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Peer advocacy in a personalized landscape: The role of peer support in a context of individualized support and austerity

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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 associated with 'living independently', 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 and adult learning provision over the last five years in the UK, particularly for persons with intellectual disabilities. Personalisation has arguably reached a tipping point shifting the focus away from collectivised services in day centres and other communal facilities towards individual, family and community based support. Where sites remain open, they are often limited to those with the highest support needs. This trend has been seen in many countries including Canada (CUPE, 2013), the Netherlands (European Platform for Rehabilitation, 2013) and in particular the UK (McVeigh, 2012). 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. It has thus sought to change the emphasis

from what *service* people want, to what kind of *life* people want. This change has been driven

by a growing dissatisfaction and stigma associated 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 choice and control of support

arrangements and 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 or with a similar impairment or stage

in the lifecourse who need support come together and advocate for each other through local

networks and associations. 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 a concordat '*Putting People First*', marking

a shared commitment amongst central government, local government and the social care

sector to transform care by enabling individuals to have complete 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 new 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), evidence also suggests that in the UK, unlike models in the Netherlands, the

USA and Canada, these opportunities are often constrained by the denial of the real support

required to help people with intellectual disabilities manage the PBs and restrictions on what

they can be spent on (NDA, 2011). According to Rabiee et al (2013) 'It's not choice, it's

about what's available' (p.2). Related to this point of what is available, the landscape of care

provision has seen a rapid erosion of collectivist sites of care, such as day services. This is a

down-stream effect of personalisation, as a result of social care departments of local councils

re-directing funding from block contracts to individual PBs. The rate of closure of day

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services as a result across the UK 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). In particular, the symbolic importance of buildings as carriers of meaning

(Yannow, 2000) is evident here: day care centres and discrete college classrooms have

become associated with outmoded collective means of support provision.

In the midst of the rhetoric of a personalised independent life – that people will be located in

and engaged with local communities – a crucial counterpoint is that there is often inadequate

or variable support to enable this to happen, depending on where you live, your family

resources etc. Moreover, there have 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 actively in the community (Roulstone and Morgan, 2009). Many

former users are receiving a PB that in many cases covers a lower level of day support than

was previously being given (Mencap, 2012). Moreover, one in four adults with a 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 and

friends (Ibid). And many with moderate intellectual disabilities are now not entitled to

support, as eligibility rules are tightened (CSCI, 2008). Even when people have a personal

assistant many 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*. Roulstone and Morgan (2009) found that a great deal of former

centre-based time was beginning to be spent at home. 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 and related supports (e.g. college provision for

adult learners (NIACE, 2014) as well as eligibility restrictions and increased charges (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 much potential in this context: to offer participants a rich

network of 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 localist

policy assumes the role of dynamic, well-resourced communities and a strong local civil-

society (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 ongoing debates over the future of welfare

and 'personalised' social care provision by tracing the very participation of people with

intellectual disabilites 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). While in reality, this is – and should be – more fluid than categorised here (Nind and Vinhda, 2015; Bigby et al, 2014), we nonetheless sought to develop a 'co-researching'/collaborating approach as a guiding principle throughout the project. 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.

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 in co-researching roles and two professional advocates from our participating advocacy partner in more advisory roles. Our advocacy partner nominated potential self-advocates who agreed to take part. We initially sought to arrange training sessions 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 and other intellectual disability groups. These co-researchers were included 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

with intellectual disabilities 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 questions included, how does self- and peer-advocacy benefit you? Why and

how do you stay involved? Where and how often do the groups meet?

We also included the two disabled researchers and the self-advocacy group in the analysis

phase by hosting feedback sessions and offering participants the opportunity to prioritise key

themes and offer advice on dissemination. 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. Two 'group-think' face-to-face sessions were used alongside the

observation. These were democratic open discussion meetings often used in participatory

research. The first was designed to capture in a group-setting what people got out of self-

advocacy and what was covered in the meetings. The participant observation also enabled the

research team to find out the dynamics of self-advocacy working in practice. The second of

the 'group-think' sessions was more focused on analysis. The researchers drew out

preliminary findings from the transcripts, and discussed these at the face to face meetings.

This therefore helped refine the research findings, 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.

The University-based researchers also interviewed two professional advocates about the

wider context of social care and advocacy, as well as photo-recorded and mapped the local

social care sector, including former day services. While these are not reported directly in the

findings, they nonetheless offered useful context for understanding the participants'

experiences and views and broader context.

There were 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.

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, Paul 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. (Int. 7)

This is a very important finding as peer friendship and frequency of social interaction are

often expressed as important ingredients for positive mental health and 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, who revealed 'I haven't got any friends!'

(Int. 2). 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. In this context, peer-advocacy

offers people the opportunity to meet other advocates, defined by one participant as 'someone

that you're comfortable with' (Int. 7). 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 some 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.' (Int. 1). This point was further reinforced by another participant 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' (Int. 2).

> [*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. (Int. 2)

The above quote reveals a very palpable sense of the monotony and boredom of life at home alone. Another participant 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. (Int. 8)

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 care. 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 people with a disability have the opportunity to network with those beyond the disability community. 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 Brian 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. (Int. 7)

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 Paul 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. (Int. 10)

In this context, peer-advocacy appeared to offer the participants vital opportunities to

problem-solve issues collectively. Throughout the interviews, multiple examples were

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. (Int. 8)

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, for example through taking part in inclusive research (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 [*Yeah*]. 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. (Int. 10)

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.(Int. 11)

> All today's useful projects, like the today's 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 (Int. 2)

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

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 LD are coping with changes and cuts, by gathering

together for solidarity, support 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-adovcacy 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 also acknowledge that these outcomes can of course help each self-advocate in dealing with their own individual encounters with professionals and other people outside the groups.

However, despite the significant potential for peer-advocacy to fill this space, it still occupies a very ambiguous position in policy. 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', as illustrated by one of the participants' experience of being at home alone 'counting tiles'. This profound experience reveals 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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