The Power to Change

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'Social workers have the power to change and shape lives as well as potentially miss opportunities to move an individual, family or group onto a more positive path……. The consequences of not having social workers in society would be detrimental to so many I believe……'

Comensus collective member CC

Introduction

We are the Comensus writing collective. We have been brought together by our experiences of social care from our perspectives, either as a service user and or a carer and our desire to improve other people's lives. We believe our involvement with Social Work education at a UK university has the power to change Social Work practice of the future, through our direct involvement and anecdotal evidence in a number of novel ways such as role play, lectures, question and answer sessions, intimate small number seminar/workshop activities, all of which compliment traditional lecture styles and information.

The Comensus group has over 16 years' experience of training social work students through sharing their personal and lived experience. We reflect on how our involvement in education has transformed our own outlook whilst considering whether service users and carers really do have the power to change practice for the better. Our thought pieces related here reflect

on our personal experiences of services, positive and negative, based around three main themes which are important to us. We use similar stories to enhance student education and understanding of the issues surrounding service users and carers in society.

Part 1 Reflecting on our lived experience of Social Work services

Establishing trust and empathy – Julia Johnson

I vividly recall a terrible argument I had with my sister many years ago when she shouted at me saying “how do you expect us to know how you are feeling if you don’t talk to us about it!”

My response was this; “My daughter is 7 years old (she’s now 26). She cannot speak, she cannot use the toilet, she cannot dress herself. She smacks her head against walls and on the hardwood floor. She drinks shampoo, eats plants, leaves, paper, raw sausages…. Do I really need to tell you how I feel about it – is it not bloody obvious?!”

I have thought about this conversation many times since and have experienced similar conversations with friends over the years though I struggled to be as brutally honest with them for fear of damaging the relationship. I have of course realised that empathy does not come easily for some – even if those people are close to you and want to try to understand. I have reflected on this since with regards to professionals and accept that they will not be able to fully understand the pain and suffering that some parents experience when dealing with a child with disabilities. Nor is it their job to do so. A social worker is a gatekeeper to services and their role is a practical/administrative one, so should they even need to understand the emotional impact on a family?

I would argue that in order to do a good job they certainly need to be aware of the difficulties and challenges – the reason that the family needs support from social services in the first

place. There is also a reality to this that the emotional state of a parent/carer may significantly impact their ability to provide adequate care for their child. Furthermore, in order to get a true picture of the challenges faced by a family, the social worker will need to create an environment where the parents feel safe to talk candidly and this requires parents to trust the social worker. I am very aware that if I feel that the person I am talking to does not understand or shows no empathy, I am unable to continue discussing my daughters needs with them.

One social worker we had consistently spelt my daughter's name wrong in reports and she would often talk about herself during meetings with little relevance to the subject matter. As a result I found it difficult to build a relationship with this particular social worker. Conversely, a subsequent social worker showed great empathy and very much embraced the person-centred way of working. They were keen for my daughter to be physically present during all meetings which was a huge step forward in my eyes as although my daughter is non-verbal and unable to communicate other than in a very basic sense (hitting out if upset, for example) her presence at the meetings felt to me that she was being recognised as a human being rather than just a 'problem'. This particular Social Worker always spelt our daughters name right in their reports too!

Why should the past stop you from being awesome? - Reflections on feeling stigmatised - CC

It's interesting that as a child in the care system most of the time we were singled out as different. What is it about challenging times that makes us feel as if we are not as good as everybody else?

Of course, my perspectives as a child and teenager were coloured by my negative experiences! But what about positive experiences? The holidays in France at the children's home when I was 9 and the amazing social worker who encouraged me to challenge the normal and believe that I could go to university. I was only 9.

What about the stigma of being ferried everywhere in a yellow minibus with County Council written all over it! I wasn't bothered about the bus as it happened, but looking back I say - why single us out? Surely society views us as people who need help but also felt pity for us? I never wanted pity; I wanted love. I wanted a family. I wanted to be hugged, everything a regular child should want, I believe. It took me until I was nearly 40 years old to realise I am so much more than my past. So much more than a care leaver. So much more than someone with a mental health condition. Why not say disability? Because it also makes me awesome at some things.

My biggest problem was learning how to live as an independent adult not a damaged child. How to realise that everyone is brilliant and individual and worthy of love and self-compassion. Even me, a schizophrenic who has made so many mistakes, but achieved so much. It was interesting that whilst in hospital, in 2010, a nurse said why not finish your degree? I replied, I'm a service user, a schizophrenic, I always will be.

It took the amazing support of my family who gave me chance after chance to realise my dreams. To gain two degrees. To believe in myself to see the person I always was but who I couldn't become. Thanks must go to the social workers who supported me, the awesome members from my community who never walked away, the handful of friends who always believed in me and most importantly my big brother who gave me an insane belief that anything is possible.

Passionate about kindness – Kizzy Felstead.

In August 1999, at 28 weeks pregnant, I went into labour in a tiny tent, in the middle of a field at a music festival. I was rushed to A and E at the local hospital where the paramedics passed on relevant information about me to the Doctor. At the time, I was extremely underweight and had no bump. The first question that I was asked was 'are you under the influence of alcohol or drugs'. This Initial judgement made me lose trust in the very people I needed to look after me and my unborn baby. My medical records could not be linked into

from the computer in Oxfordshire, so the disbelief continued until contractions got stronger and there was no question. A second Doctor came to prepare me to be transferred to the emergency premature baby delivery unit over thirty miles away. I was afraid of any intervention and showing signs of shock. As an autistic person, when I am distressed or distrusting, I shut down and cannot speak. The Doctor needed me to have a steroid injection in order to prepare my baby's lungs should he be born. The Doctor calmly explained that my baby needed me to have this injection before transfer. Eventually, I agreed. As I left in the ambulance, the Doctor gave me a kiss on the cheek, said I had made the right decision and I would now be in the best hands. This small act of kindness has stayed with me forever. I struggle with my mental health and know how difficult life can be at times. A few kind words, a look, some patience, can make all the difference to someone's day, life or decisions. This is the reason that I sign off with 'Passionate About Kindness'.

About twelve years ago, I requested a social care assessment as I felt my child had unmet needs and we needed support. We did not receive the report until seven months later, despite my ringing to see why I had not had sight of it. Much of the report was incorrect, including the name of my daughter and though my husband was out of the country on business, he was described as being 'present but silent'. The report also made the scathing judgement that I 'laid in bed all day' which could not have been further from the truth despite my having ME and fibromyalgia. The report had been sent out to the head of my daughter's school, my GP etc before I had even seen the draft. At triage, I had requested that the person we were allocated would need a good understanding of autism as my children and I are all autistic. It was clear from the way the social worker related to me and my children that this was not the case. This negative experience coloured my judgement of social workers until about seven years ago when I received an adult social care assessment for my own unmet needs. This was different, the social worker was patient and came back several times to complete the assessment as my anxiety and fatigue were so great that we could not

complete in one session. I received a draft copy to sign if I agreed it was correct, I was not patronised and the social worker told me a little about herself which gained my trust. This social worker showed professionalism and compassion and above all kindness and patience.

Part 2: The Power to change attitudes through our involvement in SW education – Angela Melling.

My “speciality” is caring for a child with complex needs. When your child has complex needs you need to be an expert in their conditions. I have read up on the condition finding out as much as I can. So I am an `expert by experience` and talk to students about coping with complex needs, the effect on the cared-for as well as the carer and the rest of the family. Everyone is different, so narrative's from numerous people is so important for students to listen to, “one hat doesn`t fit all”.

So, when asked to be involved in sessions and teaching opportunities other than caring, I found it difficult - out of my depth. It is a skill that can be learnt as you get more experience and confident in your abilities. Situations change over time in your life, you gain knowledge and understanding of many circumstances to be confident when teaching. As a carer I have so much experience I wish to share with students; hopefully making the next generation of carers and their cared for, involvement with social workers an easy passage

I have enjoyed being part of the group, especially teaching on the Social Work modules. When I first started talking to students, I found it very therapeutic. You don`t often get the chance to just talk about your life. As the years have gone by, I have become a “service user” too, so have more experience to talk about. Talking about good and bad experiences, how bad experiences could have been changed around. But the message behind any sessions I take part in, is that there is a person behind that diagnosis.

Giving the students opportunities to meet service user and carers in a classroom setting is often the first time many students have had close interaction with service users and carers.

The feedback we have had is that students are apprehensive at first at being taught by service users and carers and have said they wondered if it will be a good experience, and importantly will they benefit from this learning opportunity? Students gain a unique insight into working with service users and carers and by the end of the session they state they want more teaching with us.

Being in Comensus has given me so much, increased my confidence, making friends, being able to experience different opportunities. Respected for myself and what I have to say.

Conclusion

Understanding the value of developing a good working relationship with service users or carers is, in our opinion, a fundamental core skill to learn, as it has the power to change attitudes. The benefits of including people with lived experiences in education cannot be underestimated with regards to personal and professional development. Hearing examples of good or bad experiences can encourage the students to reflect on whether they could do things differently if faced with similar circumstances or, potentially, on times when they may not have considered all perspectives including the service user or other family members.

Meeting people from different ethnic backgrounds, from different cultures or people who are different to you (for example, with learning disabilities, autism and/or people with mental health and/or physical conditions), can help to break down barriers or alleviate any pre-conceptions that students may have.

We have related some of our difficult experiences with social work teams; in the past, we often haven't felt listened to; we have felt ignored or patronised. In some cases, written reports about us have been factually incorrect and these mistakes have had a negative impact on our physical/mental health. Trust is a significant factor to a good professional relationship. Empathy, compassion and a willingness to be open and relatable are qualities

that we emphasise to student social workers which are crucial to the needs of service users and their families.

“As a child I often felt as if social workers, especially when I had adults taking care of me forgot or chose not to ask me, the person, the service user how am I? I wasn’t going to trust them in front of my foster parents!” Comensus collective member CC

As a group, we share similar motivations for being involved with the Comensus group at our University. These are to forge strategic change following our experiences of services and to feel heard as well as listened to which leads to a consequential therapeutic response.

‘I feel it helps to share my mental health story because I feel I can rationalise my journey and clarify my lived experience through talking to the students. It is therapeutic for me as it enables me to get things of my chest.’ Comensus collective member SB

The Comensus group have a good working relationship with the School of Social Work and its students, and we engage with them in teaching and learning activity, such as role play, experiential sessions and digital stories. Learning alongside experts – those with lived experience as carers or service users - should never be undervalued and from the positive feedback we receive from students, we believe that such experts should always be partners in Social Work education.

There is a kinship amongst us which also seeks change and we derive much positivity from each other and from the work we do voluntarily, as we can see first-hand the difference our histories make. We know what is not working and we are really happy when it does work. This is not tokenistic, it is true co-production.

C*o-productionis central to what we do*

O*pportunities for all– inclusive not exclusive:*

M*others, fathers, sisters, brothers– all*

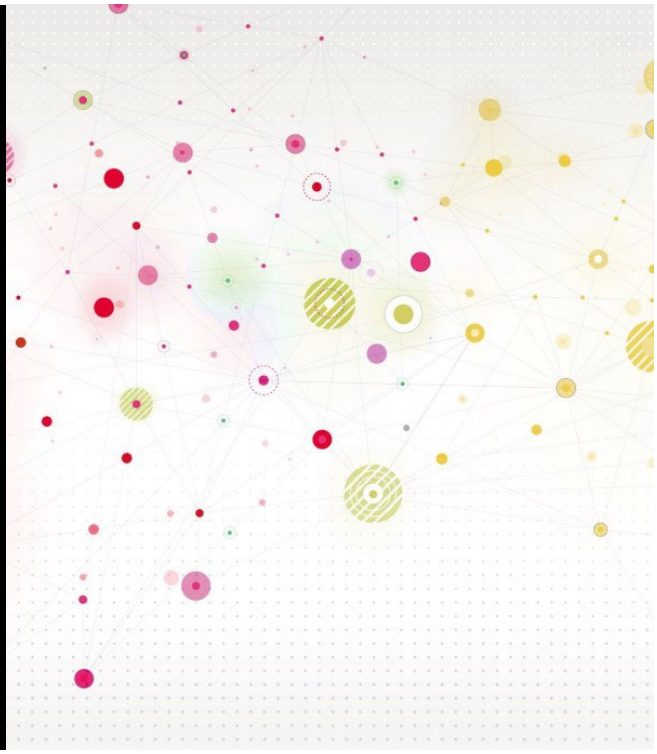
E*xperts with individual lived experiences*

N*eurodiverse and complex*

S*ynergy – the Gestalt (sum of the parts is greater than the whole)– together we are Comensus*

U*nderstanding and good communication is our message*

S*hared learning moves us towards positive change*



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