

Involving people with profound and multiple learning disabilities in social work education: building inclusive practice

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Involving People with Profound and Multiple Learning Disabilities in Social Work Education: Building Inclusive practice

Abstract

Service user and carer engagement is a foundational requirement of social work education. Despite this questions remain about how diverse experiences are represented and who might be excluded from involvement. This paper is focussed on one group of people who it is suggested are excluded from involvement, people with profound and multiple learning disabilities. Evidence is presented which demonstrates the extent to which this group have been marginalised and excluded from processes of involvement. The paper then provides a case study of one university's experience of developing work in this area, when a man with profound and multiple learning disabilities was commissioned to design and deliver specialist teaching for a group of qualifying social work students. We argue that the main barrier to inclusive involvement for people with profound and multiple learning disabilities is the attitudes and assumption of others about what they are capable of. We demonstrate how involvement in social work education helps to address these barriers by challenging the assumptions of students, the academy and society more broadly.

Keywords

People with profound and multiple learning disabilities, inclusive involvement, exclusion, attitudes and beliefs.

Introduction

Service user and carer involvement in public services is developing a significant history its profile having been raised by policy initiatives and legislative change (Bamford, 2015; Cowden and Singh, 2014; McLaughlin, 2009, 2010; Cairney, Chettle, Clarke et al 2006). The concept of involvement has many definitions; which may be focussed on levels of involvement (House of Commons Health Committee, 2007), areas of involvement (Tew et al 2004) or processes of involvement from more tokenistic forms of consultation through to citizen control (Arnstein, 1969). The language of involvement is also evolving and is perhaps reflective of our changing understanding moving from client and consumer through to service user, survivor and expert by experience (see for example McLaughlin 2009; Fawcett et al, forthcoming). In this article we consider involvement from the perspective of people with profound and multiple learning disabilities defined here as people who have more than

one disability, the most significant of which is a profound learning disability (PMLD Network).

The paper focusses on building inclusive practice considering this in the context of social work education, the experience of social work students and inclusive practice in the lives of people with profound and multiple learning disabilities. Drawing on the literature the paper begins by considering the extent to which people with profound and multiple learning disabilities have been involved and what barriers might exist to prevent involvement. Drawing on a case study we then report our experience of working together when Christian, was commissioned to design and deliver specialist teaching on working with people with learning disabilities on qualifying social work programmes. Student evaluations inform the findings on the value of this experience for their learning and development, whilst discussions with Christian and his supporters consider the experience from their perspective and how this informed their advocacy work with others. We conclude by arguing that all of the stakeholders in social work education need to question their own attitudes and assumptions when developing inclusive involvement for this group.

Before developing this paper further we would like to introduce ourselves in order to personalise and contextualise the discussion which follows.

Christian Raphael has worked as an independent consultant/adviser on matters relating to people with profound learning disabilities and complex needs for a number of years. This has included work for the Department of Health and NHS England. In addition to this, Christian is a representative on the National Forum for People with Learning Disabilities. In 2016 he was awarded the MBE in recognition of his work.

Matthew Clark has supported Christian for the last ten years, in both all aspects of his day to day life, as well as specifically in his work. Prior to working for Christian, Matt worked extensively in nursing, health and social care in a number of settings.

After a career in academia, Vicki Raphael spent time teaching in the special education system before becoming mum to Christian. In recent years, as well as continuing to directly support Christian, Vicki has worked tirelessly on a voluntary basis as a prominent figure of the inclusion movement. She is currently chair of the National Valuing Families Forum.

Nicki Ward is a social work lecturer at the University of Birmingham. Before joining academia Nicki worked for over 20 years with adults with learning disabilities in a variety of

settings. This continues to influence her work as an academic through both her research and teaching

Empowerment, Involvement and People with Profound and Multiple Learning Disabilities.

Service user involvement in social work education has a long history which pre-dates policy requirements for involvement (Cairney, Chettle, Clarke et al 2006). It is widely accepted as a foundational requirement of social work education, a principle reinforced in successive policy frameworks (Department of Health 2002; GSCC, 2005; College of Social Work 2014; HCPC, 2009). Whilst much of this policy is focussed on the UK, specifically England, there is also growing emphasis on service user involvement internationally (Zaviršek and Videmšek, 2009; IFSW 2004). Nevertheless, important questions remain about the success of these developments, particularly how inclusive service user and carer involvement is (Cairney, Chettle, Clarke et al 2006). Within social work, service user involvement is particularly important as it reflects the practice of anti-discriminatory and anti-oppressive approaches which are enacted through inclusion and challenging structural oppression.

Service user involvement aims to give voice to those who are oppressed and validate the voices of those who have been marginalised. However, whilst there have been significant developments in this area the evidence on involvement of people with learning disabilities, as demonstrated below, suggests that we still have a way to go in furthering this aim. Research on involvement demonstrates that there are many whose voices are ‘seldom heard’ (Carr, 2012; Hernandez et al 2010) and who are more likely to be excluded from processes of involvement (Bereford, 2007). In a recent text which sought to rethink Anti-discriminatory and Anti-Oppressive practice Green and Featherstone draw on the work of Judith Butler to consider the notion of ‘normative violence’ which, it is suggested occurs through routine activities such as ‘not allowing particular voices to be heard because they are not considered legitimate’ (2014: 31). This is a useful concept when considering service user involvement as it prompts questions about whose voices are heard and whose voices are omitted from the increasingly dominant discourse of service user involvement in social work education? We would argue that people with learning disabilities, and particularly those with profound and multiple learning disabilities are regularly subjected to this ‘normative violence’ by not

having their voices included and legitimated. It is important therefore to focus not only on involvement but on inclusive involvement (Bollard et al, 2012).

People with learning disabilities are amongst the most excluded within our society (Department of Health, 2001; Public Health England, 2014), and amongst them people with profound and multiple learning disabilities are likely to be more excluded still (HM Government 2009). Research conducted for this paper would suggest that this extends to a lack of inclusion within professional education. A systematic search of 6 databases¹ which included the search terms learning disability/difficulty or profound learning disability/difficulty, AND involvement AND professional education generated minimal results. The literature that explicitly discusses the involvement of people with learning disabilities in academia tends to be located within medical and nursing studies (Maestri Banks, 2013; Bollard et al, 2012; McLimens et al, 2012) or research (Boxall, 2011; McLimens and Allmark, 2011; Tuffrey-Wijne and Butler, 2010; Gilbert, 2004). A keyword search of this journal uncovered one document which involved the experience of a person with a learning disability in social work education (Pendred and Chettle, 2006). None of this literature included people with profound and multiple learning disabilities.

Research by Shaping Our Lives supports the argument that participation in service user involvement initiatives is still rare for some groups; including people with learning disabilities and people who communicate differently (Beresford, 2013), which would suggest that involvement of those with profound and multiple learning disabilities is likely to be particularly difficult to secure. Research focussed specifically on inclusion and involvement for people with learning disabilities consistently finds that people with profound and multiple learning disabilities are more likely to be excluded (Clement and Bigby, 2009; Mencap 2004; Abbott and McConkey 2006) .

As the case study considered here involved employing Christian as a visiting lecturer this is also an important area to consider. Employment is seen as a valued social role (Priestley, 2003) and a route to securing inclusion (Ward, 2009) but it is a field which people with learning disabilities are routinely excluded from. In 2012 only 7% of people with learning disabilities of working age were in paid employment - mostly part time. A similar proportion undertook unpaid voluntary work (Public Health England, 2014). Amongst people with profound and multiple learning disabilities examples of employment are extremely rare

¹ ASSIA, Social Policy and Practice, PsychInfo, Medline, Embase and HMIC

(CSCI, 2009). For many the biggest barrier to employment is not their knowledge and skills but the attitudes and assumptions of others. As 'Valuing People Now' (2009) noted the 'lack of understanding and aspiration about what can be achieved sometimes leads to an assumption that people will be passive recipients of care throughout their lives as opposed to people who can ... live as empowered citizens in our society' (HM Government, 2009: 38-39). Such assumptions about ability not only limit the opportunities available to people with learning disabilities but can also further exclude them by failing to recognise and value the contributions they do make (Ward, 2011; 2015).

Attitude change towards those who have a learning disability is particularly important. Scior and Werner (2015) conducted a review of evidence on approaches to attitude change. They found that contact with those whose lives challenge negative stereotypes, (including beliefs that people with learning disabilities are childlike or in need of protection), was more effective in improving attitudes than other methods. The report emphasises the importance of balancing this so as not to deny the needs of those 'people with severe and profound disabilities who may be at risk of being further marginalised' (Scior and Werner, 2015: 16). The beliefs and assumptions which are held about what people with complex needs can achieve and what they are capable of is a significant barrier to inclusive involvement. An evidence review on advocacy for people with high support needs found that attitudes and cultures were particularly important:

'the challenge is changing the mindset and creating an atmosphere where people with PMLD are involved as actively as possible and are seen (and see themselves) as equals' (Lawton, 2009: 46) .

The teaching initiative described and evaluated below aimed to do both of these things; challenging the attitudes and beliefs of student social workers about the potential of people with profound and multiple learning disabilities, whilst also offering Christian an opportunity to develop his own skills in relation to employment and inclusion.

The Teaching - Working with people who have a learning disability

Baldwin (2013), notes that the key to challenging dominant narratives is to identify them and then to take action to challenge them. This initiative is representative of one such attempt; challenging the dominant narrative about who can speak for people with learning disabilities and who has the skills and expertise to be 'involved' in the education of qualifying social workers. This was not just about ensuring the presence of a person with profound and

multiple learning disabilities within the teaching but of handing over control. Whilst our work did involve partnership the role of the academic was to provide more practical support; arranging teaching spaces and materials, introducing the team and participating in some of the exercises. Christian developed and led the teaching with the support of his team.

This was a two day course on working with people with learning disabilities which was offered as an option to students on a qualifying social work programmes. Students could choose two 'electives' to help them develop specialist knowledge in a particular area. The electives were part of a final year module which emphasised life course and whole family approaches to practice (Morris et al, 2008; Hughes, 2010). The teaching had previously been delivered by Nicki. In 2011, building on other work Nicki had undertaken to involve people with learning disabilities in social work education (Mencap, 2010), Christian was commissioned to lead on and deliver the two day programme.

Inclusive involvement requires positive guidance, support and mentoring and this was particularly important here. Although Christian had begun working in service user involvement some years before and had been involved with the Department of Health in the development of resources for Valuing People Now (DoH, 2009), this was his first experience of delivering social work education in a higher education setting and was a daunting prospect: 'the difference between doing a one-hour workshop and doing the whole module was a big thing' (Matthew, cited in Mencap, 2012). We had several meetings before the teaching was delivered for the first time, initially at Christian's home and then at the University so that Christian could familiarise himself with the surroundings. Nicki provided information about student numbers, level and programme of study and the broader curriculum within which the electives were located. The teaching notes and materials used previously were also provided to Christian and his team as a guide to developing the module. There was no expectation that Christian should use these and it was particularly important to Christian and his team that he had control over the development and delivery of the teaching. Both the original delivery and that by Christian and his team took a workshop approach within which presentations were interspersed by group activities and discussion with students along with the use of audio-visual (AV) material.

One primary difference between the original programme and Christian's teaching was the emphasis on the lived experience. Although the original design had drawn heavily on AV material to provide 'real life' examples of good practice (DoH 2009), it was not able to capture the lived reality in the same way. Here examples were located in Christian's own life

experiences and those of his 'Circle of Support' who have been working alongside Christian since he left school. The circle helps Christian to consider his ambitions and aspirations and to plan his life (For further information on Circles of Support see Burke and Ball 2015; circlesnetwork.org.uk), various members of Christian's circle came along with him to deliver the teaching. This included Vicki, (Christian's mother), Matthew (Christian's Employment Support Worker) as well as others involved in supporting Christian. As well as presentations and discussions materials such as Christian's diaries, photographs and videos were used to illustrate key points, model good practice and promote discussion. Developing and delivering the teaching in this way had a number of benefits. It provided the students with a very explicit example of the importance of the whole family approach and the need to respond flexibly. It also demonstrated the potential benefits of working with a circle of support when working with someone with profound and multiple learning disabilities. The teaching took on a decidedly auto ethnographic approach drawing 'upon the experience of the author/researcher for the purposes of extending sociological understanding' (Sparkes, 2000: 21). Christian's team maintained the life course approach developing this through a focus on different 'chapters' in Christian's life including birth, childhood, transition and adulthood. These were illustrated with reference to their biographic experiences and students were able to question directly what professionals did well and what they might have done differently to improve the situation. By exploring Christian's experiences students were able to consider the impact of social structural issues, the impact of legislation such as the Mental Capacity Act (2005) and the historical development and impact of policy such as educational segregation and personalised and self-directed support. Time was devoted to considering and practising person centred practice and how tools such as PATHⁱ planning might be used with people with learning disabilities.

Evaluation - The Student Experience

This case study is based upon the evaluation questionnaires completed by three successive cohorts of students and on reflective interviews which took place between the authors when writing this article.

The teaching was available for 15 - 20 students in each year. The evaluation form was circulated at the end of the two days teaching. Students were asked about their previous experience of working with people with learning disabilities, their experience of the teaching, assessment of their learning and key learning points and recommendations for the development of the teaching. Finally they were asked to provide feedback on Christian's role

in the teaching. This was a new initiative for all of us and we felt it was important to explore how students had experienced being taught by someone who had profound and multiple learning disabilities. Christian and his team especially wanted to know if students felt he was effectively included in the teaching and learning process. As this was a teaching evaluation rather than a research study formal ethical approval was not sought; however the students were informed that their feedback would be used to help Christian develop his work opportunities and may also be used in future publications. The results of these evaluations will be discussed here before moving on to Christian's reflections and those of his team.

40 students completed the evaluation. Students were not asked to indicate their programme of study (PG or UG), or to provide other demographic data such as gender, age or ethnicity. They were however all asked to indicate whether or not they had previous experience of working with people with learning disabilities and if so, whether or not they had ever worked with someone with profound and multiple learning disabilities. A majority of the students (n=30) had had previous experience of working with people with learning disabilities with a little under half of these having experience with people with profound and multiple learning disabilities.

[Insert Figure 1 here]

The types of experience which students had ranged from significant work roles in day and residential settings or personal experience supporting family members to more limited experience on placements whilst at university or interaction through school projects. It is however interesting that most of the students did have some previous experience and it may be that this generated their interest in taking the elective in the first place. However 25% of those who completed the evaluation had no previous experience.

Students were also asked to assess their own learning development as a result of participating in the teaching. Two Likert scales asked students to rate their knowledge of working with people with learning disabilities on a scale of 1 – 5 (where 1 = 'no knowledge' and 5 = 'significant knowledge') both *before* and *after* the teaching. Across all 3 deliveries of the module students indicated a growth in their knowledge of between 1.29 and 1.42 points on this scale. For the students who had no previous experience this margin increased, rising 2.25 points from an average of 1.5 to 3.75 on the Likert scale.

Five of the 40 students completing the evaluation indicated no increase in their knowledge all having assessed their knowledge as 'significant' at the outset. However all of these students

indicated things that they had learned from the teaching including tools that could be used for person centred planning such as PATH, the importance of challenging of assumptions and how to overcome difficulties in transition.

The evaluation questionnaire invited free text responses to the question ‘please identify at least two things that you have learned from the teaching’. The question was purposely phrased in this way, rather than providing a tick box of the different topics covered in the teaching so that we could assess the extent to which the experience itself had informed student learning as well as the content. Responses to this question suggest that both aspects were important with some students mentioning particular elements of the teaching and others referring more broadly to the experience as a whole. Thematic analysis suggests that the most significant topics for students included those related to personalisation and tools for person centred practice as well as the importance of family experiences and the role of communication in working with people with learning disabilities (see table 1).

[Insert Table 1 here] – Key aspects of Learning as assessed by the students

Other important but less frequently mentioned learning points included transitions, sources of practical support and wider networks.

More significantly, especially for our argument that inclusive involvement is about challenging assumptions and enabling voices to be heard, is the feedback which demonstrates that student learning was highly experiential. It did not just occur through didactic teaching methods in which the lecturer imparted the knowledge to the students. It derived from participatory and observational learning as the following quotes suggest:

‘it allowed me to witness new communication methods and it helped me to better understand how non-verbal service users can express themselves’

‘I’ve never seen such a successful example of personalisation’

‘it enabled me to recognise the importance of communication in terms of verbal, non-verbal and body language’

‘observing Christian communicating with his team was lovely to see’

‘Having Christian there really helped me to imagine the life of somebody with complex needs. I will have lots to think about and consider’

‘talking about someone is very different to actually meeting them’.

The learning gained through being part of the process and being able to observe Christian and his support network in practice moved beyond an increase in knowledge and skills; it challenged assumptions and expectations. Within the free text comments students talked about the importance of having positive expectations, the impact a lack of aspiration can have on a person’s life, and the importance of a biographic approach. Others noted the way that the experience had challenged their own assumptions about what a person with learning disabilities might achieve:

‘People with learning disabilities are capable of achieving far more than I thought possible’

‘Challenged assumptions about ability to understand information and being able to articulate’

‘it broke down my prejudices that I held by having Christian there’

‘it was great to see Christian there, in fact it was a surprise to me’

One student’s comments even reflected a realisation that she and Christian shared common interests noting that she most enjoyed *‘seeing and hearing about his love of festivals as that is something that he and I share’*.

Bamford argues that working with service users and carers can actually give practitioners a more insightful understanding of ‘the *real needs*’ of service users rather than their assumed needs’ (2015: 105 - our emphasis). This is reflected in our evaluation. The student feedback suggests that the teaching not only provided them with additional tools to draw upon in working with people with learning disabilities but that it also challenged some of their assumptions about what type of life was possible for someone with complex needs.

However, if we are to argue that inclusive involvement in social work education is a strategy which furthers anti-discriminatory practice then it is also important to consider how this initiative was experienced by Christian and those supporting him.

Evaluation - The Experience of Christian’s and his Circle

Christian, along with his circle of support, had identified as part of his PATH that it was important for him to pursue employment opportunities and he had begun to draw upon his personal expertise to work as a self-advocate and to provide training to various health and social care agencies (org ref, 2012). He was therefore ideally placed to be involved in this

teaching. He had the skills, experience and support network necessary to deliver the teaching and wanted to develop his skills in this area. It is important however to recognise both the opportunities and challenges which the teaching presented.

Whilst Christian does not communicate verbally if he is not happy or interested in what he is doing then he will communicate this through his actions. In addition if Christian is stressed or upset with a situation this impacts on his physical and emotional health. When Christian began work his family and friends reported an improvement in his health which resulted in less hospital admissions; this along with his calm demeanour and engagement during the teaching told us that he enjoyed the work that he was doing.

There was also the benefit of being in work, and being able to use the language of 'employment' and being a 'lecturer'. In this way Christian's involvement not only challenged the attitudes and assumptions of the students but also others who he came into contact with. People with learning disabilities, especially those with more complex needs, are often cast in the role of dependent (Ward, 2011) and employment can be seen as unachievable (Mansell, 2010). However being employed provides opportunities to occupy valued social roles which in turn present a challenge to the assumptions of others (Ward 2011; Mansell, 2010).

Christian's experience as a lecturer not only influenced the student social workers he came into contact with but also others within his social network. One explicit example of this was during learning disability awareness week when Christian and his family invited their neighbours in for afternoon tea. They used this as an opportunity to talk about Christian's work and many of the neighbours expressed initial surprise hearing about his work as a lecturer. Benbow et al argue that service user involvement 'carries the potential to subvert attitudes and beliefs that ... others hold' (Benbow et al, 2011: 632). In this instance Christian and his family directly drew on his experience to educate and challenge assumptions about the lives of people with learning disabilities.

Christian's involvement also had potential impact beyond those students directly involved in the teaching. We noted above that one student identified shared interests that they had in common with Christian whilst others were surprised by his presence. For Christian it offered him an opportunity to inhabit an environment which is rarely open to those with learning disabilities, to socialize with his peers in an educational environment. It also meant that students and staff within the university also had their assumptions challenged, as Christian moved around the campus and used the campus facilities. Consequently, this work and the other employment opportunities which Christian was engaged in broadened his social circle.

In 2015 Christian took a ‘gap year’ during which he spent time travelling and visiting friends, many of whom he met as he developed his employment opportunities. Here Christian’s experience reflects the arguments of Priestley (2003) and Mansell (2010) that inclusion in the socially valued sphere of employment also helps people to develop their broader social networks.

Whilst Christian and his circle experienced a number of positive outcomes from their work at the university, there were also many challenges. Christian had the expertise required for this role because of his life experiences; the teaching was rooted in his autobiography and that of his family and friends. Drawing on this experience and recounting it repeatedly to different groups of people, and being prepared to respond to questions about it, is emotionally draining. Whilst Christian has a very positive package of support now, and a team who know him well and provide excellent support, it has not always been so. For the team having the trust of the academic partner, being able to take control of the teaching and develop and deliver it in ways which were comfortable for them and sensitive of the affective nature of the work was a key consideration informing their willingness to take part.

There were also practical challenges. This teaching was delivered on three separate occasions and on each occasion a different room was allocated. This was something we had no control over and whilst all were accessible some were more conducive to the teaching and more comfortable for Christian and his team, than others were. This in turn had an impact on the experience of students. In spaces where Christian was more comfortable he was more inclined to own the space and move freely around it – sometimes sitting with students at their tables or just circulating - and this was something students commented on as a positive:

‘there was much freedom for Christian to move and use the space and communicate when and how he wanted to’.

Others have written about the difficulties of negotiating bureaucracies (Beresford, 2013) whilst at the same time ensuring a positive experience and that was also an issue here. Whilst our room booking system allows us to request ‘accessible’ rooms this tends to take a narrower, physical view of accessibility.

For the people supporting Christian there were also some practical considerations. For example, on days when Christian was less well decisions had to be made about whether he should attend or whether it would be better for him to remain at home or in his hotel room. Christian did always attend the teaching but there were some occasions when he was

experiencing seizures and unable to interact with students as much. This required a delicate balance for Christian's supporters who at these times had to take a lead in delivering the teaching as well as caring for and supporting Christian. For the students seeing Christian when he was less well informed their learning. This was apparent in student feedback which suggested that students found it useful to be with Christian because they had never '*been around someone with such profound learning disabilities*' or that they '*found it difficult when Christian has a seizure*' having never witnessed one before but that '*it helped me understand how to respond*'. However striking the balance between an opportunity for learning and Christian's welfare and dignity was a delicate one for his circle to manage.

Discussion

Nancy Fraser discusses the importance of recognition, as well as redistribution in considering issues of marginalisation and inclusion. For Fraser this is about engendering situations which allow for all members of society to interact with each other as peers, to have parity of participation (1997, 2003). In this initiative Christian and his circle of support were able to take on a relatively powerful role, not just engaging with students as 'contributors' alongside academics, but designing and delivering the teaching as a visiting lecturer. This was important in committing to the principles and *practice* of service user involvement. The model adopted here was one of service user control, just as with any other visiting lecturer Christian was provided with a remit for the teaching but within this he was free to develop and deliver the teaching; as such parity of participation in this arena was achieved. The discussion above demonstrates that this was not only important for Christian and his team, but also provided a clear example to the students which challenged their beliefs and assumptions about what could be achieved by people with profound and multiple learning disabilities.

Aiyar (2010) explores participation in governance processes in India and concludes by posing a number of questions, two of which seem particularly important to the discussion here. Firstly are we 'romanticising' participation and secondly whether, in placing such emphasis on it, we are at risk of overburdening our citizens. These are pertinent questions to pose, not in order to undermine the importance of service user and carer involvement and the ongoing development of inclusive involvement but in order to ensure that we are realistic about the possible benefits of involvement for all the stakeholders. Are we romanticising

service user involvement? Perhaps a little. We have travelled far but we have not arrived yet; involvement is not always inclusive and in considering who we might recruit to support the education of social workers we need to be prepared to explore and challenge our own prejudices as well as the structural barriers of our institutions. As noted above, there were times when Christian's health needs were apparent within the teaching environment and whilst this added to the students experience and understanding this had to be balanced against Christian's health and welfare. This suggests that we need to think carefully about how we balance the educational benefits of involvement for students with the needs of service users; involvement is important but it should not be at the expense of overburdening those who are in receipt of services.

Bamford (2015) suggests that the benefits of involvement for service users are both short and long term. In the short term they can lead to enhanced self-respect and improvements in the quality of care 'especially if service users are involved in training practitioners' (2015: 100). This would seem to reflect Christian's experience in the short term; he experienced improvements to his wellbeing and self-confidence through his employment and was also able to broaden his social network. It is difficult to know whether this experience improved the quality of care. This was not an issue for Christian personally but it is hoped that this experience will have improved the quality of care to others with profound and multiple learning disabilities; either through the practise of the students involved or as a result of Christian's broader discussions about his work.

Irvine et al (2014) suggest that as we develop our understanding of user involvement in social work education we need to focus more on outcomes. Whilst this is not something which we have measured here some of the student feedback suggests that the experience will have longer term outcomes on their practice as indicated by the student who noted:

'this experience had had a profound impact on me on a personal and professional level and I will always remember how it is possible to achieve anything in life when you have people believe in you and show you genuine support'

However as authors we also believe that there is an important social justice argument for inclusive involvement. We should do it because people have a right to be involved, to have a say in their lives, to have parity of participation - it should not be dependent on the measurement of outcomes.

This experience was a largely positive one; we were successful in furthering our aims of challenging the attitudes and beliefs of student social workers about the potential of people with profound and multiple learning disabilities and Christian had an opportunity to develop his skills in relation to employment and inclusion. However, it is important to note that in the longer term there is a risk that this experience could become a burden to Christian. As we have demonstrated few people with profound and multiple learning disabilities are currently engaged in service user involvement and, as far as we have been able to identify, Christian is the only person with profound and multiple learning disabilities who has been actively involved in designing and delivering teaching to social work students. This presents ongoing challenges both for Christian and his circle and for the social work education community more broadly. For Christian it is his life experiences and opportunities - both positive and negative - which have provided him with the skills, knowledge and support to be able to be involved in this way. His biography, his negative experiences during childhood and the transformations made possible through personalised support, are the basis of his expertise. But becoming 'the' expert involves considerable pressure and more recently he and his circle have identified concerns that involvement on this basis could become a more negative experience; one which requires him to constantly 're-live' some difficult periods in his life and which detracts from the development of different work opportunities. For the academic community difficult questions are posed about how we develop the involvement of those with profound and multiple learning disabilities and provide students with experiences which challenge their assumptions and beliefs about what is possible when so few people with profound and learning disabilities have had the opportunities in their lives to develop the experience and skills which would enable them to be involved in this way. There is, in this sense, a vicious circle of exclusion for people with profound and multiple learning disabilities which can present a barrier to their involvement.

Conclusion

Within the introduction we suggested that we needed to question our assumptions in order to develop inclusive involvement for people with profound and multiple learning disabilities. Within this article we have demonstrated that people with learning disabilities, and particularly those with profound and multiple learning disabilities are amongst those who have been identified as 'seldom heard', their voices excluded from involvement. We have argued that a key to challenging this exclusion for people with profound and multiple learning disabilities, and therefore putting an end to the normative violence they experience through having their voices silenced, is to change the attitudes and assumptions of others.

For people with profound and multiple learning disabilities building inclusive practice means respecting their expertise and knowledge and learning how to hear their voices. In our experience people with profound and multiple learning disabilities are often seen as unable to communicate, a belief which was also reflected in the student evaluations. As social workers we need to consider how our assumptions and expectations might contribute to the silencing of the voices of people with profound and multiple learning disabilities. Social work education has a key role to play here, we cannot rest upon our laurels and assume that we have done all we need to in terms of service user involvement. For people with profound and multiple learning disabilities having access to academia and the right to be involved in the education and training of the professionals who will often have a key role in supporting them in their lives, gives the voices of people with profound and multiple learning disabilities the opportunity to challenge the attitudes and assumptions of those who often occupy positions of power within their lives and shape anti-discriminatory practice. Through this, as Christian has demonstrated, people with profound and multiple learning disabilities are able to actively model what positive communication and person centred planning should look like. However, if we are to make these spaces available then we also have to question our own beliefs and assumptions about who does and does not have the expertise and knowledge to ‘teach’ and how (and if) we represent the lives of people with profound and multiple learning disabilities in our broader curriculum.

A key principle of inclusive involvement must be that people are well supported, have access to guidance, support and mentoring and that it is constructed in within the context of a partnership through which the expertise of the person with profound and multiple learning disabilities is respected; they have to be able to control how they are involved and what they choose to share. This requires careful preparation and planning and, as illustrated above, very few people with profound and multiple learning disabilities currently have the opportunities to be involved in this way. We hope that this example will provide some insight into how other such initiatives could be developed.

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ⁱ PATH stands for ‘Planning Alternative Tomorrow with Hope’ and is a style of person centred planning which has been found to be particularly valuable with people with learning disabilities. It begins by identifying people’s hopes and ambitions and then works backwards to identify the key stages which need to be addressed in order to achieve the ambition (Further information can be found at <http://www.parent2parentqld.org.au/planning/path.php>).