2023)

By using experiential knowledge, we want to bring change to society.

We tell how things can also be done differently.

We tell this to different people in different contexts.

Just think of:

- students, future support workers

"People who come here to study later end up working with people with disabilities. It is important that they know well how to interact with us." (Mieke, March 28, 2023)

- other persons with disabilities

"People with disabilities need to know that they have a right to housing, education... If people do not know that, other people can walk all over them. Support persons can decide differently about everything these people do. People with disabilities in a facility are shielded from society: they do not know what is happening outside. We bring this in." (Tom, March 28, 2023)

- support persons and institutions

"With experiential knowledge, we want to rectify the mistakes of the past: we do not want to experience this again in the future. We want institutions to learn to look at people with disabilities in a different way: as full citizens in society. People with disabilities should not be viewed as outsiders." (Carli, March 28, 2023)

- people we meet in everyday life

"Patrick: I was queuing at the checkout line. In front of me was someone in a wheelchair. The cashier lady was helping that person in a wheelchair to put everything in his bag. She used a lot of diminutives. When he was gone, I spoke to her about this. I told her that some people do not like those diminutive words. She explained that she used to work in a nursery and that is why she used those diminutive words.

Mieke: Sometimes you also have to explain to people you do not know that you have a disability. Not because they have to patronize you, but so that they understand you. That is why sometimes you have to explain that you have a disability." (Patrick and Mieke, March 18, 2023)

<u>Experts by experience versus self-advocates</u>

"We are a devil's advocate. We look with a critical eye, dare to give signals. If we do not do this, then we are not self-advocates. We know our rights and dare to share our experiences with others. We think outside the box." (Didier, April 17, 2023)

A self-advocate reflects on one's own experiences.

A self-advocate exchanges these experiences with others.

A self-advocate uses these experiences to initiate change.

Experiences are the common thread.

And yet, at Our New Future, we do not speak of experts by experience,

but about self-advocates.

The Dutch word ‘zelfadvocaat’ is a translation of the English word self-advocacy.

Like experiential knowledge,

self-advocacy is a difficult word.

Nevertheless, Our New Future deliberately chooses to use it.

It tells who we are and what we do.

"In the word expert by experience, I do think that you do not really notice that this person wants to stand up for his rights. The term refers precisely to someone who writes Sunday novels about his experiences. I have experienced this and that. You can find injustice in that. In my opinion, that is not necessarily someone who will set things in motion to change. I think that is what a self-advocate does." (Carli, April 17, 2023)

We also believe that there is a difference between a self-advocate and an expert by experience.

The image of making a cake helps us to name this difference.

An expert by experience knows perfectly how to make a cake.

An expert by experience knows the recipe.

An expert by experience has all the ingredients.

But it is the self-advocate who bakes the cake.

The difference lies in achieving change.

When an expert by experience uses his experiences to call others to action,

then he becomes a self-advocate.

So you cannot be a self-advocate,

without being an expert by experience.

You cannot advocate for yourself,

without understanding your experiences properly.

You cannot stand up for your rights,

without knowing them.

You cannot stand up for the rights of others,

without listening to their stories.

Experiential knowledge is a prerequisite for being a self-advocate.

An expert by experience can be a self-advocate,
but they do not have to be.
Both are equal.

Attention: not all has been said yet!
The self-advocates of Our New Future met three times,
to reflect on the role of experiential knowledge within their organization.
They still have a lot to say about this topic.
The last word has not yet been said.

Facing the complexity - A kind letter from the University of Milano - Bicocca

The start

It is not easy to write *to* you and *about* you, dear experiential knowledge. You are not an easy concept: your complexity is your *strength* and our *challenge*. So, this text tries to build a possible *frame* to better understand you and to let you know who are the people who work with us and who build, day by day, their personal knowledge by experience. This is a choral writing, by the research group of the University of Milano - Bicocca involved in the SEKEHE.

Hope you will find our thoughts interesting!

At first, the theoretical reference points to understand the topic of experiential learning and its connection with reflective practices are introduced. Subsequently, we explain why it is important to involve experts by experience into the higher education of future professionals in the health, social and educational work. At the end, the main steps we have followed to integrate experiential knowledge at the University of Milano - Bicocca are presented, as an ideal landing place of a study about the added value of formal and informal learning in the academic preparation of future social-pedagogical educators.

The taking for granted term *experience*

In order to properly understand the topic of experiential learning, it is necessary to have a theory of experience. In this perspective, a reference point is the *philosophy for educative experience* by Dewey[1]. Which kind of experiences can be ascribed to this definition? At first, they should live *fruitfully* and *creatively* in subsequent experiences. Then, the pragmatist philosopher attests the following criteria to see their quality:

- The category of *continuity* - the experiential continuum: every experience both takes up something from those which have gone before and modifies in some way the quality of those which come after. Each experience has an objective and an active side and it changes the objective conditions under which subsequent experiences take place.

[1] Dewey, J. (1997). *Experience And Education*. Free Press.

- The category of *interaction* - educators should know how to utilize the surroundings, physical and social, that exist so as to extract from them all that they have to contribute to building up experiences that are worthwhile.

Dear, we have understood these criteria are fundamental to build the conditions to open people's horizons and possibilities, to give them a sense of self, of the world and of the other. Experience means to know how to deal with actual possibilities and future perspectives, to develop an individuality that reflects personal needs and expectations.

Educational experience should be a *vivid experience*, which engages people to face real matters and to interact with the context. It consists of multiple and complex factors that have an impact on the contingent design of each experience.

Referring to Dewey, Jarvis affirms «experience is subjective and a form of thought, but those thoughts are constructed and influenced both by our biography and by the social and cultural conditions within which they occur»[2]. In this shape, experience is both a *lifelong* and *episodic* concept. Consequently, the author also suggests a translation from the term experience to the term *biography*.

So, we see the possibility to use both the terms *experience* and *biography*, to understand the origin of our personal process of learning.

In this horizon, a particular attention can be posed on the experience of *disease*. Disease is a wide concept. It deals with personal experiences of vulnerability, sickness, fragility. From a pedagogical perspective, disease is an educational outcome, that derives from the contemporary world which, exposing people to complexity and risk, does not support the acquisition of the ability to "learn to live" in this scenario[3]. In this perspective, it becomes more important to develop an *attitude to learn*.

This wide concept of disease is the right way to de-build stereotypes connected with *normality* and *anomality*. Disease has different shapes; it is a pervasive condition that can occur to each of us.

Different perspective on experiential learning and reflectivity

[2] Jarvis, P., Holford, J., & Griffin, C. (2003). *The Theory and Practice of Learning*: Vol. 2nd ed. Routledge, p. 54.
[3] Palmieri, C., Gambacorti-Passerini, M.B. (Eds). (2021). *Disagio e lavoro educativo. Prospettive pedagogiche nell'esperienza della contemporaneità*. Milano: FrancoAngeli.

There are different perspectives on the definition of experiential learning. We have chosen the following.

Personal growth

Weil and McGill suggest that experiential learning might be classified into four categories which they called "villages"[4]. They concern *assessment and accreditation of 'prior' experiential learning*; *experiential learning and change in post-school education and training*; *experiential learning and social change*; *personal growth and development*.

The last one looks particularly significant for this elaboration, because it explicitly links the development of our identity with a continuous process of learning.

Existential process

As quoted before, Jarvis and colleagues connect the term *experience* with the term of *biography*. In this shape, learning is a holistic process, that «occurs when individuals, as whole persons (cognitive, physical, emotional and spiritual), are consciously aware of a situation and respond, or try to respond, meaningfully to what they experience and then seek to reproduce or transform it and integrate the outcomes into their own biographies»[5].

Transformative learning

For Mezirow, at the basis of learning there is a process of *transformation* of the so-called *frames of reference*, that are «the structures of assumptions through which we understand our experiences. They selectively shape and delimit expectations, perceptions, cognition, and feelings. They set our "line of action". Once set, we automatically move from one specific activity (mental or behavioural) to another»[6].

The author explains that we do not make transformative changes in the way we learn as long as what we learn fits comfortably in our existing frames of reference.

So, we can see that transforming our models is complex and overcoming our habits is not an automatic process!

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[4] In: Jarvis, P., Holford, J., & Griffin, C. (2003). *The theory and practice of learning*: vol. 2nd ed. Routledge, p.57.
[5] *Ivi*, p. 67.
[6] Mezirow, J. (1997), Transformative learning in action, *New directions for adult and continuing education*, nr 74, Jossey-Bass Publisher, 5-12, p. 5.

It is possible also to see Mezirow's point of view about the practice of *discourse* (partly, it recalls the *pedagogy of freedom* by Freire).

He explains that to facilitate transformative learning, educators must help learners become aware and critical of their own and others' assumptions. Learners need practice in recognizing frames of reference and using their imaginations to redefine problems from a different perspective. Finally, learners need to be assisted to participate effectively in discourse. Discourse is necessary to validate what and how a person understands, or to arrive at a best judgment regarding a belief.

We are doing our best to think about higher education from a perspective of co-creation, to enhance students' value. Hope this effort will be useful in order to make a fairer university.

Why is it important?

Following the same author, «in contemporary societies we must learn to make our own interpretations rather than act on the purposes, beliefs, judgments, and feelings of others. Facilitating such understanding is the cardinal goal of adult education. Transformative learning develops autonomous thinking»[7].

Transformative learning and the social process of learning

Mezirow also sees the learning as «a social process, [where] discourse becomes central to making meaning. To become meaningful, learning requires that new information be incorporated by the learner into an already well-developed symbolic frame of reference, an active process involving thought, feelings, and disposition. The learner may also have to be helped to transform his or her frame of reference to fully understand the experience»[8].

Critical reflection

In order to make this process effective, we need to exercise a *critical reflection*.

This is a conscious process that «involves transforming frames of reference […], validating contested beliefs through discourse, taking action on one's reflective insight, and critically

[7] *Ivi*, p. 6.
[8] *Ivi*, p. 10.

assessing it. This understanding of the nature of significant adult learning provides the educator with a rationale for selecting appropriate educational practices and actively resisting social and cultural forces that distort and delimit adult learning»[9].

Theory-in-use and deutero-learning

Another important author to see the connection between experience, learning and reflection is Schön[10].

He has built the *theory-in-use* theory, to account for a person's actions, by attributing to him/her a complex intention consisting of governing variables or values, strategies for action, and assumptions that link the strategies to the governing variables. The term *deutero-learning* identifies the process by which a person changes his theory-in-use in response to experience. Theories-in-use are to be tested in part by their effectiveness, theories of deutero-learning are to be tested by their assistance in enabling the individual to develop more effective theories-in-use.

Reflectivity

Following Mortari[11], the *experience* does not coincide with the *past* itself, which identifies events that are in a pre-reflective condition, when things are lived in a condition of promptness, in close contact with the events. Past is the direct and natural way of living. The experience takes shape when the past becomes an object of reflection and the subject appropriates it consciously to understand its meaning.

To conclude, experience is a form of human relation with the world and is always present – we experience continuously. In order to learn from this relationship, to become "expert" from experience and able to know how to consciously be oriented in life, it is necessary to take note of what people live and what they live can provoke them.

Experiential learning at the University

According to McLaughlin, *experts by experience* are people who have overcome disease and now work in services, collaborating with professionals and helping people with

[9] *Ivi*, p. 11.
[10] Schön, D. A. (1975). Deutero-learning in organizations: learning for increased effectiveness. *Organizational Dynamics*, 4(1), 2–16. https://doi.org/10.1016/0090-2616(75)90001-7
[11] Mortari, L. (2003). *Apprendere dall'esperienza. Il pensare riflessivo nella formazione*. Roma: Carocci.

similar backgrounds (homelessness; care leavers; people with mental health fragilities). The author states that «this term suggests that the social worker needs to acknowledge and affirm the expertise of the other - the expert by experience - in assessing and agreeing a way forward. […] The Foundation for Learning Disabilities [uses this as a definition] […] to draw attention to the value of working alongside service users. A particular approach which acknowledges a person's capacity to work towards their own rehabilitation»[12].

The specific experiential knowledge of experts by experience is a set of knowledge and skills built through the direct experience of living, day by day – subjectively and in interaction with others – with a condition of disease. It does not mean to passively live with this condition, but to find proper strategies to deal with it and to develop personal resources, coping strategies and the awareness of services a person needs. In this sense, it is not enough to live an experience of fragility to shape knowledge and useful skills. It is necessary to associate the lived experience with a path of awareness and re-elaboration of the experience itself. It means to ideally write a *storytelling* of a personal disease, that gives an account of its meaning. It is a knowledge that is strengthened by the possibility to share moments with people with similar backgrounds, into the direction of a *co-construction* and *inter-subjectivity*.

There are two main fields where the engagement of experts by experience in higher education are widespread: mental health and social work.

In the health sector, especially in English-speaking countries, there are courses which foresee the engagement of those experts, in the following areas: nursing, in particular mental health nursing; occupational therapy; general medicine; physiotherapy; midwifery[13].

> *See the COOMUNE Project: Erasmus+ Co-Produced Mental Health Nursing Education - https://commune.hi.is/*

In the social work sector, the habit of inviting people with an experience of vulnerability and use of social services to tell their story to students is common. They traditionally

[12] H. McLaughlin, "What's in a Name: 'Client', 'Patient', 'Customer', 'Consumer', 'Expert by Experience', 'Service User'—What's Next?", *British Journal of Social Work*, 39, pp. 1101-1117, 2009, p. 1111.
[13] Happell, B., O'Donovan, A., Sharrock, J., Warner, T., & Gordon, S. (2021). They are a different breed aren't they? exploring how experts by experience influence students through mental health education. *International Journal of Mental Health Nursing*, 30 Suppl 1, 1354–1365. https://doi.org/10.1111/inm.12881.

participate as witnesses[14]. Internationally, there are also more structural experiences of their involvement in higher education of social work and social care professionals. In the United Kingdom, since 2002, service users and carers must be present in all steps of the higher education of future professionals: in the entry assessment; in the planning and development of the curricula; in teaching; in the overall evaluation[15].

> *See The PowerUs Project: it aims to promote a network between teachers, researchers of Social Service, representatives of user organizations and to develop a structural participation of experts by experience in the higher education of social workers, according to the *gap mending* approach - https://powerus.eu/*

Experiential learning at the University of Milano-Bicocca

There are different perspectives about the opportunity to build a formal course to train the *experts by experience*. Nevertheless, in order to make their intervention significant, in terms of participation and impact, scholars agree it may be important to provide them with elements of knowledge and work methodologies, to be better oriented and to make them conscious about the system of services and organizations in which they operate.

In France, there is a university degree in health and social sciences for *médiateurs de santé pair*: it completes the experiential path of these professionals, with academic preparation in different fields (sociology; health) and reflective practices[16].

In 2019, in the Italian Lombardy region, a course has been settled to certify the qualification as *expert in peer support* (*Esperto in Supporto tra Pari* [ESP], in Italian). It foresees lessons about theoretical issues in the fields of pedagogy; story of medicine; sociology and a training on the field. Although this certification has a limited expendability for job placement, the organization of this programme of study, with a regional certification, demonstrates an increasing formal recognition of the role that experts can play in services. The experienced experts in the SEKEHE project, form the University of Milano - Bicocca, have attended the mentioned course.

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[14] Allegri, E., De Luca, A., Bartocci, M. C., & Gallione, S. (2017). Diversamente esperti. *Prospettive sociali e sanitarie*, N. 3, Anno XLVII.

[15] Robinson, K., & Webber, M. (2013). Models and Effectiveness of Service User and Carer Involvement in Social Work Education: A Literature Review. *British Journal of Social Work*, 43, 925-944. doi: 10.1093/bjsw/bcs025.

[16] Hude, W., & Pinet, E. (2020). Les médiateurs de santé pair: une profession en devenir. *L'Information psychiatrique*, 96(7), 527-532. doi:10.1684/ipe.2020.2143.

How has their involvement worked? As you can figure out, our friend experiential knowledge, it has not been an easy process. As we said before, your complexity is a huge challenge for us, form different points of view.

Above all, it has been an *institutional challenge*. Usually, collaborators at university have specific background, based on Bachelor and Master Degrees, formal preparation and courses. The knowledge by experience is not conceive as a prerequisite to fill a form and, in general, informal education is still not a dimension to apply for a position. Despite that, administrative employees at our university have worked hard to find a solution and create the proper conditions to formally admit experts by experience during the Pedagogy of Social Inclusion lessons.

We have shared these bureaucratic efforts with students and it was *another challenge* in itself: to let students know the "offstage" aspects of a course, to let them know how it could be difficult, but also generative, to prepare a different model of teaching, that goes further a traditional unidirectional approach. We have grabbed this opportunity to enlarge the perspectives on teaching and to build a real co-creative way of learning in higher education contexts.

For us, it was a first step to visualize the possible perspective about a real formal integration between theoretical and experiential knowledge. It was a starting point, to generate further opportunities.

At the end, we can say we have started recognizing a significant synergy between academic preparation and a preparation that is grounded in biography, to transform the learning environment at the university and produce *more person-centred and recovery-oriented* future workers.

If you are looking for a formal job, in a context where is quite difficult to find it, as in Italy nowadays, we can think about to consolidate a collaboration, experiential knowledge ☺️

Following, you can see some pictures from our lessons in the course of Pedagogy of Social Inclusion! They metaphorically represent the main effects of your engagement in our course.

Dear knowledge by experience,

this is you in my life:

I'm an active retiree. During my lifetime, I have learned to take and give. For me, taking means using of social services and getting helped from the general public when it is offered. Giving for me, on the other hand, means sharing my experience with people and showing them that one can change one's situation if one wants to. This happens, for example, in the Faculty of Social Studies, where I am in the experts by experience group and regularly attend classes to share my story in front of students and try to break down some of the prejudices and myths. I try to do the same amongst officers and other professionals. It is important that society perceives that not everyone is the same and that there is a unique person behind every story.

I have lived on the streets and I know how difficult it is. That's why I decided to help people and find solutions in difficult situations. I can help by not keeping the experience I have gained on my journey to myself, but by passing it on to the younger generation, and by breaking down the myths and prejudices of our society about people who find themselves in a difficult life situation that they cannot cope with, for example, in the beginning, because it is a new situation for them. Specifically for people on the street (and not only those on the street), people have stereotypes that "it's their own fault", but this is not always true. Society can also be to blame for setting inappropriate conditions for some people, especially those who may be disadvantaged in any way (health, social...). Often solutions are created that are not workable for such people.

I can also help by writing down those insights and experiences in using social services that I have gained while trying to re-enter society. I have experienced times when I initially resisted working with social workers because I perceived a barrier - the social worker in a position of power and me in a position of oppression. At the same time, I did not have confidence in this collaboration and rather doubts and fears prevailed. However, over time I realized that I could not solve some of the situations that arose on my own. To break down the barrier, I then worked with a social worker to draw up an individual plan and to identify the points that needed to be addressed. At that point I realised that I had a choice and could decide how to proceed.

As time went on, I began to realise that I was giving back to society and could be a useful link to society.

As I have written before, I spent several years on the streets. At first I didn't understand what that could mean. I felt free and unbound. However, as time went on, it became harder and harder, especially in winters full of frost, or in summers when one didn't have enough fluids and got dehydrated faster. It was difficult to get not only shelter but also food or fluids. At that time, I began to question whether this was the meaning of my life and whether I wanted to continue to live my life in this way. At the same time, I encountered the interest of strangers who were not indifferent to me and my health condition. They supported me and helped me to get to the shelter. I stayed there for some time and gradually realized that I could live differently. So, I started to use social services where, for example, they helped me to sort out my debts, and with the support of a social worker I learned to organise my day and prepare myself to return to society.

Thanks to this, I know practically the concrete procedures of how a person returns. The first step was the night shelter, then the day centre, the hostel for men, then the training flat as the test for the allocation of a flat for permanent housing. The night shelter was the first experience in a long time of sleeping under a roof, the possibility of hygiene or getting clean laundry. The day centre helped me to regain my strength in bad weather, to prepare a meal or warm liquids. At the hostel I learned how to take care of my assigned room, deal with my situation and at the same time prepare for the next stage of my life in the form of a training flat. The training flat was already a full preparation for the allocation of a municipal flat where one functions like most of society.

I dealt with my life situation gradually. The social workers helped me a lot in the beginning, and I gladly accepted their helping hand with humility. The proposed solutions to my situation did not depend on them, but on my decision and creating confidence in overcoming obstacles. I perceived great help, for example, in dealing with the obstacle of debts, when the social worker offered to get in touch with the bailiff together, who suggested a solution to get rid of the debts and how to proceed further in this process.

I realized that social workers, too, are only human and approach you as a person who has been in certain life situations. There are differences between workers too. The first group consists of social workers for whom their work is a job and a source of income. The second group are those who have it in their hearts.

This had an impact on the collaboration, where I was personally happy that it was women. I think it's because my mother died and I was raised by my father. I missed the motherly love. I worked well with good women social workers and that's probably what got me to where I am today. I went from living on the streets, through night shelters and hostels, to living independently in a municipal flat. Thanks to working with the social workers, I learned how to cook, bake, learn creative things, organize my time, and most importantly, realize that I can be a full part of society.

Something begins, something ends. So it was with the use of these services. I realized that I should start giving something back to society in some way. I offered the director of *Charity* to volunteer. He declined, saying that my involvement with the services was over and I had to continue on my own. As a volunteer I wanted to help the social worker in setting up a programme for other users and I also wanted to pass on what I had learned and share my experiences. However, I was told that this was no longer possible, that one stage was over and he was not interested in working with me again.

I did not give up. I spread joy at the Charity for the Elderly and assist the social workers at St. Elizabeth and Sylabova Centres for the elderly who live there for a long time. I help with creative activities such as making cards before Christmas or helping with baking. I try to be that helping hand for the social worker and the service users themselves. I am also active in various events of the above mentioned organisations, I bake bread or Christmas cake for the service users myself.

I also work as an expert by experience and pass on my experience to social work students. I present my story to the students. At the same time, I am involved in the creation of two courses where we draw again on my story and experience.

I also travel to the offices, elementary schools and municipalities of our district. Similar to the faculty, I share my story and experience with social services and again try to break down the prejudices and myths that are associated with my story. The work is satisfying and energizes me for the path I have taken in my personal life as well.

Finally, I want to thank everyone for their help. I appreciate it, and I will do everything I can to alleviate the problem of homelessness in our society so that homeless people can reintegrate

back into society as soon as possible. As an example, I will give you this: Life is like a little child who falls down, cries, gets up, learns a lesson and moves on. This is my case.

Evžen Vojkůvka

My dear past,

I have reached a point where I think of you as a piece of me that is painful but healed...You are my motivation to live a better and fuller life. I think of you as my partner with a bad conscience. You're my betrayed friend, sad, tearful and full of pain, but we've also had moments together that we will never have again in our lives, there have been bright moments full of intoxicated joy.

Withdrawal syndrome is not for me.

Abstinence is life-changing.

I don't want withdrawal anymore,

my life is better now.

I've learned from the past,

complexities resolved.

Sobriety remembered,

I can only see a better perspective.

Katka

Dear experiential knowledge,

I have first realized you existed ten years ago. We then decided to play a theatre of the oppressed. The scenario was written based on lived experience of homeless people/actors. We decided to play forum theatre where audience can step in and replace the main character to change the course of the play and to see what consequences it brings. I was a joker of that performance. We played the theatre many times at various places for variety of audience. Among other things one stays with me I would like to reflect upon here.

We allowed people with no experience of homelessness to replace the main character – a homeless actor. I only later realized the solutions that were brought to the play in that way were patronising as no person with home could ever envision what the homeless person should and could do in order to change his/her own situation. Moreover, often there is nothing „wrong" with that person´s doing. It is the context and actions of „public"/ witnesses that we should analyse and change.

We focus here on experiential knowledge. In our faculty we see experiential knowledge as the knowledge gained from encountering difficult life situations connected with social disadvantage that led the person to use social services. We cooperate with approximatelly ten brave experts by experience who are willing to share their stories and reflect upon them, together with academicians and students. We hear them saying they fell in their lives and got up. They often came from broken family background. And in their stories we hear a lot about individual oppression they experienced. But less on cultural and structural opression that is so present yet so invisible. And this is in my view our responsibility as academicians/ as people from middle class/ as people with many more privileges to bring the invisible disadvantaging processes to the front, name them, help ourselves and our students to understand them. But this should not end there. To be privileged, to have the possibility to listen to stories of disadvantage, to meet with the people from disadvantaged backgrounds we need to make a commitment. The commitment to learn, to educate ourselves on inequalities present in the world and act upon that knowledge. For the start, in our personal lives, we need to transform from witnesses of disadvantage to active participants combating it, alongside with our experts by experience. We should allow engaged, politicised actions into the academia and not to pretend we stand in the middle, as there is no middle ground. As Martin Luther King, jr. says: *„The ultimate tragedy is not the oppression and cruelty by the bad people, but the silence over that by the good people".*

Eliška

My precious experiential knowledge,

This stream of consciousness (many thanks to Evelien for reminding us who or rather what we are), manifested as Mirka, only became aware of you with misery at the beginning of this existence.

Mirka began "collecting" you from early childhood and certainly did not consider you to be "good" experiences that she wanted to remember. And perhaps fortunately she doesn't .....

However, she did pick you up in quite large numbers over time.

Mirka slowly became consciously aware of your existence about 15 years ago when she was a peer in an organization helping women. However, she only became more deeply aware of you when she entered university as an expert by experience only six years ago. She has been incredibly grateful to you ever since!

Suddenly everything lived and experienced lost the label of "good - bad" and there were only subjective experiences. This existence began to make sense and life gradually became (and the process is still going on!!) joy-filled and most importantly meaning-filled!

Mirka has been very happy to "collect" you since then and just waits with bated breath - in what form you will appear next!

Thanks to this approach, Mirka found out what the expression "life is a gift" actually means, which she had not been able to understand for years.

Mirka also enjoys awakening and discovering you in other people and thus giving meaning to their lives, which again comes back to Mirka as an incredible joy, gratitude and awareness that we are each unique, with our own subjective life experience. Behind each of us is a unique story that is enriching and often inspiring to others. Whether we realize it or not, we are truly invisibly connected to each other and everything that each of us experiences touches all of us on some level. Just like this chain letter - each link counts and is an integral part of the whole (chain).

Mirka