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Empowerment through care: using dialogue between the social model of disability and an ethic of care to redraw boundaries of independence and partnership between disabled people and services.

Abstract

Our approach, empowerment *through* care, emerges from dialogue between social model understandings of empowerment and ethic of care based understandings of care. Whilst maintaining the principles underpinning empowerment as a challenge to disabling practice within health, social care and voluntary sector organisations, empowerment *through* care challenges a rejection of "care" as necessarily oppressive. We emphasise that relationships characterised by Tronto's (1993) elements of care can facilitate individual empowerment by redrawing boundaries of independence and partnership between people accessing support, professionals and the organisations within which they operate.

Alongside a theoretical argument for our approach, we draw upon empirical evidence from two practice-based settings. Both settings demonstrate the importance of relational autonomy, based on Tronto's framework, in realising service imperatives rooted in empowerment. We also draw upon seminar discussion data which demonstrates a pathway to empowerment: beginning with the individual, rooted in dialogue and embedded in whole organisations. Our approach establishes fresh ways for disabled people and services to work together in establishing innovative approaches to support and relationships at all levels of services.

Key Words: Empowerment; Social Model of Disability; Ethic of Care; Interdependence; Partnership; Health and Social Care Services.

<u>Résumé</u>

Empowerment par le « care » ? Redessiner les frontières de l'indépendance et du partenariat entre les personnes handicapées et les services d'aide et de soin en faisant dialoguer les conceptions du modèle social de l'empowerment et une éthique du « care »

L'approche que nous proposons – l'empowerment par le « care » – est issue d'un souci de faire dialoguer une conception de l'empowerment fondée sur un modèle social et une éthique du « care » soutenue par la conception du « care » de Tronto. Tout en maintenant que l'empowerment s'oppose dans ses principes aux pratiques handicapantes des organisations des secteurs sanitaire, social et associatif, cette approche réfute l'idée que le « care » est inévitablement source d'oppression. Nous insistons sur le fait que les relations caractérisées par les composantes du « care » énoncées par Tronto (1993) peuvent favoriser l'empowerment individuel en redessinant les frontières entre l'indépendance et le partenariat entre les bénéficiaires d'une aide, les aidants professionnels et les organisations dans lesquelles ceux-ci exercent.

La discussion théorique de notre approche s'associe à la mobilisation de données empiriques issues de deux terrains. Ces deux situations pratiques démontrent l'importance de l'autonomie relationnelle, au sens défini par Tronto, dans la mise en œuvre des impératifs d'un service fondé sur l'empowerment. Nous mobilisons également des données issues de discussions en séminaire qui ont conduit à identifier un cheminement vers l'empowerment : débutant par l'individu, celui-ci s'enracine dans le dialogue et s'intègre aux organisations dans leur ensemble. Notre approche propose aux personnes handicapées et aux services de nouvelles manières de travailler ensemble à la création d'approches innovantes de l'aide et de relations qui jouent à tous les niveaux de l'offre de services.

Mots clefs

Empowerment, modèle social du handicap, éthique du care, interdépendance, partenariat, services sociaux et de soins.

1. Introduction

This paper establishes a fresh theoretical and practical approach which redraws boundaries of independence and partnership between health, social care and voluntary sector services and people accessing those services. Our approach – empowerment *through* care - draws upon the social model of disability as a tool (as outlined by Oliver (2004)) for understanding empowerment, and an ethic of care, as defined by Tronto (1993), to acknowledge the significance of "care" in enabling "empowerment". This dialogue conceptualises care as a "*species activity*" (Tronto 1993 p103) through which people engage in interdependent relationships that exhibit Tronto's elements of care, emphasising the role of such relationships in enabling support from services that centres on choice and control for those using services. Our approach challenges understandings of empowerment that position care as disempowering and a source of oppression at the same time as challenging approaches to care that do not focus on empowerment. Whilst we do not dismiss or undermine experiences of 'care' that *have* been, and in some cases continue to be, oppressive or even abusive for disabled people and older people, our approach introduces a fresh way of redressing the power imbalances between disabled people and services.

Therefore, our contribution to this Special Edition on Disability and Care is underpinned by dialogue between specific theoretical lenses within two broader academic fields: the social model of disability as understood by Oliver (2004) (Disability Studies) and Tronto's (1993) framework (Ethic of Care). In developing this approach, we have focussed on two questions:

1. Is there a place for empowerment <u>through</u> care in the context of relationships between people accessing health and social care services and the services they are accessing?

2. If so, does a dialogue between empowerment and care provide a practical and theoretical space through which boundaries of independence and partnership between people accessing services and those services can be re-drawn?

The development of our thinking thus far has taken place in three phases. The initial idea of the potential for dialogue between disability studies and an ethic of care was a response to the tensions identified by the first author when seeking to apply disability studies thinking to the experiences of people living with dementia and older people. This led to a "Conversations in Health and Social Care" seminar at the University of Edinburgh (setting three in this paper) at which empirical examples from research undertaken by the second and third authors (settings one and two in this paper) were presented then discussed by seminar participants, including professionals, people accessing services and academics. Following the seminar we worked together to reformulate the theoretical underpinnings of the approach in line with the discussion of empirical data and data from discussion groups at the seminar.

In this paper we begin by outlining the theoretical understandings of empowerment, care and empowerment *through* care that underpin our approach to this dialogue. We then introduce the three settings and outline the empirical data from them. Drawing together the theoretical perspectives and empirical evidence, we highlight the potential limits of service initiatives that seek to promote empowerment without acknowledging the significance of relationships in facilitating empowerment.

2. Empowerment through care: theoretical underpinnings

2.1. Empowerment

Our theoretical understanding of empowerment in the context of health and social care services is underpinned by applying the social model of disability as a tool (Oliver, 2004) for

understanding the experiences of people with impairments. From this perspective, empowerment is rooted in a standpoint of disability as social oppression (Barnes and Mercer, 2010) and an emphasis on the role of service initiatives in breaking down barriers to physical, emotional and societal inclusion, thus promoting independence and citizenship (French and Swain, 2012). Service initiatives which utilise the social model of disability as a tool for their development focus on self-determination, choice and control, with the views and opinions of service users driving both development and delivery of services, leading to empowerment (Morgan, 2014). Examples of such approaches include personalisation or services which are user-led services, for example Centres for Independent Living (Davis, 1990).

Such an understanding of empowerment does not sit comfortably alongside notions of 'care'. Barnes and Mercer (2006) position the theoretical development of the social model of disability alongside the evolution of social and political challenges to disabling practice in health and social care services. In this context, Morris (1997) conceptualises "care" as inherent within power imbalances between disabled people and services:

One cannot, therefore, have care and empowerment, for it is the ideology and practice of caring which has led to the perception of disabled people as powerless (p54)

Within disability studies, care has also been conceptualised alongside other disabling concepts (for example vulnerability and assumptions that those seeking support from services are a burden) that are *inherently unequal* (Beresford, 2008, p. 9).

A social model approach to empowerment, therefore, positions relationships between disabled people and the services they access as *either* rooted in dependence and powerlessness (which is not desirable) *or* (desirably) rooted in independence and autonomy

that leads to empowerment. This approach suggests that the ultimate position for disabled people would be autonomy rooted in independence.

2.2. Care

By drawing on conceptualisations of care present within ethic of care based discussion (focusing particularly on the importance of interdependent relationships, relational autonomy, and Tronto's (1993) elements of care in both micro and macro level relationships) our approach challenges the social model view of care. In doing so, we do not seek to dismiss or undermine a history of oppression in relationships between health, social care and voluntary sector organisations and those accessing the services at all levels of organisations. Rather, our approach posits that the positive impact of empowerment is facilitated *through* interdependent relationships.

Across the work of many ethic of care theorists (such as, among others, Tronto, 1993; Sevenhuijsen, 1998; Kittay, Jennings and Wasunna, 2005), the conceptualisation of personhood contrasts with the social model perspective outlined above; rather than seeing people as independent individuals, these theorists emphasise that "humans are not fully autonomous, but must always be understood in a condition of interdependence" (Tronto, 1993, p. 162). Building on this, these ethic of care theorists emphasise that autonomy (traditionally seen as including ideas on liberty, self-rule, individuality, independence, responsibility, self-knowledge, freedom from obligation, absence of external causation and knowledge of one's own interests (Dworkin, 1989, p. 54)) must be reconceptualised as 'relational autonomy', defined by Christman (2004) as:

"...what it means to be a free, self-governing agent who is also socially constituted and who possibly defines her basic value commitments in terms of interpersonal relations and mutual dependencies" (p. 143).

This definition challenges the conceptualisation of independence as self-sufficiency while maintaining the importance of independence as self-determinacy (Held, 2006, p. 10; Tronto, 1993, p. 134). Building on this, Holstein, Parks and Waymack (2011) combine relational autonomy with Agich's (1990, 1995) work on different kinds of decision making in order to more fully illustrate the impact of a relational model. Agich (1995) compares traditional 'ideal autonomy' with relational 'actual autonomy', arguing that:

"If actual autonomy and not some disembodied ideal is to be taken seriously, then decision making cannot be restricted to assuring non-coercive decisions but must attend as well to the conditions that enhance [people's] practical capacities to express their developed sense of self" (p. 129).

Drawing on these ideas, our conceptualisation of care includes the way people interact (and care takes place) within this complex relational context, emphasising the facilitation of self-determinacy as conceptualised within ideas on relational and actual autonomy.

To add detail to this discussion of relationships, we utilise Tronto's (1993) specific moral elements through which 'good' caring relationships can be established. The five elements in Tronto's (1993) framework are: *attentiveness* (recognising the needs of others, suspending one's own goals, ambitions, plans of life and concerns in order to recognise the needs of others, p. 28); *responsibility* (looking beyond obligation or legal duty to the importance of caring for those who need support, p. 132); *competence* (provision of care leading to need being met, (p. 133); *responsiveness* (ensuring that care needs have been met from the

² Conceptualised as relational, recognising that people's preferences and desires are bound up with those around them. Rather than the conflict inherent within the nodal/paradigm model, actual autonomy looks at every day negotiation, coordination and accommodation between parties who have a shared history.

¹ Conceptualised as a 'nodal' and 'paradigm' model, where an independent, rational individual makes choices that will fulfil their desires, chooses between options which are clearly delineated and placed in conflict, and ethical dilemmas are often focussed on large, not every day, decisions.

perspective of the person receiving care, p. 108); and *integrity* (the significance of *all* of the above elements interlinking in order for 'good' care to be achieved, p136).

Within our conceptualisation of care, these elements are relevant at both a micro and macro level. For example, at a micro level, rather than focussing on the independence of individuals, ethic of care based theorists such as Kittay and Feder (2002) emphasise that what seems to be independence is actually subject to "invisible or unacknowledged dependencies" (p. 4). By recognising dependency, many ethic of care theorists emphasise that all people have needs and must rely on others to some degree at some point in their lives; need is not an unusual or peripheral case but essential to the very foundation of personhood (Nussbaum, 1992, p. 189; see also Kittay, 1999). By being attentive/responsive to aspects of dependency, the needs and contexts of individuals can be recognised. The elements of care are also relevant at a macro level, as they "direct us to a politics in which there is...a public discussion of needs, and an honest appraisal of the intersection of needs and interests" (Tronto, 1993, p. 167). Tronto (and others such as Knijn and Kremar (1997) and Sevenhuijsen, (1998)) argue for a reconceptualisation of citizenship, where citizens are not viewed as independent, separate actors but interdependent and connected, each attentively, responsibly, competently and responsively recognising their and others care-giving and carereceiving roles and how these change over time. By reconceptualising citizenship in this way, the role of the state shifts to enacting this broader responsibility for care (Tronto, 1993, pp. 177-178). Our conceptualisation of care is, therefore, as attentive, responsible, competent and responsive relationships between individuals, citizens and social institutions.

2.3. Empowerment through care

Drawing together the above theoretical perspectives, our understanding of empowerment *through* care is based on the theoretical stance that, in order for people accessing services to

be empowered, the locus of control within services must remain with the people accessing those services. We also argue that there is a significant role for interdependent caring relationships in realising relational autonomy and so enabling choice and control.

Empowerment *through* care is rooted in the conceptualisation of people as interdependent and, building on Holstein et al's (2011) view of relational autonomy, our approach is based on the idea that shaping care policies and services around actual, rather than ideal, autonomy supports individual empowerment. We also argue that by being attentive/responsive to individual needs, ways of empowering each individual can be explored. Our approach utilises Tronto's elements of care at both the micro and macro level in order to explore the impact of the current social and political context on individual empowerment.

Our approach also builds upon recent work in the context of social and political movements founded on the social model of disability. This work has begun to acknowledge the role of interdependent relationships in realising goals. For example, Chapman and Tilley (2013) apply relational autonomy and an ethic of care to understandings of relationships between self-advocates with learning difficulties and their supporters; Scott and Doughty (2012) apply an ethic of care based definition of care to the mental health peer support movement; and Rummery (2011) explores the relationship between direct payments, empowerment and ethic of care perspectives. We extend these perspectives by creating dialogue about the significance of care in the facilitation of empowerment and for empowerment as a valuable aim for care.

3. Empowerment through care: practical underpinnings

In establishing the practical underpinnings of empowerment *through* care, we draw upon two specific service contexts in which research was carried out by the second and third authors of

this paper (Webber, 2014; Beveridge, 2013). The two service-contexts (one in England (setting one) and one in Scotland (setting two)) represent two distinct policy contexts and approaches to determining the support that people accessing services receive. They were first drawn together in developing our approach at a "Conversations in Health and Social Care" seminar at the University of Edinburgh (September 2013): the third setting in this paper. Below, we outline each of the settings in more detail before presenting data which emerged from them. All three settings provide sites for exploring the extent to which empowerment through care is relevant to service-related contexts.

3.1. Setting One: self-assessment in England

3.1.1. Setting one: policy and service context

Our first example, self-assessment in two English Local Authorities, is drawn from the second author's broader PhD research (Webber, 2014) on social care assessment for older people and family carers in England. This research combined an extensive analysis of New Labour and Coalition social care policy documents with 24 qualitative semi-structured interviews (with older people, family carers, charity workers, care providers and social workers) to explore how assessment of need is supposed to work in England, what the various people involved thought about their experiences of the process, and what insights are offered by an ethic of care. The policy documents and interviews were analysed using Sevenhuijsen's (2004) TRACE framework³. Policy in this context emphasises that service users will be empowered through a focus on independence, choice and control (e.g. DH, 2005; DH, 2008; DH, 2010; DH 2012).

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³ Trace is divided into four stages: tracing the normative frameworks which underlie the text examined; evaluating the values identified; renewing policies or practices by identifying the implications of a shift towards ethic of care perspectives; and concretizing the impact on the surrounding care context.

The analyses of policies and views on self-assessment are drawn out and focussed on in this paper as, in Local Authority One (LA1), the self-assessment tool⁴ was introduced specifically to *empower* individuals (DH, 2010, p.27). Exploring views on this specific tool, and similar self-assessments in Local Authority Two (LA2)⁵, therefore allows us to explore the relevance of our approach.

The views drawn on here are those of six social workers in LA1 and LA2 (LA1/1-LA2/6), two family carers who had completed self-assessments in LA2 (FC3 and FC4), one charity worker in LA2 (PRTC/LA2) and two charity workers who work across LA1 and LA2 (PRTCi and AC1). It is not currently possible to present the views of service users on these self-assessment processes as, at the time of the research, access could not be gained to service users in LA2 and, as LA1 had only just implemented their self-assessment system, the service users interviewed had no experience of this process. It is important, therefore, for future development of our approach to explore whether the views presented below align with the views of service users and carers on self-assessment.

3.1.2. Setting one: evidence informing empowerment through care

All three social workers interviewed in LA1 had significant concerns about the new self-assessment process. They questioned whether service users would complete the self-assessment booklet themselves before the face-to-face assessment and whether a 20 page form is an appropriate response to service users who "come to LA1 in a crisis" (LA1/1).

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⁴ In LA1, the self-assessment tool is a substantial booklet with tick-box sections for the service-user to rate their needs and a small number of open sections for more detailed description. This is sent to service-users to complete before a face-to-face assessment with a social worker. The social worker's assessment is then shaped around a discussion of the answers in the booklet with the service-user and they then add their own assessment of the person's needs in the tick-box section of the form alongside the views of the service user.

⁵ In LA2, there are two different approaches to self-assessment. Service-users complete a 24 page tick-box self-assessment form, although this is then used to decide priority on the waiting list and does not form part of the social worker's assessment of need. In addition, the Princess Royal Trust (PRTC) are funded by the LA to support carers to fill in a self-assessment.

Moreover, LA1/3 stated that it is "unrealistic" to expect people to fill in a "hefty" booklet; while self-assessment is good for those who can "recognise their own needs", the locality social work teams often work with those who may not be in a position to "complete...a massive folder" (for example, those with dementia).

Similar issues with the more established self-assessment system in LA2 were highlighted by charity workers, family carers and social workers. Two charity workers emphasised that self-assessment forms are sent to "completely inappropriate" people (for example, those with "dementia...[or] Parkinson's" (PRTC/LA2 and PRTCi)) and one social worker emphasised that self-assessment would not work as people are "at crisis point" and the form would be "too much for most of the people that we work with" (LA2/4). Three of those interviewed also highlighted that there are practical issues with self-assessment for carers as well as service users; for example, carers are "tired", "stressed" and "so busy with their caring lives that they wouldn't find time to [fill it in]" (PRTC/LA2 and LA2/4). There was also concern that people "don't understand" (LA2/5) the forms; when LA2/6 raised this with those who designed the form she felt that they "don't understand service users... [they] don't realise people don't understand these forms and they don't feel well enough to fill them in...".

In addition to questions about the practical completion of self-assessment forms, those interviewed questioned whether self-assessment identifies needs. Firstly, people may not want to be seen as needy or a burden on others and so may underestimate their needs. For example, AC1 told the story of a lady who is "...going blind, she's quite immobile and she's looking to go into a care home but, because of what she's put on the form, they are not prepared to actually give her that assessment". Moreover, many of those interviewed were concerned about the tick-box nature of the form; for example, LA1/2 was particularly concerned that the rigid, tick-box nature of the booklet would limit her approach and, in LA2, the same form was supposed to be completed in the face-to-face assessments but none of the

social workers interviewed did this, instead highlighting the benefits of not following a strict structure and getting to know the service user.

Alongside criticising self-assessment, many of those interviewed highlighted the importance of face-to-face assessment for both the practical completion of an assessment and for the identification of need (LA1/3, PRTC/LA2, FC3, FC4, LA2/4, LA2/6 and AC1). For example, LA1/3 emphasised the importance of the social work role in supporting people to complete self-assessments and LA2/6 emphasised that, if assessment is solely based on self-assessment:

"...there's an opportunity for...not answering the questions properly or...not...be[ing] aware of your own needs because you haven't had someone to tease them out for you".

These interviews, therefore, raise numerous issues with a self-assessment approach, questioning whether unsupported self-assessment is practically appropriate for all service users and whether needs will be identified. Instead, a more relational approach is emphasised as beneficial.

3.2. Setting two

3.2.1. Setting two: policy and service context

Our second example provides evidence from a CHCP (Community Health and Social Care Partnership) in Scotland i.e. a community service in which previously separate health and social care services are becoming integrated. Policy within this context (Christie, 2011) calls for care services to be built "around people and communities", recognising that people have assets which, if identified and mobilised, can contribute to improved outcomes for individuals as well as for public bodies. Within this setting, our focus is on "Talking Points": a personal

outcomes approach to defining the support that people accessing services receive. The three key elements within a Talking Points approach emphasise the significance of meaningful conversations with service users in determining the support that they receive:

- (1) Engagement with individuals using services and their carers about: what they want to achieve in life; the assets, strengths and abilities they and others bring that can help them achieve this; the contribution of services and supports to help them achieve this; extent to which outcomes are achieved, what has helped and what has hindered.
- (2) Recording of information on outcomes which is primarily gathered though conversations with the individual themselves. Information is recorded qualitatively (in open ended boxes), in language meaningful to the person, and may also be summarised using tick boxes.
- (3) Use of information recorded about personal outcomes to inform decision making within the organisation.

(Cook and Miller, 2012, p. 13).

Empirical data from setting two is taken from qualitative interviews with 5 social workers from adult services within the CHCP carried out by the third author (who is also Acting Commissioning Manager within the service and therefore an "insider researcher") as part of his Master's dissertation (Beveridge, 2013). Qualitative interviews, which lasted between 30 minutes and an hour, focussed on social workers' perceptions of the role of social workers in determining access to services. The contribution of this setting to our emerging understanding of empowerment *through* care is limited by the small sample and, again, future work on the views of service users and carers is crucial. Nevertheless, the inclusion of setting two in our

framework provides evidence of reflections by practitioners within a contrasting policy and practice context.

3.2.2. Setting two: evidence informing empowerment through care

The interview data provides insight into the pivotal role of social work practitioners in determining access to services alongside insight into social workers' understanding of the significance of conversations with families and individuals that enabled families and individuals to be more involved in the decision making process. For example, one practitioner highlighted ways in which social work can become too driven by processes, with processes having stripped people of their assets, rather than "getting into what families are about, and thinking about....what we have got and what we can do [together]" (Practitioner 2). This social worker also spoke about the importance of reflecting, reviewing and monitoring within the family context. Throughout the interviews, the social workers also spoke about the significance of the conversation between practitioners and service users in developing a shared understanding of what was important to the person, alongside the importance of accurately recording this information and reflecting it back to the relevant people. Examples of (what was considered to be) good practice included developing a record of what the family and the person is saying, in order to determine the support that a family receives, continually checking how the practitioner had interpreted their situation and giving opportunities for families to contribute to and comment on the content of the assessment.

In this role, the practitioner is sharing a platform of power and control; they are not determining the outcome, but rather seeking to understand and reflect accurately from the person's perspective. It was clear throughout the interviews that the social workers accepted the value that the contribution of the carer and the person can have. For example, one notes: '...if people are involved in their assessment it is more likely to work than if they have not'

(Practitioner 1). Practitioners who were interviewed also referred to the need to reflect, to share practice within teams, and to account for decisions within the practice framework.

The social workers interviewed were keenly aware of how previous approaches to their role which focussed on the service, had led to a formulaic approach to working with people.

Consequently care was viewed as something negative and the experience of social work became mixed, both for the worker and the client. Using the Talking Points approach to refocus assessments on the core skills of listening, reflecting and planning has, as one practitioner (Practitioner 2) recalled, allowed the social workers interviewed to focus on the things that matter to people:

"...this service led culture - took social work away from its core essence of what they are there for, which is about good assessment, listening to people, hearing where that person is at, and what they still want to achieve in their life and how can we support them to get it in a way in which they have as much power as they can".

Those interviewed highlighted the importance of dynamic and multi-faceted relationships in identifying desired outcomes and ways to meet them. The data from this setting also highlights the impact of approaches to defining the support that people receive that are service-led vis a vis approaches to assessment that are led by a relationship through which practitioners seek to explore possibilities starting from the perspective of the person accessing services.

3.3. Setting three: Empowerment through Care Seminar

3.3.1. The Context

Held in September 2013, the seminar (which was one of a series of seminars exploring current issues in health and social care) began with a presentation from the first author

"Empowerment and Care: tensions and opportunities for dialogue". This was followed by presentations from the second two authors, focusing on empirical data from settings one and two (above). These examples, and examples from the seminar participants' own experiences, were then discussed in small groups. There were eight groups of 6-8 people, each led by an experienced facilitator who ensured everyone had opportunity to express their views and opinions. People were assigned to groups before the event based on their role/organisation in order to ensure a mix of perspectives within each group. Participants represented: the health sector (including NHS Lothian and Greater Glasgow and Clyde NHS); city councils (including Edinburgh, Glasgow); people who were accessing services; carers; the voluntary sector (including Keys to Inclusion, Marie Curie, Health in Mind and Places for People); the Scottish Government; JIT (Joint Improvement Team) Action Group; IRISS (Institute for Research in Social Science) and academics (from the Universities of Edinburgh, Strathclyde, Dundee, Napier, Queen Margaret and the Open University).

The groups discussed four questions:

- 1) What does effective care that is empowering look like?
- 2) How do we promote care that is empowering?
- 3) What structures enable care that is empowering?
- 4) What are the barriers and threats to care that is empowering?

The data we present in this setting is from post-it-notes on which all participants were asked to write their individual answers to these questions and facilitators' notes from the group discussions. All data was anonymous at point of collection, so we do not attribute the views expressed to specific roles/organisations.

Following the seminar, the data collected from all of the groups was collated based on the four questions outlined above. A content analysis based on word frequency revealed the most

common words used in answering each of the questions. For example, the most common words used in identifying barriers to care that is empowering were *resources*, *assessments* and *services*. The most common words used in identifying effective care that is empowering were: *person*, *needs* and *relationship*. Following this, further thematic analysis of answers to each of the four questions took place. Below, we summarise key themes within each of the four questions before outlining the themes across the discussion data.

3.3.2. Setting three: insight into empowerment through care

In response to question one (what does effective care that is empowering looks like?), the discussion focussed on three areas. Firstly, effective empowering care starts with the person at the centre; "beginning with understanding the person and their needs", it is "assets and strengths based" and "looks at the whole context". Secondly, the significance of partnership and dialogue was identified: "which everyone contributes to (collaborative, all stakeholders involved)"; and "with a shared language and equality of contribution". Thirdly, participants identified organisational factors, with an emphasis on a culture that supports the approach: "that is enabling and empowering"; "that makes effective use of resources"; that "sees it as an ongoing process"; and "that is flexible".

Question two, which asked how ways in which care that is empowering can be promoted, also focussed on the importance of discussion, including the significance of "honesty", "with involvement of a broker if needed". Participants also identified values that they felt should occur alongside a focus on empowerment of the service user. Such values could facilitate empowerment: "listening"; being "accountable to all involved"; "valuing all involved – staff, service users, carers"; "care as a societal responsibility"; and "respect". As with responses to question one, the answers to this question highlight the need to begin with the person ("increase aspirations"; "provide information in order to make choices") and the systems and

structures that are needed ("flexible and open to change" "Involving ALL stakeholders: Service providers; carers; service users"; "education and training available to all"). A further aspect of practice that was highlighted in response to this question was creativity and learning from innovation: "responding to change"; and "being ready to take risks".

Question three provided an opportunity to discuss the systems that enable care that is empowering. The data reflects the need for the whole system to be engaged and invested in the approach; a "co-productive approach, including support for staff and promoting teamwork and including commissioners and regulatory bodies" with "stronger links between frontline staff and commissioners" including "supervision and reflective practice" and with "clear pathways". Participants also discussed the significance of up-to-date IT (Information Technology) and information systems at the same time as allowing space and time for conversations to happen: "Less 'tick boxes'"; and "open and honest dialogue about what needs to change".

The final area covered within the discussion (barriers and threats to care that is empowering) identified three areas within services which could undermine empowerment through care. Firstly, participants noted the potential impact of a lack of resources: "lack of time (e.g. to do an effective assessment)"; and "lack of support for staff" or "workload/pressure". Secondly, a lack of relationships was highlighted as a potential barrier, for example: "lack of time to listen"; and "rigid approaches to assessment = barrier to more relational working". Thirdly, there were concerns about the lack of a whole systems approach: "lack of wider debate/ discussion about care, organisational/cultural values and the role of different groups in the process"; "top-down approaches"; "culture which does not acknowledge approach e.g. "needs led"; and a "lack of creativity in approach".

Drawing on our analysis of answers to all four questions, the key aspects of the nature, role and impact of empowerment *through* care can be identified; according to a range of health, social care and voluntary sector organisations, service users, carers and academics, empowerment *through* care locates the person who is using services as the central focus within a whole system and culture (both organisational and societal) that emphasises partnership and dialogue.

4. Discussion

Our understanding of empowerment emphasises the need for support from services that redresses imbalances between service providers and people accessing services, breaking down barriers to inclusion and promoting citizenship. It was convenience and coincidence, both determined by arrangements relating to setting three, that settings one and two have been set alongside each other in the development of our approach. Nevertheless, when the evidence is considered through the approach we outline, all three settings contribute to our emerging framework.

In settings one and two, new tools/ approaches had been introduced which were designed to empower service users going through needs assessment or a personal outcomes focussed approach. In setting one, those interviewed state that the self-assessment process limits the ability of service users to participate in assessments and to identify their own needs. Using our framework, participation, choice and control are crucial to empowerment; therefore, while service users were the focus of the process in setting one, in the views of those interviewed, empowerment had not been achieved. Social workers in setting two emphasised the significance of conversations in reaching a shared understanding of what support would be most beneficial; this approach puts the person accessing services and their carers at the centre while recognising the facilitative and supportive role of the professional. Therefore, in setting two, there is evidence that empowerment (as defined within our

framework) is achieved through a shift towards focusing on the views of people accessing services placed within the context of interdependent relationships between social workers and those accessing services.

Settings one and two also raise the link between empowerment and relationships between professionals, those accessing services and wider services, and this is further seen in setting three. In setting one, those interviewed emphasise the relevance of support to complete the forms and the significance of exploring needs in depth through conversation with another person; the service user's relationship with the social worker therefore enables them to identify their own needs. Those interviewed recognised that, while self-assessment forms are designed with ideal autonomy in mind, supporting people to make decisions within a relational context is more beneficial when identifying need. In setting two the social workers interviewed position the relational approach, which is integral to Talking Points, at the centre of their work. Without this, empowerment rooted in an approach to services which focusses on "getting back to what matters to people using services" (Miller, 2012) would not be realised. Data from the seminar discussion (setting three) sheds further light on these relational processes, establishing a clear pathway for such relationships: beginning with the person accessing services, emphasising dialogue and founded on partnership with everyone involved. In all settings, therefore, it is evident that individual empowerment is facilitated through the recognition of relational and actual autonomy, rather than individualised autonomy.

In addition to a focus on relational autonomy, throughout the interviews there is evidence of the relevance of Tronto's (1993) elements of care (attentiveness, responsibility, competence and responsiveness) at a micro level (i.e. in relationships between people accessing services and frontline practitioners). Within setting one, the importance of recognising dependence and care needs when designing assessment processes that empower service users is drawn

out; both social workers and charity workers note that some service users and carers currently cannot complete the forms and, therefore, do not access services. The social workers were concerned that the service users they work with would not be in a position to complete the self-assessment form alone and that the rigid nature of the form would limit the identification of need. Looking at this through the lens of empowerment *through* care, both the process of self-assessment and the content of the forms are not attentive/responsive to the complex situations and needs of many people who use care services and so it is less likely to lead to empowerment. Similarly, in setting two the social workers identified the need for the elements of care in the context of a relational approach; beginning with a conversation (attentiveness) that then shapes how support from the service is defined (responsiveness leading to competence) that in turn leads to responsibility. Evidence from setting two also highlights the importance of a relational *process* which continually returns to that point of attentiveness through developing a shared understanding which shapes the practitioner's response (competence).

Setting three extends this application of Tronto's framework to a macro level (i.e. in relationships at a wider organisational and cultural level). Those in the seminar emphasised the significance of partnership and a response of whole services and systems in order for micro-level interactions which are caring to be realised. This is also demonstrated in setting one, where the focus on enabling people to present their needs as they see them while unlimited by contextual expectations of independence highlights the need for an attentive, responsible, competent and responsive organisational and societal system.

Above, we have established the significance of Tronto's elements of care in realising empowerment. However, support within services based on these elements does not necessarily lead to empowerment. The significance of *both* empowerment *and* care in our approach therefore emerges. Fine highlights that Tronto's elements of care are "*understood as*"

an active but largely one-way process initiated by the carer...the voice of those who depend on care is invoked in the fourth stage of her approach to care, which concerns receiving care. But this voice is not given clear expression in Tronto's discussion" (Fine, 2007, p. 59). We therefore emphasise the significance of empowerment as an aim of caring relationships which sits alongside the attentive identification of need.

In setting one, while self-assessment aims to give service users a 'voice' in the assessment process, empowerment is not achieved because the tool (self-assessment) was not accessible for all of those undergoing an assessment and it lacks a meaningful relationship between those completing the forms and those who were able to support them, such as social workers. Such a relationship (linked to ethic of care ideas of interdependence and relational autonomy) would empower service users to evaluate their situation realistically, which in turn would lead to identification of needs and, consequently, access to support. The Personal Outcomes approach in setting two is an example of empowerment *and* an ethic of care being positioned alongside each other in identifying support within services. In setting three, the data which sheds light on both the interpersonal relationships and the systems required in order for empowerment *through* care to be realised highlights ways in which empowerment and care work together.

5. Conclusion

In challenging the societal oppression of people with impairments, the social model of disability has underpinned the development of approaches to support that lead to empowerment. Within this paradigm, "care" has been rejected as a one-way process that has the potential to disempower and re-enforce marginalization. Through exploring service contexts that are rooted in empowerment, we have demonstrated that processes of empowerment not only required but were greatly enhanced by an acknowledgement of the

interdependent nature of interaction at all levels of services. Without care, as defined within an ethic of care, processes that were supposed to be empowering have the potential to become disempowering. The approach set out in this paper challenges this rejection of "care" by highlighting the crucial role of relational and actual autonomy in realising empowerment.

Further development of our approach will include on-going application of the developing theoretical framework to service imperatives such as personal outcomes approaches as well as to a range of research contexts, such as design in dementia care environments and peer support. We will also work more closely with people accessing services themselves to develop and consolidate our approach: empowerment *through* care.

References

Agich, G. (1990). Reassessing autonomy in long-term care. *Hastings Center Report*, 20(6), 604–611.

Agich, G. (1995). Actual autonomy and long-term care decision making. In L. B. McCullough and N. L. Wilson (Eds.) *Ethical and Conceptual Dimensions of Long-term Care Decision Making* (pp. 113–136). Baltimore, MD: John Hopkins Press.

Barnes, C., & Mercer, G. (2006). Independent Futures: creating user-led disability services in a disabling society. Bristol: Polity Press.

Barnes, C. and Mercer, G. (2010). Exploring Disability (2nd Edition). Cambridge: Polity Press.

Beresford, P. (2008). What Future for Care? York: Joseph Rowntree Foundation.

Beveridge, K. (2013). Personalisation, Outcomes and an Ethic of Care: the experiences of social work practitioners. Unpublished Master's Thesis: University of Edinburgh.

Chapman, R., & Tilley, L. (2013). Exploring the ethical underpinnings of self-advocacy support for intellectually disabled adults. *Ethics and Social Welfare*, 7(3), 257-271.

Christie, C. (2011). Commission on the future delivery of public services. Scotland: APS Group.

Christman, J. (2004). Relational autonomy, liberal individualism, and the social constitution of selves. *Philosophical Studies: An International Journal for Philosophy in the Analytic Tradition*, 117(1), 143–164.

Cook, A., & Miller, E. (2012). Talking Points: a practical guide. Edinburgh: Joint Improvement Team.

Davis, K. (1990). Activating the Social Model of Disability: the emergence of the seven needs. Derby: Derbyshire Coalition of Disabled People.

Department of Health (2005). Independence, Well-being and Choice: Our vision for the Future of Social Care for Adults in England: Social Care Green Paper. London: Department of Health.

Department of Health (2008). Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care. London: Department of Health.

Department of Health (2010). A Vision for Adult Social Care: Capable Communities and Active Citizens. London: Department of Health.

Department of Health (2012). Caring for Our Future: reforming care and support. London: Department of Health.

Dworkin, G. (1989). The concept of autonomy. In J. Christman, (Ed.). *The Inner Citadel: Essays on Individual Autonomy* (pp. 54-62). New York: Oxford University Press.

Fine, M.D. (2007). A Caring Society? Care and the dilemmas of human service in the twenty-first century, Macquarie University. Dept. of Sociology Macquarie University. Centre for Research on Social Inclusion. Available at: http://hdl.handle.net/1959.14/24831 [Accessed March 23, 2012].

French, S., & Swain, J. (2012). Working with Disabled People in Policy and Practice: a social model. London: Palgrave Macmillan

Held, V. (2006). The Ethics of Care: personal, political, and global. Oxford, New York: Oxford University Press.

Holstein, M., Parks, J. & Waymack, M. (2011). Ethics, Aging and Society: The critical turn. New York: Springer Publishing Company.

Kittay, E.F. (1999). Love's Labor: essays on women, equality and dependency. New York: Routledge.

Kittay, E.F., Jennings, B. & Wasunna, A.A. (2005). Dependency, Difference and the Global Ethic of Long-term Care. *The Journal of Political Philosophy*, 13(4), 443–469.

Kittay, E. & Feder, E. (2002). The Subject of Care: feminist perspectives on dependency. Lanham Md: Rowman & Littlefield Publishers.

Knijn, T., & Kremer, M. (1997). Gender and the caring dimension of welfare states: toward inclusive citizenship. *Social Politics: International Studies in Gender, State & Society*, 4(3), 328-361.

Miller, E. (2012). Individual Outcomes: Getting back to what matters. Edinburgh: Dunedin Academic Press.

Morgan, H. (2014). User-led Organisations: facilitating independent living? In J. Swain, S. French, C. Barnes & C. Thomas (Eds.) *Disabling Barriers, Enabling Environments (3rd Ed)*. London: Butterworth Heineman

Morris, J. (1997). Care or Empowerment? A disability rights perspective. *Social Policy and Administration*, 31(1), 54-60.

Nussbaum, M. (1992). Human Functioning and Social Justice: in defense of Aristotelian Essentialism. *Political Theory*, 20(2), 202-246.

Oliver, M. (2004). The Social Model in Action: if I had a hammer. In C. Barnes and G. Mercer (Eds.) *Implementing the Social Model of Disability: theory and research*, pp18-31, Leeds: The Disability Press.

Rummery, K. (2011). A Comparative Analysis of Personalisation: balancing an ethic of care with user empowerment. *Ethics and Social Welfare*, *5*(2), 138-152.

Scott, A., & Doughty, C. (2012). Care, empowerment and self-determination in the practice of peer support. *Disability & Society*, 27(7), 1011-1024.

Sevenhuijsen, S. (1998). Citizenship and the Ethics of Care: feminist considerations on justice, morality, and politics, New York: Routledge.

Sevenhuijsen, S. (2004). Trace: a method for normative policy analysis from the ethic of care. In S. Sevenhuijsen & A. Svab (Eds.) *The heart of the matter*. (pp. 13–46) Slovenia: Mirovni Institute.

Tronto, J. (1993). Moral Boundaries: a political argument for an ethic of care. New York: Routledge.

Webber, S. (2014). The Lost Elements of Care: an ethic of care and social care assessment for older people and carers in England. Unpublished Doctoral Thesis. University of Bristol.