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Mental Health Advocacy Outcomes from Service User Perspectives

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Abstract

Purpose

This paper addresses a knowledge gap on advocacy outcomes from mental health service users' perspective, and the implications for evaluating advocacy impact. The studies discussed highlight challenges for measuring the outcomes of advocacy, but underline the importance of doing so, and of involving service users alongside other stakeholders in co-designing evaluation systems.

Methods

The paper uses findings from three qualitative studies of independent advocacy involving focus groups and interviews with (1) 30 African and African Caribbean men who were mental health service users; (2) 90 'qualifying patients' in a study of Independent Mental Health Advocate (IMHA) services; and, (3) nine young women in Children and Adolescent Mental Health Services (CAMHS).

Findings

A comparative analysis and synthesis of findings from the three studies identified four common dimensions: how mental health advocacy is conceptualised and understood; how service users define advocacy outcomes; wider impacts; and, user involvement in evaluating advocacy outcomes. Advocacy outcomes were conceptualised as a) increasing involvement; b) changing care and treatment; c) supporting personal development. There was evidence of advocacy acting to empower mental health service users, and of broader impacts on service regimes and policies. However, there was limited evidence of transformational impact. Evaluating advocacy outcomes is increasingly seen as important.

Originality

Few studies have focused on the perspectives of people using independent mental health advocacy, or on the experience of 'advocacy as empowerment', and none has done so across diverse groups. These studies add insight into the impact of independent advocacy. Data from empirical studies attest to the important role independent advocacy plays in modern mental health systems.

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Introduction

Advocacy is commonly framed as supporting people to 'have a voice' and is conceived of as a way to achieve social justice (Action for Advocacy, 2002). In a mental health context, advocacy has its foundations in mental health activism and the critique of psychiatry, which led in 2007 to establishing a right to independent advocacy under English mental health law. Its significance in safeguarding human rights and promoting the empowerment of people experiencing mental ill health has been recognised internationally by The World Health Organisation (WHO, 2003).

Research suggests advocacy can be 'life changing' and its outcomes wide ranging for both children and adults supported by health and social care services (Thomas et al., 2016). However, reviews of the literature highlight gaps in the evidence base demonstrating its impact (Newbigging et al., 2007; Macadam et al, 2013; Perry, 2013). Despite widely held views in the transformational power of advocacy, and reporting of positive individual stories (NDTi, 2016a,b), there is a failure to demonstrate its impact systematically. There is also little understanding of impact from the perspective of people using services, with studies mainly considering outcomes from advocates', professionals' and family carers' perspectives (Perry, 2013; Bocioaga, 2014; Lonbay and Brandon, 2017).

Background

Increasing participation, choice and control, and the self-determination of people who use health and social care services is at the heart of social policy reform intended to radically transform service delivery and support in the 21st century (Leadbeater, 2004; NHS England, 2015). At the centre of mental health policy including *Future in Mind* (DH & NHS England 2015) is an emphasis on changing the professional: user dynamic to one that acknowledges people as 'experts by experience'. This underlines the importance of co-production and shared decision-making between service users and professionals based on trust, respect and a willingness to share different forms of knowledge (Ramon et al, 2017). Concurrently, England has seen the parallel introduction of the statutory right to independent advocacy in

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mental health and wider: in 2002, the English Adoption and Children Act supported children in care and care leavers with making complaints under the Children Act 1989; the right to an Independent Mental Capacity Advocate (IMCA) for individuals deemed to be lacking capacity was introduced under the 2005 Mental Capacity Act; and the right to an Independent Mental Health Advocate (IMHA) was introduced to protect the rights of people detained under the 2007 Mental Health (Amendment) Act in England. Most recently, the Care Act 2014, made it the duty of local authorities to provide independent advocacy for people using social care who require support with decision-making and lack appropriate support. The right to choice, autonomy, inclusion and various entitlements enshrined within the United Nations Conventions on the Rights of Persons with Disabilities (UN General Assembly, 2007) and the Rights of the Child (UN General Assembly, 1989) are also relevant.

Independent advocacy

Advocacy is a contested area with the term being used differently in different contexts. In general terms, advocacy seeks to address unequal power relationships between those using health and social care services and professionals, ensuring personal perspectives and interests are represented and heard especially in situations where individuals can feel disempowered. The goal of advocacy, therefore, is framed as empowerment with its role being to enable people to exercise greater control in their lives through providing the 'seeds of empowerment' (Sadd, 2014), thus, facilitating an individual's capacity for self-advocacy. Its legal origins have led to defining advocacy in terms of upholding rights, as 'stating a case to influence decisions, getting better services, being treated equally, being included, being protected from abuse, redressing the balance of power and becoming more aware of and exercising rights' (Jugessur and Iles 2009, p.188). Advocacy is recognised internationally as a key constituent of mental health policy (WHO, 2003) and as a 'critical component' of modern mental health services (Stylianos and Kehyayan, 2012). Independence from statutory provision is a foundational principle of the Advocacy Charter Standards (Action for Advocacy, 2002), recognising that professionals will have a conflict of interest and are predisposed to make decisions on the basis of 'best interests'. This paper, therefore, focuses on independent advocacy in contrast to professionals advocating for their

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service users'/patients' 'best interests' (Jugessur and Iles 2009; Dalrymple and Boylan 2013; Harington and Beddoe, 2014).

Independent advocacy includes self-advocacy, citizen advocacy, peer advocacy, collective or community advocacy, generic and statutory forms of advocacy (Newbigging et al., 2015, p23-26). Children and adults experiencing mental health problems are at particular risk of having their views and experience dismissed and, thus, advocacy is consistent with recovery-focused approaches (Machin and Newbigging, 2015), and provides a necessary 'counterbalance to increased powers of the state', particularly when imposing psychiatric treatment (coercion) against a person's wishes (Perry, 2013).

Advocacy outcomes

The literature identifies a range of outcomes from advocacy - that it achieves user-defined goals, ensures people have 'a voice', and empowers service users. Commonly understood benefits of advocacy include better access to support options, enhanced communication between people who use service and professionals and wider change in health and social care services (Wetherell and Wetherell, 2008, Macadam et al., 2013, Thomas et al., 2017). Where it has been less successful is in bringing about changes in levels of participation in care and treatment in the context of compulsion under mental health legislation (Ridley et al., 2009; Newbigging et al,, 2012).

In an attempt to make sense of the multitude of individual outcomes Miller (2011) identified three key dimensions: *quality of life* (for example, relationships, housing, employment), *process* (having a voice and being listened to), and *change* outcomes (increased choice and control, feeling safe). The literature makes a key distinction between having an impact on processes and other types of outcome related to more tangible change (Macadam et al, 2013; Newbigging et al., 2012; Newbigging et al., 2016). The outcome of advocacy therefore, may not always be perceived by the individual as beneficial when an identified goal is not realised, even though the process may have been positive. Conversely, satisfaction with

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advocacy may not always be dependent upon issue resolution (Townsley, Marriott and Ward, 2009).

Research measuring the difference advocacy makes however, is scant (Rapaport et al, 2006). A review of research evidence found just 13 relevant empirical studies out of 10,210 articles, not all of which were mental health studies (Perry, 2013). Reviews generally identify the lack of systematic evidence and a predominance of descriptive studies (Macadam et al, 2013). Different definitions of advocacy coupled with a lack of understanding of the role, have contributed to a limited evidence base about its effectiveness, while individual case studies do not provide a consistent basis for assessing advocacy impact (Stewart and MacIntyre, 2013; Carlsson, 2014). Published evidence about outcomes based on the experience or perceptions of people using health and/or social care services is even more sparse, and is an acknowledged data gap (Palmer et al., 2012; Lonbay and Brandon, 2017). Indeed, most studies draw on advocates' views about whether outcomes have been met, which we argue is methodologically problematic with few accounts considering outcomes across different service user groups (Perry, 2013; Carlsson, 2014).

Better understanding and measurement of the impact of advocacy has been prioritised in recent years by public services as well as the advocacy sector, policy makers and commissioners (NDTi, 2016 a,b). Underpinning the difficulties with measuring advocacy outcomes are the different ways in which its impact as well as its purpose is conceptualised (Newbigging et al., 2015). In broad terms, these differences pivot around whether advocacy is viewed in transactional (i.e. resolution of a specific issue in relation to services) or transformational terms (addressing fundamental issues to do with the status of people experiencing mental health problems).

In this paper we draw on sub-sets of data from empirical research findings from three studies, all of which drew on multiple perspectives (service user, advocate, professional and commissioner) to understand advocacy and its impact. The focus for our analysis is the service user perspective, as this has rarely been considered. Our aim is to consider the

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meaning of 'advocacy as empowerment' and to consider how this perspective influences how advocacy outcomes are framed and measured. Whilst one of the studies (Thomas et al., 2016) treats 'outcome' and 'impact' separately, in this paper we use the terms interchangeably where this best reflects our respondents' understanding and how the terms are used in the literature.

Methodology

This paper adopts a qualitative meta-synthesis of primary data from three research studies undertaken by the authors on independent mental health advocacy, with the aim of identifying and interpreting patterns across the findings (Erwin et al, 2011). The studies discussed focused on three different populations, all of whom are at particular risk of having their views dismissed or denigrated and, therefore, of not accessing appropriate care and support.

Background to the studies

Study 1 (Newbigging et al., 2007) focused on African and African Caribbean men with experience of mental health services. For the decade prior to Study 1, it had been established that services often failed to meet the needs of people from Black and minority ethnic communities (BME). In particular, African and African Caribbean men are less likely to access appropriate support, to have poorer outcomes when they do, and equalities monitoring by the Care Quality Commission (CQC, 2016) shows the Mental Health Act (MH Act) is used more in some BME groups, though the reasons are complex and not well understood.

Study 2 (Newbigging et al., 2012) focused on people (adults and children) who were subject to compulsion under the MH Act 1983, and who were therefore eligible for, but not necessarily accessing, an IMHA under the 2007 MH Act. An underpinning principle of the 2007 Act was that the rights of people who are subject to detention need to be protected.

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Leading up to the reform of mental health law in England, and after a contested and protracted review, the right to advocacy was introduced in the new law as offering a safeguard, but was also intended to promote individual wellbeing (Pilgrim, 2007, 2012).

Study 3 (Thomas et al., 2016) was undertaken for the Office of the Children's Commissioner (OCC) for England as part of a wider review of the provision of advocacy for children and young people. The context was one of inconsistency in the reporting of outcomes and impact of children's advocacy, and little had been published examining outcomes from children and young people's perspectives (Oliver et al, 2006; Brady, 2011; Wood and Selwyn, 2013). Its aims were to identify and review good practice in information gathering, reporting and outcome measurement; to understand the impact of advocacy from young people's perspectives; to explore how advocacy services might effectively collate information about outcomes measurement and to assist the OCC in developing recommendations for a standard outcomes framework.

Methods

A thematic qualitative analysis was conducted of the data pertaining to the views and experiences of services users, beginning with the identification of patterns and themes (Silverman, 2006), searching for consistency and variation across the three studies, and providing a synthesis across them. The studies used mixed methods to meet diverse aims and objectives. Further detail of the research design and data collection methods in each study can be found elsewhere (see Newbigging et al., 2007; Newbigging et al., 2012; Thomas et al., 2016). All studies used focus groups, to explore the range of service user perspectives and differences in experience of advocacy, and individual interviews to enable a more searching exploration of personal experiences and the impact of advocacy. Table 1 summarises the different service user samples involved. Lines of inquiry relating to advocacy outcomes are summarised in Box 1.

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All the studies sought to recruit service users as research participants, although whether or not they had direct experience of advocacy varied. Nonetheless, participants were invited to explore the meaning of advocacy and situations where they might have found it helpful if they had no direct experience. This proved challenging in Study 1, reflecting the approach to recruiting participants and the limited access by African and African Caribbean men to mental health advocacy. All three studies involved relevant service users in their advisory groups; and Studies 1 and 2 also involved service users in the research team alongside experienced academic researchers, contributing to data analysis and the subsequent dissemination of findings.

Ethics

Ethical approvals were obtained for each study from University Ethics Committees and other relevant ethics committees. Governance approvals were obtained from all relevant NHS Health Trusts, Association of Directors of Children's Services, Association of Directors of Adult Social Services and advocacy organisations.

Findings

Four broad categories emerged from our thematic analysis across the three studies, and these form the organising framework for this paper: 1) user defined conceptualisations of advocacy; 2) user-defined outcomes of advocacy; 3) broader impacts of advocacy; and finally, 4) involvement in measuring and reporting on advocacy outcomes.

User conceptualisations of advocacy

Advocacy as a concept was understood in varying ways by different groups of service users. African and African Caribbean men in Study 1 conceived of advocates as 'defenders of

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rights'. Drawing attention to the politics of race and mental health, they outlined a model of advocacy that was collective and political in nature. In contrast to a more individualised notion focused on a relationship between an advocate and an individual - referred to as a 'partner' - African and African Caribbean men emphasised self-advocacy as the key goal, linking this to cultural identity in which self-reliance and the need to 'stand on your own two feet' were core values.

Qualifying patients in study 2 understood an IMHA as being there to support them to better understand their individual rights under the MH Act, and to ensure these rights were upheld. Those with an IMHA described the role of the advocate as a 'lever' or a 'god motherly person', a negotiator, an independent person supporting them to navigate the sometimes bewildering and frightening territory of mental health services. Advocates were the 'WD 40', oiling the wheels of the system. An advocate was also 'witness' to poor treatment and, therefore, performed an important safeguarding and quality assurance role.

The majority of young people in Study 3, some of whom had little or no prior experience of advocacy, expected an advocate to be someone who would speak on their behalf, an adult that they 'could talk to that isn't a member of staff', in other words, that they were independent of mental health services. They understood the role of an advocate was to support them to feel more comfortable in hospital meetings where they might feel intimidated and anxious, and to help them get their views across to professionals. An advocate was able to raise the issues young people wanted without them having to 'worry about being judged'. Advocacy was thus conceptualised as adult support that is child or young person centred, involves active listening, represents the viewpoint of children and young people, and protects or defends their rights. As an IMHA, they understood the advocate's role as being to help those detained to both understand and to exercise their legal rights under the MH Act.

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User-defined outcomes of advocacy

How advocacy was understood by service users had an influence on how they perceived its outcomes (both anticipated and actual). Outcomes were mapped from service user views in Study 1 of what advocacy needed to achieve for African and African Caribbean men in their relationship with mainstream mental health services. As summarised in Table 2 below, these reflected a holistic notion of advocacy identifying six levels of outcome ranging from personal to social and political change levels. These outcomes are broader in scope and potentially more ambitious and difficult for advocacy services to achieve than the outcomes identified from direct experience of advocacy in the other two studies. This wider conception of outcomes was framed in terms of the negative experiences of people from African and African Caribbean communities in relation to higher rates of detention, poor outcomes under the MH Act and the difficulties in accessing more enabling services. Thus, experiences in relation to the MHA were inextricably linked to wider experiences of racism and social disadvantage.

Table 2 here

The importance of meeting with other service users and like-minded people, at a place of familiarity, safety and reassurance was emphasised by the African and African Caribbean men in Study 1. Indeed their access to advocacy was also relatively poor and this was influenced by the way advocacy services are generally organised with advocacy provided by BAME organisations being preferred but relatively sparse. Fostering a 'oneness' with each other was valued for its potential to strengthen capacity for self-advocacy. The importance of self-advocacy, in contrast to professional advocacy, was framed in terms of cultural values of self-reliance and independence.

There were strong similarities between advocacy outcomes identified in Studies 2 and 3. Both children and adults overwhelmingly identified advocacy as ensuring they 'have a voice' in the mental health services, with the advocate working to amplify individuals' opinions in a system that often did not listen to service users' perspective. As in previous studies (e.g.

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Townsley et al, 2009), service users in Study 2 distinguished between outcomes associated with *process* (i.e. involvement and participation), and what happened as a *result* of that process, such that positive experiences of advocacy were not necessarily associated with resolution of the advocacy partner's original issue:

> *"It's not changed anything that's happening here at all… [But] it's made me feel better within myself because people are treating me as a human being and not a bit of dirt under their feet… It gives you confidence within yourself."*
>
> IMHA partner, Rehab unit (Newbigging et al., 2012, p190)

Furthermore, that perceptions of the effectiveness of advocacy are linked to the outcomes sought by service users, and that being more involved and participating in services is important in itself, was conveyed by a service user in Study 2:

> *"If I hadn't got what I wanted I could be saying `oh she was useless' but that wouldn't really be a reflection on her ability. That could be a reflection on my mental health you know. I could have been reassessed for leave and the decision could have been very clear that I wasn't well enough, but she'd made the request and got me that reassessment. So I think it depends on your personal outcomes as to how you view how effective they [IMHA] are*."
>
> IMHA partner, CTO (Newbigging et., 2012, p.191)

When asked about why they had wanted to be referred to IMHA services, the majority of qualifying patients in Study 2 identified having support to get their voice heard as the key reason, followed by revoking detention under the MH Act, addressing aspects of their care and treatment including medication regimes, representing them at meetings such as Tribunals and hospital manager's meetings, and to address various issues such as missing property, accommodation, or leave. This prioritising of 'voice' over more changes in material circumstances, strongly locates advocacy in mental health as an important mechanism for

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addressing epistemic injustice, supporting service users' interpretation of distress and ensuring their views are not discounted when systems disempower them:

> *I felt like I was on remand rather than in hospital, and it was nice that I had the advocate because I felt like it was the only voice I had apart from my own.*
>
> IMHA partner, PICU (Newbigging et al., 2012, p193)

While the young women in Study 3 highlighted how advocacy had helped them make changes or resolve issues they wanted help with, they recognised key outcomes were improvements in their self- confidence, and ultimately in their ability to self-advocate. When asked about the most important outcome, these participants underlined the importance of 'getting my voice heard' and 'speaking on my behalf', ensuring they were involved in decisions about their care and treatment, followed by 'understanding and exercising my rights' and 'getting improvements' in mental health services.

These young women reported that having an advocate had primarily improved their involvement and participation in various processes, in other words, that it had empowered them. Typically, the advocate would represent young people in meetings where they felt unable to speak up for themselves - 'it's someone to fight your corner if you're not able to'. Having an advocate speak out on their behalf meant that professionals listened more to young people. The advocate was in one young person's words, 'someone else to raise an issue without worrying about being judged'. In this respect, the advocate legitimised young people's concerns and facilitated a more constructive dialogue between them and mental health staff. In some cases, having the advocate alongside them had increased their confidence to self-advocate. As a result of the advocate being involved, the young women reported receiving better advice and information from mental health staff, and subsequently felt better informed about their care and treatment. The intervention of the advocate also made a positive difference more generally to the clinical environment, and how these young women felt they were treated by mental health staff.

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Broader outcomes or impacts of advocacy

What can be concluded, especially from a service user perspective, about the impact of advocacy on transforming institutional regimes and services, and possibly its' wider societal impact, is limited. Participants in Study 1 envisaged advocacy as having the potential to transform mental health services and support by increasing choice; improving identification and understanding of diverse mental health needs; challenging discrimination and racism; and by promoting access to complementary ways of healing and practical help. Increasing participation in decision-making had potential to fundamentally alter the service user: professional relationship and to build capacity for self-advocacy. In this respect, IMHA partners in Study 2 referred to the presence of an advocate as 'opening this place up, the more the light comes on it and the more open and transparent it becomes' (Newbigging et al., 2012, p196).

While not something that the young women in Study 3 specifically identified, professionals proffered examples supporting the notion of advocacy as impacting on mental health practice and policies at wider organisational, local and national levels. In one example, it was suggested that advocacy had had an impact on the decision-making culture and local health policy. A group of young people had complained about a blanket ban of mobile phones during leave from hospital. The advocate raised this with hospital management, and facilitated dialogue between staff and young people, which led to the service reviewing its policy, and ultimately a change to assessing risk regarding mobile phones on a case by case basis. The advocate reflected that this had a long-term impact on how staff in the unit worked with young people, which resonated with young people's conceptualisation of advocacy as representing their viewpoint to protect or defend their rights.

Another mental health professional highlighted an instance whereby young peoples' concerns raised by the advocate had resulted in health staff re-evaluating their practice:

> *There was a national piece of guidance that said young people should have access to family and friends, and she [advocate] brought this up and questioned why young*

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> *people here weren't allowed to have friends visit this unit. As a team it made us think, although we were able to justify why that wasn't really appropriate it did make us stop and think....*

Advocacy staff gave further examples of changes to institutional regimes that they felt had resulted from helping to raise young people's voices. This included inclusion of Caribbean food and healthy eating choices on the menu at one unit and timetables incorporating increased physical activity as requested by young people.

These examples demonstrate possible wider impacts of advocacy on service cultures as well as on operational practices, especially on how staff relate to, and involve service users, although such claims can only be tentative given it was not possible to establish such positive impacts to advocacy alone. As Study 2 concluded, the quality and impact of IMHA services is heavily dependent upon the mental health provider context within which the service is delivered, distinguishing between the readiness of various locations or care teams to engage with advocacy and the different kinds of social space that make involvement possible. Advocacy's potential lay in the powerful safeguarding function it performed in relation to both hospital and community contexts, supporting more person-centred and democratic approaches in mental health.

Involvement in measuring outcomes and impact

Previous studies conclude that advocacy services rarely systematically collate outcomes data, and that anonymised case studies or accounts form the main source of information about positive outcomes (Macadam et al, 2013). African and African Caribbean men participating in Study 1 had limited experience of mental health advocacy, and consequently, had little, if any, involvement in measuring outcomes. From Study 2, we gleaned information from IMHA providers regarding monitoring and reporting of advocacy outcomes, but the extent and quality of data collection and analysis was highly variable. IMHA partners reported that they had been asked to provide written or verbal feedback about the advocacy support they had received, although this was not consistently the case across all IMHA services. They

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recalled having been asked to complete brief written feedback and/or satisfaction forms, often at the conclusion of the advocacy support, and one commented:

> *"It's verbal feedback – 'have I been of help to you?' 'Is there anything else I could do that I haven't done?'"* IMHA partner (Newbigging et al., 2012, p128)

IMHA services reported using outcome measurement tools that involved gathering information from IMHA partners at the start and at the end of advocacy input. In this respect, service users were involved in evaluating advocacy, but services did not necessarily aggregate this data to provide an overall assessment of service effectiveness:

> *We ask people to rate themselves on 1 to 10 in certain elements of how much choice and control do you think you have, and then we do it again at the end of working with them and hopefully there's been some improvement there. It's good for them to be able to see that as well.* IMHA (Newbigging et al., 2012, p128)

As Study 3 was commissioned specifically to research advocacy outcomes and impact in children's advocacy services, we draw unashamedly from this study in considering involvement in monitoring and evaluation. Commonly, the young women participating in Study 3 were unaware of the advocacy provider collecting data about its impact of advocacy. They did assume that their advocate took written notes of issues they raised, and what they wanted the advocate to help them with – 'I just talk and tell her stuff, she writes it down'. In one (non-mental health) site from the wider study, some young people reported having the opportunity to review their advocate's notes, which helped them feel confident that the advocate had understood them without 'twisting words around'. Young people felt it was helpful for their advocate to keep a log of issues and actions taken to inform reviews of issue resolution:

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> *With me she writes down the issue I had a problem with and checks to see if its changed and if not, takes action to see how it can be changed.*
>
> Young person (Thomas et al., 2016, p40)

There was little evidence from any of our studies that service users were routinely involved in the framing of advocacy outcomes, or in making decisions about how the impact of advocacy should be captured and measured. Study 3 was the only study to ask this directly of participants, and found that children and young people from any of English sites including the mental health settings, had rarely been involved in deciding what outcomes should be measured or how. Key suggestions from young participants were that advocates should have a record of whether (or not) the issue has been resolved; they should ask if the individual felt they had been listened to and their views taken seriously; and thirdly, they should measure any improvements in the person's well-being. This supports advocacy services working in recovery-orientated ways, based on a notion of 'recovery' as being about each person feeling in control of, and taking decisions about, their own lives, and building a life that is satisfying, fulfilling and enjoyable on their terms.

Discussion & Conclusion

The findings are not presumed to be representative of the wider population of mental health service users, or indeed, of the specific sub populations studied. Although the small samples, particularly in Study 3, do not allow for generalisability or for inferences in terms of causal relationships, they begin to redress the paucity of evidence about advocacy outcomes from service user perspectives. The new, and importantly, user identified impacts of independent advocacy point to interesting avenues for future, more targeted research on advocacy outcomes to achieve positive change in mental health services. Notwithstanding any limitations, this comparative analysis presents thought-provoking and valid results from service user perspectives that are supportive of advocacy's role in increasing individuals' sense of agency and control, and empowering those who are most often marginalised and ignored.

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The studies discussed involved different groups across the age span, and included both putative beneficiaries (i.e. those that could benefit, but who had little or no experience), and those who had accessed statutory advocacy when subject to mental health law and their rights and liberty were severely constrained. It is perhaps, unsurprising therefore, that conceptions of outcomes differed between the study populations. In broad terms, this difference can be described as a contrast between transactional and transformational outcomes. The experience of African and African Caribbean men was of the mental health system replaying wider social processes of racism and disadvantage. Their conceptualisation of what they anticipated as the outcomes of mental health advocacy was in terms of bolstering broader human rights, including strengthening and supporting citizenship, and addressing inequality and discrimination.

The findings from Studies 2 and 3 on the other hand, highlight the important role of advocacy in empowering people who struggle to have their voices heard, especially those in restricted settings detained under mental health law. This supports findings from previous studies, that differentiated between transactional (or process) outcomes, and transformational (or change) outcomes (Miller, 2011; Townsley et al., 2009). Ensuring individuals have a voice and that their views are represented was commonly identified by both children and young people and adults subject to mental health law as being at the core of what advocacy is about. In her framing of social justice, Fricker (2007) distinguishes between testimonial justice (ie. having a voice) and hermeneutic justice (the meaning of experience being understood). This helpfully recasts the cul-de-sac in advocacy research that gives differential weight to process and change outcomes. Having impact on process aligns closely with testimonial justice (i.e. importance and value of being heard), while change outcomes align with hermeneutic justice (i.e. a shift in the understanding of the experience and action that reflects this). Both are clearly needed, and are valued by service users.

Service user conceptualisations of advocacy outcomes also resonates with Rogers et al.'s (1997) examination of consumer constructs of empowerment, in which they concluded that empowerment was inversely related to the use of traditional mental health services, and more positively related to community activism. Similarly, Nelson et al. (2001) argued:

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> *In our view, significant progress towards empowerment and mental health cannot occur with the traditional paradigm. A paradigm that underscores self-determination, community integration, and social justice offer the best opportunities to enhance mental health.* (Nelson et al., 2001: 137)

This is strongly reinforced by the conception of advocacy evident in Study 1. Thus, advocacy does not take place within a vacuum, its quality and impact are affected by the situational and organisational context within which it occurs (Newbigging et al., 2012). Fricker (2007), and others, argue that having a voice is central to the achievement of social justice. Thus, any consideration of the outcomes of advocacy cannot ignore, nor should it minimise its relational impact, and the subsequent changes that can occur in service systems as well as at an individual level. Any framework for capturing and measuring advocacy outcomes therefore needs to take into account of the complexity and diversity of outcomes and to look at aspects of service user satisfaction with both transactional and transformational impacts.

By framing advocacy in terms of social justice and empowerment, two main considerations for monitoring and evaluating its' impact arise. The first is understanding the extent to which advocacy increases an individual's propensity for self-advocacy. Rather than focus simply on whether an issue has been resolved or goal achieved, our analysis of service user perspectives on outcomes indicates that it is equally important to consider how advocacy increases people's capacity for self-advocacy. The second issue is the importance of evaluating access and whether there are particular populations that are disadvantaged in the way advocacy is being conceptualised and provided, as exemplified by the study relating to African and African Caribbean men. Despite evidence of a strong need for protection of their rights, access to advocacy for men from this group was restricted.

It was evident from our studies that including service user experiences and views can serve to deepen understanding of the purpose and effectiveness of independent advocacy, and the mechanisms by which it can achieve impact. Our analysis indicates that the conception of advocacy and its impact is situated and will, inevitably, be narrowly described by those whose freedoms are being actively constrained. Whilst a deeper meaning of needs,

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outcomes, health and social gains, can be achieved through integrating service user perspectives into outcome definition and measurement as argued by Godfrey and Wistow (1997), this needs to be both inclusive and differentiated, as well as cognisant of the situated nature of this knowledge. In line with Perry (2013), we suggest there is a need for more robust empirical research that identifies the range of outcomes and impacts, and examines how independent advocacy can achieve empowerment in different contexts. This research needs to include a range of methodologies, including participatory action research, experimental or quasi-experimental and realist evaluation approaches.

Advocacy outcomes are multi-layered and complex. In common with other commentators (Action for Advocacy, 2009), our studies strongly underline the importance of working in co-production to define, measure, and evaluate advocacy outcomes if the impact of advocacy is not to be 'lost in translation'. Service user involvement has to be a core component of any credible evaluation, and is an integral part of recovery orientated services (Machin & Newbigging, 2016). Finally, consideration needs to be given to capturing more difficult to measure impacts. Outcomes such as increased voice and control, involvement, and increased self-advocacy are challenging concepts to measure. The truism 'not everything that counts can be counted, and not everything that can be counted counts' commonly attributed to Einstein is apt in relation to measuring the impact of advocacy. However, because these are difficult aspects to measure does not mean that we should not attempt to do this better. Furthermore, the relationship between transactional and transformational outcomes is, as Townsley et al (2009) suggested, something that warrants greater research attention.

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Tables & Boxes

Table 1: Summary of the key characteristics of service user samples in each study

	Study 1	Study 2	Study 3
Number of participants	30	90	9 (Sub-sample of 33 children and young people)
Data collection method	Focus groups and interviews	Interviews	Focus groups and interviews
Description	Mental health service users	'Qualifying patients': 61 had an IMHA, 29 did not. 53% were detained in hospital; 40% in secure services (including CAMHS secure), and 7% were using community services.	Resident in either a CAMHS unit (7 young women) or forensic CAMHS hospital (2 young women).
Gender	100% male	47% male, 43% female.	100% female
Age	22 -45 yrs	Mean age – 38.7 yrs, range 15-74 yrs with 12% under 21 yrs.	14-18 yrs,
Ethnicity	Black African, Black Caribbean and mixed heritage	Most (74%) of White ethnic origin, 15% Black, 5% Asian, and 6% Other.	100% White

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Table 2: Comparison of user defined outcomes across the studies

Study 1	Study 2	Study 3
• Personal development • Changes in treatment • Changes in relationships between services and individual • More culturally appropriate and effective services and support • Changes in the family and/or support system • Changes in citizenship and participation	• Having a voice • Changing care and treatment including helping them to come off a Section • Participating in decisions • Improving relationships with mental health staff • Opening services to scrutiny	• Improving participation and giving young people a voice • Getting a result, resolving an issue, and other practical changes • Personal growth and development

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Box 1: Lines of inquiry for service user participants relating to the impact of advocacy

Study 1	**Study 2**	**Study 3**
• (Potential) need for advocacy • Experience of, and/or understanding of purpose of advocacy • Expected characteristics of effective advocacy services for African and Caribbean men • Most important things advocates should help them (or other similar people) with.	• (Potential) need for advocacy • Experience of and/or understanding of purpose of advocacy • What changes they wanted (or may want) an IMHA to help with • The (potential) difference IMHA support makes • What difference IMHA makes in relation to a) care and treatment; b) managing individual's mental health and recovery; c) individual's confidence in making the changes they want; d) how individual feels about themselves and their abilities.	The changes they hoped an advocate would make Prompts: - Changes in circumstances, particular situation or issue - Changes in how they felt, in understanding, or how they influenced things - Changes in the way service or staff did things. As a result of having an advocate, the sorts of changes that actually happened. Prompts: - Unexpected changes - Positive and Negative changes. The changes that were most important to them.

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