# Exploring the ethical underpinnings of self-advocacy support for intellectually disabled adults.

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## 1. Introduction

This paper is an exploration of the support worker role in self-advocacy. Self-advocacy is 'speaking up' for one's self (Atkinson, 1999). Self-advocacy organisations support people in a wide range of activities, including political action (at the international, national and local level); employment; skills development; research; and improvement in individual circumstances, alongside providing key social networks. Whilst intellectually disabled people have long spoken up for themselves and developed means to resist prescribed routines and patterns assigned to them, the emergence of formalised self-advocacy from the 1960s onwards marked an important cultural shift. These groups soon became associated with the pursuit of social change and the attainment of rights for intellectually disabled people (Williams and Schultz, 1982; Bersani 1998; Buchanan and Walmsley, 2006; Bylov, 2006; Caldwell, 2010) Self-advocacy is an international phenomenon, and while our discussion is based on findings from the UK, it is our belief that these findings have relevance beyond a UK context.

Cause for concern in the UK, from the mid-1980s, was the relationship between self-advocates and those who were 'advising' or 'supporting' them (Hersov, 1996). Both parties were aware of the potential tension between supporters teaching people skills to take control, whilst inadvertently assuming a powerful position in the relationship. Today, advocacy support

workers (usually without the label of intellectual disability) tend to be employed by intellectually disabled directors or trustees - to support them to be employers *of* the advocacy support workers *themselves*, in order to run the organisation. This interesting paradox hints at ethical complexities inherent in the role.  So a key challenge facing self-advocacy support workers is how they can support their employers to run successful organisations, without 'taking over'. With their own jobs often on the line, how do self-advocacy supporters enable good decision-making without wielding their power?  When does 'support' veer into 'over/protection', or even 'control'? What does ethical self-advocacy support look like and, finally, is it possible to articulate a model of ethical support for the future?

There has been growing recognition in policy and research regarding the potential of self-advocacy to support citizenship and inclusion for intellectually disabled people, yet only a small number of studies have attempted to examine this conjecture empirically (Goodley, 2000; Clement 2003; Bylov, 2006; 'Chapman, 2006; 'Tilley, 2007; Redley and Weinberg, 2007). Even less attention has been paid towards specific ways in which support is enacted in self-advocacy organisations (Johnson and Walmsley 2010).

In the UK, self-advocacy developed from an allied approach in which disabled and non-disabled people worked in partnership enabling 'voice' with previously marginalised people (Shearer, 1986; Crawley, 1988; Buchanan and Walmsley, 2006). This is quite different from the wider history of organisations and services in intellectual disability where people have been constructed as passive and dependent on staff. It is encapsulated in the nuance of language – self

advocacy *with and by* intellectually disabled people as opposed to services provided *for* people (Chapman, 2006; Bylov 2006).

Drawing on empirical data from our PhD projects on advocacy organisations in the UK, we attempt to theorise self-advocacy support and reflect on the implications for current and future practice. Both projects (described in detail below) revealed the influence of two key disability theoretical approaches in shaping self-advocacy support: Social Role Valorisation (Wolfensberger, 1983) and the Social Model of Disability (UPIAS, 1972). However, our view is that neither of these fully accounts for the complexity of practice that emerged in our research and neither of these ideologies were generated by intellectually disabled people.

In this paper we reflect on the extent to which an 'ethic of care' (Gilligan, 1982) provides an explanatory model for understanding the practice of self-advocacy support, and discuss whether it can help identify and frame ethical support. The appeal of an ethic of care, as recently articulated by Ward (2011), is its recognition of reciprocity and its dismantling of dichotomous assumptions about those who 'care' (or 'support'), and those who are cared for (or 'supported'). Although it may be controversial to posit self-advocacy as an explicitly 'caring' site, we argue that such is the complexity of the self-advocacy support worker role that we must be prepared to draw on alternative frameworks to help us better understand its practice. Finally, we touch upon the concept of relational autonomy (Meyers, 1987; Twomey, 2011), suggesting that it might provide a valuable tool in helping support workers reflect critically upon how they can support self-advocates to become more self-directed, both individually and collectively. If self-advocacy

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is to provide a legitimate space in which intellectually disabled people acquire a true sense of ownership and control *on their own terms*, then it is vital to reflect more closely on how they are supported and enabled to achieve this.

## 2. Two Research Projects

Both authors undertook PhD research on self-advocacy in the UK to address the lack of detailed descriptions of *what actually happens* within these organisational settings. In revealing challenging dilemmas of practice we hope to enable new insights that will help to strengthen self-advocacy's long-term future, rather than weaken its presence.

Chapman (2006) undertook an inclusive qualitative research study in partnership with the 'X' People First Research Team into five People First organisations across the four countries of the UK (England, Scotland, Wales, Northern Ireland), analysing the views of both members (people with intellectual disabilities) and support workers in relation to the role of support. In total 18 supporters and 24 members were interviewed as well as data being collected through focus groups, group work, observation and Communiogrammes[1]. The groups were (in the main) formally constituted to be run by intellectually disabled directors who were legally responsible for their actions.

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[1] The drawing of lines to demonstrate frequency of verbal interactions between support-workers and members at meetings.

Tilley (2007) conducted an ethnographic study of a self-advocacy group in the South-East of England. Five self-advocates and four supporters were interviewed and observed over a period of one year. This organisation was not a 'People First' group. It started life as part of a wider advocacy organisation founded by local professionals and community leaders. Although the group constituted itself as an independent self-advocacy organisation in 2000, its own particular set of historical circumstances meant it was organised along different lines to the People First groups studied by Chapman. Most notably, 'formal' organisational roles such as 'Chief Executive', 'Chair' and 'Treasurer' were held by non-disabled people, rather than self-advocates, although self-advocates were represented in all decision-making fora.

## 3. Theorising Self Advocacy Support

There has been increasing attention paid to the role of support workers in intellectual disability services, particularly focused on 'active support' for people with high support needs (Mansell and Beadle-Brown, 2012). However, with few exceptions (Goodley, 2000; Tsuda, 2004), there has been little theorising about the specific role of advocacy support workers or advisors in self advocacy for intellectually disabled people. This position is somewhat baffling given the growing emphasis on advocacy support within UK policy initiatives since 2001; especially in relation to personalisation of services (Johnson and Walmsley with Wolfe, 2010).

In both research projects we tried to address the complexities of this understated role. We drew attention to the ways in which supporters referenced two of the ideologies that have had a

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powerful influence in the field of learning disability over the past 30 years; Social Role

Valorisation (SRV) and the Social Model of Disability. However, in the ensuing discussion, as

stated above, it is crucial to bear in mind that neither of these ideologies were generated by

intellectually disabled people.


### 3.1 Normalisation, Social Role Valorisation and the Social Model of Disability in relation to self advocacy support

From the 1970s onwards, normalisation, that is, creating 'normal' patterns of life for

marginalised people, and SRV, the theory that developed out of it which emphasised the

importance of providing intellectually disabled people with 'valued roles' in society as a means

to reduce stigma, have been inextricably bound up with the development of self-advocacy

(O'Brien 1987). Much of this theory was values-based, referencing particular moral

understandings about worth and respect of all people, and integral to it was the continuing

supportive role of non-disabled professionals (Walmsley and Johnson, 2003). Because of its

adherence to 'the use of culturally valued means in order to enable, establish, and/or maintain

valued social roles for people' (Wolfensberger, 1983:234), it emerged as having significant

relevance in advocacy groups when working out (sometimes with self advocates) how their

organisations were to be structured. Such decisions regarding governance arrangements clearly

have an explicit ethical component, involving questions about autonomy and control. Informants

across both projects regularly signalled the influence of SRV in interviews – both explicitly and

implicitly – highlighting the emphasis placed on giving people opportunities to undertake valued

organisational roles and tasks. This is demonstrated by one of the supporters in Chapman's

study:

*We do take notice of SRV. We base a lot of our [X] project on that. You've got the history of disability included and we have people who have lived in [a large hospital] and they say how they feel valued now and how their roles have changed. So we use SRV quite a bit.* Donna in Chapman, 2006:189).

Fewer informants expressed an explicit affiliation to the Social Model of Disability, where societal barriers and negative attitudes are considered to be the main factors in disabling people. In Tilley's (2007)  study, supporters often referred to the 'barriers' facing self-advocates, both in terms of their involvement in self-advocacy, but also in their day-to-day lives; although intellectually disabled members did not make many references to these ideas. In Chapmans's study, one supporter noted that even if the basic ideas of the social model of disability were understood, it was never referred to directly by members, even though they may be aware of key aspects of the model:   "*I think people have found it hard to get their heads round it to be honest…I think people here feel there are barriers…'* (Ian, in Chapman, 2006: 288).  This example reiterates one of Goodley's (2000) findings in self advocacy groups, that theorising may not be explicitly verbalised by members but could be implicit in their understandings and actions.  Bearing this in mind, it may be helpful to explore other approaches.

### 3.2 The ethics of support

Traditionally, ethical approaches to the conduct of professional (welfare) roles have connected into a Global North and neo-liberal, ableist emphasis on individual choice and freedom where there is a general assumption that people are independent actors of equal stature (Banks, 2010).

This is necessarily problematic in relation to minority groups of people who can find themselves excluded from such a conception of social justice. A utilitarian approach to social justice reifies the notion of the 'common good', which can obviously be challenging in relation to marginalised groups who may require more specialised and individualised support (Johnson and Walmsley with Wolfe 2010). The label of intellectual disability inextricably links with difficulty in conceptualising and understanding. There is no equal starting point for all people based on intellectual capacity and we argue here *that we need to work with and alongside this reality rather than ignore it.*

A helpful move towards a more layered and complex understanding of 'character and relationship based ethics' has emerged alongside traditional paradigms (McSwite 2011). Relational ethics draws attention to the multi-layered interactions between emotions, feelings and the complexities of everyday life.  It is argued that these attributes are contextually specific and socially constructed. Therefore space is created for diverse, paradoxical and problematic explanations allowing escape from the traditional ableist binaries of disabled / non-disabled; supporter/ dependent; powerful/powerless.

The advocacy supporter role in the UK, unlike other professions in health and social care, is not (yet) guided by a specific set of ethical codes, although we envisage this may happen in the future[2].  In researching an ethical approach useful for understanding and illustrating the work of advocacy support workers we sought other roles which may resemble those of the support workers.  One example is Wadensten and Ahlstrom (2009:1) who focus on the ethical values of

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[2] This is likely to become an essential requirement in the UK for future advocacy posts since Advocacy qualifications have come into force. UK Children's advocacy services has standards attached already - *National Standards for the Provision of Children's Advocacy Services*

personal assistance such as autonomy, integrity, influence and participation which they describe as being encapsulated in the Swedish Disability Act (1993). They make connections with the traditional freedom, rights and promotion of welfare paradigm.  Their research focused on disabled people with physical impairments who had personal assistant (PA) support. The findings portrayed the fine balance between PA's  providing support but 'not taking over', alongside managing intrusions into the private spheres of disabled peoples' lives, which could lead to a sense of powerlessness (Wadensten and Ahlstrom, 2009: 770).  A point was made that, "disabled persons and assistants must *adapt to each other* (our emphasis) if the assistance is to function" (ibid). This resonates with the contradictory support relationship in self-advocacy. However the Swedish study was; a) not focused on the experiences of intellectually disabled people (and the added complexities that may entail) or; b) involved in exploration about disabled peoples' organisations (the study attended to the dynamics of personal relationships alone).  We concluded that the self-advocacy support worker role is unique and can only be partially informed by the ethical practices of practitioners engaged in other roles, such as the PA role.

### 3.3 The notion of 'care' and 'caring' in self-advocacy

The development of self-advocacy, while experiencing its own particular historical trajectory, has taken place within the context of significant shifts in how the notion of 'care' is understood and provided in Western democracies, and alongside the disability rights movement, which campaigned for greater choice and control for disabled people both in terms of their opportunities, and the specific ways in which their 'care' was provided (see for example Morris, 1994).  Over time, the term 'care' has become increasingly problematic, viewed by many as the linguistic legacy of an ableist/ oppressive/ paternalistic welfare regime which sought to curb and

control people's experiences (Beresford et al, 2011). The disability rights movement preferred instead to claim terms such as 'support' 'enablement', and 'empowerment' which, they argued, offered a truer reflection of peoples'  needs and re-framed people as active  independent agents rather than passive dependents (Beresford and Evans, 1999; Thomas, 2004; Redley and Weinberg, 2007; Morris, 1994, 2011).

Eschewing the notion of 'care' is widespread within much of the disability movement literature, and indeed, it is almost impossible to find reference to it in discussions about self-advocacy.  We explored the extent to which the concept of 'care' and 'caring' was present in participant narratives from our research. In a textual search of Chapman's (2006) research, 'care' was only mentioned twice by members. Once in relation to the past, i.e. 'long term (institutional) care' and the second time in relation to 'personal care' when discussing individuals' support needs. However in Tilley's (2007) research, we can find its presence in explanations from advocacy workers in articulating their role.  In an interview with one of the individuals who helped to establish the advocacy organisation from which the self-advocacy group emerged, the participant commented:

> *A lot of people in statutory authorities had spent all their working life caring for very vulnerable people, in places like X and Y…And they were very devoted. And a lot of them were concerned that when they came out into the community, who was going to fight for them? Who was going to make sure that they were looked after? And it (advocacy) did come a lot from some of the 'care' professional people.* (Tilley, 2007).

The quote suggests that some people were motivated to support self-advocacy because they 'cared' about the individuals in question; indeed, they were motivated 'to care'. However, it was

far more common for non-disabled workers to talk about 'support', 'enablement', and empowerment'. 'Care' was discussed by members and supporters as something that happens elsewhere; indeed, self-advocacy was often framed as a mechanism for addressing the deficiencies and structural inequalities that were a feature of many 'care services', where 'care' was viewed as something that constructed dependency and marginalisation. Some support workers felt compromised that their roles involved a small amount of personal care at times and that this further complicated and blurred the boundaries of the self advocacy supporter role (Wilson, 1997).

However, self-advocates also gave positive accounts where supporters had 'helped' them, both in their personal lives and in the context of organisational tasks. They appreciated instances in which support workers had gone the 'extra mile' to give them support and advice. They noted examples which demonstrated that support workers respected members' feelings and their circumstances, and drew attention to when they felt this had not been the case. A number of self-advocates valued acts of kindness by supporters and articulated the importance of 'having fun' together. While these qualities and behaviors were rarely articulated as 'care', they indicated ways of being and supporting that went beyond the 'technical', and emphasised the relational.

### 3.4 Drawing on our data to explore self-advocacy through an ethic of care

The importance of the relational elements of self-advocacy in our research led us to consider different frameworks and conceptual tools through which to explore the unique nature of self-advocacy support. We explored the relevance of an ethic of care as explicated by Ward (2011).

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We asked whether such an analysis can enable us to identify ways in which the challenges of self-advocacy support can be resolved or did it imply that we buy in to a perspective that essentialises intellectually disabled people as 'passive dependents'?

Readers of this journal will no doubt be well versed in the 'ethics of care' debates. There is not the space to thoroughly review the literature, but summaries of the discussions to date can be accessed in three recent articles for *Ethics and Social Welfare* (Lloyd, 2010; Barnes, 2011; Ward, 2011). For our purposes, the key features of the framework that speak directly to our questions about self-advocacy support are outlined below (which resonate closely with the writings of disabled activists such as Jenny Morris (1994):

1. *Dependency and vulnerability are part of everyone's experience, not just those assigned labels such as 'disabled'; 'elderly'; 'ill'. **People are interdependent** and everyone has a right to be cared for (Sevenhuijsen, 1998, 2000)*

2. *Expressions of **moral actions are enacted through the practice of care** and in reciprocal and responsive relationships, rather than through a rational application of abstract moral principles (Tronto, 1993; Ward, 2011)*

3. ***The ethic of care is political**, and can support collective action, shared experiences and the forging of valued identities (Sevenhuijsen, 1998, 2000; Barnes, 2011)*

4. *Citizenship must take account of the complex interface between the **needs of care-givers and care-receivers** (Brannelly, 2004).*

In an article that explores an ethic of care in relation to intellectual disability and caring roles, Ward (2011) notes that at the heart of many Western approaches to ethics is a belief in the individual moral agent who is able to rationally balance duties and rights, drawing on universal ethical principles. This assumption is central to a framing of self-advocacy support workers who 'enable' and help 'empower' intellectually disabled self-advocates to manage their organisations. Support workers are expected to do this in ways that minimise their own subjectivity, experience, influence and ultimately, their power. This aligns with a social model of disability perspective, in which those paid to provide assistance are viewed as a mechanism to facilitate independence, in much the same way as technological developments have removed physical and environmental barriers that have historically faced disabled people (Johnson and Walmsley, 2010).

The notion of support workers as 'neutral facilitators' was a common theme in both research projects. Some support workers articulated their role as facilitating self-advocates (or 'members') to attend to particular tasks, and to make decisions. They felt a pressure to be 'invisible', working 'in the background' to enable self-advocates to take control (Chapman, 2006: 214) What we witnessed in practice, however, highlighted the tensions in such narratives, and indicated a far more complex picture.

Groups were generally struggling with the amount of work they had to do and the pressure to acquire money. Balancing the desires of the members alongside the need to fulfill contracts for funding, address key management tasks, and ensure organisations were legally compliant was stressful. An analysis of workers' job descriptions demonstrated these were understated and largely removed from reality. Contradictions related to purpose were rife. For example, members

spoke about how they wanted supporters to *'take a back seat'* or *'not take over'* whilst at the same time other members in the same group expressed the need to be able to rely on supporters to *'sort things out',* or to be *'knowledgeable and get things done'.* Some supporters were castigated for being *'stubborn and bossy'* or *'a show off'* whilst others were described as *'lazy'* or *'never does anything'.*    What stood out for some was loyalty and affection. This was voiced by one of the members, *'We have supports, they are brilliant, I love them all. They are great to me, nothing is too much trouble; they are wonderful.'* Quotes from participants, Chapman, 2006:177-265

Some support workers felt  their hands were tied in obligation to ensure the groups were involved in attending consultations or meetings as part of agreements at a local level. Indeed it was important to participate broadly to have a voice, but it stretched the groups that were all operating on low resources.  This was also getting in the way of the grassroots aspirations of group members. These findings, about who was running the organisation were problematic. Was it the members¸ the supporters or actually the funders?

Our research demonstrated that it was remarkably difficult, if not impossible, for workers to fulfill the role of 'neutral facilitator' in ways that did not take account of their own subjectivity and the difficulties that faced members. This was both as a result of members' intellectual impairments and their lack of experience in administering and managing organisations. Crucially, rather than being discussed and reflected upon in an open and transparent way, power imbalances were camouflaged within organisational (and political) rhetoric. Official narratives

about the role of self-advocacy support were not evidenced as sustained in practice.  We would

argue that our data on the interactions between members and supporters of self-advocacy

highlight the challenges, involved in self-advocacy support. However,  we are mindful that such

an interactionist approach does not take into account the wider social context and therefore runs

the risk of re-constituting familiar (and we would suggest, false) binaries between supporters and

self-advocates. If we are to accept that relationships can be reciprocal and people are capable of

having genuine involvement in shaping their lives and organisations *on their own terms*, then we

need to reframe the classic positioning of intellectually disabled people as solely dependent. This

does not mean that people's intellectual impairments and the associated difficulties are ignored,

but rather it recognises that we have specific needs at different times and that intellectually

disabled people are also able to provide insights, care and support.


Ward (2011) has argued that using an 'ethic of care' analysis permits us to:

> … highlight aspects of interdependence (rather than autonomy) and reciprocity, (which)
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> disrupts the discourse that creates such binaries and the drivers that compartmentalise and
>
> essentialise people either as care givers or care receivers; it provides a space in which to
>
> demonstrate interdependence and to unmask the artificial boundaries of care… An ethic
>
> of care offers an alternative analysis which acknowledges dependency and vulnerability
>
> as part of every person's human experience through which we can challenge the notions
>
> of power and powerlessness. (p.172-173).

Although we may contest the essence of 'care', we find that Ward's (2011) challenge 'to

dependence and paternalism' fits well with our research findings as well as reflects our personal

experiences. Her focus on intellectually disabled carers, might, she suggests "be used to promote advocacy and self determination for intellectually disabled people and undermine the dominant discourse of vulnerability and dependence" (p.173).

Certainly traditional ableist concepts of vulnerability and dependence in relation to intellectually disabled people can be challenged by our findings. Supporters recognised opportunities for reciprocity and learning from each other, with each other, within the groups. In the Chapman's study a supporter reported:

> *My personality has changed, definitely, instead of sitting on the fence I fight for what I believe in and I will say, I will speak up, so I'm a bit like my members really, I have grown with them,* Jayne, Group B.(Chapman, 2006:183).

A support worker in Tilley's study stated:

> *…when I worked in one place, one of the people said 'whenever you talk, you always say "we did this" or "we went there", who do you mean?', and I said 'people with learning disabilities'. And it was just so natural to me…there was nothing I was doing on my own, there was nothing that I could achieve on my own. It's a 'we'!* (Tilley, 2007: 303)

Supporters were sometimes acutely aware of the power relationships operating within the groups and worked hard to address them. Likewise they could be reflective over their support and, on occasion, agonised over the quality of their interactions with a desire to improve them:

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*."…it's difficult when you know what somebody is trying to say and you've already been through it, but when it comes to it they find it really hard to get their point across. And in the end you might end up saying something like, Emma is trying to say this… I get that guilty feeling and you think you know it was what they wanted to say but other people maybe think you are putting words in their mouth. I don't try and manipulate - but that is my worry.* (Gordon in Chapman, 2006: 214)

These examples demonstrate that support workers are highly aware of the complex power dynamics they were navigating  but also acknowledged reciprocity as a key element of the interactions and relationships comprising self-advocacy. The ethical considerations of the support role were not lost on these workers, even if self-advocacy discourse has not, to date, included a detailed exploration of these issues.

### 3.5 Self-advocacy and relational autonomy

It might also be argued that underpinning the self-advocacy movement has been a framing of 'autonomy' that promotes the facilitation of understanding and choice. Reflecting on her experience as a breast cancer nurse, Twomey (2011) argues that in Western healthcare practice autonomy has been equated with active decision making. This, she suggests, prioritises the provision of information and a focus on choice-making above the processes by which a person develops autonomy. She says:

A relational concept of autonomy, by contrast, relies on working with someone to discover what autonomy means for her, in this situation now - in other words, by attending to the process by which someone expresses her autonomy. This is a concept of

autonomy which is content neutral, and so does not suppose that autonomy is promoted only if the perceived right action is selected. (2011: 409)

In this way, autonomy is something that occurs through and between relationships, and attention is focused on supporting the development of 'autonomy competency' (Meyers, 1987), whereby those with specific experiences and areas of expertise facilitate people to come to particular decisions on their terms, taking full account of their sense of self. We would argue that this concept has significance for self-advocacy support. It creates opportunities for support workers to be more transparent about the tasks they undertake, and the scope of their role (including both technical and caring elements). For example, it would provide a space in which it is acceptable for supporters to assume particular responsibilities, if both they and members viewed this work as contributing to a longer-term goal of greater collective autonomy among self-advocates. Rather than 'covering up' key aspects of their day-to-day practice, these issues would be continuously reflected upon jointly with self-advocates to discover whether they were in fact facilitating a process through which intellectually disabled people were becoming more autonomous in the context of their organisation, or whether supporters were inadvertently 'protecting' or 'controlling' them.

As Twomey (2011) suggests, drawing upon a concept of relational autonomy also supports practitioners to reflect on their own sense of self, and explore and critique how their understandings are shaped by wider discourses and normative assumptions, as well as the meanings brought to bear by those they work with. It values rather than discourages reflections on the subjectivities of supporters, as well as self-advocates. In this way, the concept of relational

autonomy might have a 'profound impact' on the way that self-advocacy supporters understand their role and the way in which they work with self-advocates (in much the same way that Twomey predicts for health practitioners).

## 4. Conclusion

In our view, the social model of disability and social role valorisation can take us only so far in understanding the practice of self-advocacy support. We think that support workers and self-advocates have been too reluctant to discuss the challenges and paradoxes inherent in the supporter role. This has led to an unfortunate situation where supporters are expected to enact their roles in ways which are untenable within the contexts of their complex working environments. The situation thus becomes strangely circular, where unrealistic expectations of the role are set which supporters cannot achieve, leading to organisational policies, behaviours and rhetoric that camouflage the complexity of the role. This results in power dynamics between self-advocates and support workers that are not addressed in a transparent way.

The current discourse of the 'neutral' support worker (mirrored in discussions about PA's) was not borne out in our empirical findings. It fails to capture the relational and reciprocal elements of self-advocacy that we witnessed. Reflecting on the personalisation agenda and the growth in PA's contracted directly by service users to provide support, Barnes argues that the purchasing of support does not necessarily mean that those so employed do not 'care' about the work they do. However, she expresses deep concern about:

…the perversity of attempts to 'remove' care from the characterisation of the type of

relationships necessary to support those for whom social care services are designed. The

danger in such a situation is that workers are not trained or supported to care, and that the

skills that are valued are those of brokerage rather than the moral, practical and relational

sensibilities of care (Barnes 2006, cited in Barnes, 2011: 163).

Barnes's arguments have resonance with self-advocacy. Whilst 'care' does not feature in the

formal discourses of self-advocacy, our research showed that support workers do care intensely

about the work they do, and the people they support. They are committed to doing their job in the

'right' way, even if the wider social context makes this difficult (if not impossible) to achieve at

times. A 'caring' approach was also valued by members of self-advocacy organisations. Our

data, therefore, looks less 'problematic' when viewed through an ethic of care lens. Rather than

'failing' when measured against justice ethics and the social model of disability, the practices we

witnessed have the potential to be more transformative. Arguably, the paradoxes of self-

advocacy support arise in the first place precisely because the dominant discourse has been one

that seeks to minimise elements such as caring and reciprocity, and instead has elevated qualities

such as autonomy, choice and control, based on ableist understandings of empowerment, which,

our data demonstrate, are very hard for people to achieve in practice.

Beyond the rhetoric of enablement, facilitation and empowerment, there is little detail and debate

in the field about what constitutes 'good' (and 'ethical') practice. An ethic of care and the

concept of relational autonomy may not provide a wholly sufficient model for re-thinking the

self-advocacy support worker role, but they usefully draw our attention to the relational nature of

this work; the importance of reciprocity; and help us to acknowledge the interdependence that frames self-advocacy (Tsuda and Smith, 2004). This provides an opportunity not only to locate the role of self-advocacy support firmly within the empirical findings, but also to think practically about the ways in which training and support for self-advocacy support workers can be developed in order to take account of the complex ethical dilemmas inherent in the role. Key to this would be to acknowledge the reciprocal relationships in self advocacy by including together self advocates and their supporters in the design and teaching of appropriate training.

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