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Research Watch: mental health services supporting social inclusion

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RESEARCH WATCH: SOCIAL INCLUSION IN MENTAL HEALTH

Research Watch: mental health services supporting social inclusion

In this article I wanted to focus on how mental health services can support people's inclusion in the kind of ordinary life that many take for granted: things that are the focus of this journal: such as having a job we want to get out of bed for; having friends we can help out and who can help us in times of need, or just to do things we enjoy with; access to transport to go where we want or need to go, when we want to; and having a voice about things important to us and having that voice heard. I discuss three recently published papers that speak to this topic. Stewart (2019) writes in this journal about her experience as a mental health service user and peer support worker in Quebec, Canada, and describes the lack of support for real inclusion. Hamer et al. (2019, p. 303) describe how mental health professionals and peer workers in Connecticut, USA can "buck the system" in order to uphold service users' human rights, because it is "the right thing to do" (p. 297). Finally, Bertram (2019) describes gradually building co-designed services in London, England, to supplement deficiencies in standard mental health care that is not designed to support social inclusion.

Being "ghettoized"

Stewart (2019, p. 53) uses the term "ghettoized" to explain her experience in Quebec when she was a mental health service user and then a peer worker with a community treatment team. She, and then other service users she worked with as a peer worker, were offered only a few activities for occupational health: "art workshops, cooking and computer classes" (Stewart, 2019, p. 55), and these were only with other service users. Whilst Stewart recognises that service users can draw strength from each other, there seemed to be almost no thinking within the mental health system about how to support people to make a broader range of connections or to engage in other activities of ordinary life that they might find fulfilling.

In the end, Stewart (2019) found her own ways to make connections with others who shared her interests outside the mental health system, but she wondered why staff with whom she came into contact did not seem to prioritise this (Stewart, 2019). She recounts how service users she

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worked with as a peer worker had similar complaints, with one saying she felt “cooped up” (Stewart, 2019, p. 55) in a drop-in centre. Another echoed her feeling about being “lumped in a group” (p. 55) with other service users. It felt as if people were “not good enough” (p. 54) to be in ordinary mainstream settings. Staff may unintentionally reinforce this feeling by believing that people cannot manage anything else, Stewart (2019) suggests.

Building bridges

Stewart (2019) describes how, as a peer support worker, she was able to work with service users to find ways to support them to do other things. Together they found ways to tackle some very real obstacles. For example, lack of money is often an issue, so Stewart sought low-cost activities open to members of the public. There were many women’s centres around Quebec that any woman could attend, and which ran activities that the women themselves suggested. Stewart (2019) found a gym that offered a discount for people with disabilities. Stewart (2019) also highlights that there are some websites that support members of the public to find others who share an interest, so that groups in specific localities in different countries can form and arrange to do things together around their interests, at low or no cost.

Stewart’s role as a peer support worker enabled her to do things like going with a service user to public places such as the local swimming pool. This could form a bridge so that eventually the person could go alone. However, Stewart (2019) wonders why there is not a more fully developed system for supporting such activities, and also funding to help with the cost of transport. Whilst Stewart (2019, p.54) suggests that “safe spaces” might be important due to prejudice, and because being together with other service users can help people to campaign for change, she also suggests a need for mental health services to work harder to support social inclusion.

Being insider activists

Hamer et al. (2019) use the concept of citizenship as a framework for thinking about social inclusion in mental health. Hamer et al. (2019) describe what staff do in supporting social inclusion

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3 as “acts of citizenship” (p. 209), referring to Isin’s (2008) theory of citizenship. This refers to making a
4 special effort to support the human rights of marginalised people. Thinking of a broader arena than
5 mental health services, Hamer et al. (2019) discuss how the organisational context of commercial
6 companies in which people work can limit their choices. However, employers and their workers can
7 espouse citizenship by respecting each other and their customers, and building mutual trust. Hamer
8 et al. (2019) apply this framework to mental health care, suggesting that managers can support the
9 rights and citizenship of staff, and in turn this enables them to support those of service users.
10
11 However, Hamer et al. (2019) also point to obstacles to this in the mental health system, in that
12 there is a bias towards restriction and often coercion, and a view that it can be risky to allow service
13 users much choice and autonomy.
14
15

16 Acts that subvert the organisational culture in order to uphold service users’ rights are, say
17 Hamer et al. (2019, p. 298), “acts of citizenship” and constitute political action. Hamer et al. (2019)
18 tell us that this idea has so far been applied in relation to refugees more than in mental health care.
19 However, they draw parallels between the marginalised groups in these different fields, and the way
20 in which, by siding with those who are marginalised, it is possible to promote their rights to
21 citizenship and inclusion.
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Recognising human rights

24 Hamer et al. (2019) point to the tendency of the dominant narrowly biological view of
25 mental distress to equate people with their diagnosis and to take a view that people need to be
26 restricted rather than enabled to exercise choice and agency. Hamer et al. (2019) also refer to an
27 account by a service user (Lampshire, 2018) in which she describes how staff broke the rules in order
28 to enable her to feel accepted and connected. Hamer et al. (2019) refer to the reality that stigma
29 and discrimination occur within as well as outside the mental health system, and suggest that when
30 staff promote service users’ inclusion and citizenship, they are acting in accordance with the United
31 Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006).
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Mental health workers’ understanding of inclusion

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Hamer et al. (2019) interviewed seven mental health professionals and five peer workers in Connecticut, USA. They analysed the data to identify themes, and produced two main themes: “breaking the rules”, and “the right thing to do” (Hamer et al., 2019, p. 299). However, they also reported on workers’ understanding of inclusion. Workers talked about feeling “like an equal, feeling connected, being similar rather than different” (Hamer et al., 2019, p. 299). In the community, one could feel togetherness when affected by common adversities such as storms, and in the workplace, one could feel it when working towards common goals and feeling connected with service users. Sharing creative interests in the community also helped people to feel included, as did mutual greeting on entering the work place.

Breaking the rules

In terms of Hamer et al.’s (2019, p. 300) first theme, “breaking the rules”, some peer support workers seemed to be following the example of professionals, who would “game the system” (p. 300). An example was changing the appointments diary to fit in an urgent case. One peer worker took a service user out to a café and noted how a relatively small act like this could make a huge difference to someone who no longer felt accepted in such ordinary spaces. Arguably this kind of thing might have been part of the support worker’s role (this was unclear), but it did not appear to be built into the wider system, in which there was a feeling that such action was questionable.

Political action

In another example of acting to uphold the rights of a service user, Hamer et al. (2019) present a story of a mental health professional whose training included more emphasis than usual on social justice. She was therefore more aware of the effects of discrimination on service users than the rest of the clinical team. She learned to talk in such a way that other clinicians could hear her, while at the same time introducing a new approach. She felt that it would be helpful to a service user to accept his offer of getting her a coffee, but it was necessary to persuade the clinical team that this would be “therapeutic” (p. 300) by talking about it in clinical terms. By this means, she got it

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3 built into his rehabilitation plan, and he was thereby able to enact the role of a valued citizen. The
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5 team also became more interested in this new way of thinking.
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Doing the right thing

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10 In another story relating to their second main theme, “doing the right thing”, Hamer et al.
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12 (2019, p. 301) describe a clinician spending 15 minutes finding out how a service user could get a bus
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14 pass. This felt like doing something that was beyond his role, but it also felt like “the right thing to
15
16 do” (Hamer et al., 2019, p. 301), and it seemed likely to do more good than other aspects of care,
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18 and therefore to be morally defensible. A peer support worker spoke about feeling invalidated when
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20 you have a diagnostic label because you are no longer seen or heard. For one professional, validating
21
22 a service user could include accepting a small gift when offered as an expression of thanks. It enables
23
24 a sense of equality in the relationship, and allows the service user to have agency (Hamer et al.,
25
26 2019). However, there was also a sense that staff may feel it was not their role to uphold people’s
27
28 rights because there was someone with that as their designated role. Other staff pointed to fears
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30 among staff that giving service users more agency would increase risk. This even applied to
31
32 registering them to vote, even though the organisation appeared to support it.
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37 Another problem Hamer et al. (2019) highlight is the way that people have to identify as
38
39 disabled in order to carry on receiving welfare benefits. It means that recovery of a meaningful life is
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41 linked with losing out financially when this can have serious detrimental effects. Some mental health
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43 professionals could feel that their efforts to uphold people’s rights were hampered by this. However,
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45 Hamer et al. (2019) do not comment on the deficits of a welfare system that requires one to be
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47 either ill or well and that pulls the rug from under people as soon as they are considered to cross the
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49 threshold between the two.
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The need for service users’ rights and citizenship to be central in mental health care

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54 Hamer et al. (2019) suggest, on the basis of their participants’ comments, that clinical
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56 supervision should routinely incorporate asking professionals about their actions to support service
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58 users’ social inclusion, and whether they had done anything to change stigmatising ways of talking
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about people. There was also a recommendation for regular training for both staff and service users about citizens' rights.

Hamer et al. (2019) provide a different take on the increasing UK interest in moving from asking "What's wrong with you?", to "What's happened to you?" (Longden, 2013). They suggest asking, "What matters to you?" (p. 302). This, Hamer et al. (2019) suggest, will bring back the clinician's role of working in genuine partnership with service users. They argue that the acts of upholding service users' rights should not have to be hidden or feel subversive. Staff should be able to feel that this is mainstream and part of their job.

Making social inclusion happen

Bertram (2019) discusses the lack of literature describing vocational support in mental health services, despite some research suggesting it can be helpful. He sets out to describe what has been happening in one National Health Service mental health trust in London, England over the past few years. He mentions the Individual Placement and Support (IPS) system of support for employment, reviewed in a previous Research Watch (Holttum, 2011). Bertram (2019) suggests that this system is difficult for some service users if they do not feel ready for employment, and suggests a need to support a wider range of activities. He also highlights that UK government policy calling for support for people to find education and employment does not state how this should happen or whether it should be built into mental health services or outside them.

Listening to service users

Bertram (2019) also points to a lack of consultation with service users, which is where he and his team began in 2006. He cites three papers he wrote and co-wrote on this issue (Bertram, 2008; Bourne et al., 2007; Josefsberg and Bertram, 2012). Bertram (2019) presents some key service user perspectives from these consultations:

- The need for person-centred support (being heard, encouragement)
- Real opportunities

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- One-stop shop to get the right information
- Support tailored to individual needs, not the service need
- Not just employment, but also training and volunteering opportunities
- Advice on welfare benefits
- Tackling stigma to support self-esteem
- Prioritising people's vocational aspirations (always making it part of the care plan)

Service users wanted a better deal out of life, especially as they often recognised the role that adversity, trauma and discrimination had played in causing their mental distress, consistent with Longden (2013). An initial examination of 278 care plans found that 96% of service users were unemployed but only 8% of the plans included support for their occupational goals (Bertram, 2019). There was also no local strategic plan to address this in 2006, says Bertram (2019).

Small beginnings

Bertram's team started with some small pilot projects, for example one with two occupational therapists and a benefits advisor (Bertram, 2019). This small team assessed people individually and gave them support to move towards their goals. As reported by Bourne et al. (2007), 22 of the 55 people assessed found activities in just a few weeks, with a further 11 engaging with continued support, and 22 unable to stay engaged.

The service director was supportive of further innovations, and a social services day centre made an office available for user-led information provision, one voluntary-sector IPS worker, and a work training and volunteering project that brought income. There was also a time bank for people to make their skills available on a mutual exchange basis. With 170 service users supported, this provided persuasive evidence for asking for service-commissioner support to do more work.

Co-design and expansion

The next stage was co-designed between staff and service users. The services included individual vocational assessments, supporting people's goals, enabling choice from a range of opportunities (not just mainstream employment and including leisure activities), and working with

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3 employers, job centres and colleges. In addition some ways of measuring outcome were agreed,
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5 such as whether people got into employment or supported employment, or were involved in any of
6
7 the other activities (Bertram, 2019).
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10 A project board was also set up, comprising a range of stakeholders to keep things growing
11
12 and improving access to service users. This led to a substantial increase in posts in the various
13
14 projects, a dedicated resource centre from 2009, and a change to the mental health service
15
16 computerised record system so that there was a box for staff to record employment.
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18
19 Bertram (2019) presents some outcomes for 470 people seen between 2009 and 2010.
20
21 According to the numbers he presents, the percentage who gained employment and came off
22
23 benefits was small (n = 41, 9%), but a further 19% started voluntary work, 19% started mainstream
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25 education, and 17% started other activities. This leaves 37% unaccounted for, but it is clear that the
26
27 majority (63%) of people were able to engage with new activities. Bertam (2019) reports additional
28
29 benefits such as improved wellbeing and reduced service use, greater confidence and hope, gaining
30
31 new skills and improvements in relationships.
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Ditching the box-ticking

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37 Bertram (2019) emphasises how effective the service user-led information and support was.
38
39 It was made part of secondary mental health care. The service user manager of the vocational
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41 support service talked about tackling obstacles one by one, and also ditching the assessment form
42
43 because it got in the way of building a relationship with the service user. I feel a need to comment
44
45 on this, because many mental health workers would love to ditch forms and box-ticking. Yet there is
46
47 a well-worn argument that ticking boxes demonstrates accountability. Indeed, the creation of a new
48
49 box in the data recording system for recording vocational assessment seems a milestone. I have
50
51 heard mental health workers talking about the impossibility of changing the IT system so that they
52
53 can make something that is important to service users easier to record. They recognise that if there
54
55 is no box for something, the organisation doesn't value it, and they have the feeling that you
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57 shouldn't be doing it because you are not paid to do it and you are not given any time to do it. So to
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3 my mind, having that extra box was no small thing. It meant that asking about people's vocational
4 goals and aspirations had finally been officially recognised.
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7 All that said, I would argue that box-ticking in mental health to confirm that certain things
8 have been discussed or assessed is a bit different from box-ticking in a medical consultation when a
9 fatal disease is suspected, and covering certain things might determine getting life-saving treatment
10 or not. In most mental health consultations the main need is that the service user feels respected,
11 heard, and understood. Anything that takes away from this, including the need to tick boxes, may
12 obstruct the thing that is the main therapeutic force, that is, connection with another human being
13 who cares and shows empathy.
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23 To return to the service user manager of the vocational support service (Bertram, 2019),
24 there were often very practical obstacles in people's lives that made it difficult for them to pursue
25 their goals. This included housing, debt and immigration issues, so information was given about help
26 lines and organisations who specialise in supporting people with such things. Pressing practical
27 needs must be addressed before vocational issues can become the focus. Listening to service users
28 and working in partnership gave them validation and spurred them to do their bit and enabled them
29 to grow in confidence (Williams, 2012, cited in Bertram, 2019).
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Financial realities and leadership

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41 The centre, unlike usual mental health services, had no glass partitions or door locks.
42 Essential work (decoration and cleaning) was done by two work training projects, which saved a lot
43 of money. One training project obtained a commercial contract to clean local authority venues,
44 bringing valuable income. The advent of austerity was a threat, with the local authority budget
45 reduced by 56% (Bertram, 2019), and NHS budgets also stretched. However, the new services were
46 maintained, although not able to expand further.
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54 Bertram (2019) suggests that he needed good communication skills to engage with many
55 stakeholder groups and to keep promoting a clear vision and holding onto hope. However, he sees
56 challenges for the future. There is still no clarity from policy-makers about how vocational support
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3 should be addressed, and it may be under threat from cuts. Most mental health care training also
4
5 tends not to see service users as experts on what can help them to move towards their goals, says
6
7 Bertram (2019).
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Warning

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12 Bertram (2019) warns that continued failure of services to address the social causes of
13
14 mental distress (mainly difficult life events, exclusion and invalidation) will lead to more and more
15
16 demand. One thing that he suggests might help policy and services to shift their emphasis is to have
17
18 a demonstration of how much money is saved by offering vocational support. He also suggests a
19
20 need for the benefits system to change, since it tends to be shaming and all too often adds to
21
22 people's distress rather than helping them achieve their goals.
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Conclusions

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28 These three articles coalesce around a common theme of how mental health service users'
29
30 social inclusion can be supported. All of them highlight the continued lack of priority given to this in
31
32 mental health services. Stewart (2019), in her role as a peer support worker, found ways to use her
33
34 role to support people to find ways to pursue their goals of taking part in everyday activities. Hamer
35
36 et al. (2019) demonstrate how both mental health workers and peer workers can be covert activists
37
38 to subvert a system that fails to acknowledge people's rights to citizenship. This is reminiscent of the
39
40 insider activism espoused by mental health professionals who also had experience as mental health
41
42 service users, and also peer workers in Richards et al. (2016). However, political action could also be
43
44 more open, suggest Hamer et al. (2019), for example when a mental health worker with particular
45
46 training experience that placed emphasis on social justice was able to bring some of the ways of
47
48 talking from that training into discussions in the mental health team, and thereby influence thinking.
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54 Bertram seems to take things to a whole new level, where he was able to drive significant
55
56 change and build parallel and integrated services that would support service users' goals for social
57
58 participation in a range of ways that were right for each individual in their recovery journey. He drew
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2
3 on the power of co-design to harness the expertise by experience of service users themselves. The
4
5 additional achievement of changing the IT recording system to include a box for recording
6
7 assessment of vocational goals, whilst raising the whole issue of how box-ticking may get in the way
8
9 of real relating, also illustrates that 'it can be done'. Things that matter to service users can be built
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11 into systems that can appear so big and remotely controlled that nothing can be done. Wider
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13 political uncertainties notwithstanding, this raises hope for real and sustained change.
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