A REPORT COMMISSIONED BY

SUFFOLK COUNTY COUNCIL

TO STUDY THE VIEWS OF OLDER PEOPLE ACROSS THE COUNTY

ON ISSUES RELATING TO THE DELIVERY OF FUTURE SERVICES

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CONTENTS

1. INTRODUCTION

Suffolk Age UK (SAUK) was requested by Suffolk County Council (SCC) to carry out this consultation on their behalf to inform and facilitate strategic decisions to be made during 2016/17. The aim of the consultation is to ascertain the views of adults across the county of Suffolk over the age of 55 years on various life style subjects which are of relevance when considering strategy and what will be required from providers of services for older people in Suffolk in the future.

2. EXECUTIVE SUMMARY

350 people between the ages of 55 and 98 were interviewed for this consultation. The breakdown in gender is 105 males and 245 females. In order to identify trends within these age groups they were then divided into age groups 55- 64 years, 65 – 74 years, 75 – 84 years, and 85 – 98 years of age. 4 people (3 women and 1 man) did not give their age but because they answered the questions comprehensively they have been included in the figures where appropriate. The numbers in each category are shown below.

Number of Interviewees in each age category by gender

	55-64	65-74	75-84	85-98	Age not known
Male	5	28	49	22	1
Female	20	72	101	49	3
	25	100	150	71	4

The results of each section 1- 4 have been analysed within age groups and where possible the results of the interviews have also been analysed to show the gender comparisons. The main results of this analysis and some recommendations are detailed below with more complete information contained within the body of the report.

3. Results and Recommendations

1. Adaptations in the home grow in complexity and volume as we age with rails and bars being the most common adaptations made. More specific individual needs, such as widening doors and putting in ramps are carried out when appropriate.

2. The majority of those interviewed are willing to pay for adaptations dependent on cost but the ability and willingness to pay decreases with age, especially with older women.

3. The term Assistive Technology is not understood by the majority of interviewees. A majority of both men and women are willing to pay, if they are able to, at all ages

for assistive technology such as alarms, but the number who cannot or would not want to pay remains steady at between 20%-30%.

4. Women are more likely to have alarms than men in all age groups but especially in the oldest age group (85-98 years) where 70% of women use an alarm. Although few interviewees answered whether they found alarms useful, efficient and value for money, of those who did express a view the majority found that the alarm gave confidence and when used, the majority found it efficient. The main concern expressed was the cost.

5. More men than women are willing to communicate with medical staff using IT but in both sexes this willingness reduces with age. This may be a reflection of having had more experience with computers in the workplace before retirement. Even if they were offered help, the majority of men who said 'no' still feel they would not wish to use IT. However, the proportion of women who would use IT, if offered help, increases with age.

6. The majority of both men and women are unlikely to wish to learn more about IT especially within the older age groups. However, a sizeable minority are interested in learning more about IT and would be likely to take lessons if the opportunity arose.

7. Work, family and courses are the most common methods used to learn IT and men particularly learned to use computers at work. Family support is increasingly important as interviewees grew older.

8. The numbers failing to plan for a time when they may not be able to cope is concerning, although women appear to plan ahead in larger numbers than men, who appear to leave adapting their life style until an older age. There may be a case for some education to suggest that planning for older age when younger and fitter is a good idea as some older interviewees felt overwhelmed by change. For instance moving home was often too much to contemplate and older people felt they had left it too late.

9. The majority of all age groups and both genders had made wills with 72% at age 55-64 having done so, which increased to over 90% of interviewees aged 85-98. The numbers arranging powers of attorney also increased across the age groups. Few interviewees knew what a living will/advance decision is and therefore the numbers completing these are low with only a small proportion in each age group of women completing a living will/advance decision and virtually no men except in the oldest age group.

10. The proportion of people paying or prepared to pay for help if necessary increases with age, although income also plays a part in any reluctance to pay. Women are more prepared to pay across all age groups than men with the age group 65-74 years the least prepared to pay for any help. The main difference is the reluctance of younger men to pay for housework and gardening but this equals out in the oldest 85-98 age group. Shopping and transport are the tasks interviewees were least likely to pay for.

11. The practical things to make life better were wide ranging but most were related to the impact on their lives of increasing ill health and those things which could improve social contact such as better transport and more social and practical support to assist getting out and about.

12. The introduction of personal budgets was unknown to the majority of interviewees at all ages. Even those who knew about it (60 of the 350 interviewed) were unable to expand on the detail when asked and only had hazy ideas about what the implications are. Only 16 of the 60 felt that they knew enough about employment law to actually employ someone personally. Further consultation was requested by SCC and the results of this research into the implementation of Personal budgets can be seen at Appendix 1.

This consultation confirms the concerns which always arise when considering the services needed by older people and these should be addressed where possible. Prompt practical support to ensure that adaptations are made in good time to enable people to remain in their own homes is crucial. What is very clear is that interviewees were willing to contribute to the cost of these adaptations when their finances enable them to do so.

Where staying in their own home is impossible, support to help people move into more appropriate homes should be made more available in order to make it easier and less traumatic for them.

The overriding issue is that of social contact which is essential to the majority of older people to alleviate loneliness and isolation. The need for social contact has been raised as a major issue in most other research on the subject. Ways of ensuring that opportunities to make social contact are made accessible to those who need support to attend, by proactively offering lifts or transport, is crucial to the well being of the very elderly, especially when they cease to drive.

This need for transport being made available is underlined by comments made during the consultation but outside the actual interviews. In order to complete this consultation, the interviewer visited lunch clubs, day centres and social events across

the county. All the people spoken to before and after completion of the interview had positive comments to make about the benefits of meeting up for a chat and a meal with friends and others in their community and how grateful they were to the people who provided this support and companionship and enabled them to attend.

4. METHODOLOGY

For this consultation 350 people, made up of 245 female and 105 males, over the age of 55 across Suffolk were interviewed between November 2015 and June 2016. 65 of these were one to one interviews undertaken in people's homes and the 285 remaining interviewees completed questionnaires resulting from visits to various group meetings and events held across the county. Every effort was made to ensure that a wide and viable range of people over 55 completed the questionnaires. The youngest interviewee is 56 and the oldest 98 years old. The age, gender, type of housing and location of participants are detailed below.

Number of people aged 55-98 interviewed in each local authority			
Babergh	33	St Edmundsbury	77
Forest Heath	39	Suffolk Coastal	49
Ipswich	47	Waveney	70
Mid Suffolk	35		
Total:			350

The interviewees were asked a series of questions about their life style:

- the adaptations they had made, or planned to make, to their home and lifestyle
- their use of technology, including personal alarms and computers
- their opinions about the future provision of services and what support they need now or may need in the future and
- what knowledge and understanding they had of planned changes to the payment of benefits.

Analysing the results of the questionnaire was sometimes complicated because a number of the participants completed the questionnaire without the personal guidance of the main interviewer. Where the interviewer was present to answer questions from interviewees, queries were dealt with and questions were perhaps more accurately interpreted by those participating. However, most of the questions were straightforward 'yes' or 'no' and therefore more easily analysed. Case studies have been used to provide examples of how older people have managed change and, in many cases,

increasing ill health. They also have been used to highlight trends and identify where difficulties arise currently and the impact of interventions at crucial moments in their lives.

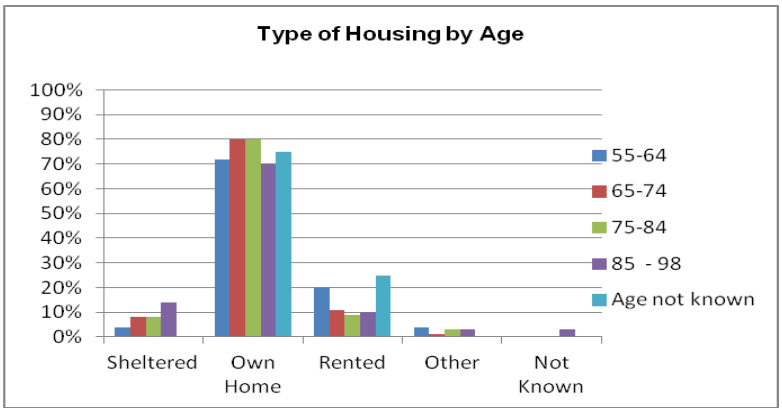
Interviewees were also asked to think where difficulties may occur in the future and what the important issues are in both younger and older age. Some case studies are inspirational in showing how difficulties are overcome through innovative ideas, positive intervention and excellent use of the income at the subjects' disposal, often in the face of significant adversity.

DEMOGRAPHICS

Type of Housing

The interviewees were given 4 options about type of housing, Sheltered, Own Home, Rented and Other (Chart 1). Describing what type of housing they lived in was complicated by the fact that many buy their sheltered accommodation but can refer to either 'living in sheltered' or alternatively consider they still 'own their home', so these figures can only be suggestive. However, the figures do suggest that only 4% of those aged 55-64 live in sheltered accommodation but at least 14% live in sheltered accommodation at age 85-98. The figures show that the majority of people still remain in their own homes and this percentage remains static at between 70%-80% across all age groups.

Chart 1



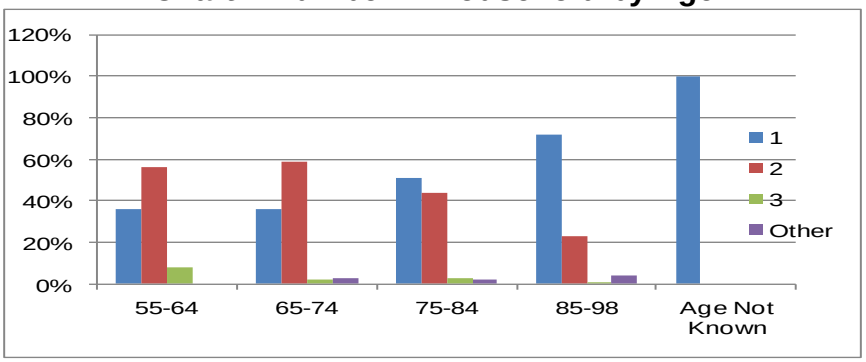
Number in Household

When asked how many people live in each household Chart 2 shows that the percentage of people living on their own increases greatly between the ages 55 – 64 and 85-98 with only 36% of interviewees living on their own aged between 55-64 and 72% at ages 85-98. This applies to both men and women with a threefold increase for

men with 20% of men at 55-64 living alone and 73% at 85-98 years. The number for women almost doubles with 40% of women living alone at age 55-64 years and 77% living alone at 85-98 years. The numbers of those living in households of two decreases as a result from 60% of men and 55% of women at age 55-64 to 27% and 21% respectively at age 85-98 years. The numbers living in households of 3 also obviously reduce greatly during this period from 8% at 55-64 and only 1% at 85-98. Across all age groups more women live alone than men and it is only in the age group 85-98 where the figures become more equal with 73% of men and 77% of women living alone.

Where the answer was 2 or more living in a household the question of who was living in the house with the interviewee was not asked therefore only assumptions can be made about who they were sharing with.

Chart 2 Number in household by Age



5. SECTIONS

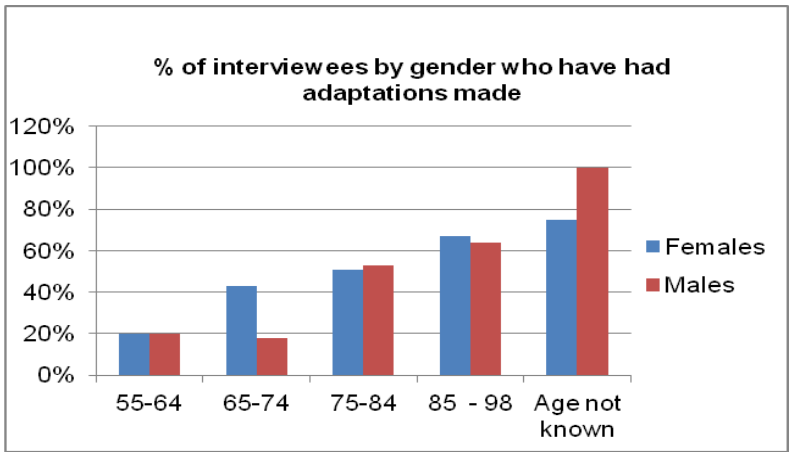
SECTION 1 ADAPTATIONS TO THE HOME

Q1 Have you had any adaptations made to your home to help you remain independent?

All interviewees completed this question and the figures show that only 20% of those aged 55-64 had any adaptations compared with 36% at 65-74, 52% at age 75-84 increasing to 64% of those aged 85-98. Of the 4 people who did not give their age 75% (3 of them) had had some adaptations to their homes.

When considered by gender, Chart 3 shows that at ages 55-64, of the 20% who have had adaptations made to their homes, there are equal numbers of men and women. This varies at ages 65-74 when over 40% of the women and under 20% of men have had some adaptations made to their home but equals out as the interviewees age with over 60% of both males and females having adaptations made by the age of 85-98 years.

Chart 3



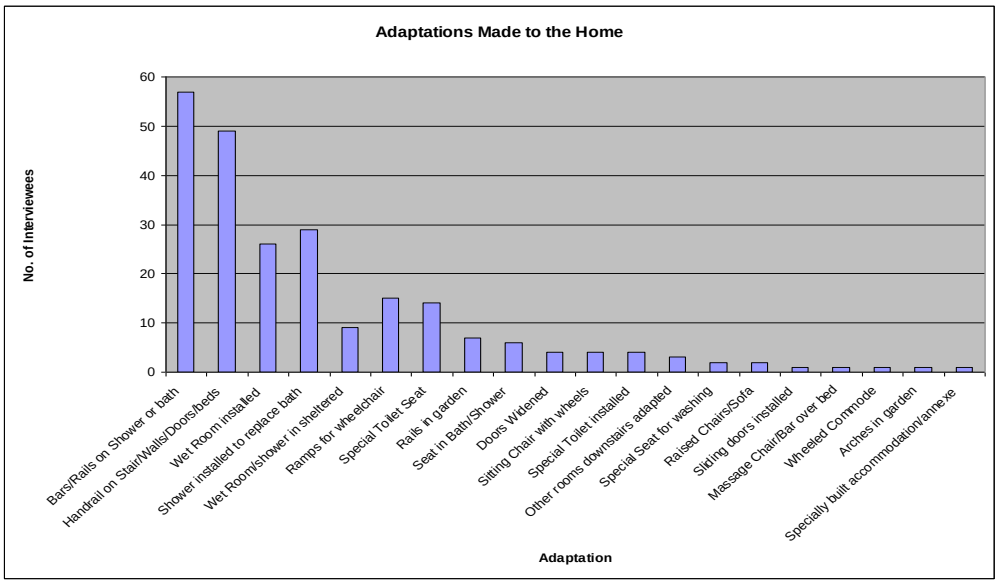
Q2. What adaptations have been made and what help did you need to make them?

There is a definite relationship between age and the number and complexity of adaptations that have been made in people's homes. At age 55-64 only 20% of homes have been adapted in some way but this percentage grows through the age groups until at age 85-98, 69% of homes have been adapted, and the number and complexity of adaptations have increased with age.

It can be seen from Chart 4 that bars and rails around the home both inside and out are the main adaptations made. Adaptations to the bathroom with wet rooms installed and

baths replaced with showers or installing more appropriate toilets are also very helpful in maintaining independence. Other adaptations include widening doors, raising chairs, and ramps to support wheelchairs. Rarer adaptations include adapting downstairs rooms to accommodate living on the ground floor and there is one interviewee who has had a special annexe built to accommodate her. This, however, may not be a comprehensive list of adaptations as many of those interviewed had had a mixture of these adaptations made at different times according to their need.

Chart 4

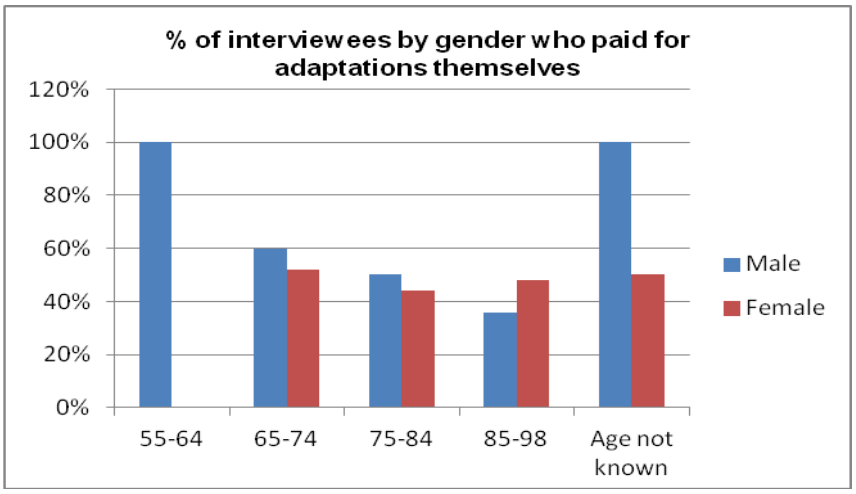


Q3. Did you or your family pay for them?

When asked if they or their families had paid for adaptations, both the numbers of those who had paid themselves increase with age as do those who answered that others had paid. This can be explained by the increase in adaptations needed as people age. There is a discrepancy in the ages 65-74 and 75-84 between the numbers who had paid themselves and those for whom someone else had paid but this may be accounted for because some interviewees paid for some adaptations themselves and also had some paid by other agencies at different times and in differing circumstances.

Chart 5 shows that those adaptations carried out for women at age 55-64 years were mostly paid for by outside agencies and that men in the youngest age bracket appear to have paid for their own adaptations. The proportion of men paying for adaptations does become more equal to that of women as they age, and in the 85-98 age group, surprisingly, the figures seem to suggest that more women pay for their own adaptations than men.

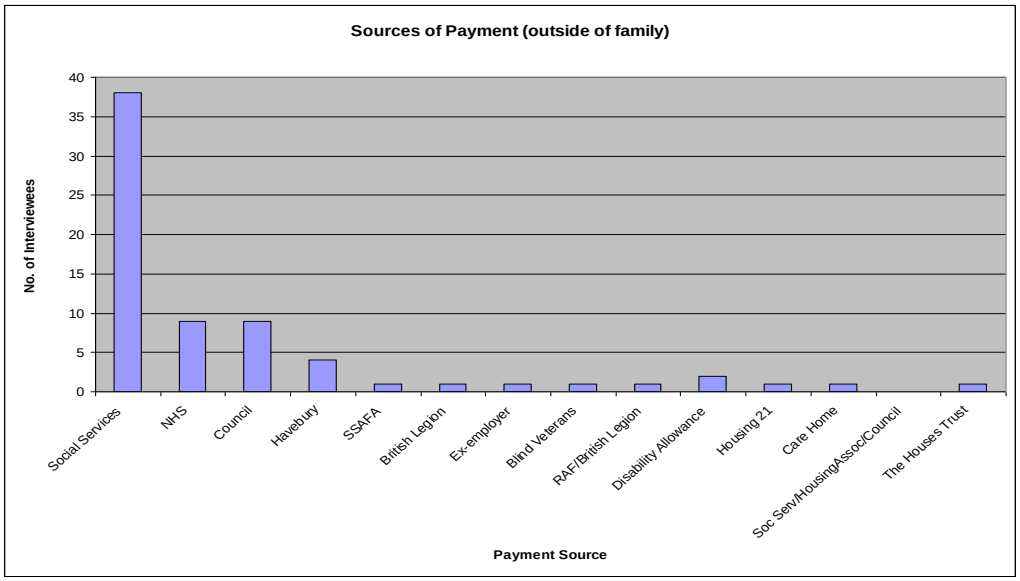
Chart 5



Q4. If you did not pay who did provide them

As Chart 6 shows when outside agencies had paid for these adaptations, Social Services were quoted as being the main source of payment, with other government agencies such as the NHS, County and local Councils and charitable agencies including housing associations, national charities such as SSAFA, Blind Veterans and the British Legion contributing finance in order to support independence.

Chart 6



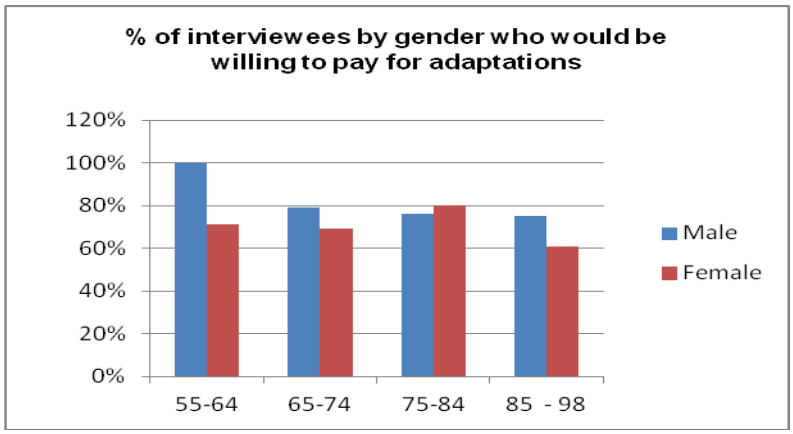
Q5 If you did need adaptations to your home would you be willing to pay for them yourself?

310 of the 350 people interviewed answered this question. However, it is clear from those interviewees who did answer the question that in all categories, except those aged 85-98 years, over 70% of interviewees are willing to pay reasonable costs for adaptations. In the most elderly category the 85-98 years olds, 67% are willing to pay. Those who say 'no' are more likely to say this because of their low income and/or lack of savings and make comments such as "they would like a wet room but can't afford it" and "I live on my pension and some benefits' or "I have now spent all my savings and can't afford any more" and 'if I had the money I would'.

When gender is considered the figures in chart 7 show that younger men are more likely to be able to pay, dependent on cost, and the percentages saying 'yes' are 100% at age 55-64 and remain above 70% at all ages. In comparison, at age 55-64 years only 71% of women were willing to pay and it was only in the 75-84 age group that women were more willing to pay than men (80% of women compared with 76% of men). The category least likely to be willing to pay are women aged 85-98 where only 61% of women were willing to pay compared with 75% of men.

The willingness to pay for both men and women decreases with age except for women in 75-84 age groups where there is a sudden rise in the percentage (80%) who would be willing to pay. The number saying 'no' they could not afford to pay for adaptations is 25% in the 85-98 age for men and 39% for women which may reflect a growing need for adaptations and differences in income.

Chart 7



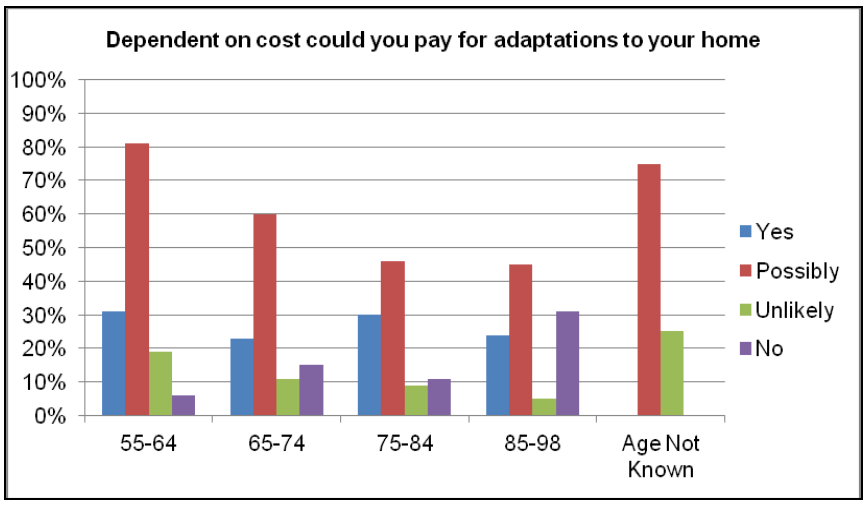
The comment most often made was that although willing to pay, ability to pay is very much dependent on cost so when asked if they could pay the answer is rather different. For instance, one of the major expenses undertaken is the installation of a wet room or

replacing a bath with a shower. From the information gained from the interviews approximately 61 interviewees had carried out this adaptation. Almost half of these were self funded and of the remainder who were funded by other agencies, the majority were paid through Social Services, and others by a mix of social services, charities, Suffolk County Council and local authorities, and the NHS, and at least 5 said that they are in sheltered accommodation and everything was done for them. Although desired, wet rooms were considered to be too expensive by most of those interviewees who did not have one but had expressed a wish to have one installed

Of those interviewees who completed the second part of this question, asking if they could afford to pay, of those aged 55-64, 31% said yes they could pay, 81% said possibly, 19% said unlikely and 6% said no. The 65-74 year olds confirmed that 23% could pay, 60% possibly 11% unlikely and 15% said no. The 75-84 year olds confirmed this too in that 30% said yes, 46% said possibly, 9% unlikely and 11% said no. In the oldest group again 24% said yes, 45% possibly, 50% unlikely and 31% said no.

The highest figure in all categories is the 'possibly' reply which underlines the view that although a majority of those interviewed would be willing to pay it was very much dependent on cost. As can be seen from chart 8 there is a definite decline in ability to pay with age and although of the younger respondents between the ages of 55-64 years of age, 31% could and 81% that they could possibly pay, this fell to 24% who could pay and 45% who could possibly pay at age 85-98.

Chart 8



When the percentages for women and men are studied (Charts 8a & 8b) the figures show definite differences. Only 17% of women at age 55-64 state they could pay with a high of 27% at age 75-84 and 21% at age 85-98 years. Those who can 'possibly' pay are much the higher group with 61% of women saying this at age range 55-64 which gradually reduces to 40% at ages 85-98. The number of women who state that they

would be unable to pay, rises considerably from 5% at age 55-64 years to 34% in the age range 85-98 years. At all ages men are more likely to be able to pay (50% at 55-64, 27% at 65-74, 31% at 75-84 and 30% at 85-98 years).

Chart 8a

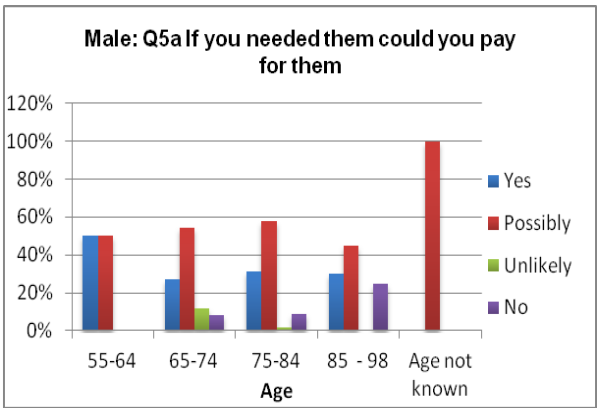
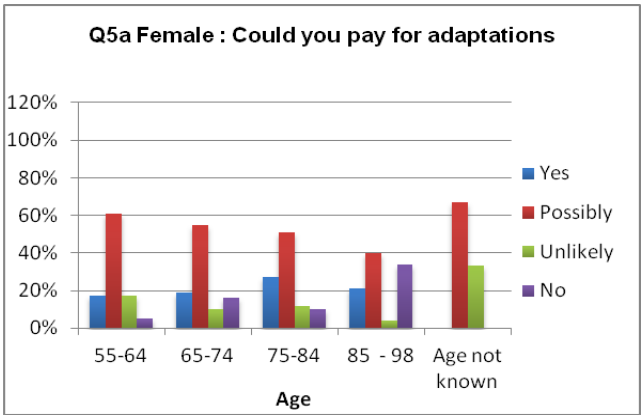


Chart 8b



These figures confirm the previous finding that most people of both sexes are willing, dependent on cost, to pay for adaptations that enable them to remain independently and more comfortably in their homes but that the ability to pay appears to decrease with age. However, it seems obvious from these figures that women feel they are less likely than men to be able to pay for adaptations across all age groups.

Q6 Are there any types of adaptation or other support which would make your life better or more enjoyable?

Because there was great similarity in the answers to this question and those given to Question 17, in order to prevent repetition the replies to both questions have been incorporated and can be seen at page 28.

SECTION 2 ASSISTIVE TECHNOLOGY

Q7 Did you know what Assistive Technology is before you read the explanation?

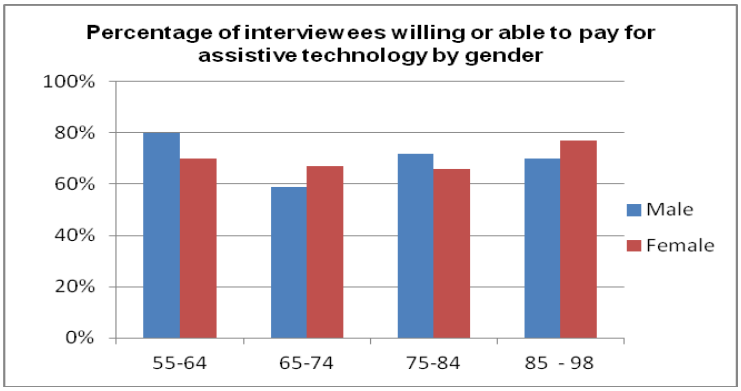
Assistive Technology is the term used for technical support which enables people to remain independent for longer. Assistive technology includes items such as personal alarms, pill dispensers, well being phone calls and visits, magnifiers for sight loss etc.

More younger women appeared to know what assistive technology is but in both men and women the level of understanding about what it means and what it can offer is extremely low with more than half of both men and women over 65 years not having heard of or understood the term Assistive Technology. This lack of understanding grew with age, with 52% of the 55-64 age group and 84% of the 85-98 year olds not knowing what the term meant without explanation

Q8 Would you be willing or able to pay for any assistive technology and technical support such as alarms, pill dispensers etc?

When asked if they would be willing or able to pay for support such as alarms and pill dispensers the majority in all age groups are willing to pay if they can, with as chart 9 shows nearly 80% of men aged 55-64 years being willing to pay and over 70% of women. The highest proportion stating that they are unable or unwilling to pay are men (41%) in the 65-74 age range. Surprisingly, a large majority of women in the 85-98 age group (77%) also stated that they would be willing or able to pay

Chart 9



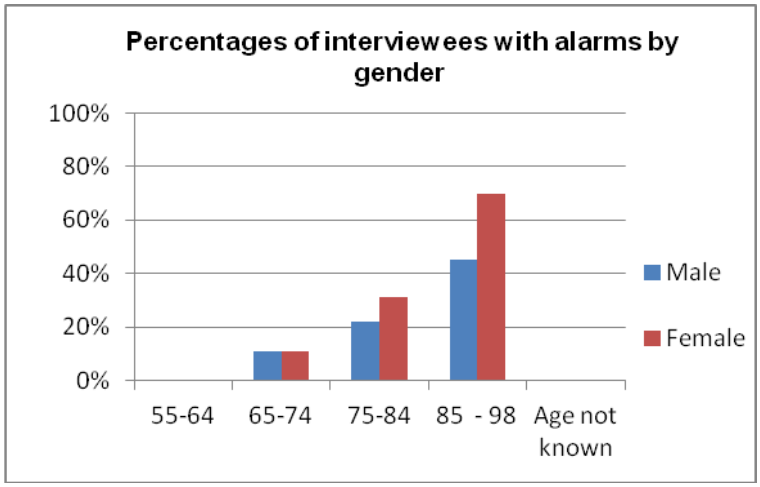
Q9 Do you have a personal alarm? If so, do you find it (a) useful (b) efficient (c) value for money?

When asked if they had a personal alarm none of the 55-64 year olds had one. As Chart 10 shows when examined by gender, as people grow older, unsurprisingly, the

numbers with an alarm in both men and women increased and although none of the men or women at age 55-64 had alarms this grew in men through the age groups to 11% at age 65-74, 22% at age 75-84 and 45% at age 85-98. Similarly, for women the percentages grew from 0% at 55-64, to 11% at 65-74, 31% at age 75-84 and 70% at age 85-98. These figures suggest that women are more likely to have alarms as they age than men.

Although only a small percentage of those who do have alarms, answered the question about whether they thought it was useful, efficient, or value for money during the personal interviews undertaken, there was a high appreciation of alarms and their usage and comments were made such as 'I have one, it gives me confidence but I have never used it' and 'everyone should have one'. Several mentioned that they were concerned about the cost. Many have had good experiences with rapid response to incidents but a small minority have had poor experiences where the system has failed for them (see case studies).

Chart 10

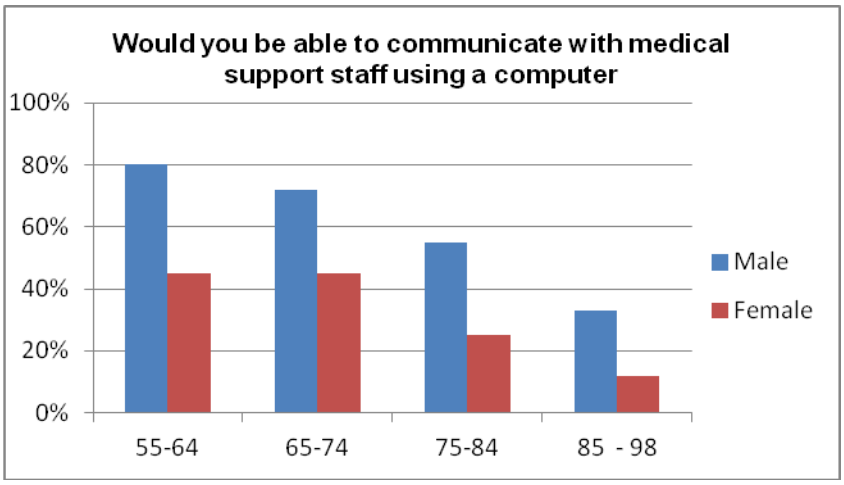


SECTION 3 INFORMATION TECHNOLOGY

Q10 If you were asked to consult with your doctor or social services by using a computer and video link such as Skype/Facetime/Telecare could you do this yourself?

The replies to this question showed that there is a distinct difference in ability within the different age categories and within gender (Chart 11). The majority of men (80%) at age 55-64 would be able to communicate with medical staff using IT compared with 45% of the women. This ability carries through at all ages with, at 65-74, 72% men and 45% women; at age 75-84 years 55% men and 25% women and at age 85-98 the proportion is 33% and 12% respectively. In addition to showing that more men than women are used to and are competent using IT, the figures also show that in both men and women the ability to communicate confidently using IT decreases with age.

Chart 11

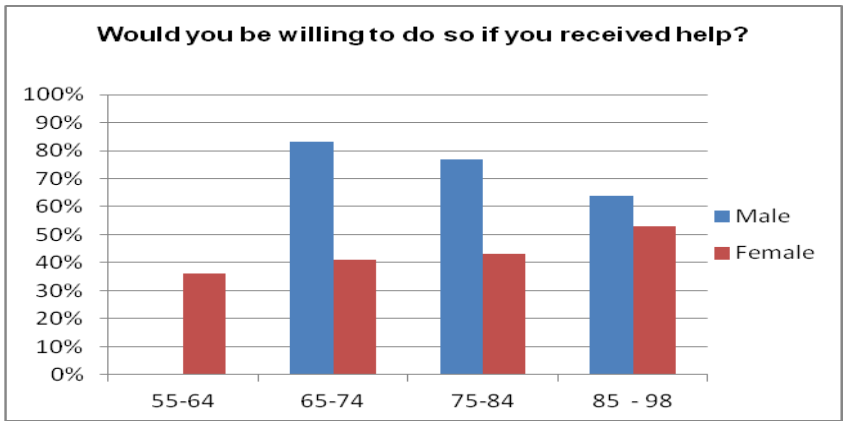


Q11 If your answer is no, would you do this if a carer or home visitor came to visit you with the IT equipment and showed you how to use it?

A gender comparison at Chart 12 shows that although the majority of interviewees who said 'no' would still not wish to communicate by using a computer more men in each age group would be willing to use IT, if assisted, than women in the same age groupings. However, the number of men willing to use IT with help and support decreases with age from 83% at age 65-74 to 64% at ages 85-98 while the number of women willing to do so with help actually increases with age, from 36% at ages 55-64 to 53% at ages 85-98. This does mean however that a small majority of women in age groups 55-64, 65-74 and 75-84 still say they would not wish to communicate with medical staff by using IT even with help, although at age 85-98 years 53% who originally said 'no' did change their minds if help and support was available. These figures indicate that where there is no experience with computers there is a reluctance

among the most elderly to use technology to communicate with medical staff. The reasons given included comments such as 'I want to see my doctor face to face' and 'I'm too old for new tricks' and 'personal contact is really very nice'.

Chart12

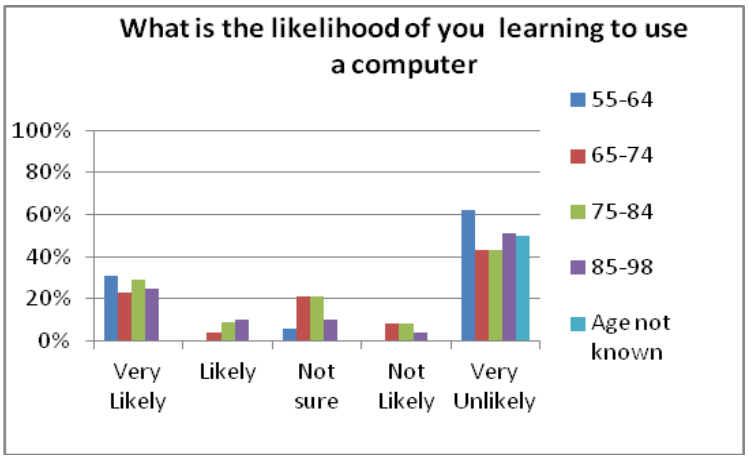


Q12 If help was offered would you like to learn how to use a computer/ipad or other equipment to help you maintain contact with health staff, friends, family etc?

When asked if they would like to learn to use a computer, iPad or other equipment on a scale of 1 – 5 with 1 being very likely and 5 being very unlikely, a total of 257 replied to this question. Chart 13 shows that those in the youngest age range 55-64 are more likely to want to learn to use a computer with approximately 31% across the age range saying they would be very likely. The high percentage of the younger age group (62%) who would be unlikely to take any lessons, if offered, could be the result of them already being competent or receiving help from their family or friends. Comments included 'I still use it for work as an active journalist' and 'my son came round when I down loaded Windows 10 and he sorted it out for me' and 'I've used a computer at work for years'. The other three age groups showed that a majority of those answering would not want to learn the computer and were very unlikely to take any courses.

When the comments interviewees made are considered this is, perhaps, because they were already competent but most because they felt they were either too old and could no longer cope with learning the new technology or are not interested in computers.

Chart 13



When the figures are broken down into gender they confirm this trend. They show that 2 of the 3 55-64 year old men who answered this question would like to learn more about computers with approximately 33% of men aged 65-74 and 75-84 years interested in learning more, reducing to 17% at age 85-98. The figures for those not wishing to learn at all and answering '4' or '5' do increase with age although this does not detract from the fact that a sizeable minority of men across all age groups would like to know more.

81% of women at age 55-64 were very unlikely to wish to learn a computer, again this may be because some are already competent, as this figure reduces to 52% at age 85-98. However, when looking at scale '1' and '2' a sizeable minority of women through all age groups (18%, 25%, 37%, and 39%) would like to learn more about how to use IT.

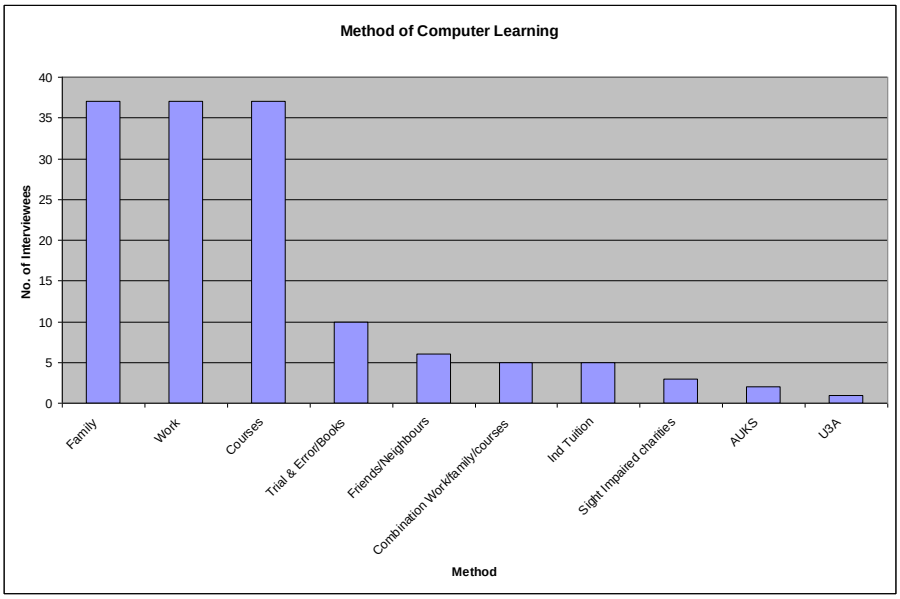
The figures do suggest that an opportunity exists to increase technical knowledge and use across all ages and both genders, if there is an investment of time and proximity (see case study 3). If older people are encouraged and given the opportunity to learn many would be willing to take advantage in order to improve communication, especially with family and friends.

Q13 If you are already using a computer what help did you receive as you started learning how to use it?

By far the most common methods of learning to use a computer were through work, family (especially grandchildren) and computer courses, with 37 interviewees stating each of these answers (Chart 14). Others had a combination of the three, with trial and error and books being the way 10 had learned. Others had learned with the support of charities such as SAUK, Aged Veterans and charities for the sight impaired such as Blind Veterans.

These findings were confirmed for both men and women, with women in particular receiving support from family and friends.

Chart 14 What help did you receive when learning to use a computer?

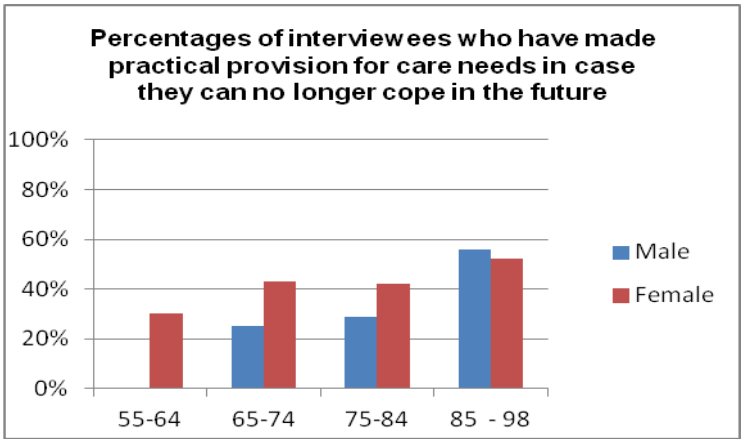


SECTION 4 LOOKING AHEAD

Q14 Have you made any practical provision for your care needs in case you find that you can no longer cope on your own?

Interviewees were asked if they had made any practical provision (eg installed a wet room, stair lift, downsized) in case they could no longer cope on their own. The figures (Chart 15) show that women are more likely to plan ahead than men. For instance at 55-64 years no men have made any provision but 30% of women have. This continues through the age groups. At 65-74 years the proportion of men to women taking action is 25%:43% at 75-84 years 29%:42%. This does, however, reverse slightly at 85-98 to 56%:52%. The highest percentage to have taken some action are the 85-98 year olds, with 56% of men and 52% of women having taken some action. The most puzzling figure is the high percentage of people who have not taken any action at all ages and it would have been interesting to have been able to investigate this more deeply.

Chart 15

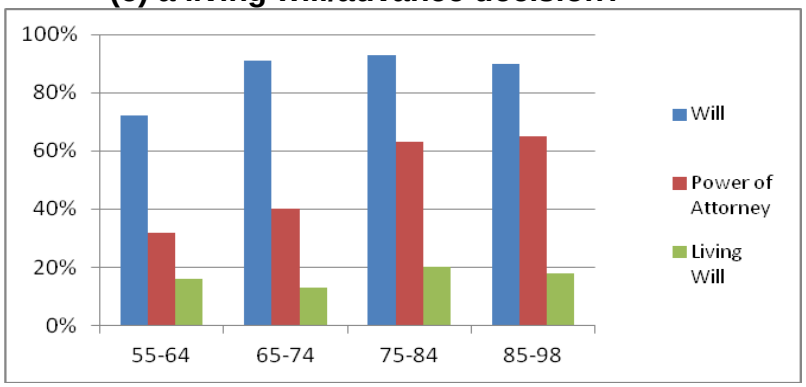


Despite this anomaly, the figures suggest that as we age we do consider our situation and make appropriate changes in response to issues in relation to health or life style. 19 said they had downsized to more appropriate houses, several said they were thinking about downsizing but felt overwhelmed by the idea of leaving a home of many years (see case study 3). As stated in question 2 about adaptations, wet rooms, showers and stair lifts had been installed but problems with cost and unsuitability of their homes prevented some interviewees from carrying out any or some of these installations. (see case study 1).

Q15. Have you (a) made a will (b) arranged a power of attorney (c) organised a living will/advance decision or (d) made any other arrangement.

Chart 16 shows that of those interviewees who replied to this question, the majority in all age ranges had made a will and although those between the ages of 55 -64 were less likely to have done so at 72% it is still a high proportion of those interviewed. Not so many had arranged a power of attorney but as the chart shows the proportion of those organising powers of attorney increases with age. Only a small proportion had organised a living will, with many needing an explanation about what this was. Several requests for copies and information were made and information sent out as a result. Other arrangements made were 16 interviewees across the age ranges who had already paid for their funeral and 3 had purchased burial plots.

Chart 16 Have you made (a) a will (b) Power of Attorney (c) a living will/advance decision?



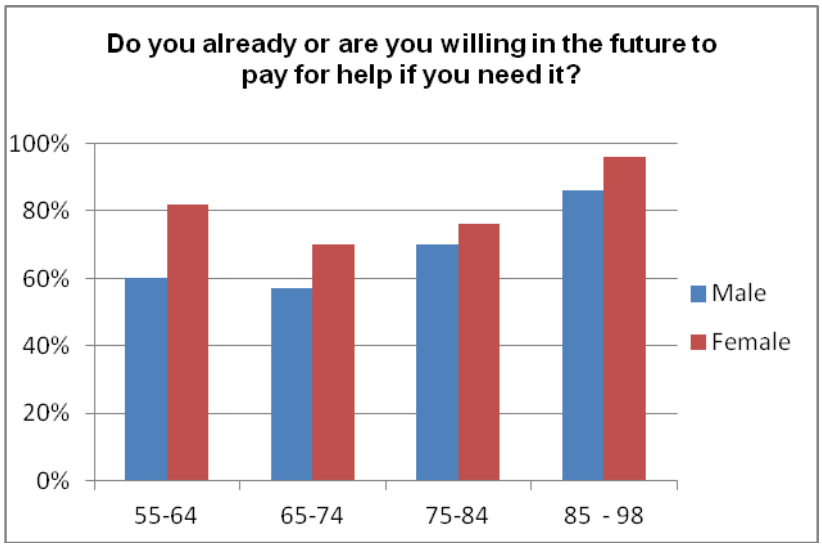
Looking at the gender figures, in the older age groups, especially between 85-98 years over 90% of both men and women had made wills. The percentages having arranged Powers of Attorney are smaller but with both men and women it can be shown to increase with age, with over 60% of men and women having arranged a power of attorney at ages 85-98 which is an increase from approximately 40% for both genders at ages 65-74. The figures for living will\advance decisions are much lower for both men and women, the highest being in men aged 85-98 and the smallest in younger men aged 55-64. The percentages for women show a small proportion at all ages making this decision (20%, 14%, 21%, and 14% respectively).

Q16. Do you already pay for or would you be prepared to pay for help in the future if you needed it?

When asked if they already did or would be prepared to pay for help in the future if they needed it, the majority of interviewees across all age groups: 76% of 55-64 year olds, 65% of 65-74 year olds 87% of 75-84 year olds and 89% of 85-98 years olds said that

they would. From this it appears that the willingness to pay for help and support increases as we age and, perhaps, need this help and support more (See Chart 17).

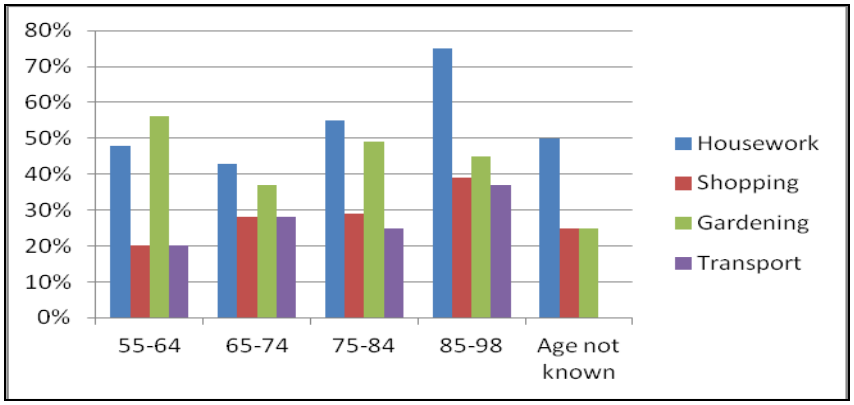
Chart 17



Women in all age groups are more willing to pay, or are already paying for, help and support with percentages of 82% at age 55-64 compared with 60% for men within the same age group (Chart 18). This figure actually drops for men in the 65-74 age group to 57% but then increases to 70% and then 86% at age 85-98. The percentage for women also drops at age 65-74 (70%) but then increases to 76% at 75-84 and 96% at age 85-98.

Several interviewees who would not be prepared to pay gave reasons for their reluctance to pay including one person who said this was because 'all her savings had gone'. Other reasons for doing so were 'they were not needing it (help) at the moment', 'I am living with my son' and 'my care home provides everything'. Other things people would be willing to pay for included Carers and Day Centres.

Chart 18 What kind of help would you be prepared to pay for?



The proportion of people willing to pay for housework grew with the age of the interviewee. Help with gardening was also a major consideration. Shopping was mentioned often with a proviso that children or neighbours helped and a small percentage shopped on line. Interviewees aged between 85-98 years were the highest in all categories showing a willingness to pay for help and support.

The figures within gender bear out the overall figures, showing that the willingness to pay for housework increases with age for both men and women. However men appear less likely to pay for housework in the younger age group 55-64 years (20%) than women within the same age group (76%). The percentage of men prepared to pay increases with age and by age 85-98 this has equalled out with 81% of women prepared to pay for housework and 86% of men. Younger women appear much more likely to pay for gardening (70%) than men (40%) but again at age 85-98 52% of men are prepared to pay and 45% of women.

There is no gender gap when considering shopping and not until the age group 85-98 years are a larger number of both men and women prepared to pay for this help (43% and 49% respectively). A minority of men across all age groups are prepared to pay for transport and a percentage increase occurs in women with 23% at age 55-64 to 45% at 85-98 years. This may be accounted for by a growing number unable to drive but using bus passes or, alternatively, paying for taxis.

Q17. What Practical things could be done to change your life for the better?

As explained at question 6 these two questions have been incorporated as the replies were almost identical. The practical issues that were raised which could be done to change lives for the better or make life more enjoyable were very wide ranging. It is therefore difficult to analyse the results as they are so individual but if taken as categories they can be broken down to include the following replies:

Category
1. Transport
1. I had to give up car because of the cost & it broke my heart, the only time I cried. 2. To be able to drive again, it was the costs I couldn't afford the upkeep 3. An improved bus service 4. more convenient bus stops 5. Bus stopping closer to the flat 6. More buses although we are not too badly served here 7. A bus service or some flexible way of getting around 8. Volunteer drivers for minibuses – it works in Yorkshire they're fabulous

2. Getting Out & Getting Around
1. A shop in the village which now has nothing 2. I would like to be in the position to walk outside 3. I would like to go out but I have no one to take me 4. I'd like to go to the cinema etc but I have no-one to take me 5. It would be nice to know there were wheelchair accessible toilets so you could get where you want to go when you want to go especially in the evening 6. A new wheelchair 7. More social care 8. More neighbours to 'pop in'. They are all very old but help where they can but we would like someone to get additional shopping things, we used to do things together in the street
3. Personal Care and attention
1. A good hearing aid 2. One person to deal with everything 3. Someone to do the small things, change lights, high dusting, deal with mould etc 4. Nothing practical but my husband back to do the practical things 5. Another pair of hands – you can't care on your own 6. A one to one to show me how to use the internet on my tablet. If they close Barclays I will need to do on-line banking 7. A walker that fits in the car 8. More financial advice available that doesn't cost the earth
4. Home adaptations
1. Probably a handrail in the kitchen as I have steps 2. The best thing would be a downstairs toilet – every house should have one 3. Extra things to get me about in the house 4. Raised beds in the garden. I would like someone to do the garden 5. We could have a wet room. We would really like one 6. I have steps from one room to another – rails might help 7. A stairlift 8. Stop cold calls and nuisance callers
5. Lifestyle Change/Downsizing
1. I need to decide where to live 2. Find somewhere more practical than this, it is inconvenient to bring in shopping 3. I've looked for somewhere else to live but can't find anything I like
6. External – Outside Issues
1. A dropped kerb outside my home for my wheelchair 2. Pavement repairs 3. Stop overcrowding in villages

There were a number of less practical comments, some negative, but these concerns were based mainly around failing health, finance and lack of social contact. Comments made included:

- a new pair of knees
- a new back. I get right in the dumps about it my first job is a cup of tea
- getting rid of back ache but nothing else
- it is not money I want it is friendship. Give me back my life. The nurse is supposed to come & is ill so I am still waiting - legs terribly swollen
- body getting worse
- To win the lottery & pay off my mortgage. I have an interest only mortgage and it is not enough
- I don't choose to be a bachelor. I miss good company
- Winning the Lottery, Losing Weight - I've lost some but not enough.

However, with many there is a surprising and general acceptance of their circumstances. Comments such as :

- we have everything we need
- I don't think there is anything practical
- I can't think of anything that we could do
- I'm quite happy doing what I'm doing - I don't like over 60s clubs 'full of old people' I'm happy on my own
- we manage very well at the moment
- we are quite well provided for although blue badge took so long
- not at the moment - I am quite reasonably fit/I have angina but can't think of anything that would help - medical treatment good
- I am quite satisfied as I am
- I don't think so I have all I could expect to have
- Continued reasonable health. I have no pain and am happy with my lot
- nothing - I've got to the point where I am independent I can't get used to having to ask

It is surprising how many of the people interviewed were quite positive about their situation and their main concerns are, not unsurprisingly, based around failing health, finance and social contact. With many there is a general acceptance that with older age there is an expectation of worsening health but there remains a great need for social contact and opportunities to meet more people outside their homes. Enabling this will require investment of both time and money but the benefits for health and wellbeing may well outweigh the cost.

SECTION 5: PERSONAL BUDGET AND DIRECT PAYMENTS

Q18 Have you heard about the introduction of Personal Budgets?

Only 60 people of the 350 interviewed across all the age categories had heard of the introduction of the Personal Budget and Direct Payments (Chart 19). As percentages of those interviewed this translates as 20% of 55-64 year olds, 29% of 65-74 year olds, 11% of those between 75-84 and 14% of 85-98 year olds. The lack of knowledge of the change to personal budgets and personalisation and the process involved is not surprising in those interviewees who are still fit and sufficiently well not to have needed health or social care and many will either never need social care or, if they do, will have the means to be self funded. The willingness to self fund is confirmed by earlier research in this report which shows that where costs are reasonable, the majority of people interviewed were willing to contribute to, or pay for, the care and support they needed.

The main concern must be with those older people who are more likely to need social care and who with advancing age may be less able to self fund. Therefore, with 89% of 75-84 year olds and 86% of 85-90+ year olds having no knowledge of the change it is these age groups who will need most support if they need social care in the future.

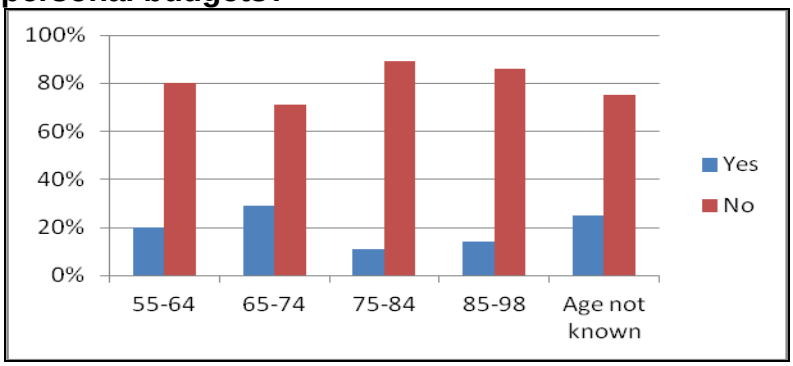
Earlier research in this report (see page 22 Section 4) shows, however, that there is a need to educate and perhaps encourage the younger older person to plan ahead, especially as access to support for social care is becoming increasingly difficult. In order to plan ahead people will need to be able to access information which explains in detail what their options are and how they can ensure that they have sufficient funds to pay for their social care, if needed. This information is available through various national organisations such as Age UK, 'Find me Good Care', Carers UK, and 'Which: Elderly Care'. However, although those using computers will be able to access this information easily, those who do not use computers need to have information readily available in paper form (See page 18 Section 3). The availability of advice centres and organisations should be widely publicised and the advisability of planning early encouraged locally and nationally.

Because of the small numbers who knew anything about personal budgets, it is proposed that in this section only numbers rather than percentages are used. **T**he breakdown of men and women who are aware of the introduction was 16 men and 44 women.

Number of Interviewees aware of the introduction of personal budgets by gender

	55-64	65-74	75-84	85-98	Age not known
Male	1	7	3	4	1
Female	4	21	15	4	0
	5	28	18	8	1

Chart 19 Have you heard about the introduction of personal budgets?



Q19. Not all those who had heard of the implementation of this change fully understood what it meant and none of the 60 who purported to know about the introduction of personal budgets completed Q20 asking if they knew about the different ways a personal budget can be paid with vague comments being made such as 'it can be paid into your bank account' and 'it's to pay for your care needs'.

Q21. However, when asked if they would want to take a personal budget as a direct payment 42 of the 60 said that they would prefer a direct payment, 4 did not answer and 14 said they would not want a direct payment.

Q22. 21 interviewees said that they would want help to manage a direct payment and of these, families were the first port of call for support to manage their payment with 17 saying they would go to them for help, with 3 opting for a private company and only 1 opting for Social Care support. Only 1 person said 'if I was capable I would do it myself'. No answer was given from the other 18 interviewees..

Q23. When asked if they knew anything about the responsibilities of an employer, of the original 60 interviewees who had heard of the personal budget introduction only 16 thought they knew enough about employer responsibilities; 41 did not and 3 did not answer the question. Certainly these figures show that many older people are

unlikely to be able to manage being an employer and care will need to be taken to ensure that the help and advice needed to support the less able older person in making decisions and managing their finances is made available to them.

As stated earlier, the main concern from this section of the consultation is the lack of knowledge in all of the age groups of the changes to the social care system. Although many will never need to apply for social care, if this system is to be implemented successfully, there will need to be a great effort made to inform the older generation, who will be subject to the change in the future, of the implications and how this will affect them.

As a result of the findings of this initial consultation and concerns expressed by national organisations about the impact of personalisation on older people, Suffolk County Council asked that we undertook further research to explore the background nationally and also to provide some information about the experience of older people in Suffolk who had been through the process of being allocated a personal budget. This further research can be read at Appendix 2 (page 36).

6. APPENDIX 1 CASE STUDIES

These case studies describe the experience of older people who are becoming increasingly less mobile and show how they manage and cope with a changing lifestyle often in difficult circumstances.

CASE STUDY 1

Mrs G is 84 and lives alone in her own home. She receives a pension which pays for the 'day to day' costs, and due to her lack of mobility and general ill health receives attendance allowance and other benefits which pay other household expenses. She also receives a small pension from her husband which will pay for her funeral. Mrs G now lives in two rooms downstairs which are the only rooms she heats and she is worried about her ability to pay her fuel bill in continuing cold weather. Despite this she feels fortunate to be in receipt of benefits which enable her to continue to live in her own home.

She has fallen many times in the past and has had rails installed in her home on the stairs and front door by social services. She has designed her home so that she also has 'plenty of chairs' to fall into and now lives on the ground floor. She has 'strip washes' as although she has a toilet downstairs there is no bathroom and she cannot afford to install one. She has a 'relaxing room' overlooking her garden and bars on the walls to help her get around.

She does have an alarm but twice when she has fallen she has forgotten to press it and her first thought is 'how do I get up'. Both times she has rolled herself toward items which helped her to pull herself up. However, when she has fallen and pressed the alarm the response has been prompt and efficient. She has nothing but praise for the response team and paramedics. She feels she falls when she makes sudden moves. She exercises daily, doing the exercises taught her by the physiotherapist following one of her falls. However, she gets up at 5am and it takes her until 9 to get herself dressed and ready for the day. She has had a cleaner and although she does not have one any longer she feels she ought to have one as she can't get to the back of her cupboards. She has herself paid for narrow shelves which help her to reach all the items she needs. She worries about the cost of help in the home. She buys in some meals but often cooks her own meals. However her increasing forgetfulness frightens her as she feels she is not in charge of what she does anymore. She feels she has slowed down in the last 6 months and is easily distracted.

She has a group of friends who, although they can no longer get out to meet each other regularly, ring each other every day, morning and evening to ensure that they are all OK. When asked what she would do if someone did not answer she said 'she'd press her alarm'. She has a loving family for which she is grateful but sometimes feels she does not have enough time to herself as she finds visits longer than a couple of hours exhausting and now needs a sleep in the middle of the day.

She loves her garden and has spent some of her attendance allowance in installing five metal arches, two seats and a shed in strategic places so that she is never more than three steps away from some support. She hangs her washing on the rungs of the arches. Because of this innovative way of spending the money at her disposal Mrs G is still able to take advantage of the garden she loves, can negotiate her way around her garden, and sit on the seats in the sunshine without too much risk of falling.

Mrs G has no TV and has never used a computer and would only want to learn if she could be shown how it would work and make a decision then. She likes a personal relationship with her doctor and would not want computer communication. She has made a will and arranged a power of attorney. She does not want to move into a home and wants to stay in her own home if possible but thinks that her children would look after her. She has never heard of the introduction of personal budgets and direct payments and has no idea if it will affect her personally and is very nervous of any change

Mrs G is a fiercely independent and intelligent woman who is becoming increasingly less able but is determined to remain in her own home for as long as she can and is grateful for the financial help she receives which facilitates this. She describes herself as a happy and contented person who would just like to stay where she is as long as she can afford to.

CASE STUDY 2

MrM is 77, a widower, living in his own home, a small cottage, outside a village in a very rural environment. He is very independent but has a limited income. He installed a wet room at his own expense some years ago as he could no longer get into the bath because of back trouble. He also installed banisters on both sides of the staircase as the stairs are very steep and narrow so are unsuitable for a stair lift. He feels he has done what he can to help himself on a very limited income.

His family live close and they also keep in touch by calling him each morning and evening to ensure he is OK. However, his home is very isolated being outside the village and he feels there is now no community feeling and he does not see his neighbours. His family help him with tasks such as changing beds, cleaning windows and other household tasks although he enjoys cleaning the house himself when he can. They shop for him and he goes to the Post Office in the village for other items he needs. His doctor lives in the village and they have a very good relationship.

He has recently been diagnosed as having leukaemia and has had several transfusions. He says the NHS has been 'absolutely brilliant' but he has refused a care package as he prefers to be independent for as long as he can and has moved his bed downstairs to make things easier for himself.

He loves his computer and contacts his family overseas regularly by skyping. He says he can't afford the cost of an alarm but has a mobile which he uses as a means of contact with his family. Although he has paid for his own funeral he has very little money and SAUK has helped him complete the forms to apply for a 24hour disability allowance. He had no knowledge of the changes to the benefit system.

His youngest son says he should sell up but he says 'I am not going anywhere'. He also feels that in his financial position he could not afford to pay for care as it is too expensive and his money would only last for a year or so before it ran out. MrM is a further example of a fiercely independent older person who manages on limited finances to maintain a home of which he is proud and in which he is determined to live for as long as he possibly can.

CASE STUDY 3

Mrs B is 85 and lives alone in an old and very large house in the centre of her town. She realises that the house she loves is inconvenient and too big for her with steps up and down into rooms and with a narrow staircase, unsuitable for a stair lift. She has searched for more suitable houses but she keeps putting off selling the house she knows and loves so well. She is overwhelmed by the prospect of moving and even with family support she feels she has 'so much stuff' she doesn't know what she would do with it all. There are only very small sheltered homes nearby and she feels she would hate an old people's home as, in her experience, 'they just sit there and get jealous of each other'.

She has had an additional stair rail installed and a rail on the bath and a bath board in the shower. Social services installed grab rails by the back door and her son-in-law installed a grab rail into the dining room from the front door. She has had discussions with her family who appreciate her dilemma and understand that she wants to remain in the house.

They are therefore discussing some adaptations to the home to help her stay there. An architect has been to give advice about what is possible but the expense involved is more than she can afford. She says she is 'asset rich but cash poor'. She would like a wet room, to move the toilet and adapt various rooms such as the kitchen including removing steps. She has contacted the council twice to see if she can get any help but no-one has contacted her or visited her. She no longer goes down to the cellar or up to the attic.

Although she has problems with mobility and balance she is very competent on her computer. She answered a Suffolk Age UK advertisement offering 5 weeks tuition for £25. She answered this and is doing the classes and has been given an ipod. She has missed one class because of vertigo. Fortunately she has been taken in to the classes because she has to be there by 9.30 which means that she would have to take two buses and this would cause her problems because of the difficulty she has in getting about. Getting there is the only problem. She has a laptop and a smart phone but feels she is not competent using the smart phone as all she can do is send texts. She would like lessons in how to use this.

She also has a personal alarm but has never used it and as she has a mobile phone she is not sure whether the alarm is useful or worth the money. She does wear her alarm round her neck but would prefer a watch type.

Mrs B still walks every day but feels quite isolated as house around her are rented and often empty and other neighbours are often out or away. She employs someone to do the housework and a gardener.

Mrs B is another older person who despite growing difficulties wishes to stay in her own home. She should seek advice about any financial aid she might be entitled to. If, however, she is to be considered under the new system for allocating benefits she will need to be advised about the implications of the changes as she does not know anything about them.

CASE STUDY 4

Mrs H is 89 and lives alone in a rented flat in a care home. Before moving here, 5 years ago, she lived in a large town house and social services provided her with things such as raised toilets and walking frames. As the house she lived in was on three floors with a cellar, the stairs were narrow and the whole house was unsuitable she made the decision to move. She wanted to stay in the centre of town close to her friends, so she initially moved into a ground floor flat but an infestation of rats meant she had to move from there. Her only sadness is that many friends have died or moved so she does not get as many visitors as she used to. However, she socialises with others in the flats when she wants to and unlike some other places she has heard about they are 'not cliquey'.

The decision to move was not difficult, she feels she has always planned ahead and knew she could not cope and she received a great deal of help from friends and family. Various items of furniture were given to the family so she knows who has them. As she was becoming increasingly less mobile she finally moved into rented care accommodation which she says is the best thing she could have done. Adaptations such as a wet room and alarm system are already installed and since she moved into the flat she has been provided with a bed which helps her sit up and a commode in her bedroom. Her sofa and her toilet have been raised and she has a wheelchair to get around inside. She is waiting for an electric wheelchair which she can use outside. Her only complaint is the kitchen which is very small.

Her increasing ill health means that she now requires more care and she cannot speak highly enough of the care she receives. The carers are there throughout the night. There is a senior carer who looks after 8 flats and organises care for residents where appropriate. The only problem is with the temporary staff who are sometimes employed and are not as well trained or competent. Her surgery is excellent and she has a co-ordinator who organises her treatments and tests which are carried out in the care home.

She would not wish to communicate with medical staff using a computer, although she still uses her ipad to keep an eye on her savings as she has to pay her living expenses from them. She has texts from the Guardian to keep up with the news. She would however, love to have someone to come in to teach her more about her ipad as she feels she doesn't get enough value from it and is afraid to do anything unusual in case she does irrevocable damage.

She no longer cooks and a local company brings in cooked meals to the home which are excellent. These are delivered to the on-site restaurant but teas can be purchased and if someone cannot get out the meals can be delivered to flats.

She has made a will and power of attorney and has also arranged advanced care plans. She is not having a funeral but has donated her body, if it is suitable, to the anatomy college in Cambridge. There will be a tea party at the care home. One of her regrets is that she cannot get out more as she needs someone to take her but is accepting of her limitations and keeps occupied so far as she can.

CASE STUDY 5

MrsP is 87 years old and lives in a bungalow on an estate for older people managed by a housing association. She owns the bungalow and pays an annual maintenance fee that pays for the maintenance of the communal gardens, personal alarms, window cleaner and other tasks such as grass cutting. The cost is about £100 a month and if the property is sold the managing company takes 1% of the price of the property.

She has lived in this property for 15 years. Prior to this she lived in a large property which, following the death of her husband, she decided to sell and purchase a bungalow because the state of her knees meant that she could not climb the stairs. The bungalow is easy to maintain and because it is on an estate for older people provides her with a good social life, although she now finds she cannot walk far so cannot get out as much as she did and is beginning to spend a lot of time on her own. However, she continues to host a coffee morning for other residents which is attended by up to 17/18 people. She has never regretted the move and is very involved in arranging social events on the estate.

She was supported throughout the process of buying and selling her properties by her family and her solicitor. She feels that she could not have done it without them. Her family helped her move by supplying lorries and vans and moving everything for her. They continue to support her with regular visits and undertake all those small tasks which become so difficult for older people, changing light bulbs, repairing leaks, moving furniture etc.

Her daughter has power of attorney and manages all her finances as her memory is becoming quite poor. She has had tests for dementia but has been told she is OK. She writes everything down but sometimes forgets to take her medication so her daughter rings her morning and evening in order to check everything is alright. She has a personal alarm which is paid for within her maintenance fee and she finds this reassuring to have. She does feel she may be interested in a pill box which sends a signal to remind her to take her medication.

Following the operation to have both knees replaced, social services installed a wet room and rails outside to help her get around. She uses a walking stick provided by social services inside her home. She would be willing to pay for adaptations but as she has a limited income it would be very dependent on cost.

Mrs P feels she is very lucky to have her family living close to her and to be a resident on an estate that provides her with friendship, company and support. Despite this her increasing lack of mobility means that she is becoming more isolated for longer periods as she can no longer get out and about as she used to and this and her poor memory are of great concern to her.

APPENDIX 2

A FURTHER INVESTIGATION IN TO THE IMPACT AND EXPERIENCE OF THE IMPLEMENTATION OF PERSONAL BUDGETS AND DIRECT PAYMENTS ON OLDER PEOPLE

At the request of SCC it was agreed that although many older people would not need to access social care at any stage of their lives, it would be useful to have some further research undertaken to show how those individuals who did need to be considered for social care support, understood and experienced the implementation of personal budgets and the process they went through . Therefore research was undertaken to see how the situation is being managed and experienced nationally and then older people in Suffolk were asked about their experience as individuals when being considered for social care support.

A personal budget is defined *as 'the amount of money that will fund a person's care and support costs. It is calculated by assessing a person's needs. It is spent in line with a support plan that has been agreed by both the person and the council. It can be either a full or a partial contribution to such costs. The person may also choose to pay for additional support on top of the budget. So the term personal budget refers to social care money.'*[1]

Nationally, the implementation of personal budgets on older people has caused some concern. Issues have been raised about the differences and difficulties faced when applying personal budgets to older people. As a result of a review carried out by Think Local Act Personal (TLAP) and the Social Care Institute for Excellence (SCIE) in 2012, Community Care UK reported in 2013 that there were massive variations in older people's experience of personal budgets[2].

These issues are reflected in a report published by Age UK[3], which indicates that older people may have different needs to those of younger disabled people. Older people are likely to be assessed at times of crisis and vulnerability and therefore are less able to predict their future needs or to have confidence in their ability to take control of their circumstances. However, most still wish to have choice and to be independent and

[1] Putting people first: measuring progress the Local Government Association and Association of Directors of Social Care, May 2009

[2] Community Care UK 'Massive variations in older people's experience of personal budgets' Mithra Samuel, Jan 2013

[3] Age UK, 'Personalisation in practice: lessons from experience' 2010

therefore, when used appropriately, personal budgets, although sometimes limited in use, can have a positive impact.

The Care Act 2014 and Care and Support Statutory Guidance 2015 introduced the principle of additional choice in tailoring social care around an individual's specific needs. The introduction of 'personalisation' has impacted on how personal budgets are implemented for older people[4] and Individual Service Funds (ISFs) have led to private and voluntary organisations agreeing to deliver services with local authorities becoming commissioners rather than providers of services. Where older people are given both a health personal budget and a social care personal budget the statutory guidance stresses the importance of both bodies working together to make sure everything works effectively.

The introduction of ISFs[5] is an attempt to provide a more flexible way of managing personal budgets, especially where people feel unable to manage a direct payment themselves but wish to have more flexibility than a council managed contract provides. ISFs have a high degree of flexibility and can be amended more quickly as older people's needs change but the plan remains under the control of the individual in consultation with the provider. In Southwark for instance using ISFs has showed significant savings and between 2010/11 and 2015 a total of over £1,795,000.00 has been saved[6]. However, in some instances councils have been unable to continue with ISFs as the contractual agreements have proved difficult to sustain because private providers have been unable to meet the strict financial and care criteria for such agreements and have therefore ceased to provide social care. The situation is becoming worse and is causing deep concern across many authorities resulting in government considering plans to reform the existing policy, that allows a 2% precept on council tax, to enable councils to pull forward increases in council tax which may have been planned for future years.

There is also a post code lottery which becomes apparent when looking at the evidence highlighted in the report 'Social isolation experienced by older people in Rural Communities.[7] This report written by Professor Sheena Asthana for the CRC indicates that rural authorities, which tend to have older and less deprived populations, receive lower grant allocations, according to the study. These LAs in more rural communities spend less on social care, charge more for home care and allocate lower personal budgets than local authorities serving urban, younger and more deprived populations. This is despite the increased cost of providing social care in rural communities because

[4] Age UK 'Personal Budget and direct payments in adult social care: Factsheet 24 April 2016 Age UK

[5] Individual Service Funds & Contracting for Flexible Support Think Local & Act Personal 2014

[6] ISFs in Action: Personalising Block Contracts, Sian Hoolahan, The Centre for Welfare Reform, March 2012

[7] Commission for Rural Communities Report '*Social Isolation experienced by older people in Rural communities) Prof Sheena Asthana June 2012'*

of the isolation and added transport and employment costs. Professor Asthana believes unfairness is due to a flawed national resource allocation formula that should be revised as these variations 'offer clear evidence of territorial injustice'.

The SCIE report 'Improving Budgets for Older People'[8] highlighted the challenges faced by older people when considering how to manage a personal budget. It recommends that there needs to be sufficient information, advice and support available at every stage to ensure that older people make choices best suited to their sometimes fluctuating circumstances. This is crucial to the success of the management of personal budgets, as direct payments can prove to be a burden to both the client and their family and friends if the support, advice and monitoring is insufficient or unresponsive to changing circumstances, especially when older people are caring for even older family members. The case studies show how effective working together can be in ensuring that those who need social care receive appropriate care and support.

The *Centre For Later Life Funding*[9] looked at the impact of changes in social care. The conclusion reached was that the settlement for social care outlined in the Spending Review (2015) does little more than paper over the cracks, which many of those in need of care are already falling through. While some will be able to rely on family to support their needs, increased prevalence of unpaid caring may have adverse consequences for those providing support and for the economy as a whole due to reduced employment and may even lead to an erosion in the quality of care provided. It states that if 'we really are moving to a model of care that is almost entirely reliant on family and community support then we must have the adequate infrastructure in place to support the needs of informal carers. Yet with local government facing more severe real terms spending cuts it is difficult to see where this capacity is coming from. The future for adult social care looks bleak'.

An Observer editorial dated 16 October 2016 stated 'that those receiving state support for the cost of their care has fallen by at least 25% in the last five years' and that there are two tests – the national set financial means test and a locally set test of their care needs. The impact is that there appears to be less care available and at a later stage. In addition, the proposed £72000 cap has been kicked into 'the long grass'. Finally it does ask what sort of society we are that we invest billions in science to extend our lifespans but 'are increasingly abandoning vulnerable older people to cruelly insufficient levels of support as they face physical and mental decline'. All the facts and available research seem to indicate that 'care' is the wrong world to be using when our attitudes to older people are examined.

[8] 'Improving Budgets for Older People, SCIE, Sarah Car, Jan 2013

[9] Centre For Later Life Funding 'The end of formal adult social care (A provocation by the ILC-UK) 2015, Ben Franklin

The National Information Board (Paper Ref NIB0607-006) 'Delivering the 5 year forward Review on personalised care 2020[10] outlines the planned use of a programme to support local authorities and service providers which will provide people with more choice and control of their health and how any support needs are met. The use of such programmes which can integrate health and social care in a seamless way, may, in the future, be very useful to older people but at the moment many are not in a position to use computers confidently and could not cope with or choose to use such a programme without a great deal of help and support.

The Directors of Adult Social Services (ADASS) Budget Survey of 2016 shows that there is increasing concern because local authority budgets are being cut substantially at the same time as growing numbers of older people with complex needs require social care. Despite the government enabling local authorities to increase council tax to assist with the cost, the view is that this will not be sufficient to cover the increasing cost of social care. Personal budgets and ISFs are becoming increasingly difficult to obtain and the prospect for the future is very negative with the majority of ADASS Directors anticipating that by 2020 fewer people will access adult social care services and that personal budgets will be smaller. So the question remains: who will do the caring and how do local authorities plan in these circumstances?

In Suffolk itself every effort is made to meet its responsibilities under the Care Act 2014 through the Supporting Lives, Connecting Communities (SLCC) scheme and the case studies attached, in which older people have gone through the process show that the government requirements are met. In addition, in order to address the issues arising from reducing funds and increasing demand, the Health & Wellbeing Suffolk: Vision for Health and Social Care Services in Suffolk Better Care Fund Plan 2016/17, was approved in August 2016, and details how Suffolk County Council, local authorities, the NHS, Social Services and neighbourhood teams plan to take forward an integrated approach to health and social care through the Better Care Fund which they hope will maximise efficiency and ensure that intervention is timely and meets the needs of each individual person. Suffolk County Council is already introducing an additional 2% social care levy but there is still concern that this sum, whilst helping to meet rising costs due to the living wage and other costs faced by care companies, will not compensate for cuts in funding and funding will still be less than in previous years.

A small consultation carried out by Suffolk Age UK (SAUK) in West Suffolk[11] confirmed research undertaken later by other organisations and SAUK showed that older people wished to maintain independence and control in their lives but that confidence and trust

[10] The National Information Board (Paper Ref NIB0607-006) 'Delivering the 5 year forward Review on personalised care 2020

[11] Individual Budgets, Steph Hill, SAUK 2007

in the people giving advice and support is essential to a successful outcome with regular 'robust and rigorous' reviews undertaken. This is confirmed in this current report which highlights the fact that people who are being assessed to ascertain their social and care needs prefer one person as a contact to prevent confusion. This preference has not changed in the intervening years but because there is less financial support available to ensure that this happens it has placed more stress on the social care system and it becomes increasingly difficult to meet the statutory requirements.

The evidence for this is clear but during a meeting with the Bury Town Cluster Team Manager in Adult and Community Services he explained how their team worked in order to meet statutory requirements. Any person needing help and support is allocated to one person who takes them through the process and manages the resulting social care plan. Following interviews with four people (including one couple with the husband diagnosed with dementia) the effectiveness of this means of support becomes apparent. All the interviewees live in very different circumstances and all have been allocated a personal budget through the auspices of this team. All four of the interviewees spoke in very complimentary terms about their treatment and the social service staff who supported them through the process. These case studies are detailed below.

In order to highlight the differences that are apparent in the system, additional case studies have been included of people in similar circumstances, where the picture is less clear. One person was unsure who was paying for what in providing his care and seemed to have several people visiting and asking questions; another where the management of the direct payment had greatly stressed the family but an ISF appears to be working well; a self funded gentleman who was not sure how the agreement was reached but assumed his sister, who had power of attorney had arranged it and a vulnerable woman who is refusing to be considered for social care but who may really need it.

Conclusions

The research nationally relating to the implementation of Personal Budgets for older people reflects similar issues to those raised in our own piece of research which was carried out by interviewing older people in Suffolk.

1. Initially there are often several people visiting to discuss issues with the person concerned and often there is some confusion about who they are and what they are doing. If not already implemented, one person should be appointed as soon as possible following the referral and full explanations given about what services are being provided.

2. Older people usually need social care at the point in their lives when they are most vulnerable and therefore efficient and flexible advice, support and implementation is needed to meet their needs which may change very quickly. This is especially important where people with dementia and their carers are being assessed as their needs are likely to be even more complex.

3. Often older people prefer to have services provided and managed for them as they feel unable to manage this for themselves. However, where possible, they should always be included in the prior and ongoing discussion with alternatives and choices explained to them. What, why and by whom services are being delivered should be discussed and agreed in writing and not imposed.

4. The level of knowledge about personal budgets and their implementation is negligible amongst the older people interviewed for this report. Some of the most vulnerable and therefore the most likely to be in receipt of personal budgets seem to be unaware that they may have been assessed. There is lots of information available on the internet to explain and advise but written information is hard to come by unless requested. Recipients of social care should receive written information about the services they receive and who is providing and paying for them.

5. Some older people do not want people who may wish to investigate their finance and personal life coming to see them as they believe it is an invasion of privacy. It is therefore essential that when social care is needed and an assessment is undertaken older people are always treated with respect, dignity and sensitivity.

CASE STUDIES PROVIDING EXAMPLES OF PERSONAL EXPERIENCE OF ISSUES RELATING TO PERSONAL BUDGET AND THE RECEIPT OF BENEFITS

Case Study 6

MrM is 82 and has suffered a series of strokes over 4 years which have left him very vulnerable and with various disabilities in speech and movement. He lives in a rented flat owned by a housing association in the centre of town. He has been in receipt of attendance allowance for 'a long time' and following his last stroke the hospital referred him to social services and he was visited by 'someone from the council' who came to visit him several times to discuss his needs. He says that they have been 'very good' and the support he has received has been 'absolutely first class'. He knew about personal budgets and he explained that after leaving hospital he was given a personal budget and that the care company looks after the 'business side of it'. He was consulted and they listened to him and to what he wanted.

He has carers four times a day, at breakfast, lunch and tea time and then to prepare him for bed although he can get himself to bed when he feels like it. He had one carer who he liked very much and who was brilliant but she has now gone and he doesn't know why which upsets him. They are still providing care but they are not so good at time keeping although he says 'they are still very good'. He gets good meals from Farm Foods. He thanks goodness for television and visits from friends who do his shopping. He has a motor scooter which takes him into town when he is feeling better but not at the moment. He pays the council £53 towards his social care and the council pays the rest. Someone he pays personally comes in to do his housework. He relies on the council to cope with any changes for him.
He has an alarm and keeps it on him all the time. He used it recently and they replied promptly and organised an emergency call out. He is very appreciative of the service he receives and is extremely grateful for the care he is given.

Case Study 7

MrsF is 87 a widow living in her own home who has had various health problems and is now very disabled with heart, hip and arthritis issues. Three years ago she had a triple bypass and because of her daughter's illness she went into a convalescent home for 4 weeks and then stayed at her daughter's for 5 weeks. When she finally came home she said she could manage on her own with help for some friends and her daughter and they were wonderful. Life went on but 1 year ago her phone rang she hurried downstairs and fell. She injured her hip and with her heart problems they refused to operate so she is still in great pain and can't get about as she did. She became increasingly incapacitated and eventually her daughter applied to social services for some help for her. A social worker came and discussed her health, social care needs and finance with her and her daughter. As a result she had a shower room and stairlift installed at her own expense. Bars were put up outside to help and she didn't pay for them. In May she got out of bed but couldn't get back so rang her son who came to stay. They rang out of hours who said to contact the GP who rather than admit her to hospital arranged for carers to come in 3

times a day. They were marvellous. She says ' I am gradually getting better and social services took over when the NHS carers ceased'. A carer comes in once a day to see she is OK and makes her a cup of tea. Her only worry is that she has never received any paperwork about what the duties of the carer are and what they can be expected to do.

She receives her personal budget as a direct debit and her daughter looks after everything for her. Her daughter and the social worker sorted it out but they 'consulted me all the time and I pay 50% of the cost and the council the other 50%'. Her social worker says if she needs more help she can arrange it but MrsF wants to remain as independent as she can be in her own home for as long as she can. She pays a friend privately to do her housework and also employs a gardener, although she misses gardening very much.
She is very satisfied and grateful for everything she receives and she says she could not have done it on her own.

Case Study 8

Mr & MrsB are aged 87 and 62 respectively and live in rented social housing. MrB was diagnosed 2 months ago with dementia and as he had been in and out of hospital for 2 years social services got involved but more with MrsB than with MrB because of his increasing difficulty in remembering things and communicating.

At first MrsB found the whole situation overwhelming as everyone 'seemed to come at once', all asking the same 'stupid questions' and Mr & MrsB became confused and upset. 'They' all seemed to be talking to each other rather than to them but eventually it was sorted it out and now Mr & Mrs B only have to talk to either the social worker or the dementia adviser who advise and support them.

When the situation was resolved the social worker visited her initially and then with both of them together so they were both included. MrsB suffers from dyslexia and gets very confused when faced with form filling and she is very grateful to social services who help with form filling and explaining things in simple terms whenever she needs help. She says they have been brilliant.

She has a direct payment into her bank account and then pays the council for the carers and the rest can be spent on help and support for her and her husband. She keeps accounts to show what she has spent the money on. The council arranged all the change over from the different benefits and helps and supports her when she needs it. She has power of attorney for her husband which was arranged before he became 'too bad'. They were advised about care companies and one was recommended who have also proved 'to be brilliant'. MrsB also has a card to say her husband is home alone in case anything happens to her while she is out. Respite is her only difficulty as her husband becomes distressed when she is away so she relies on one friend and a relative to come to sit with him when she occasionally meets up with friends. Social services and dementia care are trying to arrange more respite but MrB is reluctant to attend any day services without her.

Case Study 9

Mr C is 74, living alone in his own home and is now at home recovering from a serious stroke. He is not in receipt of any benefits. He was taken into hospital and was very ill for some time. He had been in hospital some weeks when the physiotherapist spoke to him and his sister. He was unaware about what was happening and he thinks his sister, who had power of attorney, agreed to things on his behalf, although he does not really know what was agreed as he 'was out of it'. Although the hospital felt he was fit enough to be discharged this was not possible because his house was not suitable as he had no toilet downstairs and he could not walk upstairs at that time. He does not know who suggested it but a lady visited from a local Care home and interviewed him. He was offered care there and a couple of days later he was admitted to the care home where he stayed 7 weeks at a cost of £700 per week. Nobody asked him if he could afford it although he thinks his sister may have said something to the hospital.

Before he was allowed home the physiotherapists visited and arranged to have bars installed and other equipment supplied which he does not need and will return. He does not remember anyone speaking about social care with him other than this and no help or support was offered or discussed. He thought he could sort it out when he got home but it wasn't easy. He felt it was just assumed he could afford help. His sister is not well and could not offer much help or support. He relied on neighbours to buy food and did not worry about housework. Now he is fitter he has arranged privately for friends to do his housework and shopping but he is still unable to go outside as the right hand side of his body is partly paralysed. Physios visit him twice a week and he does exercises every day.

He assumes that his sister arranged everything for him but he has not participated in any discussion with any health specialists or social services himself although he does have an NHS health package. However, if the underpinning principle of social care and personal budgets is the involvement of the recipient in making decisions about his personal needs this gentleman seems to be unaware of this and even if he is able to fund himself, no check has been made with him about his ability to pay or what his needs may be.

Case Study 10

Mrs N is 85 and lives on her own in her own home. She has had several serious health issues over the last 3 years including falling downstairs and breaking her neck and wrist. The treatment she received was not to any great standard and neither the neck nor wrist has healed properly. She was recently diagnosed with breast cancer and had an operation and radiotherapy. She is now in need of care and receives attendance allowance. She has an alarm but on two occasions when she has fallen in the night she has lain for some hours because she 'didn't want to wake anyone up'.

When we discussed the possibility of benefit assessment she was adamant that she would cope as she is 'I don't need money as I don't go anywhere so I haven't applied and there's no point in taking it if I don't need anything. She did have a good relationship with a 'man from the council' but he has since left and since then she has ceased to have contact with the Council or Social Services as she found them too domineering and she 'would rather go without'. She pays someone to help with the housework privately and also she occasionally has a gardener to keep the garden tidy. Her view is that her finances are her own affair and she will not discuss them with anyone. She says 'it is not open to discussion. If I need anything I would rather sell something'.

Mrs N is a very independent and determined and has decided views about her lifestyle. She is hoping to move and to this end she is clearing her home slowly of excess furniture but she has a large house and two cats and is worried about the stress of moving and the cats welfare.

On a limited income and increasingly infirm and vulnerable she may well be entitled to some social care but because of her reluctance to engage with the council or social services she may well fall through the cracks unless the NHS support her and encourage her to consider an application for assessment.

Case Study 11

Mrs Mc is 74 and lives with her husband who is deaf and suffering heart problems. She herself has had cancer twice and is not as fit and able as she was five years ago. Her experience of the care system is through her brother who is 57, still of working age and living near London, who suffered a serious stroke several years ago which paralysed one side of his body. He can speak well but has also now been diagnosed with dementia and cannot remember what happened yesterday but his long term memory is OK at the moment.

When it first happened, following MrMc's discharge from hospital a care package was agreed following discussions with a social worker but it was pretty chaotic for various reasons and he couldn't cope. MrsMc visited twice a week, travelling from Suffolk to London to try to support him, as his long term partner had left him. He was feeling isolated and could not understand that he had to pay bills which led to bailiffs calling. Eventually MrsMc became ill herself with the stress of it all. The carers used to come in three times a day but because he kept forgetting to take his medication they now come four times which costs him even more money.

She thinks he has had a personal assessment but he does not receive a personal budget and she thinks he is self funded. He is in receipt of individual benefits including attendance allowance, Employment Supplementary Allowance, disability living allowance and does not pay Council tax. The payments go into the bank at different times of the month and all his bills are paid by direct debit. In the beginning the actual care package he received cost £23,000 pa. He used a care agency which was closed down later because they were using employees whose visas had run out. They were replaced and now things run very smoothly but MrsMc still visits regularly and rings daily. He uses a private company to manage his care and they invoice the local council. She is not sure if this is a health care package or a social care package.

One of the main problems, initially, was lack of privacy now his only problem is coping with different carers as he finds it very difficult because of language problems when carers change. His problem lies with getting out. The carers do not have time to do this and therefore he spends a lot of time in his home which makes him feel lonely and isolated but since being diagnosed with dementia he has been allocated a befriender every Friday who is arranging for a check to see he is getting all the support to which he is entitled. Again he is receiving health care but is responsible for his own social care and does not appear to have received any support or advice to help him get out and about to improve his social life.

Although her brother lives near London, his experience has impacted on her in Suffolk as she has had to deal with everything on her own from a distance. It would have helped her to have had advice and support available to her throughout the process and to have had more knowledge of how the process works as she is still unclear about the financial and care arrangements he is receiving.