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***Title:* Hearing the voices of people with high support needs**

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Abstract

This article draws on findings from a study commissioned by the British charity, The Joseph Rowntree Foundation, to explore the needs and aspirations of older people who for whatever reason require a high degree of assistance. The study explored the personal aspirations of a small diverse sample (n=26) of hitherto un-researched people living in different parts of the UK. Most were over 85 years of age, with varied ethnicity, health status, social care needs, financial status and lifestyle. Many participants were receiving input from statutory health and social care services and were perceived by others and often themselves to have high support needs. Accessible research methods were used to enable participants to specify those factors for well-being most central to their own lives and preferences. The study found commonalities of aspiration in relation to physical, social and psychological aspects of their lives, but also unique descriptions of their individual concerns. In striving to maintain a sense of self worth, participants accepted that some choices were not realistic for them personally. Positive relationships with care-givers were an essential enabler for some. In many cases negotiation has the potential to produce simple and cost-effective ways of addressing individual aspirations and improving quality of life.

Keywords: inclusivity; participation; frailty; voice; well-being;

Abbreviations

Define abbreviations that are not standard in this field in a footnote to be placed on the first page of the article. Such abbreviations that are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

HSN = high support needs

OPHSN = older people with high support needs

JRF = Joseph Rowntree Foundation

Highlights

- Little is known about the personal aspirations of people with high support needs
- People with high support needs are primarily older, but may be younger
- Using a specially modified tool we facilitated discussion about their preferences
- Participants share some aspirations but differ in others
- Negotiation should enable people with high support needs to achieve many wishes

Hearing the voices of people with high support needs

Abstract

The British charity, The Joseph Rowntree Foundation, commissioned a study to explore the needs and aspirations of older people who for whatever reason require a high degree of assistance. The ultimate aim was to develop a model to enable older people to identify and express their needs and aspirations which could be utilized in future research. This article describes how in developing that model, the voices of older people with high support needs were heard, and what they had to say. The study explored the personal aspirations of a small sample of hitherto un-researched people living in different parts of the UK. The twenty-three participants aged over 60, eleven of whom were aged over 85, varied in terms of ethnicity, health status, social care needs, financial status and lifestyle. Many were receiving input from statutory health and social care services and all were perceived to have high support needs. Accessible research methods were used to enable participants to specify those factors for well-being most central to their own lives and preferences. Results included commonalities of aspiration in relation to physical, social and psychological aspects of participants' lives, but also unique descriptions of their individual concerns. In striving to maintain a sense of self worth, participants accepted that some choices were not realistic for them personally. Positive relationships with care-givers were an essential enabler for some. Often negotiation can produce simple and cost-effective ways of addressing individual aspirations and improving quality of life.

Keywords: inclusivity; participation; frailty, voice; well-being;

Introduction

‘High Support Needs’ - A relatively un-researched group

In all societies a proportion of the older population develops a need for a relatively high degree of support, and in ageing societies this can mean large numbers of people. The term ‘high support needs’ (HSN) is used frequently in the UK, particularly in relation to older and very old people, yet as with the term ‘frailty’ (e.g. Rockwood, 2005, Gillear and Higgs 2011) there is no universally agreed definition. In addition to frailty, notions of dependency, the ‘fourth age’, and the ‘oldest old’ have been used partly to identify sub-groups of older people with particular needs (Gillear and Higgs 2010), but much younger people can also have equally high support needs. The term HSN may be emotionally charged, and interpreted in a number of ways by different people. These include: the self perceptions of older people of their ability to undertake tasks and care for themselves; an indication of the effect on family and friends of caring for an older person with specific needs; and the ‘labeling’ given to people whose access to care services is seen as ‘critical’ or costly.

The UK campaigning charitable organisation and research funder, the Joseph Rowntree Foundation (JRF), commissioned a program of research about high support needs, which they defined as:

Older people of any age who need a lot of support due to physical frailty, chronic conditions and/ or multiple impairments (including dementia). Most will be over 85 years old, though some will be younger. Many will be affected by other factors including poverty, disadvantage, nationality, ethnicity, lifestyle etc. Some of the very oldest people may never come into this category (Blood, 2010).

The research program was commissioned following JRF’s analysis of previous research findings (e.g. Bowers et al 2009), which suggested that older people with high support needs are rarely enabled to articulate their wishes and even more rarely have their aspirations met. In a time of policy rhetoric that invites service user and care-giver involvement in policy development, older people with high support needs (OPHSN) have been described as ‘invisible’ insofar as they do not have a high profile nor a loud collective voice in decision-making. They are often portrayed as ‘hard to reach’ because they can be hard to access or interview in some circumstances, especially if confined to their private domestic settings. This situation is exacerbated by the difficulties of enabling some people with high support needs to express themselves: indeed people with certain conditions such as dementia or stroke often are specifically ‘labeled’ as unable to communicate easily. Consequently, and particularly if there is no access to independent skilled advocacy, their care-givers whether professionals or family members, are often assumed to represent their wishes. However this

might mean that the views of the OPHSN, as opposed to those of the care-giver, are not necessarily conveyed and this in itself may engender feelings of frustration and powerlessness.

The research described here therefore sought to consult older people in as wide a range of 'high support need' circumstances as possible, with the aim of producing a model for identifying wants and needs that would be applicable across the range of circumstances, rather than focusing on specific circumstances (such as visual impairment or learning disabilities). The model would capture something of the complexity of individuals' experiences within a framework that would allow people to reflect upon aspects of it, look for means of support towards a better life, and perhaps to consider where compromises might need to be made. The study was approved by The Open University Human Research Ethics Committee. This article describes how, in developing the model described in (anon) we approached the challenge of hearing the voices of people with high support needs. The article first discusses the general research context, followed by the methodology used to facilitate participants expressing their views. It then discusses the study findings in relation to the literature concerning aspects of well-being.

The research context

The lives of people with high support needs are often complex for a variety of reasons. These can include disrupting life experiences and longer-term social circumstances (for example family breakdown; poverty; natural and other disasters). This means that issues of inclusion and exclusion are important in considering the kinds of support that people need, whether conceptualized within paradigms of human rights, citizenship, or consumerism. However with advancing age the increasing tendency towards disabling and other long-term health conditions inevitably means that these figure prominently in support needs. Over the past 30 years much of the research in the UK and elsewhere which has been carried out with people with high support needs has focused on younger physically disabled people. During this period the social model of disability (Shakespeare 1993; Finkelstein 2002) was developed as a counter to the medical model of disability and it has become a reference point for investigating the subjectivities of disability. In this viewpoint the social consequences of impairment are believed to lead to disempowerment primarily because of barriers that might be environmental, attitudinal and structural.

Recently a number of studies in the UK have begun to investigate the everyday lives of both older people and others with high support needs, such as younger people with particular disabilities. Bowers *et al.* (2009) talked with older people who lived in a range of housing with care: residential care homes, extra care housing, or supported living - producing a framework called the *Keys to a Good Life*. At the same time, the Alzheimer's Society UK asked people with dementia to prioritize their quality of life indicators (Williamson, 2010). Researchers in the UK and elsewhere have also worked to involve people who use care services directly as participators in health and social care research (e.g. Toronto Seminar Group, 2005): for example Forbat and

Wilkinson (2008), in interviewing people with both learning difficulties and dementia saw themselves as ‘positioning people with learning disabilities as experts on their own lives and living circumstances’ (p. 7).

Developing a methodology

Following the lead given by these approaches that respect participants as experts in their own lives, and taking on board the stance of most contemporary research in this field which values inclusivity and the social model of disability, we aimed to explore the complexity and individuality of the experiences of people with high support needs by examining specific aspects of their actual lives. In essence this meant talking directly to people who need various kinds of support to sustain a life of reasonable quality, and being open to their ideas about what that meant and what they would like changed, modified or improved.

This was far from a simple task since notions of quality of life, well-being, needs and aspirations in these circumstances can be just as hard to define as the idea of high support needs itself (Bowling 2005). Yet concepts of the nature of ‘need’ underpin understandings of what people in general both need and might aspire to over time. Maslow (1943) and Bradshaw (1972) proposed different hierarchies or taxonomies of human needs upon which many subsequent studies are based. They suggested that the juxtaposition of issues such as accommodation, warmth, companionship, belonging, physical and mental health can be more or less meaningful or important at any one point in time. In discussing here which aspects of such previous research findings the participants in this study validated as resonating with their own experiences, it is important to emphasize the difference in people’s lives, as well as any collective experiences. Values and aspirations also develop and change over time, both for individuals and cohorts. Consequently the principles of aspiration may often be similar within groups, but nuances of detail and appropriate means of delivery will vary according to individual histories and current circumstances.

To encourage conversations in which participants could feel free to voice their own priorities, while at the same time the researchers could maintain a focus on the research themes, we adapted a interview guide tool (Figure1) developed in earlier research to enable older people to talk about their home environment (Peace et al 2006). The adapted ‘Facets of Life’ tool comprises a written disk divided into 7 topic segments. These are:

- self
- decisions about you
- support
- health
- getting out and about
- pleasure
- home
- living arrangements

Other than health which was expected to have high personal salience and complexity for each of these participants, the other topics included specific exemplar prompts. The disk can be turned, allowing the interviewee to select topics in the order of their own choosing and talk about each as much or as little as they wish. Previous research (Peace et al, 2006) had demonstrated how this enabled older participants to have some control over the conversation, without anxiety about going 'off topic' or participants wondering where the conversation was leading. Where participants had significant visual or cognitive difficulties, the researcher read out the prompts. However it was not the aim to make these topic areas drivers of the analysis. Coding of the participants' responses to these topic areas was informed by previous research and literature, and a structured approach to considering aspects of 'environment':

- **physical** – the built and natural environments, and the ageing body (including physical health).
- **psychological** – relating to the mental and emotional state; and
- **social** – relationships, social engagement and cultural interactions.

Individuals' responses to the topic areas on the interview guide tool were thus coded to these three aspects of environment (for example specific health issues might be coded as physical or psychological: descriptions of support or the lack of it might be coded to social, physical, or psychological).

[Fig.1. here]

Accessing participants

The brief was to find a sample of people with a different reasons for needing high levels of support and particularly seek out people whose voices had not been heard in previous research. We strove to include people with dementia and, where possible, people from minority ethnic groups as well as a high proportion of people aged over 80 living in a range of environments and locations. In identifying potential participants we drew on community contacts and our previous experience of working with diverse older people in participatory research (Bytheway, *et al.*, 2007; Peace, *et al.*, 2006; Holland, *et al.*, 2007, 2010). Leads were followed to find individuals with particular issues of co-morbidity, for example visual impairment and mobility issues. Community development practitioners introduced us to members of minority ethnic groups, and members of third sector organizations provided contacts.

Twenty-six people who met our broad criteria of 'high support needs, 'previously not consulted nor researched' and 'hard to reach' were interviewed: they included three younger people aged between 40 and 60 and seven between 60 and 80 where ageing rather than age was a consideration in their experience. This article focuses on the experience of those 23 participants aged over 60 who were residents of Scotland, Wales

and England. These 8 men and 15 women included four people from black and minority ethnic backgrounds and two homeless people. All had complex health conditions: several had physical disabilities, two from birth; one had learning difficulties; and many had a diagnosis of dementia. Five people lived in care homes and four in an independent/assisted living facility: the remaining people were socially and/or physically isolated. Over and above interviews with participants, additional information was gathered from volunteers and professionals working with other people with high support needs in a variety of organizations.

The brief was to contact a small purposive sample of diverse people living in a range of settings rather than to achieve a representative sample. And whilst there are obvious limitations to gathering certain types of factual information from people with cognitive impairments, useful information was gathered about their *perceptions* of their lives at that moment in time, and the value they placed on particular activities or relationships.

Validating and Developing Findings: The ‘Old’ and the ‘New’

The interviews were preceded by a review of previous studies, primarily undertaken in the UK, and theoretical literature relating to the needs and aspirations of older people in general and people with high support needs in particular. From these writings we drew on diverse accounts of significant factors related to well-being, most of which contained various elements of three inter-related aspects of the context, described above, within which people live: physical, psychological, social.

While we acknowledge that physical, psychological and social aspects of life are deeply inter-related, mutually affecting, and in practice often inseparable, nevertheless this differentiation provides a convenient mechanism for discussing aspects of the complexity of real lives. Using these three broad categories sequentially, the following discussion combines a reflection of the present literature with the views and priorities of the participants in this study. Given the size and nature of the sample of participants we purposely do not cite numbers of responses beyond indicative phrases such as ‘many’ or ‘few’. This is to avoid any implied numerical significance in what is essentially a descriptive account of participants’ responses.

Physical well-being

Physical environments in this context include aspects of health effects, mobility, and access to the outdoors as well as the immediate home environment. Much of the care afforded to older people, especially in institutional settings, centers upon an imperative to ensure physical safety and well-being and to manage disability and health conditions that might put an older person (and the institution) at risk: *Safety and security* and a *good living environment* appear in the *Keys to a Good Life* framework (Bowers, *et al.*, 2009). Safety and security may include actual and perceived physical safety, financial security, and emotional security including concerns about security of tenure or continuity of care (Means, 2007). Safety within in the local

neighborhood is important (Peace, *et al.*, 2006; 2011; Peace 2012), and people with disabilities, especially those from minority groups, can feel particularly vulnerable to crime, anti-social behavior or harassment (Neighbourhood Renewal Unit, 2005). A good living environment produces a strong underpinning for security (Williamson, 2010) whereas a poor one can affect physical and mental health, and curtail independence, for example by delaying discharge from hospital (Roberts 2002; McKeown 2007), or limiting movement around or beyond the home). Living conditions and housing arrangements therefore need to be functional, accessible, safe and warm to provide a good environment to maximize independence (Habinteg, 2010). Where they are not, information, support and advocacy are needed to help older people make housing adaptations or consider relocation options (Johnson, *et al.*, 2010). However it is important that people can also get away from their homes from time to time should they so wish: this influences physical (and mental) well-being, enabling social interaction and variety (Holland, *et al.*, 2005; Bowers, *et al.*, 2009) and it can help older people including those with a diagnosis of dementia (Williamson, 2010), to undertake forms of *physical activity*. Active ageing and encouraging good *physical health* in later life are regarded as important within ageing policy, but the evidence is that many older people need support, on their own terms, to improve or maintain physical health, (Bowling, 2008).

Participants in this study confirmed findings that older people with high support needs, like older people more generally, are both aware of and anxious about their physical health. Some of their health problems or disabilities were longstanding, while other problems such as incontinence, memory loss or mobility had developed or been exacerbated as they aged. Many emphasized those aspects of their health which remained good, yet most accepted that other aspects would remain poor, or deteriorate. Declining health was seen as an inevitable part of ageing, though some participants expressed particular concerns about memory loss: for example a retired professor was despondent that his memory appeared to be deteriorating markedly in his early seventies. Others were concerned about reduced functioning in parts of the body earlier than they might have expected. However, most of the oldest participants responded philosophically to what were perceived as inevitable physical change:

One is my knees and the other is the waterworks ... I have to wear nappies and that sort of thing, but it don't bother me that I have to wear them ... you've got to do, you've no choice, life goes on, irrespective of what.

(Male 90)

Many participants were coping with several, often complex, health problems and described how their illnesses or disabilities had impacted on their daily lives. Optimising health seemed to be a complex balancing act for many: the potential of surgery or medication to improve one condition needs to be weighed against the risks, side-effects and short-term impact on living and support arrangements.

1 Compared to health concerns, in this study, issues about environmental
2 safety and personal security were less of a preoccupation. Some participants
3 living in their own homes talked about the anxieties of their families, though
4 they were less concerned themselves: for them, safety related to familiarity
5 with their surroundings especially if, like Denise, they remained in their own
6 home:
7

8 I want to stay where I am; I've been there a long time now.
9

10 Denise, 85, with early stage dementia
11

12
13 For people with visual impairments and mobility problems, familiarity of
14 environment often outweighed the risks of continuing to live in housing that
15 was not fully accessible. For most participants, rather than generalised
16 insecurities about home or neighborhood safety, it was the fear of becoming ill
17 or falling when alone, whether within or outside the home, that was more
18 worrying. Experiences of falling, or just the fear of it, had led some like June
19 and Irene to restrict their movements, and for others such as Millie or Hughie,
20 prompted their decision to move into extra care housing. However, many
21 participants still living in their homes in the community had acknowledged
22 their changing needs, and agreed to have their properties adapted. Since the
23 municipality had installed a walk in shower, Gertrude could now live
24 comfortably on one floor. Participants also suggested other potential
25 alternatives such as getting someone to move in with them, space permitting,
26 or moving out to more suitable accommodation. Gertrude had considered this
27 possibility:
28

29 I say when it comes I would have to accept it, if it comes I'd have to move, but
30 at the moment I'm alright.
31

32 Gertrude, 74, who has osteoporosis and arthritis
33

34
35 But affordability was an important consideration:
36

37 I have my name down for a flat, but I don't want to be poorer than I am here,
38 and selling the house, you see, I've a lot to think about ... I don't want to go in
39 a home.
40

41 Vera, 89, who has dual sensory impairment
42

43 A '*good environment*' was also a physically attractive one which, ideally,
44 allowed some contact with nature, if not any longer with their own garden.
45 Two bedbound nursing home residents expressed frustration that their
46 bedroom windows were too high for them to see out. Like several other
47 participants who had been confined indoors for many years, they missed
48 being able to get *out and about*:
49

50 I've always been an outdoor man ... no I can't get out now.
51

52 Terry, 80, who has severe Parkinson's disease
53

54 I wish I could do my garden, which I can't.
55

Winnie, 89, who has poor vision, some dementia and limited mobility

Thus lack of mobility limited opportunities to get out: for example James missed his weekends at his country cottage, which without ground floor toilet facilities was now inaccessible to him. A number of participants shared an aspiration to go once again to particular places (including, coincidentally, a well known national chain store). Yet the desire to see once familiar places was counterbalanced by a number of concerns. These included: access to and the cost of private or paid for transport; availability of public transport; and mobility issues, which included the problems of physically transporting a wheelchair in a taxi or private vehicle. Most participants just desired occasional changes of scenery and access to nature and the outdoors. Where this was no longer possible, several innovative ways had been found to 'access' the countryside – and participants' memories of it – through the internet or television:

When I was younger I used to go to beauty spots in Wales ...I've found a lot of the waterfalls.....it's bringing back memories of what I used to do

Rob, 50, who has tetraplegia and lives in a nursing home

The emphasis on a 'use it or lose it' philosophy in relation to physical activity for older people, and the idea that that improved physical health can bring other social and psychological benefits, sit alongside perceptions shared by many OPHSN (and others) about the physical limitations that accompany particular conditions. Few participants currently had opportunities to undertake much physical activity or exercise, and indeed few explicitly expressed a desire to do so. Yet several participants did want to receive more support to move around indoors and to access physiotherapy as well as to get outside more

Psychological well-being

The literature describes how, as people age, they worry about cognitive decline. According to a Yougov poll (21.5.12), 63% of UK adults worry about dementia, and indeed the incidence of dementia increases in the population over 85 (Corrada et al, 2010). Susceptibility to other mental health problems including depression and anxiety can also increase with age, while losing independence and autonomy also impacts on older peoples' well-being and self-perceptions (Coudin and Alexopoulos 2010). 'Independence' as a concept varies for individuals and may differ across cultural groups (Gandhi and Bowers, 2008; Moriarty, 2008) but it is fundamental to well being, incorporating aspects of *self-determination for example* in relation to housing, support (Collopy, 1988; Welford, *et al.*, 2010; Leece and Peace, 2010) and decision-making (Ekdahl et al 2010). For some older people retaining control over their daily lives (Bowers, *et al.*, 2009; Potter, 2009) fosters a continuing *sense of self*, promoting certainty, security and self-esteem whilst *adjusting to changing circumstances*. Personal identity and self-esteem are key components of quality of life (Bowers et al 2009 and Williamson 2010). For some it is important to ensure *continuity* between the past, present and

1 future (Bigby, 2004) and individuals may face difficult decisions to balance
2 independence, support and risk, particularly where an older person's sense of
3 self is threatened (Tanner, 2001). Psychological wellbeing is maintained via
4 different strategies, including *humour* to retain control and reinforce personal
5 identity in the face of loss and change. What gives *pleasure* to individuals is
6 highly personal and may change with time and circumstances (Johnson, *et*
7 *al.*, 2010). In response to ageing, people may aim to promote their own
8 mental health and cognitive functioning through undertaking new roles, getting
9 involved in activities and making new relationships. Making sense of your own
10 place in the world may also involve spiritual or religious beliefs, political
11 affiliations or a sense of cultural belonging (Dementia Voice, 2000; Coleman,
12 2011).
13
14

15
16 In this study it was clear that self-determination was indeed central to many of
17 the participants' self-esteem, and it was experienced at different levels. Most
18 expressed a wish to retain their independence:
19

20
21 to keep my faculties, to keep my mental faculties, and to be able to
22 manage as I do now, but of course I won't be able to, I don't think so,
23 as time goes on
24 Sylvie 85
25

26
27 Most found it hard to depend on others, especially friends and younger family
28 members, for practical support: for example those with visual impairments
29 who lived independently nevertheless regretted the support they required to
30 continue to engage with their environment as they had previously..] Vera, with
31 dual sensory impairment and living in her own home, had not been able to
32 access an application for planning permission concerning a neighboring
33 house and thus had been unable to comment on it. In her view, this made her
34 unable to act as any other citizen of the community.
35
36

37
38 Yet despite wanting to hold onto some key decisions, such as where to live,
39 some participants were happy to delegate certain tasks to relatives, or were
40 content with a minimum amount of control, especially in relation to managing
41 finances:
42

43
44 I would rather they did it now, because I don't hear very well, and they could
45 perhaps answer questions quickly, which I can't.
46

47 Winnie, 89, who has poor vision, some dementia and limited mobility
48

49
50 Participants validated previous findings demonstrating how older people
51 invest emotional meaning in objects and places. Remaining in or visiting
52 places with links to the past or displaying objects with sentimental value
53 enabled some participants to remember, share and maintain *continuity* with
54 their past life and identity. Having a sense of self-determination and a strong
55 continuing sense of self seemed to strengthen resilience.
56

57
58 The study also verified the importance of *humour*, which was one of several
59 strategies participants used to express their identity, and for some, a way to
60 convey the 'real me' to other people. Some joked to help them manage the
61
62
63
64
65

challenges that they faced, laughing while saying things like “don’t put me on the roads” or describing falling out of a wheelchair. Not surprisingly different things gave pleasure to different people, with a number of participants specifically citing social interactions as most important. Day centre activities, which gave mental stimulation and a purpose to the day, gave pleasure to some and could provide specific roles for others - for example for Hughie, who enjoyed his role as bingo caller. Being with their family, for those who had descendants gave pleasure to participants, including those with advancing dementia. On the other hand solitary activities such as watching television, listening to music, painting or doing needlework gave satisfaction to others. These activities might also have other connotations: for example James enjoyed preserving some of his old habits, such as going to the theatre.

Some participants described pleasurable or stimulating things that they did to boost their cognitive functioning or mental health. Vera watched travel programs on television and listened to talk shows on the radio. While some participants described feeling bewildered when their circumstances changed - the death of a spouse being particularly difficult - others took on new roles to mitigate feelings of uselessness or depression. For some, emotional attachment and commitment to their church was a central component of who they were and a support as they aged (Jolanki 2009). Hence social activity and sociability were key factors in psychological as well as physical health and well-being.

Social well-being

Previous studies suggest that for most older people, concerns about potential physical and mental ill-health sit alongside a desire for social inclusion as key factors in ageing well (Sharf and Smith 2004). Meaningful social relationships might be with a partner, family and/or friends; face-to-face or long distance; and with places and objects as well as people. For some older people, especially those with high support needs and few family contacts, good relationships with formal care-givers are a crucial element of positive social interaction, encompassing respect for individuality (Blood and Bamford, 2010); friendliness (not necessarily friendship); kindness, reliability and continuity (Potter, 2009). In studies by both Bowers et al (2009) and Williamson (2010), the importance of meaningful personal relationships was emphasized: and for Sherman and Dacher (2005) these included both on-going and new relationships. Regular *social interaction* is conducive to current and future meaningful relationships, and this may involve maintaining some element of a previous social life (Gilroy, 2009) or developing new networks in different settings. Structured opportunities for social interaction can be particularly important for older people who require support to go out and may be at particular risk of isolation (Means 2007). Positive social interaction encapsulates engaging in activities, continuing to *make a contribution* to society, and consequently feeling valued (Gabriel and Bowling, 2004). This means different things to different people: it might for example involve volunteering, club membership, or being a grandparent. Anecdotal evidence also suggests that individuals value the opportunity to undertake small roles in communal life, such as setting the table in a care home, or

1 gardening in assisted living facilities (Blood, 2010). Despite deteriorating
2 physical circumstances older people generally may wish to participate in
3 *cultural activities* (Blood and Bamford, 2010). However there is little research
4 to date about whether and how older people who have high support needs
5 sustain or aspire to such activities.
6

7 In this study, despite diverse personal circumstances and family histories,
8 participants emphasized the importance of meaningful relationships, as in
9 previous studies of older people. The desire and need to have meaningful
10 social contacts was a unifying theme across this sample of people with very
11 different reasons for needing high levels of support. The number, type and
12 depth of significant relationships varied, but almost all the participants
13 reported close emotional relationships with at least some family members and
14 friends. In contrast to a study by Hjalms (2012), in this study actual contact, in
15 spite of warm relationships, was sometimes infrequent or difficult due to
16 geography or access issues, illness, disability, or time pressures. Social
17 interaction appeared to boost participants' self-esteem especially in settings
18 where they felt comfortable, enabling them to laugh, relax and 'be
19 themselves'. But as support needs increased, relationships with partners,
20 family and friends may have changed and *new* relationships developed as a
21 result of participants' increasing support needs. Some described new
22 friendships made within communal living settings or day centers, and most
23 participants valued the organized activities available within community
24 centers, care homes and residential schemes or day care centers. These new
25 contexts could add elements of more frequent if less rooted social contacts,
26 and for those with very little face-to-face interaction with family or friends, an
27 important way to affirm their sociability. The social contacts and activities on
28 offer were particularly important for those living alone, providing mental
29 stimulation and countering boredom and loneliness:
30
31
32
33
34
35

36 I like meeting with people, when I came to the day centre I felt like a new
37 person ... I come here two days a week, the day centre is part of like a family,
38 I relax and I'm comfortable here ... [I come] to communicate with other
39 people, you don't want to stay at home on your own, you want to come and
40 have a chat, and laugh, and do any activities going,I normally does art,
41 craft, it make you felt you're somebody, when you're doing something.
42

43 Gertrude, 74, who receives transport to attend a black elders' community
44 centre
45

46 For those participants who due to frailty or physical limitations were unable to
47 go out, paid care givers were their lifeline: an important source of regular
48 social contact, helping prevent isolation. Given the social benefits of receiving
49 paid practical care, care-givers' friendliness was valued as well as their
50 effectiveness, dependability and continuity. Conversely, inconsistency in
51 support arrangements caused concern, confusion and anxiety.
52
53
54

55 Many participants also wanted to continue *making a contribution* to society
56

57 I want to do some more work, ... voluntary, do some voluntary work ...
58 helping out with tea or something like that or serving customers ...I like to
59 help people out.
60
61
62
63
64
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Jack, aged 73, with learning difficulties and a heart condition, living in sheltered housing

In this, participants were describing a need for social participation that went beyond one-to-one meaningful relationships to embrace a wider social involvement. Several participants volunteered for formal roles in their communities. Sylvie, aged 85, a committee member of a local inter-faith group, also produced theatrical shows despite her own ill health. Whilst often acknowledging the loss of previous communal roles, participants strove to *maintain a cultural or intellectual life*, developing a new interest to give a sense of achievement and increased self-esteem where they could not maintain older roles. Even within this small sample cultural activities ranged widely: making and listening to music; watching and being involved in theatre; having intellectual discussions, using a range of media to keep informed and mentally stimulated. But practical support and encouragement was sometimes required to fulfill such roles, and for some participants a lack of time, vision, or other resources from those who supported or cared for them reduced their opportunities to contribute, particularly where they had hearing or visual impairments or mobility problems. Consequently for some there was a sense of loss of involvement. Yet others did find a different way to be involved. For example some had found alternative ways to maintain contact with their faith communities through newsletters or visits from members of the clergy to compensate for not being able to get to their place of worship. However for some participants these compromises were accompanied by sadness and loss. Since moving to a care home, Terry had to substitute running weekly bingo sessions with more passive pursuits such as making Christmas cards: an adjustment he tolerated rather than welcomed. Several participants missed travelling abroad, and June missed the theatre, which had become physically inaccessible to her:

last time I went with the guild to the theatre it was absolute agony getting up and down from the seats... I like to do all these things, but I just can't ...

June, who is 85 and has limited mobility

Over the years many participants had of necessity adjusted to changing circumstances, including the loss of their partner, adaptations to their home or moving to housing with care or a care home: these were alongside physical changes such as loss of sight and/or hearing, and practical changes in support arrangements. So, for some, this was just another time of transition within the life course. Participants reacted to their need for support in a variety of ways. Some felt the loss of independence keenly; others were philosophical about it and some had found new opportunities as a result. Whilst continuity was valued, and many participants demonstrated considerable adaptability, some felt they required additional support to help them adjust to change.

Discussion

This study corroborated much of the previously available evidence in relation to the values and aspirations of groups of people with specific kinds of high

support needs. It showed that since having high support needs in later life stemmed from a range of circumstances, people in this situation should not be considered as a homogenous group. This is important when considering people described as having 'high support needs'- this is a catch-all description rather than an explanatory category and therefore there can be no single solution to meeting their aspirations. Most participants in this study demonstrated some realism about 'pie in the sky' aspirations, and those which they felt others could actually facilitate. However, most participants emphasized that they were simply living day to day, and hoping that no further deterioration in their physical or mental health would occur (and in some cases, dreading it). While many regretted losing aspects of their old capabilities, many were loathe to impose upon others, even close relatives. The context for this study is the UK, where many of the participants grew up during the Second World War, prior to what they saw as the advantages of the welfare state. Their family and communities experience had for some included poverty or anxiety about access to health services, and they volunteered expressions of gratitude for the services they now received. While these circumstances may be specific to the UK, the gratitude they felt could well reflect the 'inverse satisfaction law' (Bowling 2002) where needy older people are less likely to express dissatisfaction with service.

Similar to previous studies, for many of these participants their primary relationships were with family and long standing friends. But like those interviewed by Cloutier-Fisher et al (2011) many had suffered significant losses and talked about feeling increasingly isolated and in spite - or possibly because - of this, some stressed the importance both of the prospect and the reality of meeting *new* people. Eight participants had no descendants, and several others had none living nearby, and were dependent on paid care-givers. In some cases this led to the development of new relationships of reciprocity, based on the exchange of stories, confidences, and small acts of kindness, with these paid care-givers or with neighbors. Arguably, the likelihood of developing new relationships by people late in life and living with challenging conditions has been underestimated both as a capacity and as a component in well-being. Yet given the centrality of meaningful contacts with others to the social well-being of people who, despite their differences, because of their support needs share some vulnerability to isolation, we would argue that supporting their sociability is fundamental.

A strong sense of self, whilst having to depend on others in some areas of life, was retained by others through making what they considered to be a valued contribution elsewhere: perhaps through caring, volunteering or simply 'getting involved'. Participants had found simple yet creative ways to retain some access to nature, via the internet or television programs about gardening, nature or travel. Some could do these things successfully in spite of significant health problems, but others who aspired to a socially engaged life were not getting the opportunities and support they needed. Often they did not know what was available, or what they could ask for without impacting their relationship with the person who was their key to the outside world. This resonates with Jolanki's findings, from discussions with people aged over 70, which 'suggest that older people's agency and enacting one's agentic

potential involve a balancing act between contrasting and even conflicting experiences and expectations' (Jolanki, 2009, p225). For people with high support needs who do not have frequent contact with family and friends, formal provision for social engagement is essential, reinforcing the need to maintain community centers particularly in times of recession when other opportunities diminish, as well as ensuring reliable and on-going transport arrangements. Supporting people in this situation as they maintain old relationships and forge new ones, wherever they may find themselves, is essential to well-being and a key aspiration.

Just as the concept of high support needs were interpreted in individual ways, self-determination and independence meant very different things to different people, and they were mediated by their individual biographies. 'Independence' might infer managing as many tasks as possible on one's own; remaining in and maintaining one's own home; not imposing on others; or being able to pursue one's own interests. Yet for some, independence did not conflict with consultation or delegation to relatives or other trusted advocates regarding key decisions. Indeed those without this kind of support found making important decisions difficult. Everyday problems were exacerbated by reduced expectations and confidence, or lack of information. It is a salutary reminder that the type of 'choice and control' a person will want is not 'one size fits all'. For example, the current UK policy of offering budgetary control to older people with high support needs is not appropriate for all (Glendinning, *et al.*, 2008; Moran et al, 2012): indeed several participants in this study found this system frightening and complex without the support of others, and felt bludgeoned into making decisions.

This was a small and diverse sample of people with high support needs, many of whom were experiencing several severe health and mobility problems, and a couple of whom were also caring for a partner. In the context of such complexity, and often with limited information about the options available to them and given sparse opportunities, it was far from easy for them to realize aspirations. Compromise rather than positive choice was often their reality: for example losing a view in order to have a room with more space; or leaving familiar surroundings in order to access an appropriate level of care and reduce isolation. The model developed in this study, discussed in depth elsewhere (anon), can provide older people who have high support needs with a structure for identifying and expressing their wants and aspirations as they make such decisions, and a framework to understand the trade-offs and compromises they might need to make.

Conclusions

This study sought to enable people with a variety of conditions and histories to reflect on the findings of recent studies about what they are perceived to need, to see whether such findings resonated with their own aspirations. Not surprisingly, the findings from this small purposive sample has emphasized that just because people have high support needs, they are no more homogenous than any other 'age' or 'disease' specific population. Their disparate histories, social and health circumstances, aspirations and values

are accompanied by very different circumstances that give rise to their need for support. But they shared a desire to make the best of their circumstances and hoped that those people supporting them would take heed of their very individual needs and aspirations. For many participants in this research their lives had not necessarily turned out as they as they would have wished, but some saw this period as a time of transition and adjustment to a more dependent existence. Autonomy and independence could be rather theoretical aspirations, while what really concerned them was getting through the day and maintaining some agency and some sense of self and self worth. Yet though for many, their preferred choices did not seem to be realistic options, there were sometimes simple and cost-effective ways of addressing individual needs and aspirations for improving their lives and bringing in some pleasure and stimulation. Negotiations are key, particularly where independent advocacy is unavailable. For example the life of a person confined to bed might be immeasurably improved by repositioning it to give a better view; and a life-long music devotee might be sustained by occasional attendance at live events. Small niceties can make a huge difference, but they are highly individual and require thoughtful communication and attention to detail: for example tuning and retuning the radio to suit the care receiver's preferences rather than those of the care-giver. Given the centrality of formal care workers in the lives of many people with high support needs, good relationships with care-givers are of even more importance than in most service user/care-giver situations. They can sometimes be an end in themselves in providing positive social interactions and even friendships, but in all cases they need to produce a style of care that is appropriate, effective and respectful. In this way the voices of older people with high support needs may be heard and acted upon.

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Appendix: The facets of life wheel (adapted version)

Source: (anon)

Appendix

Appendix: The facets of life wheel (adapted version)

Source: XX (2011)