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Living a 'normal life'? Formal and informal supports in the lives of adults with cystic fibrosis

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Drawing on a small-scale qualitative study of the life experiences of adults with cystic fibrosis (CF) in the UK, this paper explores the formal and informal supports used by the adults to achieve and maintain a lifestyle of their choice. Many adults with CF do not have visible impairments and are faced with deciding to disclose CF so they can claim the formal supports of independent living, or presenting as 'normal' and forfeiting the formal supports which may accompany disclosure. At an individual level, both strategies can offer a route to a 'normal life'. However, wider analysis of independent living and formal and informal supports in the lives of adults with CF is overdue; this paper presents an initial such analysis in the context of the UK coalition government's vision for adult social care and the voluntarism of 'Big Society'.

Keywords: cystic fibrosis; informal support; formal social care support; independent living; models of disability

Introduction

Drawing on a study of the life experiences of adults with cystic fibrosis (CF) in the UK, this paper explores the formal and informal supports which the adults used to achieve and maintain a lifestyle of their choice. These supports approximate to what is understood as 'social care' in the UK where there has been ongoing debate about the escalating costs of social care provision (DH 2010a). Debates of this nature relate to disabled and elderly people in need of daily living support but rarely include the experiences of people with CF. As a result of advances in medical treatments, people with CF are now living longer, yet CF is still mistakenly viewed as a 'childhood illness.' The term 'adults with CF' was originally adopted by adults with the condition to challenge the image of CF as a childhood condition (Kerr 2005). This paper similarly adopts 'adults with CF' terminology and seeks to broaden current debates about adult social care to include the experiences of adults with CF.

Many adults with CF do not have 'visible impairments' and may have a choice about to whom, and under which circumstances, they self-identify as having CF. Whilst disclosure may facilitate the formal supports of independent living (welfare benefits, direct payments, personal budgets, etc.), some of the adults in this study were reluctant to identify as having CF because of fears about discrimination; they chose instead to present as 'normal' and to rely on supports from family and friends.

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At an individual level, both strategies (disclosure and non-disclosure) may offer a route to a 'normal life' for adults with CF. However, analysis of formal and informal supports in the lives of adults with CF is overdue.

Our aim in this paper is to present an initial such analysis in the context of the UK government's vision for the 'personalisation' of adult social care. We begin by briefly reviewing existing research on CF and discussing models of disability and go on to consider findings from the study. Discussion then turns to the 'personalisation' of social care in the UK – the allocation of personal budgets to individual service users for the purchase of social care support (Carr 2010). Finally, we discuss the potential implications for adults with CF of the UK coalition government's promotion of 'Big Society' in which it is envisaged that civil society will play a greater role in solving 'social problems' (Cabinet Office 2011).

Cystic fibrosis

Cystic fibrosis is a genetic condition caused by two affected genes, one being inherited from each parent carrier. It is a complex, long term, fluctuating health condition which primarily affects the lungs and digestive system. Because CF is a progressive condition, as people age CF-related complications such as diabetes, liver disease and arthritis may also develop (Conway et al. 2008). The severity of CF varies between individuals and this individuality is reflected in the amount of treatments needed. In general, the treatment of CF involves a daily routine of physiotherapy, exercise, a high calorie diet to counteract low absorption of food nutrients, the taking of tablets to aid digestion of food and regular oral and intravenous antibiotics to combat frequent chest infections. The development of new treatments, the improvement of older ones and the setting up of specialist CF centres in the UK has meant that the life expectancy of adults with CF has steadily increased (Greenop et al. 2010). As a result, more and more adults with CF are entering higher education, employment, living independently, having long term relationships and becoming parents. Yet, there is little research which explores the lived experiences of adults with CF or the ways in which they achieve a lifestyle of their choice.

The limited research which has been undertaken with adults with CF tends to view difficulties they face in participating in the mainstream of social life purely as a consequence of disease severity and their ability to manage, or 'cope with', their CF (for example, Abbott 2009). Whilst research of this nature provides important information about medical aspects of CF, it gives little insight into the structural, cultural and attitudinal challenges faced by adults with CF when striving to achieve a lifestyle of their choice. When these challenges are examined, a different picture emerges which highlights a range of external barriers which are not 'purely a result of CF' (Edwards and Boxall 2010).

Several studies have examined the role of 'lay carers' (unpaid relatives and friends, some of whom have received training in related medical procedures) in providing support to adults with CF, although this research also has an illness focus. Lowton (2002) found that lay carers routinely performed tasks for adults with CF that were once performed by nurses such as helping to administer intravenous antibiotics when given as home treatment. McGuffie et al. (2008) found similar roles performed by families of adults with CF and other daily tasks such collecting prescriptions, cleaning nebulisers and assisting with physiotherapy. Whilst the findings we describe in the current paper are consistent with these studies, we also

found that adults with CF utilised a range of other supports; these were not purely to assist with the demands of medical treatments but extended also to assistance with daily living tasks (shopping, cooking, gardening etc.) which enabled the participants to achieve and maintain a lifestyle of their choice.

Models of disability

Existing research on CF has tended to adopt an illness-focused epistemological stance, in which the medical condition of CF provides an exclusive focus for the research. Within disability studies, this approach has been broadly conceptualised as the **medical model** where illness is viewed as a temporary organic state located in the individual who is subjected to biomedical diagnosis, treatment and cure; CF however is a lifelong condition rather than a temporary illness. Although CF is incurable, its symptoms are controllable for number of years with daily medical treatments. Without these treatments, the life expectancy of people with CF would be reduced. Because CF is a fluctuating condition, even with daily treatments, people with CF experience times when their symptoms worsen (Greenop et al. 2010). Although the experiences of people with CF are rarely included in disability studies discussions, there are parallels between people with CF and other disabled people who have objected to the medicalisation of their lives and experiences on the basis that 'their impairments, even if they were disease-based, were not amenable to being cured by medical advances' (Oliver and Barnes 1998, 7). In relation to CF however, it is important to acknowledge the vital contributions of medical model approaches in developing new treatments which have extended considerably the life expectancy of people with CF (Simmonds et al. 2008).

In the UK, the dominant paradigm in disability studies, and in much recent disability policy, is the **social model of disability** (Barnes and Mercer 2010). The social model distinguishes between impairment (functional limitation) and disability (socially imposed restriction) and aims 'to switch the focus of attention away from the functional limitations of individuals with an impairment onto the problems caused by disabling environments, barriers and cultures' (Oliver 2009, 45). Thomas (2007, 14) argues that 'chronic illnesses/diseases' are also categories of impairment. The social model does not however distinguish between impairments by type and disabled people whose impairments were less central to the early development of the social model have raised concerns about failures of the model to account adequately for their experiences (Crow 1996). This lack of distinction between impairments is however also a key strength of the model as it provides a unifying statement of political principle and intent which underpins the UK disabled people's movement. Both of these points are of particular relevance to adults with CF whose experiences thus far have not been central to the development of social model ideas; nor indeed have adults with CF been substantially engaged in UK disability politics.

The social model's removal of the causal link between impairment and disability offered an understanding of disablement (restriction of activity) as purely socially imposed. This impairment/disability distinction however has also led to divisions within the disability studies community with some scholars instead favouring **social relational approaches** where disability is understood as a 'gap between individual functioning and societal/environmental demands' (Tøssebro 2004, 4). By not adhering rigidly to the impairment/disability distinction of the 'shorthand' social model, social relational approaches allow for restrictions of activity which do arise

directly from people's impairments and which are not therefore purely socially imposed. One such restriction is what Thomas (2007) refers to as *impairment effects*: 'restrictions of bodily activity and behaviour that are *directly attributable* to bodily variations' (Thomas 2007, 136, emphasis in original).

For many adults with CF, the necessity to integrate essential treatments into their daily lives is an inescapable everyday consequence of living with CF; it is an *impairment effect*, not a socially imposed restriction. Many of these treatments do not take place in hospitals or medical centres but in people's own homes and in workplace or education settings; thus the treatments form an integral part of people's everyday lives. Social model advocates counsel against focussing on individual experiences of illness or medical treatment because, they argue, this detracts attention from the wider social structures highlighted by social model approaches (Barnes 1998). However, because people with CF are frequently viewed as having a 'serious lifelong illness', medical model approaches to understanding and explaining their lives tend to prevail (Pfeffer et al. 2003) and their experiences are rarely included in social model discussion.

Social care

The UK Department of Health (DH 2010b) describes social care as 'a wide range of services that can help people to carry on in their daily lives' and suggests that at 'any one time, up to 1.5 million of the most vulnerable people in society are relying on social care workers and support staff for help.' The boundaries of formal social care service provision are becoming increasingly blurred as some service users now receive a (means tested) 'personal budget' from the local Council which they can use to purchase their own social care support. Because this support can be provided by personal assistants who are direct employees of the service user, or indeed can legitimately be spent on equipment or items other than human assistance, it may not conform to what has historically been understood as formal social care support (Carr 2010).

In order to differentiate between formal and informal social care support in this paper, we initially adopted the following definitions:

> *Formal* social care support consists of publicly funded social care services from local Councils (or other agencies contracted by Councils to provide such services) and/or Direct Payments or Personal Budgets awarded to individual service users by local Councils for the purchase of social care support.
>
> *Informal* social care support consists of support (from family, friends or paid helpers) for which the adult with CF receives *no* public funding. This support extends beyond the demands of medical treatments to assistance with daily living tasks to enable the individual with CF to achieve and maintain a lifestyle of their choice.

However, a recent Department of Health (DH 2010a) policy document suggests a further addition to the social care mix in the form of voluntary schemes such as *Timebanks*, which form part of the Big Society vision for adult social care; for example, projects which 'allow people living far from their relatives to partner with local people in the same position to provide reciprocal care' (DH 2010a, 4–5). Schemes of this nature appear to blur the boundaries between 'formal' and 'informal' social care support.

In addition to the development of personal budgets in social care, it should be noted that personal *health* budgets are also currently being piloted in the UK; our concern in this paper however is with the personalisation of *social care*.

Independent living

The term 'independent living' is rarely used in relation to adults with CF. Whereas UK policy discussion has historically conceptualised disabled people as in need of care, welfare and charity, the notion of independent living used by the disabled people's movement represents a radical challenge to conventional thinking on disability (Barnes 2004). The central principles of independent living are that disabled people should have the same control, dignity, freedom and choice as non-disabled people; independent living is not measured by the number of tasks disabled people can perform without assistance but rather the quality of life they can achieve *with* assistance (Brisenden 1986; Barnes and Mercer 2010).

If disabled people receive assistance with the tasks which they find particularly difficult or time-consuming (for example, washing, cooking, cleaning) this then frees up time and energy for other aspects of independence (for example, employment or social activities). Those involved in UK disability politics are likely to be familiar with this view of independent living and recent policy changes supporting personalisation also promote similar understandings of independence (Carr 2010). Elsewhere however, 'meanings of the concept of independence are often confused and contradictory' with the understandings of those providing personal assistance differing sometimes from those who are in receipt of such assistance (Leece and Peace 2010, 1848).

Methodology

This paper draws on findings from an earlier study which explored the extent to which social and medical models of disability could explain the life experiences of adults with CF. The first author, who herself has CF, undertook all the fieldwork for the original study (Edwards 2007). Conducting research with adults with CF presents challenges, particularly when the researcher has CF. It is acknowledged by health professionals and adults with CF that face-to-face contact should be avoided in order to prevent cross-infection of the bacteria unique to people with CF (Jacklin and Hillyard 1999; CFT 2004). For this reason, the research methods employed in this study had to avoid face-to-face contact between the participants and between participants and researcher. Self-answer questionnaires and telephone interviews were therefore selected; undertaking qualitative interviews by telephone provides data comparable with face-to-face interviews (Sturges and Hanrahan 2004). Vastly increased internet access in the last few years, with 73% of UK households with an internet connection in 2010 (ONS 2010), has opened up a range of virtual research approaches which could be employed today. However, adults with CF, like other disabled people, are more likely than the general population to be living on restricted incomes and to find themselves on the wrong side of the digital divide (DRC 2004).

Following resistance to the study from health service gatekeepers, a self-selecting sample of twenty-three adults with CF were recruited to the study via advertisements in the former Association of Cystic Fibrosis Adults' magazine and through participants passing on information about the study to others they knew with CF.

The sample was not intended to be representative but incorporated diversity in terms of age, gender and age of diagnosis of CF. It should be noted however that CF is uncommon in people of Asian and African decent (Conway et al. 2008) and no-one of that origin volunteered for the study.

Fieldwork was divided into three stages: self-answer questionnaire; first telephone interview; and second (analysis) telephone interview. The initial sample included a diverse group of adults with CF (13 female, 10 male) aged between 20 and 43 from a range of occupational class groups (though it should be noted that the incomes of those from professional occupations were curtailed due to medical retirement or part-time work). The initial questionnaire asked about health and medical treatment, welfare benefits, employment, education, leisure activities and discrimination and also allowed space for participants' own issues. Key concerns raised by the participants at this stage included **support for daily living** and problems caused by **the fluctuating nature of CF**. Twenty-one respondents (13 female, 8 male) were then interviewed over the telephone using topics generated from the initial questionnaire.

Charmaz (2008: 161) argues that 'grounded theory has evolved into a constellation of methods rather than an orthodox unitary approach.' Our study adopted an abbreviated grounded theory approach (Willig 2008): this adhered closely to the coding techniques advocated by Strauss and Corbin (1998) but because of problems recruiting larger numbers to the study (due to health service gatekeepers) theoretical saturation and negative case analysis were not employed. Interviews were tape recorded and transcribed verbatim and data were repeatedly compared, contrasted and reviewed. Through axial coding, codes were refined into categories and core categories eventually identified. However, in the final analysis a decision was taken to deviate to a thematic approach.

To validate and authenticate the findings, the analysis was discussed with ten participants (7 female, 3 male) in the second (analysis) telephone interviews; participants' views on the findings were recorded and then used to further refine the themes in the analysis. In relation to lifestyle choice, the key themes identified were *(a) formal and informal supports*; and *(b) justifying support*. The following section briefly outlines these key findings. Participants' names have been changed.

Findings

(a) Formal and informal supports

An important finding was that *none* of the participants in this study were receiving support which conformed to the definition of publicly funded *formal* social care above. However, analysis revealed a further category of *privately funded support* where participants made arrangements for limited paid support without the involvement of the local Council. Those participants who paid for support were on low incomes (from employment and/or benefits) with little spare money to fund their own support.

Although participants did not receive Council funded support, descriptions of their attempts to achieve lifestyles of their choice resonated clearly with discussions of independent living within disability studies literature (Brisenden 1986; Barnes and Mercer 2010). Informal support had several dimensions: it was about having someone close who 'rates your opinion' when disputes arose with health professionals over treatment options and practical support with daily 'chores' such as

cooking, cleaning and other tasks related to their living accommodation or garden. This practical support was used when fluctuating symptoms were at their worst, but also on an ongoing basis in an attempt to keep symptoms under control, and was provided by parents, partners and church members, as well as through participants buying in help with their own income. Support of this nature was used as a means of conserving energy for employment, study and social activities which were difficult to balance with the impairment effects of CF.

In the absence of such support the health of some of the adults deteriorated because, without assistance with daily living tasks, they were unable to manage exhausting treatments alongside work or study. This resulted in having to make choices between their health and study/work. Kate described how she had to leave home aged 17 years due to family circumstances as the instant loss of parental support quickly brought her lifestyle choice under threat. The main issue for Kate was that without assistance from her parents, managing full time work as well as daily treatments, cooking meals and other daily living tasks was simply too much.

> I actually left home at 17 to live on my own because my father was a heavy smoker. And so, you kind take for granted the fact that when you are at home you have everything done for you. So I found it quite a hard jump going to full-time work, doing everything for myself and so I think my health was put under strain. So I gave up full-time work to concentrate on my physio which helped a lot. My health sort of got better for a while then because I was just concentrating on my physio and stuff and looking after myself.

Pia also found that she required the daily support of her parents to undertake the higher education course of her choice. Like Kate, Pia found balancing the workload of her course with daily treatment requirements and daily living tasks (such as cooking meals and generally looking after herself) too much. Without her parents taking turns to provide assistance with chores, Pia did not believe she would have completed the course. Other participants required support for daily living tasks such as cleaning the house, cutting grass or providing an unofficial 'meals on wheels' service. This was because they had insufficient energy to carry out these tasks themselves – either as a result of undertaking treatments for CF, or because of the effects of the condition itself. Sally described how she found it difficult to balance her treatment needs (which included over three hours of physiotherapy a day) with other daily living tasks such as housework whilst at the same time trying to maintain a social life to prevent her getting depressed. Sally's solution was to employ a cleaner to carry out most of the housework tasks she lacked energy to do herself.

Similarly, George explained how, when he was awaiting a heart and lung transplant and was able to do very little for himself, church members organised themselves on a rota basis to make meals and help reduce his sense of social isolation whilst his partner was at work. Like Kate, George talked about how he had lost the support from his parents once he left home and married. Although he received support from his wife, she worked full time out of financial necessity and was unable, on her own, to provide all the assistance he required.

(b) Justifying support

Social model advocates have argued that definitions of independent living in medical model literature are problematic for disabled people because such definitions place

emphasis upon self-reliance and doing everything for oneself (Swain et al. 2003). Seen in these terms, requiring support to carry out daily living tasks is viewed as 'dependency' rather than a means by which independence can be achieved and overall quality of life improved. Moreover disabled people's assistance from others is often conceptualised in different terms than non-disabled people's use of such assistance, as was reflected in the experiences of the participants in this study.

It seemed that many participants in this study had been influenced by these medical definitions of independence and they appeared to have internalised them. They also tended to measure their additional requirements against the 'normal expectations' of independence and saw the support they required as a 'deficiency' rather than their having differing needs from their non-disabled peers. Many also felt it necessary to justify the support they required. As mentioned earlier, Sally had a cleaner because her condition limited the amount of housework she could do alongside an intensive daily treatment regime. However, rather than using the argument of needing to conserve energy for a social life, Sally justified employing the cleaner on the basis that she disliked housework.

> I have a cleaner who comes in once a month. I know it's just an excuse because I don't like cleaning. They come in and do things. Well they clean the house really.

Pia, on the other hand, pointed to the intense nature of her course and its workload, rather than how, with support, she had successfully completed the course.

> Well it was an intensive course, I probably shouldn't have really done it but it was the fastest way you can get a recognised professional qualification in [high status profession] . . . .

The necessity for many participants to justify their requirements by focusing on something other than CF appeared to have arisen through internalisation of what constituted a 'real' disabled person and an awareness of how wider society might react to disclosure of CF. It was not so much that participants did not see themselves as disabled but rather that they felt they did not fit pre-existing criteria of a 'disabled person' in mainstream society. Moreover, many participants were aware that society did not look favourably on disabled people in general; this appeared to prevent them from identifying with what they believed were 'official' criteria of what constituted a 'disabled person', with many believing that they had to keep up with their non-disabled peers. Pia, for example, worried that her need for support whilst studying might jeopardise her chances of securing employment after her course finished. Consequently she did not tell her tutors about her additional requirements and thus denied herself access to any formal support through official channels. It is not unusual for disabled people to fear disclosing their impairments out of concerns for how it might impact on their life chances (Fuller et al. 2004). Moreover, other participants' stories of discrimination appeared to resonate with Pia's concerns. For example, Michael disclosed his CF to tutors at University and found it was mentioned in employment references provided by them. He felt this went against his securing employment and, more importantly, removed his choice about whether or not to disclose CF to potential employers. For others, obtaining welfare benefits to support their additional requirements was a struggle in itself.

Research for this paper was undertaken prior to the recent change of government in the UK and subsequent 'savings' in disability benefits (DAUK 2011) yet, of the 23 participants in the study, only six were in receipt of disability benefits. Three other participants described having their benefits withdrawn once they reached sixteen years of age and were still fighting to get these reinstated at the time of the research; others had struggled against eligibility criteria which were not compatible with the fluctuating nature of CF. Several participants had chosen not to claim disability benefits, one fearing that if she disclosed CF when claiming benefits, this information would be available to potential employers. Those participants who were happy to disclose CF, found benefits such as Disability Living Allowance (intended to cover personal care and mobility needs) did not cover some of the additional requirements they had. For George and Sally who needed a gardener and cleaner respectively, the support was simply not available through official channels.

The design of the welfare system appeared to militate against participants claiming benefits. Jenny for instance was struggling financially to meet her dietary requirement for a high calorie diet, often innate to survival for people with CF who need to eat additional quantities of nutritious (frequently expensive) food because their digestive system is unable to absorb nutrients as efficiently as people without CF (Greenop et al. 2010). Because Jenny was not 'ill enough' she was unable to obtain benefits to fund the diet she required and without which her health was beginning to suffer as jobseeker's (unemployment) allowance alone was insufficient to cover the food she needed. This emphasis on a certain level of 'illness' was problematic for participants and set up a 'no-win' situation: when claiming benefits they had to demonstrate how 'ill' they were and emphasise the difficulties they had managing on a day-to-day basis, yet because of the fluctuating nature of CF many were not considered 'ill enough' to qualify for disability benefits at the time of assessment. At the same time, when applying for education courses or employment they had to minimise the impairment effects of CF in order to demonstrate that they were 'healthy enough' to work or study.

Where support was lacking, or limited, participants found themselves having to make very difficult choices; for example, giving up work or taking a (lower paid) local or part-time job so that they had the time and energy they needed to look after their health and complete essential treatments (Edwards and Boxall 2010).

The personalisation of adult social care

Direct Payments schemes were introduced in the UK during the 1990s, following legislation permitting local Councils to make payments to disabled people in lieu of services. Personal budgets which have more flexibility were introduced a decade later. Service users assessed as needing social care services can take their personal budget as a direct payment; or leave responsibility for commissioning the services they need with the local authority; or have some combination of the two. This move towards 'personalisation' or 'self-directed support' is also evident internationally (Carr 2010). In the UK, the coalition government's *Vision for Adult Social Care* 'challenges councils to provide personal budgets, preferably as direct payments, to everyone eligible within the next two years' (DH 2010a, 4).

At first sight, the flexibility of personal budgets may appear attractive to adults with CF however, before they can benefit from such flexibility, they have first to

qualify for formal social care support. According to UK Department of Health (DH 2010c, 21) guidance, it is likely that most of the participants in our study would, most of the time, be assessed as having 'low' or 'moderate' rather than 'substantial' or 'critical' social care needs. The same guidance is clear that:

> ... councils should prioritise needs that have immediate and longer-term critical consequences for independence and well-being ahead of needs with substantial consequences. Similarly, needs that have substantial consequences should be placed before needs with moderate consequences and so on. (DH 2010c, 22)

When adults with CF are 'well', formal social care support may be unavailable despite the fact that in order to maintain their health at the level which denies them access to such support, they may need regularly to engage in exhausting treatments, fund their own additional dietary needs, rely on family or friends for support with daily living, or fund this support themselves from limited benefits or employment income.

Social care policy

Welfare policies which distribute resources to those in need require 'administrative definitions' specifying criteria for inclusion (Stone 1984). Disability-related administrative definitions are underpinned by the *medical, relational* and *social* model understandings of disability outlined earlier (Barnes 2003). These definitions can be found in the 'disparate range of legislative provisions' which underpin UK social care and reflect 'the differing policy imperatives and understandings that have been current at various times in the period since 1948' (Law Commission 2011, 1). Whereas earlier legislation such as the National Assistance Act 1948 was based on orthodox medical understandings of disabled people, policy moves towards the personalisation of social care in the UK appear initially to support the 'radical' socio/political interpretation of disability (Barnes 2003). However, these policies need to be viewed in the context of eligibility criteria based on individualised medical model understandings of disability; criteria which may also serve to preclude people who expend considerable time, energy and resources in maintaining their own health.

Recent debates about the failures of universalist welfare policies to accommodate diversity advocate 'sensitising' policies to particular groups' needs through the involvement of those groups in policymaking processes (Imrie 2004; Harrison 2009). 'Such opportunities are based on (policy makers) seeking to understand what groups value, require and need, and of responding to their moral frameworks and social expectations' (Imrie 2004, 301). But just as understandings of disability underpin the policies of nation states, so too do understandings of disability underpin the 'moral frameworks and social expectations' of those individuals and groups who policymakers seek to engage in policymaking processes. If these individuals and groups have internalised 'individualistic' medical model understandings of disability and independence and feel that their need for social care support also has to be justified in medical model terms, there is little possibility of sensitising universalist policies to anything other than the dominant individualised medical orthodoxy (Barnes 2003).

Conclusion

For participants in this sample, the fluctuating nature of CF frequently complicated access to formal supports and placed the adults with CF in a precarious position: to access formal social care support or welfare benefits, they had to demonstrate how 'ill' they were but to access employment and education they had to demonstrate how 'well' they were. Moreover, the welfare benefits system did not cater for their additional requirements (for example, the costs of a high calorie nutritious diet) and left them heavily reliant family and friends. A further related issue was that of 'visibility' and decisions about disclosing CF. Several participants chose not to disclose CF, fearing that this would lead to ongoing discrimination; because of this they had to forgo entitlements to formal social care support and welfare benefits.

Although some adults with CF in the sample were reluctant to identify as disabled, there were clear parallels between the participants' experiences and discussions of independent living in disability studies literature. The UK social model of disability, with its 'shorthand' impairment/disability distinction, does not however highlight 'impairment effects' which, for some adults with CF in the sample, included essential treatments of several hours duration each day. Social relational approaches (Tøssebro 2004; Thomas 2007) do acknowledge impairment effects and appear initially to be more helpful. But when this individual/societal 'gap' is not visible to others, either because the adults choose not to disclose CF because they wish to be seen as 'normal', or as a result of the fluctuating nature of CF itself (which can mask visibility when assessments are undertaken at times of relative 'good health'), social relational approaches can offer only limited insight.

People with CF frequently require continuous, ongoing management of their condition by medical professionals; because of this increased exposure to the medical model they may face greater medicalised barriers. The Coalition government in the UK has emphasised the role of informal supports in Big Society solutions to older and disabled people's increasing needs for social care, but the experiences of the adults with CF in this sample suggest that reliance on informal supports from family and friends may result in further exposure to dominant medicalised understandings of 'normality' and independence and, for some, the internalisation of dominant views of their 'deficiencies'. 'Radical' socio/political interpretations of disability on the other hand emphasise entitlement to support rather than charity and view the problems encountered by disabled people as 'political issues that can only be resolved by deep-rooted structural and cultural change' (Barnes 2003, 21). Although their aspirations in relation to achieving a lifestyle of their choice resonated with ideas about independent living promoted by the UK disabled people's movement, the adults with CF in this sample tended not to see themselves as disabled and had little exposure to UK disability politics.

The findings of this study suggest that there is much work to be done in relation to the failures of the UK social care and welfare benefits systems to accommodate the impairment effects of CF, in particularly the fluctuating nature of the condition. However, people with CF may also need 'stronger' social model approaches and the political force of the wider disabled people's movement in order to counter the overwhelmingly medicalised understandings of CF which prevail not only in medical and social care settings but also in their own homes. In writing this paper, we have identified common ground between people with CF and other disabled people and scope for political allegiances in challenging dominant medicalised understandings

of disability. There are however particular issues pertaining to face-to-face meetings of people with CF (due to the risks of cross-infection) which may have limited their opportunities for politicisation. Vastly increased access to the Internet and Web 2.0 technologies in recent years may now offer much needed opportunities for the political engagement of adults with CF with more 'radical' interpretations of disability and opportunities to identify common experiences and barriers with other disabled people. The need for such engagement is particularly urgent in the face of Big Society solutions which emphasise informal supports and charity at the expense of rights and entitlements to formal social care.

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