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Service User Participation: Contemporary Issues and Obstacles for the National Service Users Executive and Service User Participation

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Abstract

This paper explores the current issues facing service user participation in the Irish mental health service. Firstly the paper looks at the history of service user participation as well as discussing the benefits of and obstacles to full participation. The National Service User Executive (NSUE) was set up because of recommendations made in *A Vision For Change* and this paper looks at the work the NSUE is undertaking as well as the challenges and issues obstructing their work. The conclusions drawn were that while lots of work has been undertaken there is a need for more, so that proper full service user participation can become a reality and not an aspiration.

Keywords: mental health; service user participation; *A Vision For Change*

Introduction

This research examines what is currently happening in Ireland in the field of service user participation in mental health services and specifically to investigate how service user participation is being promoted by the National Service Users Executive (NSUE). I investigate the history and background of service user participation movement including the benefits of and challenges facing participation. After this one

must look at the research methods utilised. In addition to this I discuss the findings from undertaking the research focusing on the issues, challenges and obstacles preventing service user participation. Finally I examine some of the key conclusions and themes that have been identified through undertaking this research.

Service User Participation in Mental Health Service Policy-Making

The Emergence of the Mental Health Service User Movement

The mental health service user movement emerged from the disability movement whose campaign was to show that disability is a ‘quality of the physical environment that excludes individuals from social and economic environment’ (Gould, 2005:16). This social movement undertaken by the disability movement was the catalyst for the emergence of the mental health service user movement (Gould, 2005). The movement also gained strength from the anti- psychiatry movement which was demonstrating other means of care and treatment for service users with mental health problems (Lakeman et al, 2007). This movement was also questioning the research into and effectiveness of anti-depressants and other types of drugs used in the treatment of mental illness. These were just some of the influences on the service user movement which began in Ireland and England in the late 1970s and 1980s.

Consumerism can also be seen as another influence on the service user movement. This came about from people who were using services now being regarded as health care consumers, being able to give their opinions and ideas in aspects of the service which they were using and mental health service users felt that they should also be allowed to give their viewpoints on the service they had received (Pilgrim, 2005). Barnes (1997:31) also outlines this move from patient to consumer when he describes how ‘the term consumer started to replace ‘client’ or ‘patient’ within the health and social care services as well as becoming a means of describing users of public services in general’.

Globalisation was also identified as a mechanism which allowed for service user participation as it instigated the move towards user participation with the main focus being on the public having a greater say in health care delivery. Kemp (2008:24) outlines how dissolving of the ‘power of the state’ is one of the many factors that led to the ‘development of service user involvement in mental health’. Kemp (2008:24-

25) believes that ‘there is an increasing reliance on non-governmental organizations’ as a result of this move away from governance; ‘new forms of governance are evolving in which the state must collaborate with a wide range of stakeholders’. While the above deals with how the government introduced mechanisms for the inclusion of service users in policy making, service users themselves were also campaigning for their involvement. Kemp (2008:27) identifies the British National Association for Mental Health which was working during the 1960s as a key service user involvement organisation it was ‘run on behalf of service users by individuals who were concerned about the way mentally ill people were cared for and being treated’. Organisations such as this went some way to bringing the involvement of service users in policy and service delivery to the forefront of people’s minds and began the movement towards service user involvement in all aspects of care.

The Irish Perspective and A Vision For Change

In Ireland service user involvement in areas such as policy, service development and service delivery is a relatively new movement. The inclusion of service users in the discussion and planning of the policy document *A Vision For Change* which is the current document underpinning the development of mental health services in Ireland, was marked as the beginning of a new era. The aim for this new era was the inclusion of service users in important areas of service provision and planning. *A Vision For Change* was a ‘framework of mental health service delivery with the service user at its centre’ (Government of Ireland, 2006:4). It was accepted that the service user and their carers would come up with care plans together and that carers and service users involvement ‘should be a feature of every aspect of service development and delivery’ (Government of Ireland, 2006:9). Service users were involved in the development of *A Vision For Change* because it was sensed that in order to be able to make the changes that would be of benefit to the mental health care system it was felt that this would ‘depend on engaging with the views of service users and their carers’ (Government of Ireland, 2006:12). It was felt that the service users and their carers are the people who have gained the best insight into the problem areas within the service as they have witness these problems first hand.

Official accounts of the development of *A Vision for Change* tell us that service users were consulted on every aspect of the mental health care system and were asked to

give their opinions on how they felt about the current system and what they felt could be done to improve it. The opinions of these service users were what began to shape the policy development. From the views that these service users held, many recurring problems and issues were identified by all service users. Some of these problems were ‘The need for multidisciplinary teams’, ‘The need to adopt a recovery perspective’, ‘The need for the service to become community-based’, ‘The need for service users to be viewed as active participants in their own recovery’ and a need for ‘greater access to psychological or ‘talk’ therapies’ (Government of Ireland, 2006:13). These opinions were taken into consideration and were the foundations of the policy and it was felt that these foundations ‘should be reflected in all mental health service planning and delivery’ (Government of Ireland, 2006:14). It should however be mentioned that there are a number of issues regarding the implementation of *A Vision for Change* including the monitoring group who were put in place to ensure its implementation. This monitoring group is currently on its third report and in each has stressed its disappointment with the slow pace and lack of implementation of the objectives outlined in *A Vision for Change*.

Benefits to Service User Involvement

The literature outlined many of the advantages to service user involvement in the areas of policy and service development. One of frequent themes outlined was how service users have a knowledge of receiving the service which is invaluable as no professionals can gain the ‘inside knowledge’ that service users hold. Beresford (2005:39) talks about this knowledge base when he talks about ‘a massive body of unrecorded and hidden service user knowledge’. Service users have a huge amount of firsthand knowledge on what they deem to be the drawbacks of the service. Identifying these drawbacks and recognizing ways of overcoming these problems through service user involvement is priceless in the development of mental health services. Beresford (2005:40) also discusses the distinctive knowledge that service users obtain ‘Their knowledge alone is primarily based on direct experience of such policy and provision from the receiving end’. Service users can use this knowledge and relate the problems back to policy developers so that in turn mental health services will be changed for the better and service users experience of the service improved.

Involving service users in the planning of their care and the planning of policy and service development has the ability to empower service users. This ability to empower was another persistent theme in the literature. Barnes (1997) and Barnes and Bowl (2001) are some of the many writers on the area of empowerment of service users. Barnes and Bowl (2001:21) believe that empowerment can be viewed 'as a process in which people develop 'power to' take decisions, take actions, make choices, or work with others which they previously unable to do'. This view of empowerment can be seen in a way that it enables others without taking away or giving power to someone else. This type of empowerment allows for a good working relationship between service users and professionals as it is 'a generative process which increases the capacity to act and to enable others to do so' (ibid).

From the literature it would seem that empowerment also has the ability to advocate the service user. Advocacy is something that is very important for a patient receiving mental health treatment. Advocacy can be defined as 'supporting service users to speak and persuading service providers to shut up and listen' (Independent Advocacy Service, 2000 cited in Henderson, 2004:203). If this in turn gets the service users opinions listened to, then this has the ability to empower the person, as service providers and professionals are now listening to their opinions and ideas. Henderson (2004:203) feels that 'if the act of speaking up is empowering, then the act of being listened to is doubly so. Service users have already had an impact on policy and service provision. The service user movement has 'played a crucial part in developing informal self-help networks and support'(Bamber, 2004:193). In addition to this, user groups have 'begun to offer alternative services, sometimes in partnership with either the voluntary or statutory sector providers' (ibid). When advantages from user involvement in services is recognised and is seen as being of benefit to the service providers they then become 'keen to engage users and cares in service design' (Bamber, 2004:194). When this occurs and service users see their voices being heard and appreciated, this has the ability to empower the service users and make them feel good about their care plan and recovery as they now feel like their ideas are being listened to and they feel involved in their recovery. These are just some of the advantages of service user involvement.

Challenges Facing Service User Involvement

While the literature looked at the positives to service user involvement, it did also look at some of the negatives associated with user participation. One of these drawbacks identified is the questions of representation. When users are taking part in policy discussion, and service development, who exactly are these users representing? The user or user groups in question are giving their views and their opinions on the pros and cons of the mental health service. It's impossible to say if these views represent the views of the majority of service users. Kemp (2008:33) backs up this point when he says 'each participant potentially represents a different perspective on a situation and sometimes these perspectives will conflict or contradict each other'. If this is true then this leads to many questioning the validity and value of user involvement in policy, service development and delivery, because one could not be sure that they are representing the overall view of mental health service users. Lakeman et al (2007: 15) also argue this point when they discuss the authority of groups who are claiming to represent service users. 'The authority of these groups often arises from some kind of claim to represent service users generally or particular sub-groups'.

Research Methods

Methods Used:

The methods of research used were qualitative. One of the aims of qualitative research is that it enables one to understand the world in which the participants of the research are living in. It enables the person doing the research to learn 'about their social and material circumstances, their experiences, perspectives and histories' (Snape and Spencer, 2003:3). This method also allows for comfortable communication between the researcher and the participant.

As part of my research I undertook one in depth interview on the 18th of March 2010 with the development officer of the National Service Users Executive, Liz Donovan. The interview that I conducted with Liz was a semi structured interview. One of the goals of semi structured interviews according to Esterburg (2002:87) is to 'explore a topic more openly and to allow interviewees to express their opinions and ideas in their own words'. As I had emailed Liz the questions in advance this did give the interview some form of structure however, it was agreed upon that if anything

interesting came up in response to one of the agreed questions that gave rise to a new topic than we both agreed that new questions could be introduced. In semi structured interviews it is necessary to listen to the response of the participants as this allows the interview to run smoothly and enables one to ask questions where appropriate. The second aspect of my research is a detail analysis of documents that have been published by the NSUE. Documentary analysis according to Knight (2002:104) allows researchers to ‘use documents to clarify policies, expectations and issues’. The data collected was analysed in an interpretive manner. Themes from the interview were identified. The documents were then analysed to see if the themes already identified were present in the literature. Points made in the interview were looked at critically to identify current issues facing the executive.

The National Service User Executive as a mechanism of service user participation? Discussion of Research Findings

Current Issues for Service User Participation

Since the publication of *A Vision for Change* and *the National Strategy for Service User Involvement in the Irish Health Services*, the importance of service user involvement in their own care as well as recognition of the ability of service users to become more involved in their own care has been realised. There are still however a number of issues in this area. One of the areas that were outlined by Liz during the interview was the need for service user participation to be consistent throughout all levels of the health service and for this to happen, *A Vision for Change* needs to be rolled out properly. As outlined already the NSUE is one of the few things that has been implemented since the publication of *A Vision for Change*. This shows how that the need for *A Vision for Change* to be adequately implemented as already mentioned in Chapter 3, is also affecting the involvement of service users and is one of the issues for service user participation.

Another burning issue for service users that has been raised through the NSUE that Liz discussed is the issue of ‘capacity’ and how this is affecting service user participation. This refers to the ability of service users to freely give consent to something, be it treatment or something else. When a matter arises and one is unable to give consent or does not have the capacity to give consent, Liz outlined how procedures need to be put into place to deal with this situation,

‘The whole issue of capacity and the ability too freely give ones consent or whatever that is an issue and then you need to have protection in place for those who don’t have capacity. You need proper structures set in place so people are properly protected again it comes back to human rights’ (Interview on 18/03/2010).

She outlined how this issue in particular infringed on peoples human rights. She explained that ‘Most of mental health issues come back to human rights law’ (Interview 18/03/2010). A further problem for service users is that there needs ‘to be an acceptance proper acceptance not just lip service that service users can have a positive input into their own recovery’ (Interview on 18/03/2010). Liz outlines how across all disciplines, it has been shown that when people have contributed to a solution ‘than that solution has a much greater chance of being affective for whatever the problem is’ (ibid). While if someone feels that a decision is being made in or around them without their proper consultation than this can only have a negative effect as you are disempowering the person from their right to be involved.

In addition to the above point, is the attitudes and openness of some staff to change and new forms of treatment. Liz spoke about how the attitudes of staff in being open to new forms of treatment and how this has a positive effect on service users. She outlined that some staff can be resistant to change and others can be totally open to change, but also pointed out how you can have this in any field or industry and that it is ‘just a human condition’ (Interview on 18/03/2010).

Obstacles to Service User Involvement

The obstacles to service user involvement are the factors which are affecting the full service user involvement in mental health. One of the factors affecting service user involvement is the lack of policy in ‘that you need a firm underpinning of the whole concept of service user participation in their own recovery underpinned in policy’ (Interview on 18/03/2010). One of the issues in this area is the fact that is it not a right of service users to have an advocate. They have to go in search for the advocate. If an advocate was available to a person instead of them having to go in pursuit of one this would put a whole different perspective on the situation for the person seeking the advocate. Liz explained how

‘the Irish advocacy network provides advocacy to people who are in approved centres in other words hospitals which have been approved by the mental health commission

for treatment of people with mental health difficulties. That is not an actual legal right that a person has to an advocate and people think it is, but it isn't an actual right, and people should have the right to an advocate' (Interview on 18/03/2010)

Another obstacle that service user involvement needs to conquer is the fact that the service user groups themselves; do not know how powerful a group they could be if they joined together. Liz explained how the statistics show that one in four of us have had a mental health difficulty, and if you take this as a whole than the body of people who have come into contact with the mental health service is a huge number of people. She outlined how if you took that number in terms of the voting public than the power that this group has is vast. Liz explained that 'if mean if people shed their stigma etc. Than that's a hugely influential group' (Interview on 18/03/2010). The need to empower this group and show them that social change is possible and that their views can be listened to is one of the obstacles to service user participation. One of the obstructions to service user participation that was also spoken about is society and the part society has to play in ensuring service user participation is enabled. Liz explained how there is still stigma attached to someone who has had a mental health difficulty. She outlined how there had been change over time but that more change still needed to occur in order to allow for user participation. What would help solve this obstacle would be if it was to become the norm for people to be able to discuss their mental health issues with people without feeling as though they are being judged. This shows us that social change is possible and that 'we need to be able to reach a stage I think with mental health where you know when a topic comes up in conversation, I'm not saying going around with a banner saying 'I had a breakdown' or whatever.... we need to do the same as what we've done with for other issues in society and that is bring mental health issues out of the closet' (Interview on 18/03/2010). This is one of the obstacles that user participation needs to overcome. Liz also gives a solution to the above problem by outlining if mental health issues were put on the curriculum for primary school, in an appropriate manner than this would help alleviate the problem. Liz believes that this would have a huge effect on the future of mental health in this country. If it was seen to be believed that if you had a mental health problem, like if you had any other medical problem, that it was the norm to see such a person when this issue arose than this would go some way to decreasing stigma.

A willingness of medical professionals to open their minds past the medical model is also an obstacle for service users. The professionals who rely on the medical model without looking at other forms of treatment need to become more open. Liz wanted to stress that ‘she wasn’t bashing the medical model’ as she felt that the medical model has ‘its place but it is not the only option and people need to realise this’ (Interview on 18/03/2010). Access to education, housing and employment are also obstacles to service users as well as having ‘their views listened to properly and their wishes given priority being treated with respect and dignity and including people in a meaningful way in discussions about their own futures’ (Interview on 18/03/2010) were also some of the contemporary obstacles that service users face.

Conclusion

For this research project I set out to investigate the contemporary issues and debates surrounding service user participation in the mental health services in Ireland. Firstly one looked at the background and history of service user involvement including the benefits and challenges of this inclusion. In the course of my research I decided to focus on the National Service Users Executive (NSUE) and to investigate it as a mechanism of mental health service user participation. The NSUE was set up because of recommendations made in *A Vision for Change*, a key mental health policy document published in 2006 following an extensive process of consultation with various ‘stakeholders’ including service users. The research that I conducted to investigate these questions included a review of relevant social science literature, a review of Irish mental health policy, together with an analysis of NSUE documents and a lengthy in-depth interview with the NSUE development officer.

The key conclusions that emerge from my research are that while a lot of work has been done since the establishment of the NSUE and the publication of *A Vision for Change* in terms of service user participation, service user participation in the mental health services in Ireland continues to be an aspiration rather than a reality. One of the main conclusions is that for the service user inclusion and participation to become a reality for service users in general, rather than for a selected few, full implementation of the policy document *A Vision for Change* needs to occur along with a radical change in people’s (including health professionals’) attitudes and understandings of mental health and illness away from the purely medical model, towards a more holistic approach. The NSUE development officer who I interviewed discussed in

detail both this lack of full implementation of the landmark policy and the need for attitudinal change. She argued that recognition of and respect for service users' views needs to be accepted in the mental health area and she believed that this problem was one of the key challenges' facing the NSUE. If this were to occur it would seem that service user participation would directly benefit and service user participation would grow out of this improvement.

While stigma has been reduced a huge amount over the past number of years it still seems to be prevalent in society. This is true in two different situations, society and professionals themselves. Liz drew on the fact that some professionals are very slow in accepting and implementing change, while she stressed that this was not all staff. The benefits of involving service user far outweigh the negatives of not including service users. In society the problem lies with the fact that it is still deemed as not a normal thing to do to discuss mental health difficulties in public. For change to occur mental health difficulties need to be able to be discussed as the norm and stigma needs to be removed completely. This would require some type of social change so the taboo that is associated with mental health difficulties would be removed and this would enable proper participation of mental health service users within society.

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