## **OUR VOICES**

# "The experiences of people ageing without children"

### **Foreword**

The <u>Beth Johnson Foundation (BJF)</u> is proud to be working with <u>Ageing without Children (AWOC)</u> on the production of a report that provides a *voice* for people in the UK who are ageing without children. As a national charity dedicated to making the UK age-friendly, the Beth Johnson Foundation works with a variety of key stakeholders and organisations to speak up for the rights of older people, and push for change, at a strategic and practical level, to give everyone the opportunity to enjoy a great later life.

Apparent in this significant piece of work is that many issues related to ageing (e.g. loneliness and isolation, Alzheimer's disease) have garnered considerable attention over the past few years. However, ageing without children remains a topic under reported and under researched. This report raises its profile and begins to address the concerns many people have about the future of/for older adults without children.

Our Voices provides crucial background information on a subject that has received minimal attention in the past by explaining why more people are continuing to enter later life without children and what impact this may have on their care and support. Many people ageing without children believe, and are rightfully concerned, that they will not have anyone to speak for them, or may be ignored or mistreated. As such, many of the quotes and stories shared in this report provide first hand experiences of what it means to be ageing without children in our current society.

A critical question that *Our Voices* raises is how will, and should, older adults without children approach their later years. Evident is the fact that much more needs to be done. Organisations and policy makers working with older people need to recognise that people ageing without children are an increasingly large demographic and that policy, planning and services for older people will need to reflect these societal changes. Potential solutions to these issues have been introduced in this report along with essential suggestions for future research in this area.

Colin Hann Executive Chair BJF Kirsty Woodard Co-founder AWOC

### Introduction

"Our Voices" details the experiences and thoughts of a previously invisible group of older people, those ageing without children. While there has been extensive and widespread coverage of many ageing related issues such as loneliness, dementia, pensions and the pressure on the NHS, ageing without children has received virtually none. How is it possible that there is so little understanding, discussion or consideration of how ageing without children may impact individuals, services for older people and the wider community when 1 in 5 people over 50 have no children?

As many of the stories in this report demonstrate, ageing without children is what could be described as a "wicked problem" (i.e. a problem that is difficult to solve because of incomplete, contradictory, and changing requirements that are often difficult to recognise).

Part of the reason it is a challenging issue to solve, is the lack of widely available detailed data. Statistics are kept on the numbers of women who have not become mothers and this has more than doubled in a generation from 9% to 19%². Unfortunately, no such data is kept on men although it has been estimated by Finland's Population Research Institute to be around 23%³. There are also significant gaps of statistical information on the experiences of people with disabilities and people from black and minority ethnic communities who are not parents. LGBT experiences are slightly better detailed but again there is much more research to be done in this area, specifically in terms of what can be learned around "families of choice". Overall, there is a significant need for more research to fully understand the issue and for that research to be both quantitative i.e. to give a better understanding of the absolute numbers, and qualitative to help us better understand people's lived experience.

The increasing number of people without children in later life is a new issue that previous Governments, certainly not since the implementation of the welfare state in 1948, have not had to consider, but one which current and successive Governments will have to. Pressure on public spending is at unprecedented levels and social care in particular has been hit very hard. Government solutions to this problem have focused on placing greater emphasis and expectations on adult children to care for their parents.

Jeremy Hunt, Secretary of State for Health, in a speech to the Local Government Association in June 2015 called for:

"a wholesale repairing of the social contract so that children see their parents giving wonderful care to grandparents – and recognise that in time that will be their responsibility too".

and Alistair Burt, Minister for Care in an interview with the Guardian stated:

"We're not going to turn overnight into a society where everyone can live in large housing units, but all sorts of things suggest that more people will probably have a mum or dad living with them at some stage in the future"<sup>5</sup>.

<sup>&</sup>lt;sup>1</sup> Rittel, Horst W. J.; Melvin M. Webber (1973). "Dilemmas in a General Theory of Planning

<sup>&</sup>lt;sup>2</sup> Bristol Institute of Public Affairs <u>'Fertility and women's education in the UK: A cohort analysis'</u> by Anita Ratcliffe and Sarah Smith

<sup>&</sup>lt;sup>3</sup> <u>'Europe: time trends and country differences'</u> by Anneli Miettinen, Anna Rotkirch, Ivett Szalma, Annalisa Donno and Maria-Letizia Tanturri 2014 working paper from Finland's Väestöliitto Väestöntutkimuslaitos (The Population Research Institute)

<sup>&</sup>lt;sup>4</sup> https://www.gov.uk/government/speeches/personal-responsibility

<sup>&</sup>lt;sup>5</sup> http://www.theguardian.com/society/2015/oct/14/social-care-minister-multi-generational-households-state-costs-old-age

However, there has been no recognition that significant numbers of older people will simply not have children to fall back on. Even for those who do have children it is not always possible, for a myriad of reasons, for these children to provide support and care.

Moreover, society in the UK remains extremely ageist. While sexism, racism and homophobia are deemed unacceptable, derogatory comments and assumptions about older people pass by without remark. Older people are often seen or portrayed as a burden on society, lacking value or importance<sup>6</sup>.

There are also still strong taboos associated with being an adult without children in society. People who have chosen not to be parents in particular face a lot of criticism, and the implication is that they "deserve" anything that happens to them in later life as they should have thought about that before. Even for those who wanted children and were unable to, there is a suggestion that they have no stake in the future, have no interest in what happens to wider society and that they are "less finished, less emotionally complete, and less capable".

Ageing without children therefore is a very a challenging subject to think about because it asks all of us, both those with children and those without, to consider our own expectations about later life, the role we believe that the family and the state should play if we need support, and what plans we have made should we need care and support in later life.

Nevertheless, ageing without children is about far more than thinking about who will provide support, help and care to those without children. As will be seen in this report, people ageing without children say they feel invisible and marginalised, ignored in discussions on ageing and lacking a place in a family orientated society. Many worry about being disconnected from younger generations and that their stories will go unheard especially if they develop dementia in later life. Tackling these feelings of exclusion and prejudice are equally as important as the practical aspects around support and care.

This report is not meant to be a formal exhaustive piece of research; rather it gives room for just a few of the stories of people ageing without children to be heard. However, it is important to remember that there are hundreds of thousands of people ageing without children whose stories are not being listened to.

It is time that we all started to hear them.

<sup>&</sup>lt;sup>6</sup> http://www.theguardian.com/society/2014/nov/12/ageing-without-children

<sup>&</sup>lt;sup>7</sup> http://www.theglobeandmail.com/life/parenting/why-childless-people-are-persecuted/article12005541/?page=all

## **About Ageing Without Children**

Ageing without Children (AWOC) is a newly founded organisation (2014) targeting people aged over 50 who are ageing without children. It was founded by Kirsty Woodard, Jody Day, Mervyn Eastman and Robin Hadley in response to the growing numbers of people ageing without children and the fact that the issue had been largely overlooked in any discussions, planning and policy on ageing. The organisation has 4 aims:

- 1. To carry out more research into the issues associated with ageing without children to inform policy, practice and planning
- 2. To develop a network of local groups for people ageing without children
- 3. To campaign for issues affecting people ageing without children to be included in mainstream thinking and planning on ageing and challenge the judgements made about them
- 4. To work with other organisations to develop solutions to some of the difficulties faced by people ageing without children

AWOC currently has no funding other than the money kindly given by Beth Johnson Foundation for this report.

### **Context**

Britain is an ageing society with approximately 23 million people over the age of 50<sup>8</sup>. While many people enjoy a long and happy later life, older people can often need care and support to help maintain their independence. This can range from small scale reassurance and social contact to high end personal care. A rise in the numbers of older people has coincided with a time where access to social care has dropped significantly. Age UK and the International Longevity Centre have found that numbers accessing care services have fallen by half a million since 2008/9 (a drop of 30%) while older adults over the age of 80 have risen by 800,000 in the last decade and estimate that approximately 1.86 million people over the age of 50 in England (1 in 10) have unmet care needs – an increase of 120,000 people (7%) since 2006/7<sup>9</sup>.

## Who are the people ageing without children?

AWOC defines people ageing without children as people over the age of 50 without children in their lives either because they have never been parents or because their children have died, they are estranged from them or they live far away. Interestingly, very little data is kept on people ageing without children. Statistics are kept on the numbers of women who have

<sup>&</sup>lt;sup>8</sup> Later Life in the United Kingdom Age UK, December 2015 http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/Later\_Life\_UK\_factsheet.pdf?dtrk=true

<sup>&</sup>lt;sup>9</sup> http://www.ilcuk.org.uk/index.php/publications/publication details/the end of formal adult social care Age UK and ILC. December 2015

not become mothers; this has more than doubled in a generation from 9% to 19%<sup>10</sup> However, no such data is kept on men although it has been estimated that around 23% of men over 45 are without children<sup>11</sup>. 90% of LGBT people are estimated to be ageing without children<sup>12</sup>, of the 11.9 million people with disabilities in the UK, only 1.7 million are parents meaning an estimated 85% of people with disabilities have no children<sup>13</sup>. We have not been able to find any data on the number of older people from black and minority ethnic communities without children which is a huge gap in our knowledge.

Even where we do have numbers, we have very little idea where people ageing without children are in the UK. We do not know if they are spread evenly across the UK or more concentrated in certain areas e.g. cities or in coastal towns with high populations of older people.

Exploring why more people are entering later life without children is vital if we are to fully understand and appreciate the diversity and experiences of people ageing without children.

## **Terminology**

There is still no absolute agreement on which terms to use, and at AWOC we prefer to say "without children" because we believe that people should not have to explain or justify why they are not parents, or why they are parents but their children are not in their life. However, as most discussions around people without children use the terms childfree or childless, it is helpful to define what is usually meant by these terms. People who have chosen never to have children are often described as "childfree" while people who wanted children but were unable to achieve that for a variety of reasons are often called "childless".

#### Childfree

There has been much focus on the greater numbers of women choosing to be childfree but much of this research is focused on women between the ages of 15 and 44. A meta-analysis of women who are post fertile, deemed to be over 45, estimates that 10% of women proactively choose to be childfree<sup>14</sup>. It is not yet known how many of the next generation of women will be childfree but it is likely to be much higher than 10%. Childfree people often face the harshest criticism and judgement about the choice they have made not to have children.

<sup>&</sup>lt;sup>10</sup> Bristol Institute of Public Affairs <u>'Fertility and women's education in the UK: A cohort analysis'</u> by Anita Ratcliffe and Sarah Smith

<sup>&</sup>lt;sup>11</sup> <u>'Europe: time trends and country differences'</u> by Anneli Miettinen, Anna Rotkirch, Ivett Szalma, Annalisa Donno and Maria-Letizia Tanturri 2014 working paper from Finland's Väestöliitto Väestöntutkimuslaitos (The Population Research Institute)

<sup>&</sup>lt;sup>12</sup> Brookdale Center on Aging of Hunter College and Senior Action in a Gay Environment (SAGE) (1999). Assistive Housing for Elderly Gays and Lesbians in New York City: Extent of the Need and Preferences of Elderly Gays and Lesbians. New York: Hunter College and SAGE

<sup>&</sup>lt;sup>13</sup> Liveability Key disability facts and stats

<sup>&</sup>lt;sup>14</sup> Keizer, R. (2010) http://www.nwo.nl/actueel/nieuws/2010/Kinderloosheid+is+zelden+een+keuze.html

#### Childless

The reasons people are childless are many and varied; for some it is for medical reasons but the majority are childless by circumstance. Childless by circumstance people include:

- People who never met the right person they wished to share having a child with
- Being in a relationship with someone who is infertile
- Their partner does not wish to have children
- They felt unable to afford to have a child
- They did not wish to pass on hereditary conditions to their children
- Discrimination we have heard from LGBT people who would have liked to have children, but were unable to do so because of the high levels of discrimination against LGBT people legally and by wider society

For people who wanted to become parents and couldn't, the added grief and emotional trauma can make ageing without children even harder.

### **Bereavement**

We have been unable to find data on how many parents lose their child as an adult; however as life spans increase it is likely that more people may outlive their children. People may lose their adult children through:

- Illness
- Accident
- Suicide
- Murder

Outliving your child goes against the natural order of things and older people whose children die feel isolated and beset by ageist expectations about how they should react to death. It is often assumed that older people whose children die in adulthood do not grieve in the same way as those whose children died whilst they were still young. Compassionate Friends describe is as "discounted grief" and describe common elements such as:

- Being told that they should be grateful their child had lived to be an adult and had a full life;
- Grieving the loss of a relationship with an adult child than has also become a friendship;
- Questioning their own purpose in life now they are no longer a parent;
- Being angry that their child died when they still had so much left to give to the people around them;
- A feeling that the death could have been prevented:
- Feeling pushed aside as focus is on the spouse/partner/children of the person who died;
- Worry for their own future.

<sup>&</sup>lt;sup>15</sup> https://www.compassionatefriends.org/brochures/death\_of\_an\_adult\_child.aspx

"There is a curious social phenomenon in which older individuals are expected to be less grieved by death. Some people assume that previous loss has made you immune to grief or that advancing age means that you are comfortable with death because you are closer to it"

### Peter's story

Peter is 81 and has lived a long and very varied life. He spent 30 years working as a printer in Fleet Street where he ran amongst other things the "tea and whiskey club". After a head injury he took early retirement and with his wife bought a hotel. Sadly his wife died of cancer not that long into their retirement "she never got to enjoy all her hard work". At the same time as his wife had cancer, Peter's son Gary was also diagnosed with the disease. Although they were never close, "we never really hit it off", Peter spent time at the hospital with Gary every day.

After his wife's death, Peter and Gary became estranged and Gary moved to Japan. Peter himself moved to America and remarried and they did not see each other for many years.

By this time, Gary had remarried and then one day he received a phone call from Gary's mother in law to say that Gary was very ill and would like Peter to forgive him for the past. Peter came to England to see Gary and the two were reconciled. Gary's cancer got worse but he hoped to live until the June to see his father again. However sadly he did not. Peter's daughter in law phoned but Gary died before Peter was able to get to England.

Although it was painful, Peter needed to see Gary "I had to go, I had to make sure it was him".

"Gary was 53 when he died; he was cremated in his wedding suit with a carnation in his buttonhole.

"I do my crying on my own, I don't want to cry in a room full of people".

"It's against the natural order to bury your children. What do other people in my situation do?"

#### **Estrangement**

There are parents who have no, or very limited, contact with their children for a wide variety of reasons, some by their choice and some by the choice of their child. Standalone, an organisation that supports estranged adults, estimates that 1 in 5 adults become estranged from their families.

This can particularly affect men who lose touch with their children after separation or being widowed. In the Independent Age Report "isolation: the emerging crisis for older men", 23% of men reported less than monthly contact with their children compared to 15% of women.

<sup>&</sup>lt;sup>16</sup> From "death of an adult child" by Theresa A Rando PhD https://www.trucare.org/wp-content/uploads/2014/04/death-of-an-adult-child.pdf

#### Children who live at a distance

People whose children live a long way away often also consider themselves to be ageing without children as their children are not physically present in their lives.

"My son lives in Australia and my daughter is in Ireland. They do call but it's not like they can just pop round if I need help"

## Role of family carers

The role of family carers is critical in helping older people to live independently for as long as possible. The 'oldest old' are predominantly cared for by their children, whereas married older people predominantly receive spousal care<sup>17</sup>. More than 80% of disabled older people receiving informal care and living in private homes are being cared for, in almost equal measure, either by their adult children or spouse or both of them together. This needs to be considered in the context that not only are more people ageing without children but that the numbers of people living alone is also increasing: 28% of UK households are single person households and over half (51%) of all people aged 75 and over live alone.<sup>18</sup> People ageing without children, who are also single, will be hit by a double whammy in terms of access to informal care.

The most common tasks for carers were 19

- 82% provide practical help such as preparing meals, doing laundry or shopping
- 76% keep an eye on the person they care for
- 68% keep them company
- 62% take the person they care for out
- 49% help the person they care for with financial matters
- 47% help the person they care for deal with care services and benefits
- 38% help with aspects of personal care
- 38% provide physical help

It is important to remember that it is often the little things that keep people independent and that it is exactly this kind of low level support which is becoming harder to access.

"When people talk about children caring for elderly parents, it is all the small pieces of support that are so important, not whether they end up living together with the child caring for the parent."

Time constraints means that we were unable to research the level of care and support provided by nephews/nieces/siblings/cousins, other family relatives and/or friends. However, it is important that this information is identified at a later date for two reasons. Firstly, because when we raise the issue of people ageing without children, people often say that

<sup>&</sup>lt;sup>17</sup>Current and future challenges of family care in the UK Andreas Hoff Zittau/Goerlitz University of Applied Sciences March 2015

<sup>&</sup>lt;sup>18</sup> Households and families Jen Beaumont Edition No: Social Trends 41 Editor: Jen Beaumont Office for National Statistics

<sup>&</sup>lt;sup>19</sup> NHS Information Centre for Health and Social Care (2010) Survey of Carers in Households 2009/10

there will be other relatives to help, and it's important to know to what extent this is true. Secondly because of the widespread use of the phrase "friends and family" when discussing support and care for older people. It is important to unpick whether the reality for older people without children is a network of "friends and family" involved in or interested in their care in the way that policy assumes there are. If the reality of family involvement is in the vast majority of cases spouse/partner and children, then that needs to be acknowledged. Equally, as people age, the role of their friends in providing care and support will change and in the oldest old, the numbers of friends will decrease as people die.

At the moment, no policy document that we can find has a realistic alternative to the assumption that friends and family exist and/or want to be involved in care and support arrangements.

The increase in the numbers of people ageing without children has also led to the rise of the so called "bean pole family". This is when there are increasing numbers of generations within the family still living but with fewer members of each generation<sup>20</sup>. The impact of this is that more people will grow old not only without children but also without siblings and nephews/nieces.

In 'Generation Strain'<sup>21</sup> the Institute for Public Policy Research discuss the growing gap in care between the numbers of older people needing care and the falling numbers of informal carers available to provide it and suggest:

"Most care for older people is not provided by the state or private agencies but by family members, at an estimated value of £55 billion annually. However, as the baby-boomer generation ages, a growing 'family care gap' will develop as the number of older people in need of care outstrips the number of adult children able to provide it. This is expected to occur for the first time in 2017"

The report goes on to highlight that the number of people aged 65 and over without children to care for them will almost double by the end of the next decade and that by 2030, there will be 2 million people over 65 in England without a child to care for them if needed.

The "End of Formal Adult Social Care?" highlights that:

Andreas Hoff Zittau/Goerlitz University of Applied Sciences

March 2015

<sup>&</sup>lt;sup>20</sup> Current and future challenges of family care in the UK

<sup>&</sup>lt;sup>21</sup> THE GENERATION STRAIN COLLECTIVE SOLUTIONS TO CARE IN AN AGEING SOCIETY Clare McNeil and Jack Hunter Institute for Public Policy Research

"Reduced access to formal social care means many are increasingly reliant on unpaid carers including family and friends whose numbers continue to grow. The most up to date and reliable information on informal carers comes from the 2011 Census. This showed a stark increase in the number of carers in England and Wales, from 5.2 million in 2001 to 5.8 million in 201. Women were notably more likely to be unpaid carers than men, accounting for 57.7 per cent of unpaid carers in England and Wales. Women aged 50-64 are particularly likely to take on caring roles – in 2011 nearly 1 in 4 women of this age took time to care for others" 23.

Whether or not people expect their children to care for them in their old age, the reality is that many adult children do and even more importantly, the state assumes and expects that they will.

#### Ming's story

"This is not the life I imagined, or planned, for myself. But yesterday I turned fifty - single and childless.

I never made a conscious decision not to marry or have children, but neither did I actively seek those things. I just assumed they would happen, in the normal way of life, as they did to most people

An academic high-achiever, growing up in the 1970s and 80s (the shoulder-padded decade of the "Yuppie") I may have been subconsciously influenced by the prevailing narrative that pregnancy meant the end of life chances, not the beginning.

Remember Marlene, the hard-nosed lead of Top Girls, Caryl Churchill's defining play of the era, who gave up her daughter with learning difficulties, in pursuit of her (ultimately empty) executive career?

As an only child, having attended hot-house single-sex schools, I had no template for forming positive romantic relationships in my teenage years; I went on to university, however, and started a career in television - both fruitful grounds for finding a partner, you might think. But for me, it just didn't happen. The men I worked with were older, married or gay. There was no internet dating or social media in those days, when my online "stock" would have been high. Not so now, when most men of my age are looking for a woman at least ten or twenty years younger, with whom to start a family!

I could still have had a child on my own, you might argue; but that's not something I would have done by choice. I know and respect that some women have a maternal urge so strong that they will prioritise that above waiting for the "right" relationship or professional and financial security. I am not one of them.

But neither am I a "Marlene". I lost my father to cancer when I was a student - I have always known that family matters more than material success and am very much a nurturing person. I find myself looking after others in many ways, and those nurturing instincts have been diverted primarily into care for my mother, who has lived with dementia for well over a decade - nearer twenty years from the earlier symptoms. Her needs have become paramount, arguably to the detriment of both my career and my personal life. The social and financial contribution of carers (particularly the freelance or self-employed, who don't show up in any HR stats) is often invisible and vastly undervalued.

So now I find myself facing older age with no family to care for me, as I have done for my mum and I admit it scares me. I have seen, through many crisis points with mum, how vulnerable you can be in the social care system and the NHS - let alone wider society - with no-one to speak up and fight for you.

## <u>Methodology</u>

This report is based on 4 focus groups held in York, Leeds, Kingston upon Thames and Henfield in West Sussex. A total of 42 people attended the focus groups which included 4 people from an all-male focus group and 9 people from the LGBT community interspersed throughout allfocus groups. In addition, 2 people were interviewed on a one to one basis and 4 people contributed case studies. This was to give people ageing without children space to tell their own stories in their own words and to help people see the individual behind the statistics. This report also draws on discussions on social media, the AWOC Facebook group and a survey carried out by AWOC in 2015 <a href="http://awoc.org/survey-findings/">http://awoc.org/survey-findings/</a> <sup>24</sup> which was completed by 400 people ageing without children .

\*Some names in this report have been changed to protect the anonymity of the research participants

## **Themes**

<sup>&</sup>lt;sup>24</sup> AWOC survey 2015 Woodard, Day, Hutten and Sanches

The aim of the research was to identify key themes and trends for people ageing without children. The following 6 were the most common issues that arose in the focus groups, survey and on line discussions:

- Invisibility
- Felling Judged
- "Who will tell my story?"
- Being a carer is a trigger
- Practical support
- Disconnect from other generations

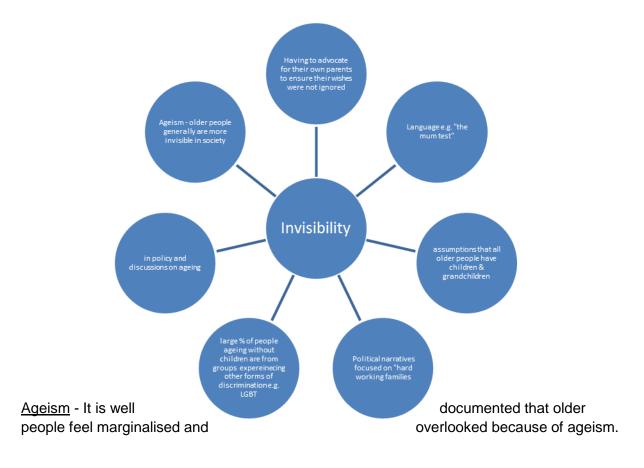
### **Invisibility**

"Family is the baseline and everything is measured by that"

Despite the growing numbers of people ageing without children, many people in the focus groups talked of feeling invisible. This invisibility was made up of a number of factors:

- Ageism
- The experience of having to advocate for their own parents
- Political Narratives focused on hard working families
- Assumptions that all older people have children/grandchildren
- Language
- In policy and discussion on ageing

We have illustrated these in the diagram below:



In a YouGov<sup>25</sup> poll of people between 65-93 - almost two-thirds (62%) were concerned about being seen as a problem by society and 47% complained of ageism. 48% said they thought their generation was "ignored" and more than a third (37%) felt treated disrespectfully because of their age.

<u>Having to advocate for their own parents</u> - coupled with the realisation of what it means to have no one to speak up for you is expressed in a quote below:

"It's a constant battle to get any help for my mum even though she's in her 80s and has dementia! I feel like I'm always having to shout really loudly to get anywhere. I wonder, who will be shouting for me? Or will I be the old lady dying alone in a hospital bed because no one cares?"

<u>Political Narratives focused on hard working families</u> - There is a strong feeling that Governments are only interested in family by which they mean mother, father and children. Anything outside of that is considered abnormal and therefore unimportant.

"Politicians they're just living in the past, it's all hardworking families! What about us? What about single people?"

<u>Assumptions that all older people have children/grandchildren</u> - One of the many consequences of there being more people ageing without children is that more and more people are not, and never will be grandparents. 1 in 5 people over 50 have no children and therefore of course no grandchildren. Nevertheless, the assumption that all older people are grandparents remains very strong.

"I felt excluded because I wasn't a mum and now I feel excluded because I don't have grandchildren".

<u>Language</u> - The Care Quality Commission uses what it calls "the mum test" the aim is laudable, essentially that every service they inspect should be good enough for their mum to use but for those people who will never be mums or indeed dads, such language feels excluding. Similarly older people are routinely referred to us as grannys/grandads/ grandparents whether or not they actually are. In the USA, the term 'elder orphans' has been coined to describe those ageing without children; people ageing without children in the UK found this term particularly offensive:

"'elder' implies to me more wisdom and calm than I ever intend expressing and 'orphan', apart from being a word that seems to instantly strip a person of any empowerment, links too directly to being about a child, horribly ironically for the group it seeks to describe".

"I think this is horrific terminology to use, both words are insensitive. Once again society treats childless people as aliens and now makes you feel even more isolated if you are single".

<sup>&</sup>lt;sup>25</sup> http://www.bbc.co.uk/news/education-23697349

<sup>&</sup>lt;sup>26</sup> http://www.cqc.org.uk/content/making-mum-test-real-our-new-model-inspecting-adult-social-care-has-launched-today

In policy and discussion on ageing - As we highlighted earlier, there has been an unprecedented level of media coverage on issues relating to ageing. The fact that media organisations are not aware of the numbers of people ageing without children is not surprising given its current low profile. What is more worrying is that organisations concerned with age have also been slow to pick up on the numbers and the impact on individual older people, services and the wider community.

In 2014, the Ready for Ageing Alliance published "Getting ready for ageing: A manifesto for action" which said that "policy must adapt to the future challenges of demographic change" but it did not mention the increasing numbers of people ageing without children.

Similarly, the "Ageing in the UK – Trends and Foresight" report prepared for the Big Lottery Fund was published in June 2015 with the aim of "exploring issues and emerging needs related to ageing in the UK". The report makes reference to changing family structures and references a British Social Attitude Survey from 2012<sup>29</sup> which showed that 46.4% of people agreed that adult children were an important source of help for elderly parents and only 13.3% disagreed.

The report suggests that "Having adult children is considered a vital source of help in old age" and goes on to say "adult children have long played a role in caring for their elders, it seems clear that with more and more people living into their 80s and beyond, the role of adult child carer may extend into the 40s, 50s or even 60s" but then makes no mention of older people without adult children and the potential impact of this group on ageing policy.

"Ageing: the silver lining - The opportunities and challenges of an ageing society for local government" prepared for the Local Government Association, sought to "explore the challenges and opportunities that an ageing population presents for local government and local communities, now and over the next 20-30 years".

The report highlights that LGBT people over 55 are more likely to live alone, not have children and not be in regular contact with their family and are therefore more likely to age alone. It also mentions changing family structures and that the number of women without children will mean fewer informal carers to provide support to people with care and health needs. The report recommends that local authorities apply an ageing lens to policy and practice which we completely support. However, to our knowledge, no local authority has any current plans in place to address the specific needs of people ageing without children.

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<sup>&</sup>lt;sup>27</sup> http://www.independentage.org/media/816052/r4aa-maifesto-report-22-08-2014.pdf

<sup>&</sup>lt;sup>28</sup> https://www.biglotteryfund.org.uk/research/research-round-up/foresight

<sup>&</sup>lt;sup>29</sup>http://nesstar.ukdataservice.ac.uk/webview/index.jsp?v=2&study=http%3A%2F%2Fukdataservice.esds.ac.uk%3A80%2Fobj%2FfStudy%2F7476&mode=documentation&submode=variable&variable=http%3A%2F%2Fnesstar.esds.ac.uk%3A80%2Fobj%2FfVariable%2F7476\_V620&top=yes

<sup>&</sup>lt;sup>30</sup> http://www.local.gov.uk/publications/-/journal content/56/10180/7357727/PUBLICATION

"I don't think people at the government have the faintest idea how many of us there are. If they did, I think they'd be worried!"

<u>Large Percentage of people ageing without children are from groups experiencing other forms of discrimination</u> - The invisibility also stems from, and is exacerbated for, certain groups of people who are more likely to be ageing without children such as LGBT people. Already potentially facing homophobia and other forms of discrimination, older LGBT people worry of being forced back into the closet in later life in order to receive care. LGBT people are often absent from national strategies around ageing e.g. dementia and their needs overlooked or ignored by providers and commissioners<sup>31</sup>. People from other black and other minority cultures, especially those which are seen as having strong devotion to traditional family structures, are also particularly invisible.

### Case study - Jacq Applebee's story:

I ran away twenty-three years ago. I fled my huge, abusive family for a life of poverty and ill health. It was also a life where I wasn't treated like a punching bag or a sex toy. It was a life of freedom. Freedom has a price of course. Every medical check-up where I'm asked about illnesses that run in my family, I have no answers for them. When good-natured folks ask if I'm spending Christmas with my family, I shake my head and move the subject on to something else. As my age increases and the medical problems escalate, my worries increase too. I'm asked questions about my carers (of which there are none), my family (still don't have one of my own) and my strange medical history (abuse-related scars, burns and internal injuries). Medical staff still seem unprepared for the fact that when it comes down to it, I don't have anyone. One of my girlfriend's names is down as my next of kin, but she lives 200 miles away with her other partner. Her existence does little for the assumption people of all ethnicities have: that for black people, family is everything, and to be without one is downright freakish. After all, we are supposed to come from big jolly families. We are never supposed to be victims of child abuse. We are breeding machines, straight, able-bodied, young at heart, with a great sense of rhythm. Well I am none of the above, although my dancing is pretty decent. I am a black, bisexual person who only identifies as a woman 70% of the time. My hysterectomy due to fibroids means I really have tied the knot on children ever being a part of my life.

I face racism, homophobia, biphobia and sexism on a daily basis from all sections of society. Ageism is just another form of bigotry that makes up part of my life now.

<sup>&</sup>lt;sup>31</sup> LGBT older people with dementia should not be forced back into the closet http://www.theguardian.com/social-care-network/2015/mar/10/lgbt-older-people-dementia-social-care

The Lesbian, Gay, Bisexual and Trans communities in the UK tend to be young and very white. I rarely feel at home in any of these spaces where alcohol seems like the only thing to drink when you're out, where gay white men are free to channel their inner 'feisty black woman' as they make racist comments to my face, and where lesbians will refuse to speak to me once they find out I'm bisexual. It's not possible to make everyone happy, but it's also very difficult to make new friends or meet potential partners in these environments. Living a life of freedom is hard when so much is stacked against me, but it is the life I must lead. I have no choice but to live, to look after myself, for there is nobody else to do it for me. Both of my girlfriends have their own partners and caring responsibilities. My closest friends live miles away.

I am honestly scared about the future, because I never imagined I would live this long. I do know that I don't want to hide or keep parts of my identity secret when I'm in hospital or in a care home. My abusive family thrived on secrets and denial. I don't want to be anything like them. But I'm scared of ageing all the same.

## Being judged for not having children

For people who have never been parents, tactless, thoughtless and sometimes deliberately hurtful comments are sadly very common, more so than people realise. "I went into the Building Society to change something on my account and the cashier was chatting with me as you do and she asked me if I had any children. When I said no, she said 'oh you selfish cow"

"I was having lunch with a friend and she told me that people who don't have children can't look after old people as they don't have any empathy".

Childfree people in particular can face very hard criticism as the treatment meted out to Holly Brockwell a young woman who wrote about her choice never to have children for the BBC in November 2015 shows. Holly was abused and castigated for her choice<sup>32</sup> and sadly, the comments and treatment she describes are not uncommon. People who choose not have children report routinely being described as selfish, self-centred, immature, not knowing their own mind and accused of hating children.

People who wanted to have children and couldn't face different but equally insensitive comments.

It is often the very casual nature of such hurtful and judgemental comments that make them so hard to respond to. Jody Day from Gateway Women describes them as "bingos" i.e. common responses people make without stopping to think; we are reproducing some of them here:

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<sup>32</sup> http://www.bbc.co.uk/news/magazine-34916433

- "You should have thought about that when you were gallivanting around for your career!" (Not knowing about infertility, lack of partner, etc. and also ascribing any woman with a job as a 'career woman').
- "If you'd really wanted children, you would have tried harder." (To someone perhaps who has endured multiple failed IVF cycles or maybe took the decision not to be a parent because of a genetic condition that made being a parent unwise.
- "I didn't have children so that they could look after me when I'm old!" (Though when challenged by asking what plans they *do* have in place to ensure their children *don't* have to, these people are often strangely quiet! As well as denying the reality that children often do participate in their parent's informal (and sometimes formal) care as they age.
- "Well, what have *you* got to worry about, you've got loads of money that you've saved from not bringing up children!" (Unaware of the cost of living crisis for the many who live alone and don't get family tax breaks... let alone fertility treatment debt.
- "You can all just live together when you're old." (As if that's what they'd like for themselves and not taking into consideration the needs of the individual nor later life care needs).
- "You can't expect the state to support you now, you should have thought of that earlier!"
   (Not considering that childless/free adults have paid taxes their entire working life to support the infrastructure used by families such as education, health, roads, leisure, sports, etc.).

The narrative around men aging without children also contains its own bingos:

- "Lucky escape mate!" implying that the idea of being without children is an enviable state to most men. However, the poor health of men ageing without children shows this is far from the case.
- "Charlie Chaplin was fathering them into his 80s." Implying that men can go on fathering children until well into old age. Research shows that is definitely the exception rather than the norm.

As outlined earlier in this report, people enter later life without children for a whole host of different reasons. They are as diverse a group of people as parents are and assumptions about them are unhelpful and often hurtful often leading to direct or indirect discrimination.

Case study - Linda's story (age 52)

I knew I didn't want children right from when I was young. My friends all had dolls they dressed up and pushed around in prams but I never played with dolls, I was out on my bike.

I thought though that it would happen one day because, well, that was what all the women I knew did. I kept waiting to feel different; people said I would all the time "oh you'll feel differently when you're older" but I never did.

When I met my now ex-husband, he wanted children and I honestly thought I would change my mind but I never did. He couldn't accept it and we split up. It was very sad but it's a big thing to disagree on. I mean you can't just have kids on the off chance it's going to be OK and you might like it. That's not fair on anyone!

I'm lucky, I've had a nice life with good friends and I never worried until last year when I had to go into hospital. It was quite a minor operation but quite debilitating and the hospital nurse said "oh you'll be needing your family to help for a few days" and when I said I didn't have one she looked shocked and then sad and said "how will you manage?"

I hadn't thought about it at all until then, getting old without children, but it made me think then. People always assume you have a family and I just don't. No children and only one brother who lives on the other side of the country. It made me think I really need to start planning for when I get old".

## Who will tell my story?

One of the most poignant issues raised by people ageing without children is "who will remember who I was when I don't remember?"

"I know it seems silly but who will go through my stuff when I'm gone? Who will care about it?"

"If I get dementia who is going to tell the carers I don't like sprouts and hate Eastenders? Noone is going to know are they? And I won't be able to tell them".

All of us have our life story; the person we were, the person we are, the person we will be. Often those life stories are preserved in the people around us - family and friends, but if we don't have a family and our friends are getting older and dying, who will remain to tell our stories? For people ageing without children there will be no one to do that leading to an immense feeling of loss and lack of legacy.

There has been wonderful work done in the field of dementia by people living with dementia and their children around telling the story of their parents ensuring that they are seen by NHS and social care as people with a life history. Dementia is a particularly strong fear for

people ageing without children; despite the high profile campaigns around dementia, people ageing without children have not featured in any debates or discussions. Initial conversations with organisations working in the field suggest that most contact with people with dementia is done via carers and therefore if someone does not have a carer, they are hard to reach and involve. People ageing without children present a real challenge in this area but it is one that must be addressed.

## Becoming a carer is a key trigger point

For many people, the reality of what ageing without children could be like first surfaces when they become a carer for their own parents.

"How I will be able to organise my care with no family here in this country?"

"I cared for all my elderly relatives including my mother until I was 70 and until they had all died. I know from this how awful it is to be old and dying, the lack of services and the struggle to access what is available".

Many people participating in the focus groups talked about their experiences of caring for their own parents and the difficulties they had encountered. People were supporting their parents in a range of ways including:

- Telephone reassurance and contact to make sure they were OK
- Helping with practical things like shopping, gardening, DIY and housework
- Dealing with the increasing number of services that have to be accessed online
- Organising care e.g. contacting social services or private care agencies, arranging assessments, ensuring a care plan is in place and is being adhered to, dealing with problems, managing payments and making sure that care provided is of a good quality
- Holding Power of Attorney
- Stepping in to deal with scammers
- Sorting possessions to help with downsizing
- Assisting their parents to sell their home and move into more appropriate accommodation

All people participating in the focus groups were acutely aware that while those things were easy to do for yourself in your 50s and 60s, the ability to manage them did become harder as you get older.

### John and Lindsay

John and Lindsay are both 64 and live in a small village in rural Cheshire. They would have liked children but there was a possibility of Huntington's disease in the family and they decided that it wouldn't be fair to pass on the disease to their child. By the time they found out that the illness affecting Lindsay's mum was not in fact Huntingdon's disease, Lindsay was in her early 40s and they felt it was too late to try for children.

"People ask if I have a family and when I say no, I don't have children they say 'oh you're so lucky, you can do what you want' they've no knowledge of the decisions I had to make along the way. It did used to upset me quite a bit when I was younger, then in my 40s/50s I accepted it but now I worry more because of what I've seen with mine and John's parents".

Lindsay has found in particular that people are very judgemental "it's nobody's business – why do people think they have a right to have a view. Even if people have chosen not to have children, it's not as if they won't have thought about it a lot".

They have both found that people automatically assume they are parents/grandparents and that very few of their friends in their 60s don't have children.

"They say 'oh my kids won't look after me' but you know, I bet they do when push comes to shove".

Like many people who come to Ageing without Children, it's been the experience of caring for their own parents that has made them worry about their own old age. Lindsay's father lived independently with care at home but Lindsay had to arrange and manage all the care and his finances. As Johns' mum became much older she, as John describes it, "began to give up on things" and became very withdrawn and forgetful. After a lot of searching they found a very good care home for her but it costs £32,000 a year.

"John's mum phones us most nights for reassurance and that's fine because we are her children. Both our parents' quality of life was enhanced by having us there. We remember the little things that they like or dislike and can tell a person; that's what matters, the little things that make their lives better. You need someone looking out for you, someone who loves you".

The experience of caring for their parents has made John and Lindsay think a lot about their own future.

"We are looking for an apartment in retirement housing somewhere close to all the services and with good transport links".

They believe that it is vital that people ageing without children have "just someone you can trust, who you can discuss things with. Dealing with financial stuff in particular is a massive thing".

## **Practical help**

One of the biggest problems facing older people over the last 25-30 years has been the withdrawal of services by the state that provided small amounts of practical help with tasks such as transport, housework and shopping. These services are now almost entirely provided by the voluntary sector, often charged for but subsidised; however, even the funding that enables voluntary organisations to provide these services at a low or lower cost than market rate is disappearing.

"You know they won't let me go home from hospital unless there's a named person to pick me up. They insist they have to ring them to come and get me. I tell them I don't have a name to give and they look surprised as if it never happens. Perhaps it is just me who doesn't have anyone".

Many people talked of the smaller aspects of the practical help they provided to their own parents or grandparents that helped them stay at home:

"Nan didn't have care as such but her neighbour did her shopping thank god and we phoned every week and went down at least once a month. We arranged for someone to come and do her feet and for social services to put grab rails and a bath seat in. I know the hospital had tried to do that but she insisted she was fine, well we knew better than that and she couldn't tell us to go away like she could a nurse".

In summary, practical help, whether one off to help people cope with illness or injury or longer term to help manage the effects of longer term conditions, is absolutely vital. For many people, this is provided by their children.

### Louise's story

"I was unable to have children and this resulted in a short first marriage as my then husband turned broody and was desperate to have a family of his own. Luckily I went onto meet my second husband Andy; we have been together for 28 years. Being childless hasn't stopped us from leading fulfilling lives as many people thoughtlessly assume.

Like many people, I found myself starting to support my parents and relatives more and more through various illnesses and less ability to manage admin and finances as they grew older. This meant getting more involved in their daily lives and admin, as well as taking steps to ensure they could continue living independently at home. Whilst busy juggling my own working life and household over a 30 year corporate career and then setting up my own business in 2010, I found it useful to have information to hand about my parents and their household information, so that I could manage day to day tasks such as household admin remotely – a real time and stress saver.

I found that many of my clients shared the same issues – one person often ends up as the family administrator and problem sorter, simply because they had made the first move to help or just happen to live closest or in other cases they are aging without children and wonder how they will manage as they get older. So I took my home made life management system and designed and expanded it into My Life Pack ... Your Life at Your Fingertips ® My Life Pack is a one-stop personal organising manual that makes managing personal and household admin simple; whether you are looking after elderly parents or other dependents, or you're concerned about getting your affairs in order to make daily life easier as you grow older. With its tick list feature it is also a handy tool for managing life's milestone events such as moving house or dealing with probate and helps you consider making a will and set up Powers of Attorney. Essential for ensuring your wishes are observed and particularly if you know there will be no family members around to take care of you in when aged or in ill health.

## **Losing touch with other generations**

The importance of forging and maintaining relationships across all generations is key to enabling people ageing without children to feel part of the wider community and society. However, without their own children or grandchildren to give them an "in", people ageing without children felt that there was no easy way to sustain intergenerational relationships especially when they had retired.

"I used to go to the pub with work and there were lots of different ages, now I'm retired I don't seem to see anyone young anymore. I miss that".

"It's all the technology isn't it? My friends say 'oh I got my grandson to show me' but that's not an option for me".

A feeling of disconnect from younger people was palpable. Nearly everyone we spoke to wanted to spend time with younger people even if they had never wanted children themselves. People were anxious to pass on knowledge, skills and experiences to younger people and there was a great deal of sympathy for the difficulties many younger people are facing. However there was enormous frustration at the lack of opportunities for intergenerational contact particularly after retirement. Both men and women felt people were suspicious of them if they wanted to have contact with young people especially children.

### **Solutions**

There are no easy answers to the issues affecting people ageing without children. It is important to remember that many are the same issues that can affect all older people. However, older people ageing without children have the added issue or concern of already feeling invisible. The following are some of the solutions suggested to combat these issues. These solutions come from people ageing without children themselves and include suggestions made during AWOC's first conference<sup>33</sup>, responses to our survey<sup>34</sup> as well as suggestions made in the focus groups:

- Central Government planning on ageing takes into account that increasing numbers of people will get old without family support
- Local authorities identify how many people in their area are likely to age without children and incorporate this into their strategies on ageing
- GPs, hospitals and social care services are able to identify people without family, provide support or care at an early stage and guarantee involvement of other services to ensure they are not left without support
- Investment in intergenerational programmes and activities so that people ageing without children still have the possibility of engaging with other generations
- Advice and assistance offered to everyone for making plans for their later life that take into account what will happen if they do need care or lose capacity to make their own decisions

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<sup>&</sup>lt;sup>33</sup> AWOC15 - The Ageing without Children Conference: 'But Who Will Look After You When You're Old?

<sup>&</sup>lt;sup>34</sup> Ageing without Children survey results 2015 Woodard, Day, Hutten and Sanches 2015

- Develop a national strategy for people ageing without children that brings together individual people, Ageing without Children along with national and local Government, the NHS, housing providers and key bodies from civil society
- Create social awareness around the issues of ageing without children
- Education/training for service providers who will be working directly with older people
  without children. It is vitally important that those who write policy, plan services and
  work directly with older people understand all of the issues associated with ageing
  without children
- Campaign for childlessness data to be collected for men on the national census, as well as reasons why both men and women are ageing without children
- Explore the feasibility of creating a national online hub and telephone service that would link all the currently available services (both government and independent) available for adults ageing without children
- Look into currently existing advocacy services for older people and see how they
  might demonstrate best practice in terms of creating a national network of advocates
  for those ageing without children

### Areas for further research

As we have identified in the report, there is a great need for further research around this issue. In particular we have identified the following areas:

- Greater understanding of what is meant by "family" and the expectations society services and Government has of family carers and how this impacts of people ageing without children
- The male experience of ageing without children
- LGBT experiences of ageing without children
- Experiences of people from other cultures ageing without children
- Identifying if there is any difference in outlook in later life between childfree and childless
- Greater understanding of older people estranged from their children
- Experiences of older people whose children have predeceased them
- Research with different cohorts of people ageing without children to look at the solutions they have put in place to help manage their situation

## **Acknowledgements**

We would like to thank the following people and organisations for their help with this report: Jody Day, Mervyn Eastman, Dr Robin Hadley, Ed Vanderlee, Jean Basson, Janice Leeming, Age UK Horsham District, Jan Wise, Shane Brennan, Carol Rawlings, Laura Carroll, StayWell, Saxon Weald Housing, Sue Lister, Ann Murray, Leeds Older People's Forum.

The Beth Johnson Foundation and the Beth Johnson Endowment Trust.

All of the people ageing without children who so generously gave up their time to talk to us and tell us their stories.