

Peer-Advocacy in a Personalised Landscape: The role of peer support in a context of individualised support and austerity

Abstract

While personalisation offers the promise of more choice and control and wider participation in the community, the reality in the UK has been hampered by local council cuts and a decline in formal services. This has left many people with intellectual disabilities feeling dislocated from collective forms of support (Needham, 2015). What fills this gap and does peer-advocacy have a role to play? Drawing on a co-researched study undertaken with and by persons with intellectual disabilities, we examined what role peer-advocacy can play in a context of reduced day services, austerity and individualised support. The findings reveal that peer-advocacy can help people reconnect in the face of declining services, problem-solve issues and informally learn knowledge and skills needed to participate in the community. We argue that peer-advocacy thus offers a vital role in enabling people to take up many of the opportunities afforded by personalisation.

Keywords: self-advocacy; welfare; social care; day services; personalisation.

Introduction

There have been dramatic changes in social care provision over the last five years in the UK, particularly for persons with intellectual disabilities. Personalisation has arguably reached a tipping point away from collectivised services in day centres and other communal facilities towards individual, family and community based support. This trend has been seen in many countries including Canada (CUPE, 2013), the Netherlands (European Platform for Rehabilitation, 2013) and in particular the UK (Needham, 2014). The changing context of day service provision is an outcome of broader social care policy, prioritising personalisation (self-directed support) which emphasises giving people ‘choice and control’ in the services

they receive. This change has been driven by a growing dissatisfaction with specialist collective support services, known loosely as ‘day services’, in which disabled people gather for meals, social interaction, ‘independent living’ training and activities. The dissatisfaction has stemmed from criticisms of day services being insufficiently flexible with limited development of wider community links (SCIE, 2005) as well as growing demand for more individual rights-based thinking (Power, Lord and DeFranco, 2014).

In this context of personalisation and declining day services, one key question is what potential avenues are left to people with intellectual disabilities for meaningful social encounter? And is there a space for providing the support and glue to bind people’s individualised, person-led lives? According to Wiesel and Bigby (2014), while people with intellectual disabilities may ‘become known’ in local areas, these brief encounters often do not develop into more meaningful relationships. In answering these questions then, we examined the potential for peer-support to fill this space. Peer-support (sometimes referred to as peer-advocacy) is where people in a similar situation who need support come together and advocate for each other through local groups. This often overlaps with self-advocacy (when someone advocates for themselves), with many people with intellectual disabilities coming together as ‘self-advocates’ and acting collectively in formal and informal groupings. As a result of this overlap, the term peer-advocacy is often used interchangeably with self-advocacy. It also stands in parallel with citizen or professional advocacy, when someone speaks on behalf of another, and has that other person’s best interests in mind when they are speaking (TLAP 2014). This latter form of advocacy is primarily for people with little capacity for independent decision making and more complex needs.

Drawing on findings from a co-researched study undertaken *with* and *by* persons with intellectual disabilities, this paper examines the experiences of some people’s involvement in

peer-advocacy groups within the broader context of personalisation and declining formal services. The findings reveal a feeling of precarity in this context and a tangible sense of support and learning derived from peer-advocacy.

Personalisation, Peer-Advocacy & Declining Formal Services

In 2007, the UK Department of Health published '*Putting People First*', marking a shared concordat amongst central government, local government and the social care sector to transform care by enabling individuals to have more choice and control over the support in their lives through the use of personal budgets (PBs) (self-directed support payment, in lieu of provision from the local authority). This was extended by the Care Act (2014), which placed a duty on local councils to put personal budgets on a statutory footing for the first time.

While personalisation promises much, and has been shown to improve some people's lives (IBSEN 2008), there has been a rapid erosion of collectivist sites of care as a result, such as day services. This has been driven by social care departments of local councils re-directing funding from block contracts to individual PBs. The rate of closure of day services has been considerable. Mencap (2012), the national intellectual disability charity, has found that nearly a third of local authorities have closed day services in the last three years, mirroring other reports of their decline (Needham, 2014; Dunning, 2010).

There have also been reports that day care and adult education services are not being replaced with adequate support for people with intellectual disabilities to live, work, learn and participate in the community (Roulstone and Morgan, 2009). According to Mencap (2012), one in four adults with an intellectual disability are now spending less than one hour a day outside of their homes, and are becoming progressively more reliant on advocates and informal help from families (Ibid). Meanwhile, people with moderate intellectual disabilities

often occupy an ‘inbetween’ space – judged to be ‘too able’ to receive care/support, but unable to gain employment or get involved in mainstream college or community activities that may secure inclusion (Hall and McGarrol, 2012).

This policy direction thus fails to appreciate that part of ‘personal care plans’ should be able to offer, if nothing else, opportunities for ‘social encounter’ which should therefore not be so deeply *decollectivized*. This does not square well with notions of self-directed support and reduced informal care spending being predicted by the Department of Health (Hurstfield *et al.*, 2007). The rapid trend of closing day services has been accelerated by government austerity cuts to local authorities which has driven significant reductions to social care budgets (Duffy, 2012; Watt, 2015). This leaves many people with moderate and mild intellectual disability caught in a care/support ‘no man’s land’ with families and local voluntary organisations doing their best to fill in the gaps.

Peer-support appears to hold some potential in this context: to offer participants opportunities to meet, empower and befriend others (Goodley, 2000; Gray and Jackson, 2002). Peer-advocacy networks are arguably distinctive, and more integrated in local communities than some dementia-friendly groups which are often led by local branch offices of national charities. Operationally, these networks typically have a mixed model of funding, which includes the galvanising of local resources (e.g. public and private grants, shares, crowd funding). Ultimately, they share a common purpose to create individual *and* collective support in order for members to live and participate more fully in society.

While Featherstone *et al* (2012) recognise the surfacing of *progressive* localism – a term used to convey the emerging organic forms of local politics in the wake of austerity – most localism policy assumes the role of dynamic, well-resourced communities (alongside private sector firms) and fails to recognise the radical plurality of many localities (Clarke and

Cochrane, 2013). People with intellectual disabilities rarely get considered in terms of their role or stake in contributing to the community. This study thus offers a timely and relevant contribution to current debates over the future of welfare and ‘personalised’ social care provision by tracing the very participation of people with intellectual disabilities in developing learning and support communities (under the guise of peer-advocacy) with potential to have transformative consequences for those seeking support.

Methods

At the outset, the study adopted an inclusive ‘co-produced’ research methodology, to empower people to undertake more active/powerful roles as conductors and advisors of the research (Nind, 2014). There are identified inclusive research models, ranging from (i) advisory/reference group, (ii) ‘co-researching’/collaborating, and (iii) ‘beyond co-researching – taking charge’ (Bigby et al, 2014). In reality, this is – and should be – more fluid than categorised here and often compromises have to be made, particularly the goal that the people implicated by the research should be involved at all stages (Nind and Vinhda, 2014). The value of this approach is the shared sense of engagement in the project by people with intellectual disabilities, and the opportunity to offer more democratic solutions to power and resource imbalances within the research relationship (Ibid.). As Blomley (2006) suggests, for research to be ‘critical’, it must involve a solidarity with people, particularly those who are marginalised

The research underpinning this article was undertaken in 2015 from a British Society of Gerontology funded study. Ethics were approved by the University of Southampton. All

participants consented to take part in the study via the use of plain-language information sheets and consent forms. Pseudonyms are used in this paper.

Drawing on Jeanette et al's (2012) model of community-based participatory research, we designed the study with the involvement of two (self-identified) self-advocates with intellectual disabilities (Mike, 40s and Dee, 40s) in co-researching roles and two professional advocates from our participating advocacy partner in more advisory roles. Our advocacy partner nominated 10 potential self-advocates who agreed to take part. This self-selected sample included an equal split of men and women in their 40s and 50s with intellectual disabilities. We initially sought to arrange training for the participants to help them develop their skills at facilitating interviews. However, the advocacy organisation felt that they would be able to manage in these roles, as they were already actively involved in the local partnership board. These co-researchers were paid and took part in the design of the research, including the drafting and fine-tuning of questions. The advocacy organisation also helped identify potential participants. The co-researchers undertook 5 interviews each with different people from the sample as well as an interview with each other (12 in total). At each interview, the researchers were joined by a social work intern student to help facilitate where necessary. The interview schedule involved 20 questions. It comprised introductory questions such as, how do you keep in touch with your friends? Do you have any groups that you meet up with? It also comprised specific questions about self-advocacy: What group/s do you take part in? What do you talk about? How does it benefit you? Why and how do you stay involved?

The University-based researchers also conducted participant observation at four of the peer/self-advocacy groups within the region to assess *how* the groups operate and the degree to which they were self-led. A 'group-think' face-to-face session at one of the larger groups

was also organised. This was a democratic open discussion meeting often used in participatory research. This was designed to capture in a group-setting what people got out of the self-advocacy meetings. These findings were recorded on a flip-chart at the meeting.

The researchers carried out open coding of the three forms of data, obtained from participant observation notes, printed interview transcripts and the flip-chart sheets and drew out preliminary findings. These were synthesised and discussed at a second ‘group-think’ session focused on analysis allowing the members of the group to highlight what were the most important aspects of self-advocacy, and how it helped in a context of declining formal services. This therefore helped refine the research findings that are presented in this paper.

The University-based researchers also interviewed two professional advocates about the wider context of social care and advocacy, as well as mapped the local social care sector on a flip-chart sheet, including former day services. While these are not reported directly in the findings, they were nonetheless useful for understanding their experiences and views about the broader context.

There are some limitations with the study. The interviewers did not ask additional prompts; as a result the interviews were short, typically 15 minutes, although some were longer, at 30 minutes. On reflection, the questions could have been more framed towards capturing people’s everyday lives and used photo-voice or other less discourse-intensive methods, rather than relying on a script of questions. This is reflected in the data below which does not offer as much background context to the participants as we would have liked. Another limitation was the self-selected sample in this study. We acknowledge that the accounts of the participants may not be representative of people with intellectual disabilities more generally.

Findings

1. Social networks

At the outset, the participants talked about the opportunities for social encounter offered by peer-advocacy. People went along to a peer-advocacy group because they would see people they knew and this was one of the primary reasons people regularly attended. When asked what participants like about the groups, Caroline below says:

Good, because you can see people like [John] and [Thomas] and [Ann], people like that, I don't normally see and it's quite nice to see them, very nice to see them.

(Caroline, 40s, own place)

This is a very important finding as peer friendship and frequency of social interaction are often expressed as important ingredients for positive mental well-being. This focus on the need for friendship and interaction is most commonly featured in gerontology literature and age-related health campaigns, as older people are often portrayed as being especially vulnerable to loneliness (SCIE, 2015). However, our study revealed that loneliness and isolation are also experienced by people with intellectual disabilities. The assumption of having friends was questioned by one participant, Henry (50s, own place), who revealed 'I haven't got any friends!' This exposed a bias in our question, *how do you keep in touch with your friends?* and made us reflect further on the potential for peer-advocacy. We must acknowledge however that despite often experiencing loneliness, the interviews also revealed examples where participants socialised and gained support from people with intellectual disabilities outside of the peer-advocacy group. Many spoke of texting or phoning their friends, going to drama group and one even used Twitter.

Nonetheless, peer-advocacy enabled people to meet other advocates, defined by one participant as ‘someone that you’re comfortable with’ (Caroline, 50s, own place) and in a group setting. This idea of being comfortable with others was another important finding, as most participants did not self-identify as confident and/or vocal people. Indeed, many in the ‘group-think’ session admitted being initially very shy and only built enough confidence to contribute to a group over time.

Another participant revealed that it offered an opportunity to get out of the house, as a way of overcoming being stuck and isolated at home. ‘It means I can get out, meet people, make friends’ (Kate, 40s, supported living). This point was further reinforced by Henry who said that he tried to remain active with going to groups, otherwise, ‘if you don’t, you get sort of lonely, sad and depressed’.

[*What do you like about it, how does self-advocacy benefit you?*] In many ways. One for social, it’s wonderful. I don’t like staying indoors, because when you count the tiles on the ceiling, one, two, three, after you’ve done that a few times it gets really boring life, and so to be able to go to a group of people, to learn, to socialise, it is a wonderful thing. (Henry, 50s, own place)

The above quote reveals a very palpable sense of the monotony and boredom of life at home alone despite Henry being one of the more vocal participants. Another participant Aidan sought to try and articulate how services were becoming increasingly fragmented, and this reinforced the importance of having a space for communication.

people need self-advocacy groups, they’re important, link them together. Like people need communication; it’s very important, and link all the services. All the services like on, in the UK or any, anything, people need linking together when they do

something. They done really good. People need advocacy keep going, you know, they're very good speaking up. (Aidan, 50s, with parents)

The above passages reveal a sense of social precarity shared amongst the participants. This term is generally used to describe the growing sense of vulnerability and risk in the context of the increasing casualization of labour, the recent economic crisis, and political activism mobilized in response to multiple, heightened conditions of social inequality (Korte and Regard, 2014). We use it here to characterise the same feelings but with the additional context of being situated with fragmented and residual spaces of support. The findings show that the social networking associated with peer- advocacy offers a way to combat this.

Our study also found that these groups occur within ordinary places in the community (e.g. local pubs and leisure centres). By networking in ordinary places members of the non-disabled community have more opportunity to interact with people with disabilities, and vice-versa. Such opportunities are an important factor in the integration of people with disability into mainstream society for they show that there is a 'mutual responsibility' for making integration work (van de Ven, et al, 2005).

2. Collective Problem-solving

As well as the opportunities for social encounter, another key finding was the participant's views on the changing context of disability services and the role that peer-advocacy was playing. Some accounts of not having support were reported, as illustrated by Caroline below:

- I: Does anyone check you're doing okay?
- P: Not really.
- I: No. You don't have any support or anything?

P: Not at the moment. I've had problems.

I: Okay. Does anyone help you get your voice heard and say what's on your mind?

P: No.

I: Does anyone help you with information?

P: No. (Caroline, 50s, own place)

While this finding of having no support was only explicitly mentioned by two of the participants, it nonetheless reveals how people with social care needs are falling between the cracks. One challenge is the lack of support for people deemed to have mild intellectual disabilities, which links to Hall and McGarrol, (2012) about those occupying an 'inbetween' space – judged to be 'too able' to receive care/support, but unable to fully participate in mainstream community life. This is very plainly illustrated by Geoff in the quote below.

I: Do anyone check that you're doing okay?

P: Probably not. Probably not. Only when I see them at the hub, probably not any other times.

I: Okay. Do you have any help here at Way Ahead?

P: At Way Ahead yes, probably at Way Ahead I have some help.

I: Yes.

P: Because I don't get, because I don't, because I'm what they call medium, middle of the spectrum you don't get help in the home. (Geoff, 40s, Shared Lives¹)

In this context, peer-advocacy appeared to offer the participants vital opportunities to problem-solve issues collectively. Throughout the interviews, multiple examples were

¹ Shared Lives is a scheme where a person with an intellectual disability moves in with or regularly visits an approved Shared Lives carer.

expressed where peer-advocacy groups offered people vital opportunities to ‘group-solve’ issues. The groups also had a professional advocate present, who helped facilitate the meetings and offered support where necessary.

The way I see self-advocacy means speaking up clearly. If people have got a problem, people have to shout it out, people [have] got [an] advocate, if [advocates] are asked, they promise [to] sort it out. People need that... In my opinion, my own opinion it has benefits for me. If...people speak up clearly, if people have got a problem, hopefully they sort it out for them. (Aidan, 50s, with parents)

These are just a few examples of what people were gaining from these networks. As well as helping to resolve current issues, and as a vehicle for accessing the support of a paid advocate, there were also opportunities for wider informal learning, discussed in the section below.

3. Informal Learning

Another key aspect of peer-advocacy appears to be the informal learning opportunities offered by peer-advocacy groups. This was an important finding as it links back to our earlier point about the decline of collective places in colleges and ‘independent living’ training in day centres. Indeed, adults with intellectual disabilities are a group who are particularly poorly served by formal education, and often must seek informal opportunities where available (Nind, 2014). The peer-advocacy meetings served as vehicles for learning about key skills and information needed to get by safely in the community.

It’s depending on if a certain, if it’s our subject or a certain subject comes and talks to us. Like, when we had a big, we had a big one didn’t [we] on being safe around the

home and that was a big one, and we had a big man come from the Council and talked on it, talked to us all about that. (Geoff, 40s, Shared Lives)

The interviews revealed a wide range of important topics relating to living independently and participating in the home and community, including employment, housing, transport, first-aid and more, as shown in the two quotes below.

[*What do you talk about?*] What do we, we talk about, there's a whole range of things, like health, and issues affecting benefits, employment, and different, and housing and other services that are on, like transport, that will affect people with disabilities. (Mike, 40s, own place)

All today's useful projects, like how to deal with the Police, how to deal with things of what could happen to you these days, and having knowledge in what to do and how to deal with a problem, first-aid, social problems, all so very useful, which all of us are lacking so much so it's really great to know about these things. (Henry, 50s, own place)

In the absence of other opportunities for learning, these topics identified above hold particular relevance for those who often have to face marginalisation in their communities. The latter point about helping with social problems illustrates how this informal learning takes place within a space that is safe, and where the participants clearly felt comfortable discussing their issues openly with their peers.

However, we discovered in the course of the study that there used to be more tailored groups associated with different themes including housing, health, welfare and getting their voices heard. There also used to be a men's group and a 'Ladies who never stop talking group'. However, these have been 'amalgamated' into two generic groups ('Busy People' and 'The

Hub') due to cuts to advocacy funding and the resultant challenges in facilitating all these separate groups. This shows that despite the significant benefits of peer-advocacy, it is itself precarious and vulnerable to cuts.

Conclusions

While personalisation has undoubtedly helped advance people's choices and control over their lives, and destabilised the culture of provider-led, inappropriate service provision, as evidenced and reported on elsewhere (see Oliver and Sapey, 2006; Leece and Peace, 2010), this 'success story' is tempered by an appreciation of the growing individualisation of people's lives in a personalised welfare state. One of the most visible and less favourable outcomes of personalisation in the UK has been the comprehensive de-collectivization of spaces of care. While the authors do not advocate the return to static, inflexible day centres, given the often poor outcomes involved, the findings nonetheless reveal a growing social precarity in people's lives, an individualisation of risk and evidence of deep isolation and boredom when collective sources of support are removed and not replaced or re-imagined.

Within this context, the findings also show that peer-advocacy offers the participants some opportunities for re-collectivizing but in a more bespoke, flexible, community-based and user-led manner, thus filling some of the residual spaces left from personalisation. The study reveals how some (not all) people with intellectual disabilities are coping with changes and cuts, by gathering together for solidarity and friendship and building informal networks of support. The groups offer opportunities for defensive coping, as well as for problem-solving and informal learning. The everyday experiences of the people in the study are very much situated within the broader context of personalisation, which is reshaping the landscape of care they encounter and have to respond to. While the guiding principles of personalisation are still welcomed (by most), those charged with its implementation should not ignore the

value and importance of being together and speaking out as a group (not just as an individual – hence emphasis on *peer* advocacy). We thus argue that peer-advocacy is the ‘mortar’ that helps bind the individualised ‘bricks’ of personalisation, or at the very least ‘oiling the wheels’ of personalisation. While we acknowledge the overlap between peer-advocacy and self-advocacy (indeed most of the participants self-identified as self-advocates), we would argue that the positive outcomes reported here stem from the peer-opportunities in the groups. We would also argue that these outcomes can help each self-advocate in dealing with their own individual encounters with professionals and other people outside the groups.

We must also acknowledge the limitations of peer-support/advocacy groups. It is difficult to argue that a peer advocacy group, meeting once a week, is sufficient to compensate for the loneliness and lack of purposeful activity that many participants described. They also do not have an ‘analogue’ with other support groups that non-disabled people form. Nonetheless, having a point in the week, described by Mike (40s) as a ‘ray of sunshine’, in an otherwise solitary week can be an important anchor point in their lives. Another limitation was the degree to which the group is organised and led by people with intellectual disabilities themselves. We saw evidence of the participants taking the lead in nominating some agenda items, actively taking part in the discussions and voting on decisions. However, we also were aware from the participant observation that without paid facilitators, these meetings and organised talks would have likely ceased. We therefore are not convinced that the peer-led support groups could easily evolve into more user-led organisations as per mental health, although we are aware of some People First groups who have successfully done so (Goodley, 2015). Further research is therefore needed to assess the extent, nature and forms of emerging self-build networks in local areas in the UK and examine how they sustain themselves, innovate and evolve.

Notwithstanding these limitations, we recognise there is still significant potential for peer-advocacy to occupy an important space within the personalised care landscape. And yet, it is not mentioned in the Care Act 2014 and is often seen as a soft cut as evidenced in this study and more widely elsewhere (Goodley, 2015). If left to continue to decline, people arguably will become more at risk of being further ‘de-collectivised’. The experiences of the participants reveal the need for more spaces of hope, resilience and cohesion. But more importantly, a space that is not filled by cruel optimism (Runswick-Cole & Goodley, 2015), a term borrowed from Berlant (2011) to illustrate the neo-liberal idea that people will be able to become active participants in welcoming communities and able employees in the labour market. Rather, the self-led ethos of peer-advocacy offers people with intellectual disabilities the opportunity to honestly and safely build their own pathway to a life in the community based on their own aspirations, needs and abilities.

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