“Don’t judge a book by its cover”: Lived Experiences of the involvement of older people in social work education

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The involvement of service users and carers in social work education is a mandatory requirement and considered to be an essential element of the training for new social workers, particularly in enabling them to develop value driven and competent practice. This involvement allows students to gain the benefit of hearing about shared experiences, but also of hearing the individual’s own unique perspective on that experience. It enables student to learn that, alongside shared experiences, there are individual stories as well. This is the focus of this chapter which discusses the involvement of older people in social work education and highlights some of the diversity of this ‘group’. The assumption is often made that older people come into contact with services on the basis of needs that arise as a result of ‘being old’. However, being ‘old’ does not qualify one for the receipt of social services and making assumptions about someone on the basis of their age alone is discriminatory. We should not assume that we know what challenges or experiences an older person brings, just because they are older. In short, we should not judge a book by its cover.

This chapter builds on this starting point to highlight the importance of involving older people in social work education. It does this by drawing on the experience and knowledge of four authors, three of whom are older people themselves with a range of experience of being involved in the education of social work students. The authors share some of their own experiences about social work and their perspectives on being involved in social work programmes. The main aim of the chapter is to challenge assumptions about the homogeneity of this group and to highlight the value of their varied experiences and perspectives as contributions to educating future social workers. Social work students need to be able to understand and respond to the needs of an older population and, as this chapter will demonstrate, for this to occur they need to learn directly from older people.

**Social work involvement as an older person**

There are currently over 901 million people in the world who are over the age of 60 and this number is set to increase to 2.1 billion by 2050 (ONS, 2018). This global increase in the older population is reflected within the UK; in 2016 there were close to 12 million older people (over the age of 65) in the UK, an increase of over 2 million since 1991, and the older population is expected to increase by a further 8.6 million by 2066 (ONS, 2018). Discourse around the ageing population often focuses on the challenges, rather than the opportunities, that this presents and older people within this discourse are frequently reduced to a homogenous group. In reality, however, the older population is a very diverse group. There are differences in relation to life stage (whether working or retired), income and wealth, marital status, age (the population age spans from, arguably, 60 through to end of life), and living arrangements, as well as in relation to ethnicity, religion and sexuality, amongst other things (ONS, 2018). For example, results from the 2011 UK census showed that 8% of people over the age of 65 are BME and 2.1% of people over the age of 50 identify as gay, lesbian, or bisexual (AGE UK, 2019). Despite this diversity, services often work from an assumption that the needs of older people are similar and forget to consider the wide range of experience and difference that exists amongst the older population. Moriarty & Manthorpe (2012, p.12) found that sexual orientation, religion, belief and gender identity were “almost wholly absent” in research, leading them to conclude that diversity in the older population was being largely ignored. Others have also concluded that sexuality in older age has been “rendered invisible (Cronin & King, 2010, p. 881). As Milne et al. (2014) have pointed out, the older population as it grows will become increasingly diverse and this needs to be recognised by policy makers, services and social workers. As highlighted within the introduction, older people do not come into contact with services simply by virtue of being an older person. Such experiences arise from a diverse range of reasons and the route through to involvement in social work education can also vary. Three different experiences are shared below.

**Sheila’s experience**

I have been involved with social services for other thirty years now which started with the death of my mam. I have also had experiences with social workers due to being a kinship carer. Through this I became involved with Relative Experience who first introduced me to the university. Relative Experience give support for kinship carers. Kinships carers are grandparents, aunts, uncles, and others who are raising a child because the parents are unable to care for them. They deal with drug addiction, alcoholism, parents with a learning disability who can’t look after their own children, death in the family and all sorts of other things. They take grandchildren on as adoption or special guardianship, or guardianship. It’s not just “looking after the grandchildren”; it’s a 24 hour a day job. It is also an unpaid job in most cases. Although we get told in lots of cases “well you are grandparent so it’s part of your life” that is not the case. We take on children who might have been traumatised and don’t know how to deal with life. You’re giving up the rest of your life as you’re starting all over being a parent again. It can also cause you to be cut off from the rest of the family which is not easy. I don’t think when you take a child on like that social services give you enough support as they don’t look at the wider family. They just look at that one person and the child.

**Pat’s experience**

In 2017, I was diagnosed with Autism and since then I have been passionate about raising awareness of the condition, especially in relation to autism and ageing. In 2004 I enrolled on a social work degree, however, due to personal and health issues I was unable to complete the degree. In 2015 I became a member of a service user reference group which was involved in the recruitment and training of social workers at the same university. Our remit included participating in the selection process, training, design and content of advertising materials, policies and practice documents, and their summer school education programme. This included preparing and delivering training, as well as role-play scenarios with students. In every case where there was direct contact with the students the feedback was always very positive, especially in relation to our sharing personal experiences. Since also becoming involved with the social work department at another university I have chosen to bring my own experiences of living and ageing with autism, in order to share these experiences and to raise awareness of the complex needs of people with autism. This will hopefully expand the knowledge and skills base of the social work students and future practitioners.

**Shirley’s experience**

Being a carer for my husband has changed my life! My husband was a very complex case of ill health; following 2 TIA's he suffered a severe stroke when he worked abroad. This left him with lots of side effects, for example short term memory loss, swallowing and choking fits, burst heart with aneurysm, legs at 25 and 35 degrees, as well as a recent cancer scare. Fifteen years ago he was a very active man trebling the size of our bungalow in time spent at home when he was not working in the Middle East! He was always outside in the fresh air and a regular walker. He found his lack of mobility very frustrating. He lost 7 stone and said he had become “a crooked man with a crooked stick”. I did not know I was a carer until someone made me think that looking after my husband, mother and uncle, I could possibly call myself a carer.

It took me 8 years to accept this caring role and it was only when my mother died and my husband suffered further ill health that I realised I needed help and stepped over the threshold the local Carer's Centre. Here I was given an instant interview in a caring, quiet environment where I was allowed time to explain my situation. Tears came and went but when I left the building an hour later I knew I had found the listening ear I needed. I had found somewhere where staff were empathetic and provided me with the mental support, coping language and signposting to other agencies that I required to be a “Carer”.

As a carer it is important to know your rights. I attended 1 of 16 Conferences across the country hi-lighting Human Rights. I feel It is vital to have emotional stability and give yourself permission to say “No”, or be late, or whatever you need on the day when you feel down. But most of all, don't “judge a book by its cover” and try to retain a sense of humour. It is not easy, but the help of an empathetic Social Worker can make all the difference to a carer’s survival.

**The importance of involving older people in social work education**

Older people are frequently discussed in very negative ways, for example, in relation to the ‘challenges’ of an ageing population, or with a focus on ill health or frailty. However, *their* voices are often missing from these discussions. This concurrently excludes them from sharing their own perspectives whilst allowing assumptions about them, which are often negative and ageist, to flourish. Without direct input from older people within social work education there is a risk that students miss the unique perspectives which can help to challenge a predominantly negative narrative. Duffy (2016, p. 7), for example, stated that the pervasiveness of ageism in society has meant that negative views about older people and ageing are “often accepted as truth and internalised unwittingly”. This has been supported by research undertaken by Cherry and Palmore (2008) who reported that ageism was “widespread and frequent” (p. 852) amongst college students, older adults living in the community and people who were “members of a university community” (p.851). Allen, Cherry and Palmore (2009) also studied the extent to which social work students and practitioners reported engaging in ageist behavior with similar results. In both studies participants reported engaging in more “positive ageism” (for example, agreeing with items such as “compliment older people on how well they look despite their age” p.130), however, as the authors pointed out this could bleed into paternalism which can undermine and reduce people’s choices and independence. Lee, Jung, and Sumner (2015, p.2) also found “generally negative ageist attitudes among social work students”. Other research has also provided evidence that ageism is widespread (e.g AGE UK, 2011; Fealy & McNamara, 2009; Okoye & Obizeke, 2005, Weicht, 2013). Regardless of whether ageism is ‘positive’ (“hold doors open for old people because of their age”) or ‘negative’ (“avoid old people because they are cranky”), the impact is predominantly harmful, reflecting as it does an underlying assumption of incapacity (Allen, Cherry & Palmore, 2009, p. 130). Research by WHO (2002) and O’Brien (2011) also highlighted that older people feel that ageism constitutes, as well as contributes to, abuse.

Given these findings, it is vital for social work students and social workers to reflect carefully on their own perspectives about ageing and for a focus on ageing to be firmly embedded within social work curriculums. Social workers need specialist knowledge in order to work with older people. This includes the need to be aware of theories and models of ageing, to understand the ageing process and to know about health conditions that may be more prevalent in later life, amongst other things (Milne et al., 2014). Social workers also need to have “knowledge about the local services and the wider community” (p. 17). Through their learning, within which educators by experience play a vital role, social work students are encouraged and supported to reflect on their own misconceptions about ageing. Hearing directly from older people who bring different perspectives and lived experiences into the class room can help them to consider what their prior assumptions have been and how these relate to the experiences that are being shared with them. For example, studies have shown that contact with older people and increased focus on gerontological content in courses can increase students’ willingness to work with older people (Curl, Simons & Larkin, 2005; Nane, 1999; Ortiz , Cross & Day, 2012). Ortiz, Cross and Day (2012) also found that direct contributions from older people within the curriculum helped students to identify and reflect on ageism, with students making comments such as “I have learned that older adults do not have a lower quality of life simply because they are aging, it is the individual circumstances surrounding the adult.” (p. 861). The importance of involving older people in social work education becomes abundantly clear when the impact on the students is considered. The accounts below explore other perspectives about the importance of older people’s contributions to social work education.

**Pat’s perspective**

It’s important to share personal experiences, so that it can help to inform best practice in social work. I have experienced both negative and positive social work input in the past and both have had a lasting impact upon my mental health and my life in general. That’s why I think it’s important to share those experiences, so that in the future more people will have positive experiences instead of negative ones. Perhaps if I had been diagnosed sooner with autism, I may have had more positive experiences and more structured support. I personally feel that sharing my own experiences can contribute to the knowledge base of students because there are many things which the student cannot learn from books. These include, for example, how someone is feeling and thinking in relation to their life experiences and what impact these experiences can have on a person’s ability to cope, or not, as the case may be. They can also learn about exactly what assistance the person requires, instead of making assumptions about their requirements, based on reading alone. I know sharing these experiences does make a real difference, because they have told me so. They have completed feedback questionnaires stating how much they enjoyed hearing about my experiences and the difference it has made to their understanding not only of the topic, but how it will inform their own social work practice and how it broadened their knowledge base.

**Shirley’s perspective**

I hope to support their learning at University in a practical way to enable them to have a wide range of experiences and to understand the value of their work.  By empowering them and working with the University in this way, together we should make a difference and provide the all round education that will strengthen our Social Services for the community.  We need to encourage the students to use self-help for their physical and mental wellbeing.  I want students to be confident and have enough information to be able to make informed decisions and help others do the same.  I want them to be aware that “there is more to me than meets the eye".

**Sheila’s perspective**

I think it’s a big thing for students to listen to people with the experience because the experience that they get is a wider one; it’s not just about my experience as a kinship carer, it’s about disability and all sorts of things so they are getting a wide range of what is out there. It has to do some good if everyone is working together to get the same standards in social work. I think over the years that I’ve been with social services, when we’ve all worked together as a team (for example, social workers, psychologists – everyone involved with that person) it has worked well and the students need to know those sorts of things. They need to know what works well and what doesn’t work well.

The feedback from students is always really good and the interest from them is good. They all say they enjoy it and that is really good to hear. Even if one person comes back and says “I was interested”, that’s quite good. I have been in lectures with the lecturers where students have fallen asleep – they didn’t fall asleep with me! I really think it’s a good thing that everyone gets the opportunity to do this. It’s certainly done me a lot of good. At the beginning I was terrified to speak. I’m not really an outgoing person, but I did enjoy talking to the students.

**Older people’s motivations for engaging with social work education**

There is limited research which directly explores the reasons *why* people with lived experience choose to get involved in social work education. Data from my own research (which included older people amongst other participants involved in this area) suggest that the motivation comes from a desire to give something back and to contribute to bringing about positive change with this profession (Lonbay, in press). Participants in this project also spoke about personal benefits, for example, increased confidence and understanding of social work (Lonbay, in press). These reasons are reflected in research which has explored motivations for becoming involved in other areas. For example, older people involved in a participatory research project spoke about both the benefit of the project for others, but also for themselves. Personal benefits included increased knowledge and making new friends (Doyle & Timonen, 2010). Pat, and Sheila also speak to this within their accounts below, with a common theme between them also suggesting that a key driver for wanting to be involved in social work education is the aspiration to improve things for others who may find themselves in similar positions.

**Pat’s motivation**

I am motivated to share my experiences because I feel that it is possible to make a real difference to the social work students’ experience and that of the social work client. My experiences can help to inform social work practice and in turn help to ensure students have the benefit of life experiences not otherwise available to them. There is no substitute for these experiences and it is so important for students to have the benefit of hearing those experiences from real people. It also gives students the opportunity to ask questions and receive answers they might not otherwise get. In turn, I have the satisfaction of knowing that I can make a real difference to the experience of students and hopefully clients by helping to inform best practice, especially in the case of autism and ageing, or mental health. I am rewarded through my involvement in social work education, because I am passionate about social work education and the difference it can make to people’s lives. I enjoy being part of something that can be such a force for good if it is delivered in the correct way. Since my own chequered experiences of social work, and the impact it has had on me personally, I have been determined to try and improve, or add, to the social work curriculum. That includes sharing my experiences with students which I hope in turn will in some small way help to prevent other people having negative experiences in the future.

**Sheila’s motivation**

I was introduced by the relative experience project to the university because of being involved with them as a kinship carer. I share with the students by speaking to them or teaching a bit about my experiences with social workers. I really just felt like I had a wealth of experience to be able to talk about those experiences. I think it made me feel a lot better because I was telling people all about my situation and letting them hear about it. I’ve had social work involvement in my life for a long time and the things that I’ve dealt with over the years have been quite hard so for someone to be interested in what I had done was really nice as well. It’s given me more confidence to be able to speak up. I also think that some of the knowledge that you pick up at the university helps you with the situation that you are in and to feel free to speak up and say how you feel about the situation. For most people it’s a positive experience. They are getting more out of it than they are putting into it. You’re talking about personal situations and sometimes it’s deep and it hurts, but I feel that people get more out of it than you might realise. I certainly do.

**Enablers and barriers to involvement in social work education**

Some of the factors which help or hinder involvement with older people have been well documented in various places (see, for example, Lonbay, 2018). For involvement within HEIs, there is an additional difficulty in relation to how different types of knowledge are valued. For example, there is a drive to produce research based and ‘traditional academic knowledge’ and this focus does not always leave space for recognising the value of students learning via sources based on more experiential knowledge (Lonbay & Cavener, in press). Both have a role to play in HEIs, particularly when it comes to professional courses such as social work. It is vital that those with lived experience are recognised and valued as a core part of the teaching team, but it is difficult to fully achieve this when they are not formally recognised as employees by HEIs. However, there are steps that can be taken to help move towards that goal. For example, ensuring that fair pay and reimbursement is offered for people’s time, offering library or IT access and ensuring that Educators by Experience are involved, not only in teaching and admission, but in the development of the programme itself. To assist with this it is also vital that there are clear structures in place for offering support and training (should this be identified as a need by someone). Developing structures and training with experts by experience also helps to ensure that they are useful and actually meeting people’s needs (Lonbay & Cavener, in press). For older people, as with others, the important aspect is to ensure that any individual needs or support requirements are met in order that everyone is able to contribute effectively. Clear and effective communication and taking the time to build positive and supportive relationships are therefore both essential components. Pat, Shirley, and Sheila share some of the factors which help or hinder their involvement below. Each of them has a slightly different perspective on the most important factors, highlighting again the importance of considering the individual, rather than making assumptions based on age alone.

**Shirley’s perspective**

Every individual has a different "story" to tell.  It is not always what you see or hear, but what is not said that is important.  A calm listening and non-judgemental approach is so important for someone to share "their story" and it takes time to reach the truth by careful questioning, for example asking;  "How did you feel when that happened?".

**Pat’s perspective**

Some of the barriers I have experienced have been both physical and psychological. I am physically disabled and some of the barriers I have faced have included stairs in venues where the education was going to take place. I have hidden disabilities and it is not always obvious that I am disabled, which is why it is important to ask the person prior to their involvement whether or not they need any adjustments to the venue. Unfortunately, some of the barriers come from other people’s assumptions about my capabilities, especially in relation to my physical and mental health. It has been assumed in the past that autism affects my cognitive abilities and my I.Q. to the extent that I am unable to contribute or cope within a teaching environment, all of which is untrue. While it is true that I need some adjustments to be made, such as lower lighting and noise levels where possible, or temperature adjustment, I am more than capable in relation to my ability to communicate both verbally and in writing.

Some of the enablers have been in relation to good communication, for example, asking me beforehand if I have any requirements, or informing me of the layout of the venue. Having a support worker attend with me and a quiet space where I can unwind if necessary is also helpful. I need to have familiar routines and to feel safe. In physical terms, I only eat and drink certain foods and liquids, so I need to know in advance what will be provided, if anything at all otherwise I bring my own. Travel can also be difficult for me in terms of accessibility because I am unable to travel using public transport, without a support worker. This means using taxi’s or the car which can be expensive and prohibitive in terms of cost. Giving some form of reimbursement for travel is a huge help and enables me to participate in social work education. These may seem like simple things, but they make a huge difference to someone with autism and enable me to feel comfortable in the venue and situation, so that I am better able to contribute to the session.

**Sheila’s perspective**

The academic team help a lot; working together at the university is good. The staff have been really helpful and helped us. It’s not us and them – “we are the professionals”; we are working together. I get the sense that we are part of the team. When I’ve been there the lecturers have helped in a big way. They understand the situations you are in and they will help in any way. People ask after you and want to know how you are. It’s also good working with other people who want to do the same thing.

**Some key messages for social workers and social work students**

A key message within this chapter is that, whilst we may consider older people as a distinct group, there is in reality a great diversity with the older population, particularly in relation to experiences and individual responses to these. The authors of this chapter also wanted to highlight some key messages for social workers and social work students, which are drawn from their own varied experiences. These are presented below.

**Pat’s message**

Some of the key messages I want social work students to hear from me include the importance of not making assumptions regarding a person’s abilities, either mental or physical. If you are in doubt, ask the person, or their support worker, carer, or family member. Just because I am someone with high functioning autism, don’t assume that I don’t have difficulties, for example, I struggle with using public transport, bright lighting, noise, temperature differences, smell and touch, because I am hyper sensitive to all of these things they restrict my socialisation. I can’t use public transport and I struggle to read facial expressions; I am vulnerable because I believe what I am told, which can and has led to my being abused in the past. I am also a literal thinker, and this can lead to my interpreting words and meanings wrongly, or literally. It’s ok to make mistakes, as long as you are honest about it, explain what has happened and then do something about it. That is not only good practice, it helps to build trust between the social worker and their clients. Even if you can’t change the situation, just be honest about it, people really appreciate honesty and clarity, so please don’t use jargon either, because it only serves to confuse people and doesn’t contribute anything to their experience. It’s very important to include clients in the design and implementation of care packages, because it enables them to feel in control and included in the process. It also helps to leave a positive view of social work and social workers.

**Sheila’s message**

The key messages for me that I want social work students to hear are to listen to families and then act on what you’ve listened to because families know the person better than you do. One of the things I don’t like is when they promise to do something for a child or a young adult and then they come back and say sorry we can’t do it. Never ever promise something to someone unless you can come back and do it.

Social workers also need to empathise, especially with the grandparents, but they need to also think about the wider family. I think as well that they should ask the grandparents “can you afford to do what you are doing?”, because a lot of financial difficulty comes with this (being a kinship carer) as well and you don’t get any support with that. I had my house smashed up on a number of occasions, but no-one asked me “can you afford to keep doing what you’re doing?”. I’ve seen a lot of grandparents like this. As a person looking after someone, I don’t like asking for things. I think a lot of people are like that, but we have to ask for it. We don’t want to but we have to. People need the help otherwise they wouldn’t be asking for it. It does effect people if you don’t want to ask for money or service, but you’ve got to in some cases. So social workers should ask us what we think we need and show that they can empathise with our situation.

**Shirley’s message**

Nobody tells you how to be a carer and most people accept it as part of a loving and caring relationship without thought for themselves.  Being a carer has to be accepted by "the said person" as well as the "cared for".  Pride sometimes gets in the way of acceptance but if it can be taken on Board by both parties, it allows them to gain access to training, ‘being an expert’ during hospital visits and doctor's surgeries, Carer’s List,  and information at a Carer's Centre as well as enabling them to meet other people who have personal knowledge of how it feels.  The Social Worker needs to have lots of helpful hints to encourage this acceptance.  Therefore, when Social Workers are working in this situation it is very important that the words “you are a carer”, if used, are used with sensitivity because it takes a long time for some people to accept this situation, never mind the words themselves.  They are reluctant to be "Not coping" and therefore shy away from the reality.  This can affect their own wellbeing and thus reduce their effectiveness in the caring role.

It is also important for social workers to know what is available for all parties and to give practical advice because "the Carer" does not always know what their rights are and certainly what is available to them to help in their daily lives. For example, check out if they have an Emergency Card form their local NHS or local council.

**Conclusion**

Each author in this chapter has shared and contributed their ideas about the importance of being involved in social work education. These accounts highlight the differences in people’s experiences which reinforce again the importance of not making assumptions based on someone’s membership of a particular ‘group’. However, there are some important similarities as well. All of the authors highlight the importance of involvement being about challenging and changing students’ perceptions and ensuring that they think about the individual in front of them, rather than stereotyped ideas about that individual. This focus was reflected within the ‘enablers and barriers’ section which also highlighted the importance of tailoring support to be involved in social work education to that individual. As Pat points out, there is a danger in seeing one thing about the person to the exclusion of others. To see someone as only ‘an older person’ means missing other important aspects of that person which can have negative and exclusionary consequences. To see only the ‘older person’ means to miss so much more. In social work the consequences of this can be devastating for a person. Involving older people directly in social work education should be a core part of increasing gerontological input into social work programmes and is a step towards ensuring that social workers do not “judge a book by its cover”.

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