# Reading 2 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.

**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 aging 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. Gilleard & Higgs, 2011, Rockwood, 2005) 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 (Gilleard & Higgs, 2010) [ … ].

**Accessing participants**

The brief was to find a sample of people with 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. [ … ]

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 aging 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 [ … ].

**Physical well-being**

[ … ]

Participants in this study confirmed the 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 aging, 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. Optimizing 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.

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

I want to stay where I am; I’ve been there a long time now.

Denise, 85, with early stage dementia

For people with visual impairments and mobility problems, familiarity of environment often outweighed the risks of continuing to live in housing that was not fully accessible. For most participants, rather than generalized insecurities about home or neighborhood safety, it was the fear of becoming ill or falling when alone, whether within or outside the home, that was more worrying. Experiences of falling, or just the fear of it, had led some like June and Irene to restrict their movements, and for others such as Millie or Hughie, prompted their decision to move into extra care housing.

[ … ]

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:

… I don’t watch rubbish on the television, I hate pop music, but there’s some interesting programmes on, like travel and Countryfile and things like that. …

Vera, 89 who has dual sensory impairment

[ … ]

**Psychological well-being**

[ … ]

In this study it was clear that self-determination was [ … ] central to many of the participants’ self-esteem, and it was experienced at different levels. Most expressed a wish to retain their independence:

to keep my faculties, to keep my mental faculties, and to be able to manage as I do now, but of course I won’t be able to, I don’t think so, as time goes on.

Sylvie 85

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

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

I would rather they did it now, because I don’t hear very well, and they could perhaps answer questions quickly, which I can’t.

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

[ … ]

The study also verified the importance of humor, which was one of several strategies participants used to express their identity, and for some, a way to convey the ‘real me’ to other people. Some joked to help them manage the 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 center 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 theater.

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 were 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**

[ … ]

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

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

Gertrude, 74, who receives transport to attend a black elders’ community center

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

Many participants also wanted to continue making a contribution to society

I want to do some more work, ... voluntary, do some voluntary work ... helping out with tea or something like that or serving customers …I like to help people out.

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. While 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 theater; having intellectual discussions, using a range of media to keep informed and mentally stimulated. But practical support and encouragement were 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 traveling abroad, and June missed the theater, which had become physically inaccessible to her:

last time I went with the guild to the theater 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. While 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. [ … ] 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, Kobayashi, and Smith (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, while 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, p 225). 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 was 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. [ … ]

**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 have 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 important 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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