

**What does it mean to be disabled and growing older?:
project report 2018**

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Published version

PLUQUAILEC, Jill (2018). What does it mean to be disabled and growing older?: project report 2018. Project Report. Sheffield Institute of Education, Sheffield Hallam University. (Unpublished)

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Partners for Inclusion

What does it mean to be disabled and growing older?

Project Report

August 2018

**Sheffield
Hallam
University**

This project was commissioned and funded by Partners for Inclusion, Sheffield, 2017 - 2018.

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Acknowledgements

The project would like to thank the participants who gave their time and energy to contribute their experiences. Your enthusiasm was much appreciated.

Jill would like to thank the Partners for Inclusion group for their closer collaboration and commitment to the commissioning, designing, and delivery of this project.

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Forward

Partners for Inclusion came into being through disabled peoples' organisations, disabled individuals, health and social services starting to work together in 2003. The aim was to form a partnership with people who had experience of physical, sensory and cognitive impairments as they were not represented on any decision-making body in Sheffield. From its inception, Pfl has listened to and acted on what disabled people have told us they wanted/felt what was needed, and in 2006 the partnership was the recipient of a national Community Care Award for its innovative way of working.

Pfl's vision was that of disabled people being equally valued, being able to access excellent services and to have full citizenship rights. Since that time, Pfl has had many successes and when people with physical, sensory and cognitive impairments identified a gap in advocacy and information services as an important omission, Pfl set up the Pacesetters Project (delivered by Sheffield Centre for Independent Living) and which has now transformed into services offered by Disability Sheffield. Over the years, Pfl has also contributed to numerous consultations seeking the views of disabled people on a variety of issues, hosted events and delivered disability equality training.

Unfortunately, with the changing landscape in the statutory sector, our erstwhile partners are no longer involved with Pfl so the partnership can no longer function as originally intended. Nonetheless, the remaining community representatives are still concerned with what seems to be the lack of influence and disappearing voice of people disabled people, particularly those with physical, sensory and cognitive impairments.

As a result of this concern, in 2016 Pfl published the report 'Overview of voice and empowerment issues for disabled people – the local and national picture', with the research confirming that disabled people are, indeed, becoming more disempowered, whether it be due to the impact of welfare reform, negative attitudes in society or not having their authentic voice heard.

Likewise, we are concerned that the voice of disabled people who are growing older is not being heard as it is largely missing from the literature and conversations surrounding ageing - the aim of this report is to help rectify this.

Finally, on behalf of Pfl, I would like to thank Jill for her enthusiasm and support for the research, and to all the participants who have given valuable insights into their journey and experiences.

Jacquie Stubbs, Chair, Partners for Inclusion

1. Summary

- Disabled people's experiences of growing older are missing from conversations about what it means to grow older, with rather more focus being on those that acquire impairment during old age.
- There is a wealth of knowledge, expertise and experience about disability and ageing that currently isn't discussed within services, communities and society more broadly, or the research literature.
- This collaborative project with the disabled community representatives of a Sheffield-based partnership Pfl aimed to explore and collate older disabled people's experiences, views, and opinions on issues they felt were important parts of their lives
- 22 people participated in the project through focus groups and questionnaires around
 - The social impact of ageing (thinking about community, isolation, interaction with services)
 - Attitudes and perceptions towards disabled people who are growing older
 - Barriers faced and the experiences of these
 - Sense of identity and community as a disabled person growing older
 - Experiences of services
- The findings of the project were situated around 6 themes:
 - The importance of independence, control, and choice
 - The relationship between disability and growing older
 - Disabled older people as active and contributing
 - Service cliff-edges
 - A wealth of expertise
 - The value of being heard
- The report makes a number of recommendations relevant to services, policy, and social issues found in section 8.

2. Introduction

In late 2017, the disabled community representatives of Sheffield-based Partners for Inclusion commissioned a small-scale piece of research in collaboration with Sheffield Hallam University. The project aimed to explore the voices and experiences of disabled people in the local Sheffield area who were growing older. With many years of lived experience of disability and now entering the period of life in which one was considered to be 'getting older', the group felt that the experiences of disabled people were missing from conversations about what it means to grow older, with rather more focus being on those that acquire impairment during old age. It was felt that there is a wealth of knowledge, expertise and experience about disability and ageing that currently isn't discussed within services, communities and society more broadly, or the research literature.

The project researcher, Jill Pluquailec, began working with the group in September 2017 to plan, design, and deliver a project which would explore themes pertinent to the intersection of both being disabled and growing older. The following report details the evolution and findings of this project along with discussion and recommendations as to recognising and supporting the importance this distinct experience and period of life.

3. Position of the project

Partners for Inclusion, and this research project follow the social model of disability which is concerned with working towards the removal of discrimination and barriers to daily life for disabled people collectively (Oliver, 2004). Rather than focusing on the medical or biological definitions of conditions, impairment, or individual rehabilitation, the focus instead is on the way different parts of society exclude disabled people (Oliver, 2004). To this end, the project sought to work in partnership with disabled people to explore their views and experiences so as to speak back to services, structures, attitudes and social issues. So doing could better enable opportunities to grow older with independence, dignity, control and choice. The project valued the multiple perspectives and experiences of being disabled and growing older, both positive and negative. Recognising that experiences of pain, impairment, and bodily limitations have real impact on people's lives, whilst also recognising the collective experiences of ageing as a disabled person, were a key focus. 'Impairment is

understood as something negative, and positive aspects of aging with a disability are rarely if ever discussed' (Aubrecht and Krawchencko, p. 8). The population, locally, nationally, and internationally, of disabled people who are growing old does not have a single experience nor a unified voice. This project makes a contribution to the voicing of a collection of experiences and views from a group of participants, in the Sheffield locality in summer 2018.

4. Research, policy, and services context

22% of people across the UK reported living with one, or multiple impairments, which increases to 45% for those of state pension age (Family Resources Survey, 2018). What prevalence data does not tell us is the proportion of those older disabled people who have been disabled for all of, or a long period of their lives rather than acquiring impairment due to ageing.

The UK research context of projects exploring the relationship of being both disabled and growing older is sparse, bar the exception of a large project now nearly 25 years old by Gerry Zarb and Mike Oliver in 1993. Their project, 'Ageing with a disability: What do they expect after all these years?' evidenced a dearth of interest in the experiences of growing older as a disabled person in the UK. Oliver and Zarb found that many older disabled people felt that their needs, and even, their very existence, had been overlooked (p.1). Twenty five years later, though this topic has emerged on the research agenda elsewhere internationally (Ricki, 2016; Aubrect and Krawchencko, 2016), in a UK context, it is apparent that research from an experiential perspective is still largely missing. Whilst the significance of this may not be immediately apparent, research trends often act as a mirror to broader social concerns, which makes this absence more pertinent. Disabled people have long evidenced the marginalisation of their experiences from everyday social, cultural, and political issues which it would seem is emphasised further for people from multiple identity backgrounds, such as disabled people who are growing older. Whilst there may be commonalities between many older people and many disabled people, such as accessing health, social care, and other public or third sector services, there are also important differences which as yet are underexplored. Taking seriously the dearth of research literature as an indicator of a broader social dearth in interest and understanding within this field, this project sought to contribute to a body of knowledge that is sorely lacking in a UK context.

The material significance of disabled people's experiences of ageing is an important concern in contemporary, post-austerity Britain. Welfare reforms beginning in 2010 with the coalition government and continuing as a priority of the current government's agenda have been shown to be impacting disproportionately on marginalised groups (United Nations Inquiry, 2016, CRPD/C/15/R.2/Rev.1; Beatty and Fothergill, 2016). Disabled people are more likely to live in poverty (Tinson, Aldridge, Born and Hughes, 2016) than the non-disabled population which the 2016 UN Inquiry found to have been exacerbated and further entrenched due to changes in welfare, social care, and NHS provision.

The Office for National Statistics shows that the population of the UK is getting older with 18% aged 65 and over and 2.4% aged 85 and over (ONS, 2017). Based on the most recent data, the ONS projects the number of people aged 65+ to rise by over 40 per cent (40.77%) in the next 17 Years. By 2040, nearly one in four people in the UK (24.2%) will be aged 65 or over.

The current government policy relating to the economic impact of an ageing population has been high on the public agenda, often conflated with a population seeing an increase in particular acquired impairments such as dementia. Considered one of the government's 'key issues' of 2015, 'Vastly improved life expectancy, one of the great triumphs of the last century, looks set to be one of the great challenges of this one' (UK Parliament, 2015). The narrative of an ageing population as a marker of social progress is a common one with 'successful ageing' often cited as a social victory over nature (Aubrect and Krawchenko, 2016). Where this narrative is less robust beyond a political or policy agenda is when ageing encounters disability. Within the successful ageing narrative, the success comes in staving-off bodily or mental decline, in which disability is positioned as a state to be avoided as long as, or as well as, possible (Rubinstein and de Medeiros, 2015). Thus, disabled people who are growing older are positioned as beyond the bounds of the possibility of successful ageing due to the virtue of their status as already lived with impairment. The risk here, as is explored by this research project is the oversimplification of age and disability as two distinct states serving to marginalise the experiences and voices of disabled people who are growing older (see Cook and Halsall, 2012; Putnam, 2007). This notion paints a picture of both disability and ageing as unrelated beyond the conflation that disability is an inherently negative state and one which the ageing population both individually and through government agendas around social care and fiscal spending, need to avoid.

Instead of this reductive and problematic separating out of disability and ageing, this project explores disabled people's experiences in a way that recognises both the positive and negative aspects of growing older, complications, and contradictions, barriers and creative solutions that people take individually and collectively. As can be seen through discussion of the project findings, disabled people growing older hold a wealth of knowledge and experience that is vital in contributing to discussions about policy, practice, and social issues.

5. Methodology

The project was designed to be as inclusive as possible to a wide range of disabled participants, within the confines of a small project and a short time-scale. It was important to consider issues of access in terms of the methods of data collection used to respond to the project's aims and in keeping with the ethos of Partners for Inclusion and inclusive research design.

The main method of data collection was two separate 90 minute focus groups with participants held at a local city-centre community space. Participants were invited to opt for this method of contribution or to choose from options of completing an online or paper questionnaire, or a telephone interview. It was felt that this range of methods to participate offered the opportunity for people with a variety of communication preferences to take part, and also accounted for participation for those who could not, or preferred not to travel or participate in a face-to-face group.

Participants were recruited through project advertisements circulated by Partners for Inclusion to local community and service contacts known to them. This included local Disabled People's Organisations, local disabled activists, former colleagues and acquaintances. These contacts were asked to circulate the advert through their own communities to reach a broad spectrum of local disabled people. This opportunity sampling was considered the most viable means to advertise the project widely in the local area within the timeframe of the project and maintaining the geographical remit of the Sheffield area.

Neither demographic or impairment data was collected as part of the project in keeping with the principles of social model of disability research - our primary interest was people's lived experience rather than their impairment characteristics or other traditionally classifying characteristics. The only eligibility criteria set was participants self-defining as over the age of 50 and having lived with impairment for 'all of, or a long period' of their life.

In total 22 participants were recruited with 6 taking part in the focus groups and 16 completing either the online or postal questionnaire.

To address the aims of the project the following themes were addressed in focus group scheduling and questionnaire design:

- The social impact of ageing (thinking about community, isolation, interaction with services)
- Attitudes and perceptions towards disabled people who are growing older
- Barriers faced and the experiences of these
- Sense of identity and community as a disabled person growing older
- Experiences of services

6. Data Analysis

The questionnaires were qualitative in design, which means that the questions asked participants about their experiences, views, and opinions were in free-text responses rather than through the gathering of numerical data.

All focus group responses were audio recorded, anonymised, and transcribed so that this data could be analysed alongside the questionnaire respondents. A series of close readings of the data identified initial themes in relation to each of the scheduled questions. From these themes, further close reading drew out the broader themes below which are each now discussed in to relation to the research aim.

7. Findings and Discussion

7.1 The importance of independence, control, and choice

The theme of the importance of independence, control, and choice, recurred throughout the focus groups and questionnaires, perhaps unsurprisingly. The history of disability rights in the UK evidences the experiences of marginalisation disabled people have faced, and continue to face so it perhaps no wonder that resistance to a passive acceptance of oppression was high a priority for many people who participated.

'To be able to be as independent and mobile as possible to not feel totally dependent on others to get out and about. To be viewed as relevant.'

To be 'viewed as relevant' was woven with desires to be treated with dignity and respect about current and future provision of support and care moving in to older life. Being at home, with family, friends, or communities were also significant in this respect.

'That I am treated with dignity and respect; that I can continue to participate in the community.'

'That I will have access to care if/when I need it. That I can get access to medical attention at home if I need it.'

7.2 Relationship between disability and growing older

When asked about the impact of growing older as a disabled person, in keeping with traditionally conceptualisations of ageing being a process of the body and mind, many participants talked of their individual experiences of their own bodies. This included comments about the slowing of the body and mind, aches and pains, needing more assistance to carry out tasks, and having lower energy levels than in younger years. Some participants also thought reflectively about the emotional impacts of growing older.

'I feel more angry and have a sense of time and opportunity stolen. I have more of a sense of urgency.'

'Scary! Immobility comes to all older people but to be disabled at a younger age makes the future very worrying.'

'I feel a greater sense of loss, partly as I am becoming less involved with disabled people's campaigns. I am more aware of loss.'

'Feel wistful about what I took for granted when I was fit. Usual stuff - eyes, hearing and forgetting things but I remain positive in my outlook.'

'I am having to adapt my social groups as my disability progresses, often with people who don't know me and I don't know them. Can feel overlooked in lots of social gatherings, be it access or people not comfortable with me being in a chair.'

Being asked about the impact of growing older inevitably provokes reflective responses upon younger life and upon the potential picture of later life. Disability provided an additional dimension to these examples and responses from other participants. This included fears and anxieties about future living arrangements, care provision and the potential for social isolation. Where this may be an experience shared by many people as they grow older, disabled people in this project spoke of the additional attitudinal and practical barriers they faced in relation to retaining a sense of community and staving off feelings of social isolation.

Large campaigning bodies like the 'Campaign to End Loneliness' are calling for practical, financial, and structural supports at the highest level to reduce older people's experience of loneliness and/or social isolation. This includes the recognition that many older people report feeling trapped in their own homes and are unable to access public transport due to financial, physical, or geographical constraints. In response, the call for providing the means of transport to allow older people to access the places, spaces, and communities which help them feel less isolated is being addressed. However, the experiences of disabled people expressed here and within section 7.3 show that issues of accessible transport are potentially creating additional barriers for older disabled people. Campaigns, services, and policies developed for the benefit of older people need to recognise the differing access needs and requirements of disabled people as a priority.

Others spoke more specifically of how their priorities and responsibilities were changing as they aged,

'Growing older is a little bit enjoyable as I found myself with less of a need to socialise with all my friends and stuff like that my immediate concern is for my children.'

'In some ways I have more freedom with fewer responsibilities in other ways I can do less as I have less energy.'

'Unlimited time to do the things I could not do when working e.g. more holidays and hobbies.'

Participants also spoke more specifically of the attitudinal impact of ageing that they themselves felt, and that they experienced when encountering others,

'I sometimes I wonder if other people view me in a different way. My knees are knackered but my brain is good!'

'I noticed people look straight through aging people as if they are invisible. I feel pushed to the fringes of society.'

'For me it's when people make assumptions. Because of what they see, they automatically assume that I haven't got any brain power and can't make my own decisions.'

'They haven't got the time, so you're just treated as a commodity, aren't you? This is a unit that wants this, this and this doing to it. We'll do this and then we'll move on to the next unit. Probably the answer to the question is it would be nice to be treated as a human being, not just as a unit.'

'In fact in some ways (experiencing the impact of ageing) much less traumatically as I am used to not being 'perfect'.'

These examples suggest that some participants felt there was a disconnect between the way they understood themselves as an ageing disabled person, compared to the way they were perceived by the outside world. This was sometimes also internalised,

with participants choosing to distance themselves from the category of 'old' through various means,

'I've never really had to think of myself as old because I look at lot younger than I am. So people don't know my actual age'

'I've never identified as old either. I've always felt in my mind the same as I did when I was about 45-50 no matter how many birthdays coming up....I just want to prove to myself I can still do things at 70 and after today it's not going to make a blind bit of difference whether it's 70, 80 or 90. It's just another part of my identity. Wife, mother, baby sitter, dog sitter, supporter.....'

'In fact, disabled people, we're the vanguard of improving services for older people as well, particularly in terms of the architecture, buildings, access to places. It's disabled people who got those things happening....It's mostly older people, it makes their life hugely different, and people with pushchairs and other things - done by disabled people, but actually to the benefit of everybody.'

This is perhaps reflective of the wider social attitude of older age as an undesirable state which needs to be staved off as long as possible (thinking back to the earlier idea of 'successful ageing'). It was clear through many of the participants narratives that growing older, for them, was going to remain a continual process of *becoming* older which was accepted to a greater or lesser degree rather than reaching a fixed state of *being* old.

7.3. Disabled older people as active and contributing

Many media narratives around both disabled people and the ageing population centre around a notion of economic burden and/or marginalised groups of people as passive recipients of the welfare state (Henney, 2015; Runswick-Cole and Goodley, 2015). What was quite apparent in the data collected in this project was that disabled people who were growing older were both active and contributing, not only economically, but socially through activism both formal and informal, mentoring, volunteering, and community participants. Their experiences were far from the mainstream narrative of a population to be positioned as benevolent receivers of state care. Below are some narratives that speak to the active contribution older disabled people are making to their local communities.

'Years ago....we wrote a book and the professor of Sociology at Sheffield University said 'you can't do it, you're disabled people'. Anyway, to cut a long story short, he had a massive heart attack and became very severely disabled, and we managed to fundraise the lot and he made it (the book) mandatory for all his students.'

'I felt very uncomfortable about using walking sticks, crutches, and eventually felt very embarrassed about using a wheelchair. The embarrassment soon went to be replaced by anger and frustration at the problems I experienced as a wheelchair user - crap wheelchair provided by NHS, access problems, environmental issues.'

'I'm actually helping people who used to help me, because they've got older and they're struggling with things and now, because I can pass some of my knowledge on, I can't physically help them, but I'm just a help to them. You can see by their facial expressions that because you have enough time to talk to them and not just shoo them off out of the way, that has improved their life.'

'We need to fight back - not just for ourselves, I would argue, but for the generation below us who haven't most of the advantages that we have had being our age - free education; reasonably accessible cheap housing and things like that. Those people coming up who are going to be in debt by the time they're 21, have got almost no prospects. What happens is you're disabled then and there are no services?'

Similarly to the earlier examples of participants reflecting on the impact of ageing and participation in communities, participants also spoke of a sense of frustration or isolation due to access barriers locally,

'Fear that may become more isolated if funding transport becomes more difficult.'

'Have an excellent support system around me but reluctant to go to community events - as a scooter user I worry I can't get in or there is no disabled loo when I get there.'

'It's much hassle to organise going to/ getting to groups/ clubs. Too much paperwork to access a taxi/ door to door bus as need to be a week in advance for booking (with specialist firms/companies). Feel isolated sometimes.'

These examples relate to the following theme about the provision of services for this population.

7.4. Service cliff-edges

The following three examples were given by participants as times in which the ways services understood 'disability' and 'growing older' appeared disconnected and created contradictions and barriers to people receiving the support, services, or access they needed. These were 'cliff-edges' in which people were only able to be recognised by a single service, in a single way.

'When I went to renew my disabled person's bus card and I was told by the woman that I was no longer disabled, I was now old. So I could go out of the place saying, 'I'm cured, I'm cured!!!' After all these years it was so easy. All I had to do was get to be 65, or whatever it is, and I would be made whole again.'

Here, the participant used humour to highlight the flaw in the bus pass system which served the purposes of financial processes (i.e. where the funding for the bus pass was received from), rather than serving, and recognising, its population. The system could not simultaneously recognise one as both disabled, and in need of the affordances of the disabled bus pass scheme, and growing older. This is particularly pertinent for disabled people who are in work beyond the eligibility age for the 'senior' bus pass (currently set at the state pensionable age for females) as if their disability bus pass is no longer provided, they are left without the concession to travel before 9:30am i.e. peak travel times for workers. This creates a contradiction with the narrative of the importance of work, independence, and contribution to the labour market that disabled people are so readily reminded of. A systematic barrier as seemingly mundane as this has real consequences for disabled people who are growing older.

'One issue I've got at the moment, because I'm coming up to 70, everybody has to renew their driving licence at 70. So I filled my little form in and it asked you about medical stuff and had we been informed about this – well yeah etc. Then I had to fill in a medical form that they sent asking questions like when did you last

see your GP about this condition? I can't remember, it was several years ago. When did you last see a consultant? That was my annual review last year. So then I've got a letter saying we think we need to contact the spinal unit. So to me that is discrimination, because I've already said the condition I've had, it's not changed...Nothing has changed, it's not degenerative like motor neurone or anything like that. It's never going to get any better, but hopefully it's stabilised. They already knew about that because it was on my old licence, so why...Why am I having to go through this system?'

Again, here, another participant highlights how a system has been designed and delivered with a narrow view of its population - i.e. at best, a population which has only acquired impairment in their life beyond their last license renewal. As such, this participant was left with additional hurdles to the process of renewing her license in old age due to her status as disabled, despite this already being on record. Whilst many drivers will acquire impairments in their later life, additional bureaucracy and labour (with the potential of needing to arrange and attend appointments) were to be an inevitable part of the process for those who had been disabled all of, or most of their lives.

'One thing that concerns me is that if I end up in a nursing home at some point or heavily dependent on services, neither the system or staff will be able to meet my needs. This stems from being in hospital and staff not knowing how to support me (bad news if I've developed dementia or can't communicate) and asking me to tell them what to do, as well as my previous experience of being a lay inspector visiting residential homes, when I didn't visit a single one that would have been suitable. Hopefully, the day won't come but it is a worry that raises its head now and again and would be a major issue.'

This final example again reflects the potential void in recognising the experiences of growing older as a disabled person but also speaks more broadly to the additional concerns and considerations participants were making in relation to their futures. This particular participant raises the concerns that traditional social care services for older people will not be equipped to cater for her disability-related needs. This speaks back to participants vocalising of the need to maintain a sense of independence, control, and choice about their support and care as they aged.

7.5. A wealth of expertise

Disabled People's Organisations, communities, and individuals are the original 'experts by experience'. This came about as a reaction to the ways the medical profession historically excluded disabled people from decision-making about their care. Many disability rights campaigners, activists, community members and allies have long since adopted 'nothing about us, without us' to remind service providers, policy makers, and broader society that disabled people hold a wealth of expertise. In the arena of ageing, this expertise, whether it be in relation to self-advocacy or dealing with everyday practicalities of navigating a world organised around non-disabled people's needs, was certainly evidenced by the participants in this project.

My background as a teacher involved problem solving for kids who didn't gain anything from the 'normal' education system, so part of my 'identity' changed in to becoming a problem solver for myself, i.e how could I still shower myself, do my hair, maybe a cuppa, hand the washing up to dry, etc. How could I avoid becoming a person who had carers thinking I would just need to be washed, dressed, fed, and put to bed? How could I enjoy doing the majority of things I used to do? So I learned to solve my own problems, and to raise awareness amongst 'professionals' in all sorts of fields, and this led to more and more 'advocacy' type of voluntary work for friends, neighbours, and then complete strangers. I might not be able to do much physically, but I still have a brain that I can use for the benefit of others.'

'So you actually have a huge amount of knowledge and experience from being disabled a long time, which you can then take back and use in a different way for these people who are getting older and have no idea how to cope.... We have, generally speaking, learnt how to deal with that and know the solutions and know the answers... As disabled people, we have had to acknowledge that we're not perfect and therefore getting old, it could be argued, is much less of a problem on an individual level.'

'...with regard to health services and stuff, it's respecting the fact that disabled people, they're the expert on themselves, so while they've got the expertise in whatever it is, which obviously, you know, people need that, but then how you cope with it as an individual might be different. Basically I know what works for me and what doesn't, so if somebody says (...), I'll say I can't do that, because I've either done

it all and experienced it before, or you know how your body works or whatever your circumstances. You get some practitioners who, because they've got the expertise, think they know everything...To me it's respecting that some people do know what they're talking about and you might have been doing the job ten years, but you're not the expert on me, so give me some credence sometimes.'

What is apparent in each of these examples is the creativity and knowledge that participants have used throughout their lives, continuing in to older age, to navigate the social, attitudinal, and practical barriers disabled people face. This knowledge and expertise was now coming in to particular fruition as they entered the period of growing older as being tools for problem-solving and resilience in a world not designed for an ageing population. This was serving as potential emotional and physical resilience to the process of ageing that non-disabled older people may not be equipped with. This expertise and knowledge was of benefit to those around them as they were able to share the resources they had been acquiring throughout their lives to then apply to the experience of growing older.

7.6. The value of being heard

Zarb and Oliver's (1993) study documented the ways in which disabled people who were growing older felt marginalised and excluded; with their very existence often considered overlooked. Resonant throughout our participants responses was a similar theme both implicitly referenced and explicitly stated. This varied from fear and anxiety about the future to a strong sense of advocacy and battle against the barriers they faced, or felt they would face as they aged. When asked what message participants would like to give people about their experiences of growing older as a disabled person there were words of caution,

'You need to beware.'

'You have to stand up for your rights.'

'We need more facilities to be able to support my independent life so I at least feel I am contributing to society and not as some view me as a burden. I am older disabled but I have a wealth of knowledge to contribute, if allowed.'

Alongside this were messages of optimism and activism and a call for a better understanding and appreciation of the value and importance of being heard,

'Growing older is a disabled person is great and my experiences I would like to use to explain to older people to stop perpetuating the myth that older people sometimes lives' in younger people's bodies 'as of this encourages ageism and wrong thinking around growing older. Hopefully my experiences could show all the people who are afraid of becoming a 'disabled person' that there is not so much to fear. Also that medical professionals stop working towards notion of fixing people's bodies when they don't work for example making older people use walking frames when the legs may give under them causing broken legs or hips encouraging further damage to an older person's body.'

'Try and be positive as people will enjoy being with you. Mardy people don't encourage contacts. Don't be afraid to ask for help when you need it.'

'My experiences are valuable. Listen to me.'

'Be kind. Be patient. Try to be understanding. Remember me.'

8. Recommendations

As the findings of this project have shown, there are distinct experiences of being both disabled and growing older that services, policy, research, and society more general are currently not hearing or not addressing. The findings situated around themes of independence, control, and choice, the uniqueness of having a life-long or long-term disability whilst growing older, the cliff-edges people face between services for older people and services for disabled people, and the wealth of knowledge and expertise disabled older people can offer communities, services, and policy makers in relation to their experiences. Taken from these findings, the following recommendations should be of interest to a number of parties including; service providers and commissioners, supporters of disabled older people's daily lives (paid carers, PAs, social care workers etc.), local authorities including social care, NHS professionals, Disabled People's Organisations and local communities.

- 1. Support disabled older people to retain independence, control and choice:** Retaining independence, control, and choice in one's life was an overarching finding of the project. Whether this be in relation to support and care needs or in relation to family life and community participation, disabled older people told us they want access to the means to do this on their own terms.
- 2. Recognise disabled older people as more than the sum of their parts:** Disabled older people want to be recognised as more than the sum of their parts as either simply 'disabled' or 'old'.
- 3. Don't act in silos:** Currently service provision acting in silos does not seem to acknowledge the complexity of ageing for disabled people and the additional needs, assistance, and emotional recognition that this requires.
- 4. Provide accessible means to participate in society:** Disabled older people become frustrated and anxious about interacting with multiple services for everyday tasks which have the potential to either enable or prevent them from living active and independent lives. This ranges from accessing transport to accessible community spaces such as shops and public spaces. If local and national priorities are to reduce older people's experience of social isolation, the

issue of providing accessible means to participate in society are essential for disabled people.

5. **Acknowledge the expertise and knowledge of disabled older people:**

Disabled older people value being treated with respect and dignity, with a genuine recognition of their expertise and knowledge about their own experience, particularly where this informs how they approach ageing and their adaptations to later life. Enabling the means for disabled older people to share this wealth of expertise with practitioners and others in the ageing population could allow people the opportunity to remain active and contributing to their communities.

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