

Sandwell Carers Report 2019

Introduction

Healthwatch Sandwell are the independent voice of the public in health and social care services. We collect feedback from people using health and social care services in Sandwell about their experiences and use that feedback to work with service commissioners and providers to look for ways to improve services.

One of the ways that we do this is to carry out projects that focus on particular services or groups of people living and using services in Sandwell. On this occasion we have carried out a project that looks at support for adult carers in Sandwell. This project is designed to help to inform the Joint Carers Strategy 2020=2024. This is a joint strategy between health, social care and the voluntary sector. The partners are Sandwell MBC, Sandwell and West Birmingham CCG and Carers support services in voluntary sector.

The Local Authority has undertaken a significant amount of engagement with Carers in the development of their strategy engaging with around 300 carers. However, it is estimated that the current number of Carers is 35-36,000 with approximately 3000 accessing services and support targeted at carers. Therefore, there are potentially unmet needs amongst the wider carer population and the project was to find out more about these.

Support for carers has been the subject of a range of projects by Healthwatch nationally but these have largely concentrated on carers who are already accessing services. However, Healthwatch Essex found that 'carers will often only recognise and use services to support themselves in their caring role if they have identified themselves as a 'carer'. They also found that this often only happens when a carer is in 'crisis'. Earlier identification of carers can help to prevent crisis point being reached and enable carers to have their needs met earlier.

This project endeavoured to engage with as many adult Carers as possible but especially those who do not necessarily identify as carers or those who are not currently accessing services to understand their needs in relation to support for carers.

Methodology

This project made use of a survey that consisted mainly of closed, multiple choice questions, focus groups and interviews.

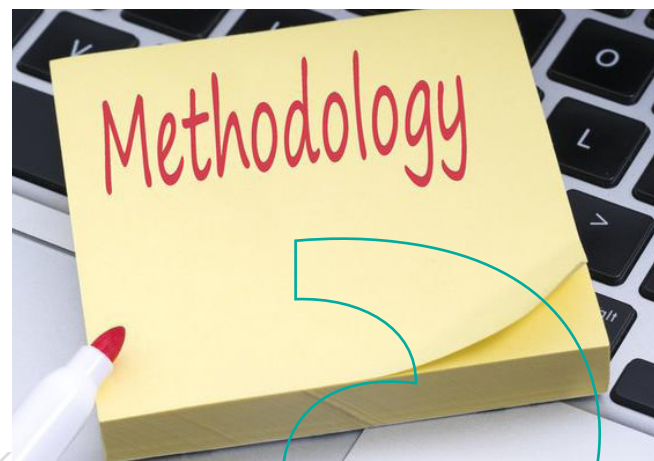
The surveys were hosted on-line but also made available as a paper copy to ensure that a wide range of Adult Carers were able to complete it. There were 190 valid responses to the survey.

There were six focus groups undertaken across Sandwell. In total 17 participants took part in a focus group.

In addition to this there were 20 telephone interviews undertaken with people who carers. The interviews used semi-structured question to allow participants to expand on their answers and Healthwatch facilitators to ask further questions to deepen understanding and clarify the answers given by the participants.

Therefore, across the three methods of engagement 227 Carers were engaged with for this project.

For all three methods of engagement the participants were self-selecting and as such are a 'convenience' sample. Therefore, the results that are presented in this report are not necessarily representative of all Carers in Sandwell and they give a snapshot of the needs and experiences of the individuals who took part. However, the themes from the feedback provide an insight into the needs of Carer's in Sandwell and will be used to help to inform the Strategy and plans around the provision of future services.



Key findings

Who took part in the surveys?

There were 222 respondents to the survey however, they were asked if they were carers. 32 respondents said that they were not carers and therefore, they did not go on to answer any further questions in the survey. Therefore, there were 190 survey responses overall. Not all of the respondents answered every question.

Demographic information on the participants in the survey can be found in Appendix 1. The demographics for those who took part in the survey do not match exactly those of Sandwell overall. Survey respondents were self-selecting and there were no quotas attached to types of respondents.

Who do Carers care for?

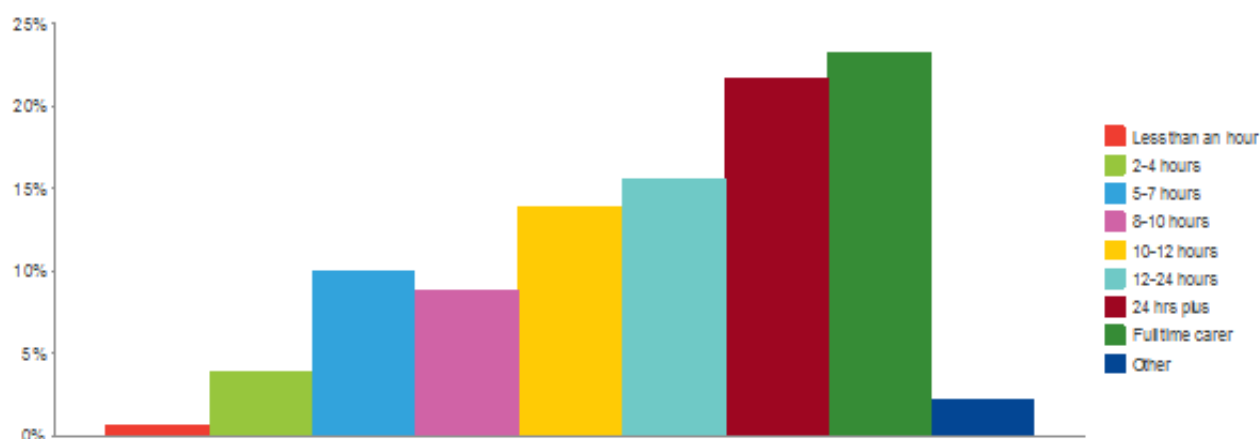
Of the 190 survey respondents that said that they were a Carer; 49% said that they cared for an adult family member; 24% said that they cared for their spouse and 24% said that they cared for a neighbour. 10% said that they cared for their child and 6% said that they cared for a neighbour. The percentage is higher than 100% as respondents were able to indicate more than one type of caring role.

Do you care for: (please tick all that apply)



The highest number of Carers said that they were a full-time Carer (23%) and another 22% said that they spent more than 24 hours a week caring for or supporting the person they cared for meaning that 45% were spending more than one day a week caring for someone. Only 1% of respondents said that they spent less than an hour per week as a Carer. One of the survey respondents commented that *'caring is a full-time job'* and this was echoed by a participant from a focus group who said that they had *'no break from it.'*

Approximately how many hours a week do you spend supporting the person you care for?



One of the participants in a focus group said that they did not define themselves as a carer saying that they *'don't see myself as [their] carer. I'm [their] Mum. I look after [them]'*. This was echoed by other parent carers that took part in the interviews*. Another participant spoke of being *'duty bound'* to look after their parent and that they also did not see themselves as a Carer. When asked how they came to see themselves as a carer there were various routes to how they had become a Carer. For some it was because the health of a family member had worsened, others that their child had had a diagnosis that meant they were *'going to be a Carer, not a usual Mum'*. Others were caring for a spouse who either had a long-term condition or disability when they married or in one case becoming *'her Carer when she accessed mental health services.'*

*There were 3 parent carers in the focus groups and 9 parent carers who took part in the telephone interview.

Carers Assessments

37% of respondents to the survey said that they had had a Carer's Assessment with 63% saying that they had not had an assessment.

Have you had a Carers' Assessment?



Participants in the interviews were also asked about their experiences of Carer's Assessments. 13 of the participants said that they had not had an assessment, but this was sometimes because they had chosen not to have an assessment because they 'didn't need one' and that they could manage without an assessment.

The respondents to the survey that had an assessment were asked how easily they had been able to access an assessment. The highest number of respondents (55%) gave a neutral answer. However, 14% said that they had found it difficult or very difficult to access a Carer's Assessment. 31% of the respondents said that it had been very easy or easy to access an assessment.

How easy was it for you to be able to access a Carer's Assessment?



One of the survey respondents commented on their experience of having had a carers assessment saying that *'Sandwell's answer to a Carers Assessment was to give me a lump sum payment. No help with signposting or securing services to help me at all.'*

Participants in the interviews were also asked about their experiences of having a Carer's Assessment. Not everyone had had a Carer's Assessment. Having a Carer's Assessment did not mean that participants had had access to additional support as a result. One participant commented that they had had an assessment by a social worker but that they *'didn't get anything, not even information on support services'* and this experience was echoed by other participants in the interviews. One said that they had been told at the end that they were *'in the system now'* but because their spouse was in work they *'would have to pay for everything'* another commented that *'it didn't meet my needs, I got nothing and no help.'* For some of those who had had an assessment but cared for their children said that they had been assessed with their child and that the assessment did not always meet their needs with one commenting that *'the assessment focussed on my son. Not me.'*

Support services

When asked if they had used any support or services in the previous 12 months 57% said that they had used information and advice services; 10% said that they had accessed support from carers groups or someone to talk to in confidence. Only 1% said that they had accessed training for carers. Less than 1% said that they had accessed support to keep them in employment.

Nine participants in the focus groups spoke about the support services that they had accessed, however it was generally the case that they were not carer specific groups and were more related to the conditions of the people that they cared for.

One focus group participant told how they were able to access *'Sandwell Parents for Disabled Children'* and that this service meant that they could do things as a family and also have the support to spend time as a couple. The service provided by Sandwell Parents for Disabled Children was also spoken positively about by an interview participant as providing support for their whole family. Another said that they and the person that they care for were supported by *'Sandwell Visually Impaired Service.'*

There was positive feedback about the carers group provided by Black Country Mental Health Partnership with one commenting that it had been their *'lifeline'* and another telling of how the group produced a newsletter that they had found beneficial.

However, the group is restricted to those who are caring for someone currently receiving treatment from the Trust and as such the participant who had considered it a lifeline was no longer able to access it saying they could only access it if their loved one *'got worse'*.

Some of the focus group participants said that they had used Sandwell Cares but that this service had now closed due to financial pressures. Although 94% of survey respondents had not used the service and there were a small number of participants in the interviews and focus groups who raised concerns about the closure. One interview participant described the closure as *'a disaster'* because they had been able to go to a place of 'bricks and mortar' place where they could *'meet real people and have a coffee'*; for one of the focus group participants Cares had provided a service had meant that they could *'pop in just for a chat'* and that the service *'knew me and my situation.'* One also told how they had taken a level 2 qualification and that they had found the service to be *'good'*. It was commented that Sandwell Cares had been a source of information and that since it had closed getting information was a 'mish mash' and that they *'don't know where to go any more.'*

Impact on health of caring

Respondents were asked if their health had been impacted in the last 12 months by their caring role.

26% said that they had developed their own health conditions as a result of their caring responsibilities.

80% of respondents said that they had felt tired in the last 12 months because of their caring role.

59% said that their sleep had been impacted by their caring responsibilities.

29% said that they felt depressed due to their caring responsibilities.

14 % said that they had suffered loss of appetite due to their caring responsibilities.

55% said that they felt generally stressed because of their caring responsibilities.

Almost even numbers said that they had suffered physical strain as a result of their caring duties.

40% of the survey respondents said that their mood had been affected by their caring duties and that they could be short tempered or irritable as a result.

57% said that they had needed to see their own GP in the last 12 months due to their caring responsibilities.

Findings from the Carers UK survey 'The State of Caring 2019' found that 22% of Carers taking part in their survey reported poor or very poor physical health and 27% reported poor or very poor mental health.

Although comparison is difficult between the findings of Carers UK survey and the survey carried out by Healthwatch Sandwell, the percentage of respondents saying that they felt depressed due to their caring responsibilities was broadly similar to those saying they had poor or very poor mental health in the national survey.

The participants in the focus groups spoke about their own health, and for two of the participants this was not necessarily because it was directly as a result of their caring responsibilities but that they also did not have good health with one commenting that *'I don't have good health, so we muddle through together'* whilst another said that although they had started as their spouse's Carer *'now we actually care for one another'* because their own health was not good.

Caring for their own health was discussed by some participants and one participant said that they were *'worried that one day I'll be really ill because I've neglected myself and there will be no one to look after my child.'* It was also commented that *'I'm tired all the time but don't have time to go to the doctors to get myself looked after. I think I need a general health check up but I just keep going.'*

Being tired was discussed by others in the focus groups with comments made about being *'worn out'* because *'as a Carer I am a firefighter'* and that caring meant that they were 'exhausted' because *'it's 24.7'*. This was also the case for some of the participants in the interviews using words like *'exhausted'* and *'tiring'* as well as *'stressful'*. One of the interview participants also said that they felt that they had to 'fight' for the person that they cared for to get the support that they needed. They did not speak about getting support for themselves.

Loneliness

Being lonely was discussed by participants in the focus groups and interviews with one participant saying that *'I am lonely, I look like I am ok, so people think I don't need any support'* and another saying *'I can't socialise, I have no friends'*. Feeling like there were *'no friendly faces'* and that they were 'trapped' meant that another felt *'so isolated'* because they *'can't leave'* the person that they care for.

Being able to access befriending services was suggested as a way to reduce loneliness with participants suggesting *'a friend or a buddy'* who they could *'talk to'* and be *'listened to'*. One participant felt that it would be helpful if they had *'someone to talk to, maybe someone in the same position as me.'* However, one participant had found that when they had tried to access a befriending service, they had received no response from the organisation that they had contacted. Not all of the participants wanted to spend time talking about caring with one saying that whilst they wanted company, they did not want to go to a group *'where all they talk about is their caring responsibilities' but where they spoke about 'normal everyday things.'*

Employment and caring

35% of the respondents to the survey said that they were employed full time and 20% said that they were employed part time. 20% said that they were retired and 26% said that they did not work and had not retired.

Do you currently work?



There were two participants in the focus groups who told how they had been made redundant and had subsequently become carers of family members. Being able to access employment was seen as difficult if not impossible for those with caring responsibilities with one telling how they *'gave up'* their job as they were *'needed'* to *'look after'* their family member and that now they *'can't get a job because I'm needed to care for' two family members. Support around 'filling in application forms and jobs that understand that I am a carer at home so I might need time off'* was seen as being something that would benefit this participant. Four participants also told how they had either given up work to care for their family members or that they would like to have support to find employment.

One of the participants in the survey said that they *'need support around work'* as their *'managers [were] not happy when called out of work for emergencies'* and that they could do with *'contingencies like working from home or flexibility around annual leave.'* This was also the case for others who were participants in the project who were working and had caring responsibilities.

For another survey respondent it was felt that being employed restricted their access to support services saying that *'I don't qualify for support in lots of areas unless I pay for it.'* This was echoed by another participant who said that because they worked full time they had been told that they would have to pay for anything that they needed.

Financial impact and access to money advice

There was an almost even split between survey respondents who said that their caring role had not caused any financial difficulties (51%) and those who said that it had had an impact (49%).

For those taking part in the focus groups and interviews, money and access to it was a key theme. One participant said that no longer being in paid employment meant that *'money is a problem, because of a lack of money this affects what I can do for myself'* whilst another said that their *'standard of living has dropped since I gave up work to care.'*

Having access to money advice and benefits advice was pinpointed as a theme from the focus groups with one telling how they had been in a situation around *'bedroom tax'* that had been *'very stressful but there was no-one to help'* and another saying that they had needed a welfare rights advisor but *'there weren't any available.'* One participant had been able to access welfare rights advice but felt the advice they had been given was not reliable because they had *'spoke with two welfare rights advisors and they contradict each other.'*

One participant did say that they felt that 'money isn't a problem for most carers' however, this was not a view voiced by any other participants in the focus groups.

Being listened to

Participants in both the focus groups and the interviews spoke about being recognised as a carer and their knowledge and expertise in the care and needs of the people that they care for. One participant commented that *'being valued and listened to'* was what mattered to them the most. They said that *'my opinions matter, I have a lot of knowledge about my family, but there is a 'we know better' attitude.'* This was echoed by another participant who cared for a child who said that *'they have a knowing best attitude. I know this child better than anyone but they won't accept my views.'* However, it was not elaborated on as to what professionals they were specifically speaking about.

Another commented that they wanted *'recognition of what I do'* as they felt *'taken for granted'* as a Carer.

Types of support

Survey respondents were asked to rate the importance to them of different types of support. 59% of respondents rated support to be manage their physical health as being very important or important.

Support managing your physical health



58% said that support around money and finance was important or very important.

Support around money and finance



49% said that support with their emotional wellbeing was important or very important to them.

Support with your emotional wellbeing



49% rated support to have a life outside of caring as important or very important

Support to have a life outside caring



45% said that support managing at home was important or very important to them.

Support in managing at home



24% said that support around education and work was important or very important to them.

Support around education and work



Information, advice and guidance

Respondents to the survey were asked how easy they had found it to find information and advice on the support available to them in the last 12 months.

48% of the respondents said that they had not tried to find any information in the last 12 months. 39% said that they had found it easy or very easy to find information and advice on the support that was available to them. 13% said that they had found it difficult or very difficult to find.

Being able to access information when they needed it was important to participants in the focus groups and interviews. Findings out about *‘what can help me’* was pinpointed by one participant. For another participant the experience of trying to find information was poor saying that they had been *‘ping ponged from here to there, then there’s nothing, so I gave up.’* For another it was important that they were able to access ‘up to date information’ saying that there was ‘stuff in libraries but it could be better.’



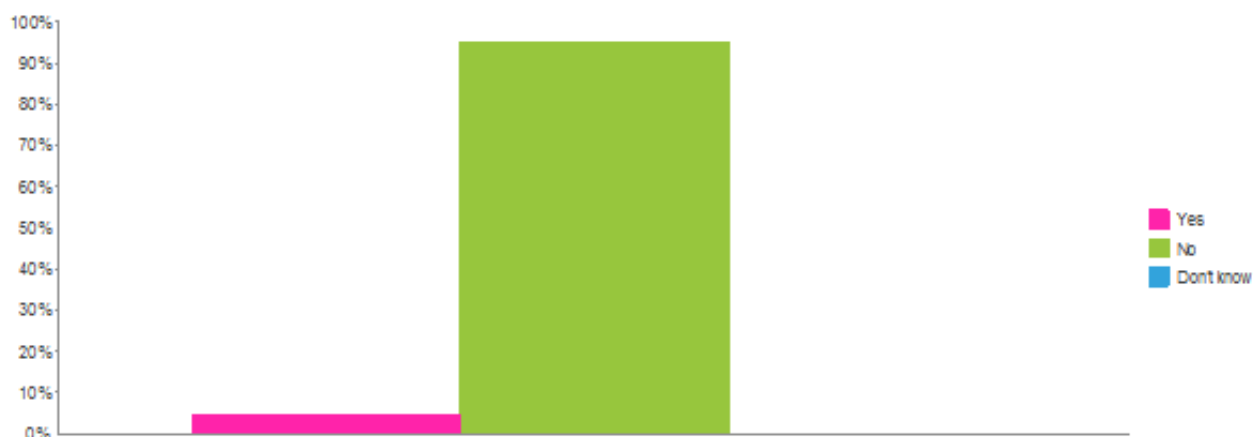
Others wanted access to a service where they could *'go to someone or somewhere where they could signpost me to the right place.'* It was also suggested that a *'Sandwell website just for carers so I can get knowledge about conditions as well as information for carers'* would be helpful or *'social media, leaflets in libraries and GP practices.'* Having information such as *'booklets in one place'* was also seen as something that would be helpful.

Importantly, having the *'right information at the right time'* was mentioned by one participant with others commenting on the information needing to be 'accurate'.

Support for the cared for

95% of 190 respondents to the survey said that the person that they cared for had not used support services that would enable them to take a break from caring at short notice.

Support services allowing you to take a break from caring at short notice or in an emergency.



94% of the survey respondents said that the person that they cared for had not used support services that would allow them to have a break from caring of more than one day.

Support or services allowing you to take a break from caring for more than 24 hours.



87% said that the person that they cared for had not used support services that would give them a break from caring for up to 24 hours at a time.

Support or services to allow you to have a rest from caring for between 1 and 24 hours (e.g. a sitting service).



70% did not access day centres or day activities and 99% did not access a luncheon club.

Day centre or day activities



Lunch club



Participants from the focus groups spoke about having a break from caring and one participant said that they would like the person they care for to *'go to a day centre'* but this was problematic because their relative did not speak English as a first language and *'language is a problem'*. Others spoke about how they would like the person they cared for to be able to access a day centre *'where there were people like'* the person that they cared for or *'a day centre for people with mental ill health.'* Others commented that they would like *'time out even if it's for a couple of hours'* but they needed to know that the person they looked after would be *'safe and cared for... like I would do it.'*

Being unable to leave the person that they cared for was a recurring theme for ten participants in the focus groups and interviews so that they were able to have *'some space'* with one commenting that they were unable to follow any of their interests because the person that they care for *'interrupts all the time'* and that they *'need a break.'*

Three participants in the project spoke about respite provision but that it was *'so complicated to explain what'* the person that they care for *'needs'* and that *'it wears me out to have to explain everything so now I just don't bother having the respite'*. They went on to explain that they *'look after [them] in the family'* rather than accessing formal respite. One of the survey respondents said that they *'did not find it possible to book respite... well in advance... as it seems you are unable to book respite more than 4 weeks in advance.'* An interview participant echoed that they found it difficult to arrange respite care for their child because *'the agencies are full'* but if they *'do not use'* their 'respite hours' they will lose them.

7% of survey respondents said that the person that they cared for used a personal assistant and 4% said that they used home care services or a home help. 1% accessed a meals service at home.

Some of the focus group participants spoke about the use of domiciliary care services with mixed experiences. One participant told how the person that they cared for used to have *'a domiciliary care company to make lunch'* for them but they *'would not do it for me. So, I had to make my own, to be honest I can make both, so I cancelled the service'* as it was not giving them a break as it was *'not on the care plan.'* Another said that they had 'no continuity of care' and as a result they had to *'tell [their relative's] story over and over again, particularly about physical care.'*

However, another participant told how *'the care agency are really good now'* as *'they liaise with me...so I can have peace of mind.'*

68% of survey respondents said that the person that they cared for had not accessed any equipment or adaptations in the last 12 months.

Equipment or adaptation to their home (such as wheelchair access or handrails)



Being able to access adaptations was commented on by one participant in the focus groups saying that *'I needed a ramp fitted to get a wheelchair in the house. It's all such as fuss and palaver. So many excuses why it can't be done. So, I got a builder and sorted it myself. I got no support.'* Another said that it would be helpful to them to be able to get *'equipment to help with lifting a person'*.

Those that had had access to equipment did not always have the practical support to use it effectively with one participant saying that they would have valued *'practical advice'* on *'how to dismantle the hospital bed.'*

95% did not have a lifeline alarm.



Survey findings according to age group

Financial

When asked if there had been any financial impacts from their caring role, survey respondents in the age groups 45-54 year olds (57.4% of respondents in that age group) and 55-64 years olds (55.6% in that age group) were most likely to say that they had been impacted to some extent.

What is important to you?

The age group 65-74 years old were the most likely to say that they felt that support to look after their physical health was either very important or important. 80% of respondents aged over 75 years said that they thought support to look after their physical health was very important or very important and 77.7% of 55-64 year olds thought it was very important or important.

When asked about how important support to manage at home was, 100% of those aged 75 and over said that it was very important or important.

Support around emotional wellbeing was seen as being very important or important by 100% of over 75 year olds and 70.3% of 55-64 year olds said that it was very important or important. However, for those aged 18-24 years, 66.7% of respondents in that age group said that it was not very important to them.

Support around education and work was seen as important to around a third of respondents aged 18-24 year olds and 45-54 year olds. As might be expected it is less important to people who were over working age.

Being able to have support to have a life outside caring was seen as very important or important by 100% of the respondents aged over 75. For those who were aged 55-64 year olds 74% said that support to have a life outside of caring was very important or important and 70% of 65-74 year olds.

Having support around money and finance was seen as very important or important to 100% of over 75 year olds and 79.3% of 65-74 year olds. Around two thirds of 55- 64 year olds and 35-44 year olds also felt that it was very important or important. However, only a third of 18-24 years olds felt that it was important and none thought it was very important.

Finding advice

80% of over 75 year olds said that they had found it difficult to find information in the last 12 months. However, this group was the only one where there was such a high percentage of respondents who had tried to find information and found it difficult.

76% of 25-34 year olds had not tried to find information; and 66.7% of 18-24 year olds had not tried to find information either.

10% of 65-74 year olds said that they had found it fairly easy to find out information and this was the highest percentage age group.

Survey findings by ethnicity

Financial.

Those identifying as Black African were most likely to say that there had been no financial impact from their caring role (71.4%). 100% of those identifying as being Pakistani said that there had been either some or a lot of financial impact from their caring role. 75% of respondents who identified as Mixed White and Black African said that there had been some financial impact because of their caring role.

What is important to you?

When asked about the importance of support to maintain their physical health there was little difference between respondents from most of the ethnic groups with most saying that it was either very important or important to them. However, respondents who identified as Mixed White and Black Caribbean were more likely to give a neutral answer (55.6%) than other groups except those identifying as White Irish (66.7%). However, respondents identifying as White Irish were a relatively small group with only three respondents identifying as that ethnicity.

Support in managing at home was largely given a neutral rating by respondents from most ethnic groups. However, those identifying as Black African were more likely than other groups to rate support managing at home as being not very important (57.1%) compared to other groups. For other groups around 40% rated support managing at home as very important or important.

Respondents to the survey who identified as Asian Pakistani were most likely to say that having support with their emotional wellbeing was important (60%). Respondents identifying as White British were also more likely to say that support with emotional wellbeing was either very important or important to them (56.8%). Those identifying as Black African were less likely to consider support around emotional wellbeing as important (57.1%).

For survey respondents generally, when considering the importance of support around education and work most gave neutral answers or considered it relatively unimportant irrespective of their ethnic origin. However, 50% of respondents identifying as Mixed White and Black African and 40% of respondents identifying as Asian Pakistani felt it was very important or important. It should be noted that for both of these groups there were relatively low numbers of respondents and this means that high percentages are attached to relatively small numbers of respondents.

Having support to have a life outside of caring was seen as very important or important to 60% of Asian Pakistani respondents and 56.7% of White British respondents. 50% of respondents who identified as White Other; Mixed White and Black African; or Asian Indian said that support to have a life outside caring was either very important or important to them. 57.1% of respondents identifying as Black African said that support to have a life outside caring was not very important to them.

Having support around money and finance was seen as very important or important to 75% of respondents who identified as Mixed White and Black African. It was also seen as very important or important by 65.3% of respondents who were White British and 60% of respondents who identified as Asian Pakistani. Of those who identified as Black African, 57.1% said that it was not very important. Other respondents were more likely to give a neutral answer than not attach importance to such support.

Information and advice

Across all ethnic groups there were relatively high percentages of respondents who had not tried to find information and advice in the last 12 months. However, 50% of respondents identifying as Mixed White and Black African said that they had found it fairly difficult to find information and advice. 17.6% of respondents who identified as Asian Indian also said that they had found it fairly difficult to find information and advice. Only respondents identifying as White British said that they had found it very difficult to find information advice (6.7%).

Religion

There were very few respondents from religions other than Christian with the next highest number of respondents defining themselves as having no religion followed by a number of respondents choosing not to share their religious beliefs. Therefore, although percentage breakdowns are provided it should be considered that they cannot be seen as being a representative sample of Carers from particular religious backgrounds.

What is important to you?

Having support to maintain their physical health was seen as being very important or important by 68.3% of respondents identifying as Christian and 66.6% of Muslims (due to the low number of Muslim respondents, this percentage should be treated with caution). 9% of Sikh respondents said that it was not very important.

Having support in managing at home was seen as very important or important 54.2% of respondents who identified as Christian. 66.7% of Muslims said that they felt that support managing at home was not very unimportant.

The highest percentages across respondents from all religious groupings for support around education and work were neutral responses. However, none of the Muslim respondents felt that support around education and support was very important or important.

Being able to have support to have a life outside caring was seen as being very important or important by 66.6% of Muslim respondents; 54.8% of Christian respondents and 45.5% of Sikh respondents.

Having support around money and finance was seen as very important or important 66.3% of respondents who identified as Christian; 50% of Muslim respondents said that it was very important. For those that identified as Sikh 45.5% said that it was either very important or important.

Advice and Information

Two thirds of the Muslim respondents to the service had not tried to find advice and information in the last 12 months. The respondent that had said that they had found it fairly easy to find. 11.3% of Christian respondents said that they had found it either fairly difficult or very difficult to find information and advice. 9.1% of Sikh respondents said they had found it fairly difficult to find information and advice.



Gender

Financial Impact

68.1% of respondents who identified as Male said that there had been no impact on them financially due to their caring role. However, less than half (44.8%) of female respondents reported that this was the case. Female identifying respondents reported that they had been financially impacted a little (49.3%) or a lot (6%) because of their caring role. Only 31.9% of male respondents reported that they had been impacted financially at all.

What is important to you?

When asked about how important support to maintain their physical health was to them, 42.6% of respondents identifying as male said that it was either very important or important to them. 65.4% of female respondents said that it was either very important or important to them.

Having support in managing at home was seen as very important or important by 49.3% of respondents who identified as female compared to 31.9% of male respondents.

Receiving support with their emotional wellbeing was seen as very important or important by 57.1% of female respondents in comparison to 27.6% of male respondents.

Support around education and work was seen as very important or important to 29.3% of female respondents compared to 8.5% of male respondents.

Female respondents were more likely than male respondents to feel that having support to having life outside of caring was very important or important with 53.8% of female respondents saying it was important compared to 34.8% of male respondents.

Having access to support around money and finances was also seen as being very important or important to a higher percentage of female respondents (66.7%) in comparison to male respondents (34.7%).

Information and advice

When asked about accessing information and advice 6.8% of male respondents and 41.8% of female respondents said that they had not tried to find information or advice in the last 12 months.

27.7% of male respondents said that they had found it very easy or fairly easy to access information and advice and 43.3% of female respondents.

8.5% of male respondents said that it had been fairly difficult or very difficult to access information advice and 14.9% of female respondents said that it had been fairly difficult or very difficult.

Disability

There were a relatively small number of respondents who considered themselves to have a disability with 22 out of 186 respondents saying they have a disability.

Financial

54.5% of the respondents who considered themselves to have a disability said that they had been impacted financially because of their caring responsibilities. 49.7% of respondents without a disability said that they had been impacted financially.

Importance of support

68.2% of respondents who saw themselves as having a disability felt said that support to maintain their physical health was either very important or important to them in comparison to 58.3% of respondents who did not have a disability.

54.6% of respondents who had a disability said that having access to support to manage at home was very important or important to them compared to 44.1% of respondents who did not have a disability.

Having support with their emotional wellbeing was very important or important to 68.4% of respondents who considered themselves to have a disability. 47.6% of respondents who did not have disability considered access to support for their emotional wellbeing to be very important or important.

Access to support around education and work was seen as very important or important by 27.2% of the respondents who were disabled. This does not differ greatly to the 24.5% of respondents without a disability who considered it to be very important or important.

Support to have a life outside of caring was considered very important or important by 66.7% of respondents with a disability. 47.8% of respondents without a disability said that they thought it was important or very important.

63.7% of respondents with a disability said that support around money and finance was very important or important to them. 58.9% of respondents who did not have a disability said that support around money and finance was very important or important to them.

Advice and Information

Just under 43% (42.9%) of respondents with a disability said that they had not tried to access advice and information in the last 12 months which is slightly lower than the percentage of respondents without a disability (47.5%).

23.8% of respondents with a disability said that finding information and advice had been either fairly difficult or very difficult compared to 12.3% of respondents without a disability.



Conclusions

Across the three methods of engagement there were some common themes that emerged about the experiences of the Carers that took part in the project.

Whilst most did see themselves as Carers there were some that said that they did not identify themselves as a Carer because they either had a duty to care for their family members or they were a parent first and caring for their child was expected. Others said that they had only realised they were a Carer when there was a medical diagnosis for the person they looked after or they were defined as such by an external agency. This suggests that there are still those that do not ask for support, seek support or are not identified as needing support by professionals in health and social care because they do not define themselves as a Carer.

A loss of employment and its impact on their finances was a theme throughout both the focus groups and interviews. There was a sense that a number of those who had been working previously still wished to be economically active but could not find work that would enable them to fulfil their caring responsibilities too. Those that were employed also felt that there was a lack of flexibility on the part of employers where their caring duties were concerned. Losing employment meant that many had lost their income and were reliant on welfare benefits but for some this was difficult to navigate and there was a requirement for support to find out about entitlements and claim them.

A lack of employment and income was seen by some as a factor in how they had become socially isolated since becoming carers. Being lonely and unable to access social activities was a theme for a number of participants and having support to be able to access peer support groups would be welcomed. Survey responses demonstrated that very few people had accessed sitting services or respite care that might have enabled them to have a break from caring and access social activities.

Feedback suggested that there could be an impact on Carers' health as a result of their caring responsibilities, with a number of participants saying that they found their role stressful and that in that context they would welcome some emotional support to assist them in their role. For some, this was as simple as having someone call them to see how they were, as well as being able to speak to people who were in the same position as them so able to empathise with their experiences.

There were a limited number of respondents to the survey who said that they had had a Carer's Assessment. Feedback from interviewees suggested that those who had received an assessment generally felt that the assessment had not meant that they gained any more support and indeed that there was a limited amount of support available. Some respondents who said that they had not had an assessment also went on to say that they did not want or need an assessment.

Closure of a local Carers services had created a gap in social support and information and advice for some Carers.

Some participants had accessed services related to the conditions of the people that they cared for. This included support from Black Country Partnership Mental Health Trust, however, in this case the support was limited to Carer's of those who were open to the Trust and when they were no longer receiving treatment that support for Carers was lost.

Being able to access information on services that they can make use of was important to participants. Having a single point of contact for up to date relevant information was something that participants considered to be needed.

For some participants being able to access appropriate care and support for the person that they cared for such as respite services or day centres would help to alleviate the stress of their caring roles and allow them opportunities to have a break from caring.

Being able to access services to assist with home and garden maintenance was also raised by some participants as being able to maintain their home as well as carry out their caring role could sometimes be too much and as a result their home environment was sometimes neglected.

Recommendations

1. A publicity campaign by the Local Authority or relevant voluntary sector to publicise tasks which would define a person as a Carer, Carer support services and promote the Carer's Assessment.
2. Provide a central point of access that would give relevant information to address financial, social support, practical support, respite, health information (for Carers and the cared for) and support and support for back into employment.
3. Adult practitioners and associated staff to receive training in the needs of Carers including their role as sign posters to support.
4. Promote/provide services for people who provide emotional support to Carers e.g. a buddy/befriending service to alleviate loneliness and isolation.



Appendix

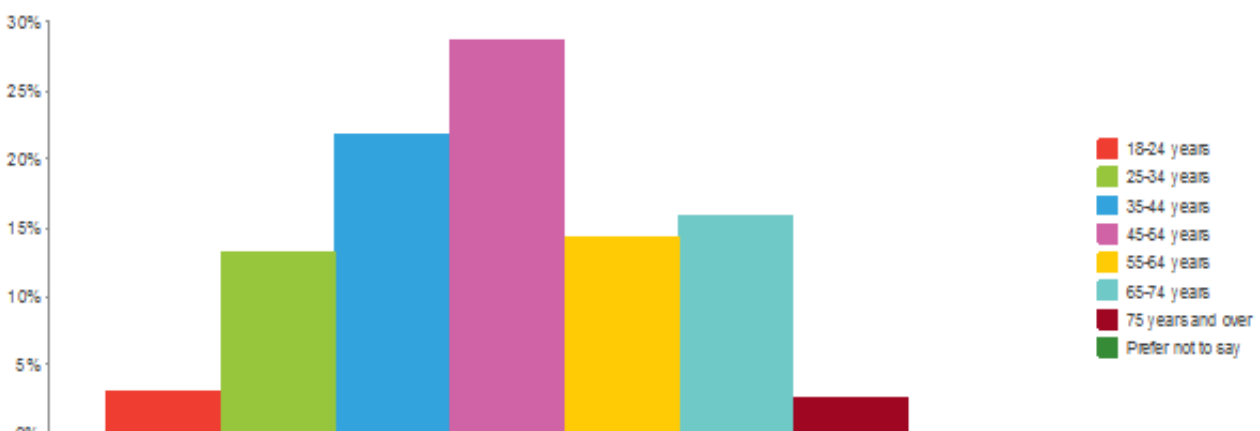
Demographics

Age

The highest percentage of respondents to the survey were aged 45-54 years at 29% of the respondents. Those aged 35-44 years were the second highest group (22%). In total respondents of working age (up to the age of 64) made up 81% of the respondents to the survey.

The 2011 Census does not provide the same age bands for a direct comparison but the working age population between 16 and 60 in the Census data is 58.3% of the population. Therefore, the percentage of working age respondents to the survey was higher than that in the general population.

What age band are you in?

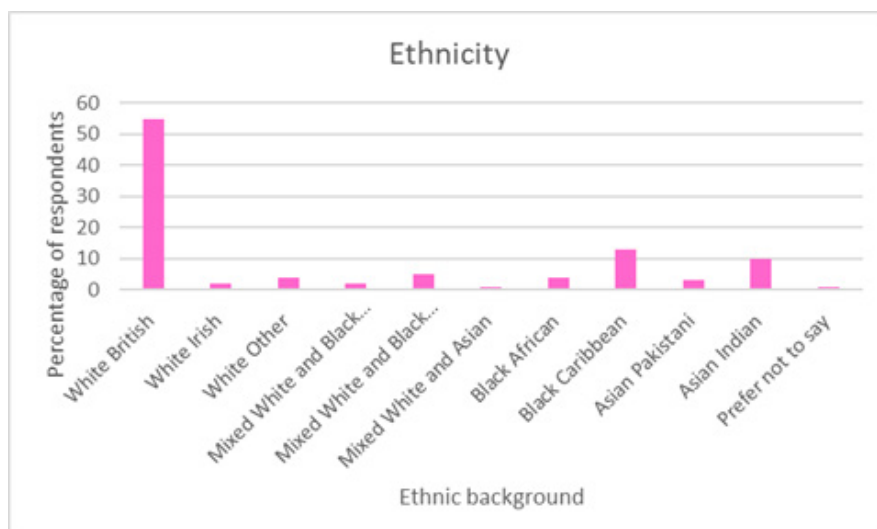


Ethnicity

The 2011 Census found that the White British population of Sandwell was 65.8% of the population which means that the percentage of White British respondents was lower than that of the census.

The percentage of Black Caribbean respondents (14%) was higher than the percentage of the population in the 2011 Census (3.7%).

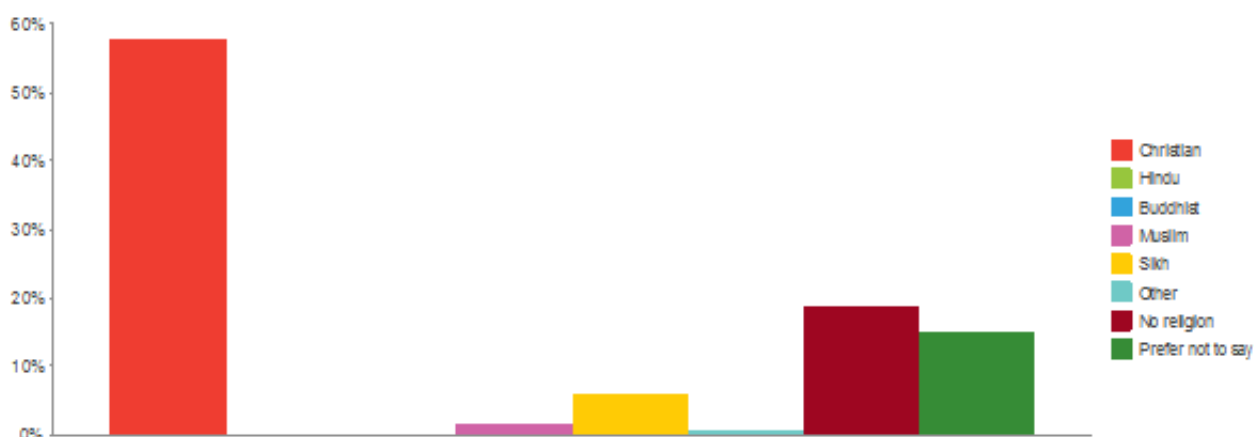
The percentage of respondents who identified as Asian Indian (10%) was in line with the percentage indicated in the 2011 Census (10.2%). There were no respondents from the Gypsy/Irish Traveller community or Bangladeshi community.



Religion

Those identifying as Christian made up the largest group of respondents (58%) with those who said that they had no religion making up the second highest group (19%). There was a relatively high percentage (15%) of respondents who declined to give an answer to this question.

What is your religious belief



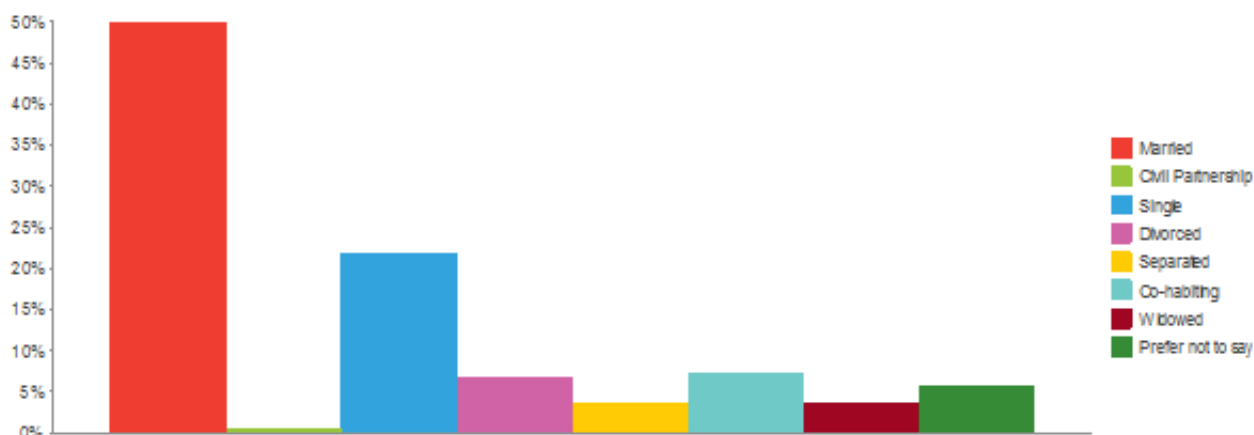
The percentage of people identifying as Christian in the 2011 census in Sandwell was 55.2% which means the percentage for this survey is broadly in line with the general population. Those identifying as having no religion in 2011 was 18.7%, again this means that the survey respondents were broadly similar to those in the general population.

There was a lower percentage of respondents who identified as Muslim taking part in the survey than in the general population and this was also the case for those who identified as Sikh.

Marital Status

Half of the respondents to the survey said that they were married and 22% said that they were single.

What is your marital status?



The 2011 Census counts households by marital census which means that a direct comparison is not possible.

Gender

73% of the respondents to the survey identified as female and 2% of respondents said that they identified as a different gender to the one they were at birth. The 2011 Census only asked for gender in terms of male or female. People identifying as female made up 50.8% of the Sandwell population in the 2011 census. Therefore, the survey responses reflected a higher percentage of women than the general population.

What is your gender?



Is the gender you identify as the same as you were born as?



Disability

87% of the respondents to the survey said that they did not consider themselves to have a disability but 12% said that they did have a disability.

The 2011 Census found that 20.9% of the Sandwell population had a limiting long-term illness. Therefore, the percentage of respondents to the survey with a disability were lower than the general population.

Do you consider yourself to have a disability?



Sexual orientation

79% of the respondents said that they were heterosexual, only 2% identified as homosexual with 20% saying that they preferred not to say what their sexual orientation was.

What is your sexual orientation?



Response from Sandwell Metropolitan Borough Council (MBC)

“The Council welcomes Healthwatch Sandwell’s report on the support available and experiences of carers within the Borough and the recommendations being made.

These issues will be addressed in the emerging Joint Carers Strategy which we shall shortly be presenting to the Sandwell Health and Wellbeing Board for endorsement. This will provide us all with a blueprint for the development of support for carers within Sandwell”

Stuart Lackenby, Director of Adult Social Care

Sandwell MBC

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