

HEALTH AND SOCIAL CARE

Carers Census, Scotland, 2019-20 and 2020-21

The Carers (Scotland) Act 2016 took effect on 1st April 2018. The Act puts in place a system of carers' rights designed to improve consistency of support and prevent problems in order to help sustain caring relationships and protect carers' health and well-being. The Act also introduces the right to an Adult Carer Support Plan or Young Carer Statement based on each carer's personal outcomes and needs for support. The data reported here relates to carers being supported by local services during years two and three following the implementation of the Act.

Key Points

- This is the second publication of the Carers Census data, covering financial years 2019-20 and 2020-21. Some data providers were still implementing new systems to collect and record this information during the collection period. As a result, the figures presented in this publication are incomplete. Care should be taken when interpreting the results.
- There were 32,690 individual carers being supported by local services across Scotland that were identified through the Carers Census in 2019-20. In 2020-21, there were 31,760 individual carers supported by local services.
- There was a notable deprivation effect for young carers supported by local services. For example, in 2020-21 14% of young carers lived in the most deprived Scottish Index of Multiple Deprivation (SIMD) decile, while 5% lived in the least deprived SIMD decile.
- The most commonly reported impact of providing unpaid care in both 2019-20 and 2020-21 was on carers' emotional well-being. Where this information was available; around 4 in 5 carers experienced an impact on their emotional well-being due to their caring role.
- Based on records where information on Adult Carer Support Plans (ACSPs) and Young Carer Statements (YCSs) were available; 41% of carers supported by local services had a complete ACSP or YCS in place in 2020-21, while for 47% their ACSP or YCS was incomplete.
- Based on records where information on support provided to carers was available; the most common form of support provided to carers was advice and information. Young carers supported by local services were more likely to be provided with short breaks or respite than adult carers.

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1. Introduction

Unpaid carers provide care and support to family members, friends and neighbours. Any person can become a carer at any time in their life. The exact number of unpaid carers living in Scotland is not known but it was [estimated in the Scotland's Carers - Update Release](#) that there were around 700,000 to 800,000 before the Covid-19 pandemic. A [YouGov poll commissioned for Carers Week 2020](#) suggests that number could have since grown to over a million.

The Carers (Scotland) Act 2016, which was taken effect on 1st April 2018, aims to enable unpaid carers to be better supported so that they can continue to care, if they wish to do so, while also having a life alongside caring. The Act introduces the right to a new Adult Carer Support Plan or Young Carer Statement based on each carer's personal outcomes and needs for support. These are available to everyone providing unpaid care regardless of whether they are providing, or intend to provide, care on a substantial and regular basis.

This report presents an overview of the results from the Carers Census data collection covering financial years 2019-20 and 2020-21. The Carers Census collects a variety of information on unpaid carers and the support they are provided with, in order to help monitor the implementation of the Act. Data is collected directly from Local Authorities and Carer Centres, which are independent charities that offer practical support, advice and information to unpaid carers.

The implementation of the Act was a significant change to practice. It has required changes to the data that is collected by Local Authorities and Carer Centres and the implementation of new systems to collect and record that data. This process is still ongoing and therefore not all providers were able to collect and record the information requested. As such, data for most areas is incomplete. The results presented here have been published as 'Data Under Development' and should not be considered as National or Official Statistics.

1.1 Effect of the Covid-19 pandemic

The effects of the Covid-19 pandemic have been particularly acute in the area of social care. As stated above, the number of unpaid carers is thought to have risen as access to health and social care services was limited due to demand and restrictions. Support for unpaid carers also changed through the pandemic as there was an increased emphasis on providing the necessary information on infection control and the correct use of Personal and Protective Equipment (PPE).

However, it is likely that not all effects of the pandemic are reflected in the data presented here. While many carers registered with local carers services when they were prioritised for the Covid-19 vaccine, they will not have been included in the Carers Census unless they received a support plan or some kind of formal support. This means that carers who were registered with local services but only received newsletters or informational leaflets without any further contact would not have been recorded in the Carers Census.

1.2 Note on Data Quality

As the Carers Census is still a relatively new data collection, many data providers were still in the midst of implementing new systems to collect and record the [required data](#) during the collection period. Data returns were received from around 70% of data providers; however, some providers were only able to return information on a subsection of the carers they support. As such, the figures reported here will be an undercount of the true number of carers being supported by local services.

The data completeness of returns also varied. On the whole, demographic variables were well returned while other variables such as those related to support plans and carers' needs were less well returned. This means that certain analysis presented in Sections 3.3 and 3.4 is based on a smaller number of carers for whom the relevant information was provided.

Due to this variation in data completeness, the figures presented here will not reflect the true number of adult carer support plans and young carer statements prepared or the support which carers receive under the Carers (Scotland) Act 2016. We expect to see improvement in the number of variables returned over time as data providers' systems are improved in order to better collect and record this information.

As such, the results in this report should be interpreted with care. All figures presented here are rounded. Please read the notes accompanying the tables and charts for further information on data quality. The results in this report should not be directly compared to the 2018-19 publication, since the 2018-19 figures cover a 6 month period rather than a full year.

The data for the tables and charts is available in an accompanying Excel document.

2. De-duplication of Carers Census Records

Unpaid carers can be supported by more than one local service and may therefore appear in the systems of more than one data provider. To ensure that carers are not being double counted as a result different organisations returning information on the same people, the figures presented in this report refer only to records that have been de-duplicated.

2.1 De-duplication process

First, instances where a data provider had returned more than one record for the same carer were removed. Then, records where month and year of birth, gender or data zone were missing were removed. This is because de-duplication is not accurate without all three of these identifiers present. Of the records submitted, 19% were removed in 2019-20 due to missing identifiers and 17% were removed in 2020-21.

A de-duplication ID was then created for each remaining record by combining month and year of birth, data zone and gender. In cases where the de-duplication ID was not unique, further analysis of the data was carried out to identify where those records with the same de-duplication ID referred to different carers.

If multiple records submitted by a single data provider had the same de-duplication ID, but different record IDs (e.g. Carer 1 and Carer 2), it was assumed that these records referred to different carers. In cases where the same system was used by multiple providers (e.g. Carer Centres run by VOCAL), a single record was taken for each carer.

As a result of the de-duplication process outlined above, 74% of the records submitted were included in the final data analysis in 2019-20 and 76% were included in 2020-21. This is compared to 68% of records submitted for the 2018-19 publication.

Table 1: Number of records included in analysis following de-duplication

Year	Records submitted	Unique number of carers (de-duplicated records)	Duplicates and records unable to be de-duplicated
2019-20	44,190	32,690	11,490
2020-21	42,030	31,760	10,270

In future years, we intend to link the Carers Census data with the National Records of Scotland's population spine, which contains the personal identifiers of everyone in the Scottish Census, in order to obtain an accurate number of individual carers from the information submitted.

2.2 Analysis of duplicate records and records unable to be de-duplicated

The de-duplication process removed 11,490 records (26% of those submitted) from the dataset in 2019-20 and 10,270 (24%) in 2020-21. Further analysis was carried out on these records in order to ascertain if certain areas or groups of carers were impacted more than others.

Effects of de-duplication by local area

Some areas were more impacted than others by the de-duplication process. The table below shows the areas impacted the most by the de-duplication process.

Table 2: Areas with highest percentage of records removed as a result of de-duplication

Area	% records removed (actual number)	Main reason(s) for removal
Falkirk (2019-20)	46% (880)	Multiple rows provided for some carers; multiple records where de-duplication ID was not unique; month and year of birth were missing for nearly 300 records
West Lothian (2020-21)	76% (250)	Nearly all records removed were missing month and year of birth
North Lanarkshire (2020-21)	59% (3,670)	Nearly all records removed were missing month and year of birth
Shetland Islands (2020-21)	34% (200)	Multiple rows provided for some carers; multiple records where de-duplication ID was not unique; month and year of birth were missing for around 80 records

Note: Area is based on carers' residential postcode rather than location of data provider.

Effects on equality groups

Just over 10% of records were removed for each of the adult age groups (11% of records for 18 – 64 year olds and 14% of records for 65+ year olds) in both 2019-20 and 2020-21. This is slightly higher than the 0 – 18 year old age group, for which roughly 5% of records were removed during the de-duplication process (4% in 2019-20 and 5% in 2020-21). This means that the de-duplication process affected adult carer records slightly more than young carer records.

Similar proportions of records for male and female carers were removed in both years. In 2019-20, 24% of male carer records were removed compared to 26% of female carer records. In 2020-21, the proportions removed were 22% and 25% respectively.

There is slightly more variation across ethnic groups, though the proportion of records of each ethnic group removed varied between 17% and 29% in 2019-20, and between 18% and 26% in 2020-21 (not including the groups: 'Multiple ethnic groups', 'Not Known' and 'Not Disclosed'). The proportion of records removed for each deprivation decile varied between 20% and 26% in 2019-20 and 17% and 27% in 2020-21, but there was no clear trend.

3. Information on Carers

The analysis in the following section is based on the individual carers identified through the de-duplication process, as set out in Section 2.1.

A carer was included in the Carers Census if they:

- had an Adult Carer Support Plan (ACSP) or Young Carer Statement (YCS) or review of their needs as a carer during the reporting period; or
- were *offered* or *requested* an ACSP or YCS during the reporting period; and/or
- received a specified support service (including short breaks or respite) during the reporting period.

However, systems to collect and record the required information were still being implemented at the time the Carers Census data was submitted. As such, multiple providers were unable to return information on all of the carers meeting the above criteria. The figures presented below will therefore be an undercount of the true number of carers being supported by local services.

3.1 Number of Carers across Scotland

There were 32,690 unique carers identified in the Carers Census in 2019-20 and 31,760 in 2020-21. This is greater than the 23,180 unique carers identified in the 2018-19 publication. However, it should be noted that since the 2018-19 publication covered 6 months as opposed to a full year, the figures in this report should not be directly compared to the 2018-19 publication.

Returns were not received from all data providers for 2019-20 and 2020-21, therefore there are some gaps in coverage across Scotland. Due to these gaps and the differing completeness of the submitted data returns, there are no local area breakdowns included in this publication. This is because, given these issues with data completeness, any differences observed between areas are as likely to be reflective of the underlying data quality and coverage as to be due to differences in the number of carers being supported.

3.2 Demographics

Age and Gender

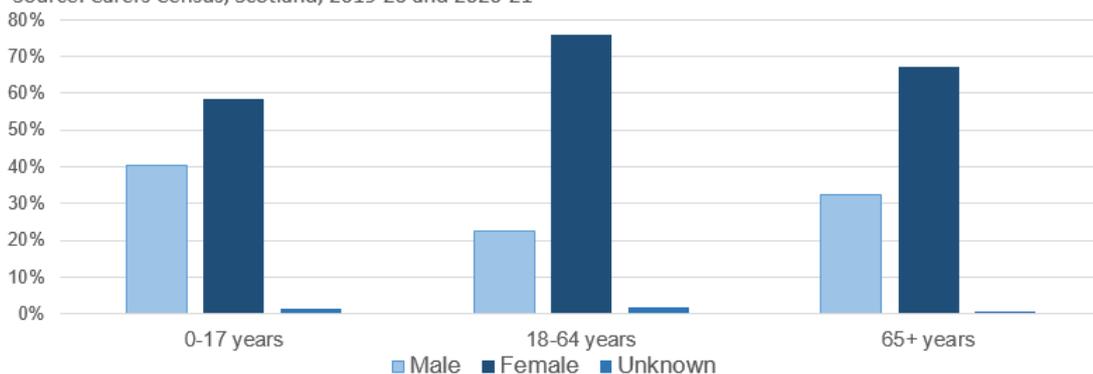
Around 3 in 5 carers (62%) included in the Carers Census in 2020-21 were working age (18 - 64 year old) adults, compared to 57% in 2019-20. Adults aged 65 and over accounted for roughly a quarter of carers identified (24% in 2020-21 compared to 29% in 2019-20). Young carers (carers aged under 18) made up 14% of the individual carers identified in 2020-21, compared to 13% of carers in 2019-20. This proportion is higher than [the previous estimates in the Scotland's Carers - Update Release](#) concerning the total carer population, which suggested that young carers account for less than 5% of unpaid carers. This may indicate that carer support services are reaching a greater proportion of young carers than adult carers, since the Carers Census only includes carers who are being supported by local services.

Around 7 in 10 carers in the 2020-21 Carers Census (71%) and the 2019-20 Carers Census (73%) were female. This proportion is higher than that seen in [the Scotland's Carers report](#), which was based on the total carer population, which suggest that closer to 60% of unpaid carers were female. This difference might suggest that female carers are more likely to seek out support from services than male carers.

There are more female carers than male carers in every age group in both the 2019-20 and 2020-21 censuses, but the difference is most pronounced in the working age carer group. Figure 1 shows that 76% of working age carers were female in 2020-21. This is consistent with previous findings based on the total carer population which suggested that females of working age are more likely to provide unpaid care than working age males. The data indicates that the gender gap is narrowest for young carers in both years, with females accounting for 58% of young carers and males accounting for 40% of young carers in 2020-21.

Figure 1. Female Carers accounted for around three-quarters of working age Carers in 2020-21

Source: Carers Census, Scotland, 2019-20 and 2020-21

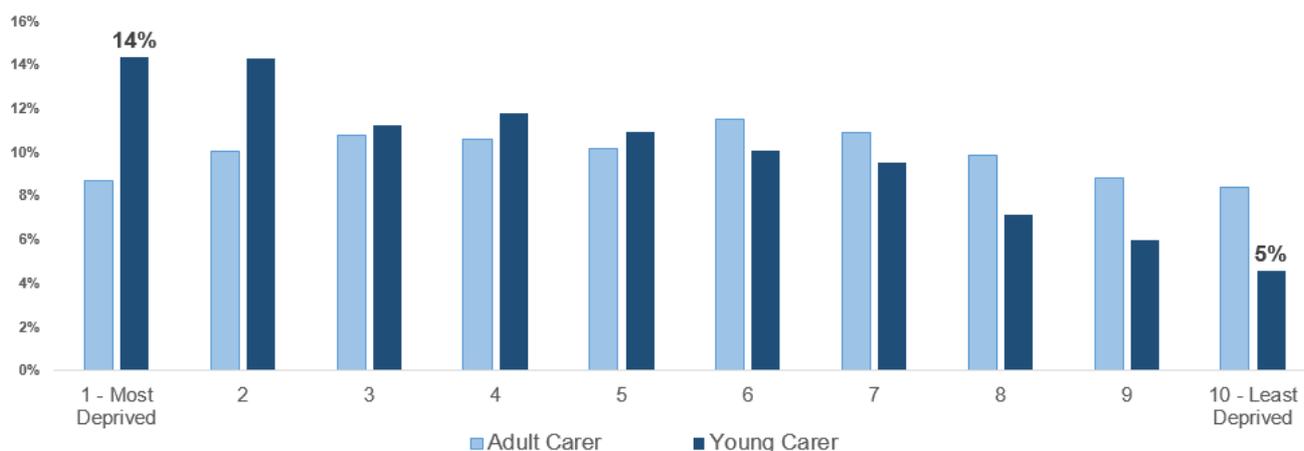


Deprivation

There does not appear to be much difference in the number of adult carers by deprivation in the Carers Census in 2020-21; however, there is a marked difference for young carers. As shown in Figure 2, 14% of young carers in the Carers Census lived in the most deprived Scottish Index of Multiple Deprivation (SIMD) decile compared to 5% who lived in the least deprived SIMD decile. This difference is also seen in 2019-20 and is consistent with previous findings such as those included in the [report on Scotland's Carers](#).

Figure 2. Young Carers were more likely to live in the most deprived SIMD deciles in 2020-21

Source: Carers Census, Scotland, 2019-20 and 2020-21



3.3 Caring roles

The roles of unpaid carers are highly varied. Carers can provide many types of care for the people they care for; such as providing emotional support or helping with shopping, cleaning and other domestic tasks. Some carers will be caring more intensively than others and may be caring for more than one person. This will all contribute to the impact that providing care and support has on a carer.

The analysis in this section is based on those carers for whom information was available. Data completeness for the information in this section was fairly low overall, which should be taken into consideration when interpreting the results.

Carers' Ability and Willingness to Care

The Carers (Scotland) Act 2016 aims to enable unpaid carers to be better supported so that they can continue to care, if they wish to do so. There will be some cases where carers are not able or willing to provide care and support but may still have to continue to do so.

Based on the 6,240 records for which information on both carers' ability and willingness to provide care was available, the data suggests that 99% of carers were willing to provide care and that 97% were able to do so in 2020-21. This is a similar proportion to 2019-20. The data also suggests that 97% of carers were both able and willing to provide care. However, it is important to note that information on both ability and willingness to care was only available for a fifth of records in 2020-21, so these results should be treated with care.

Table 3: Percentage of Carers Able and / or Willing to provide care in 2020-21

Carers Willingness to provide care	Carer Able to provide care	Carer Not Able to provide care	All
Carer Willing to provide care	97%	2%	99%
Carer Not Willing to provide care	<1%	1%	1%
All	97%	3%	100%

Note: Based on the 6,240 records containing information on both carers' willingness and ability to provide care.

Intensity of Care Provided

Based on the 17,150 records with information on intensity of care in 2020-21, 54% of carers spent an average of 50+ hours a week providing care. This is slightly less than the 59% of carers in 2019-20 but is double the proportion (27%) reported in the [Scotland's Carers report](#), which looked at the total caring population. This may reflect the fact that people with more intense caring roles are more likely to seek support from local services.

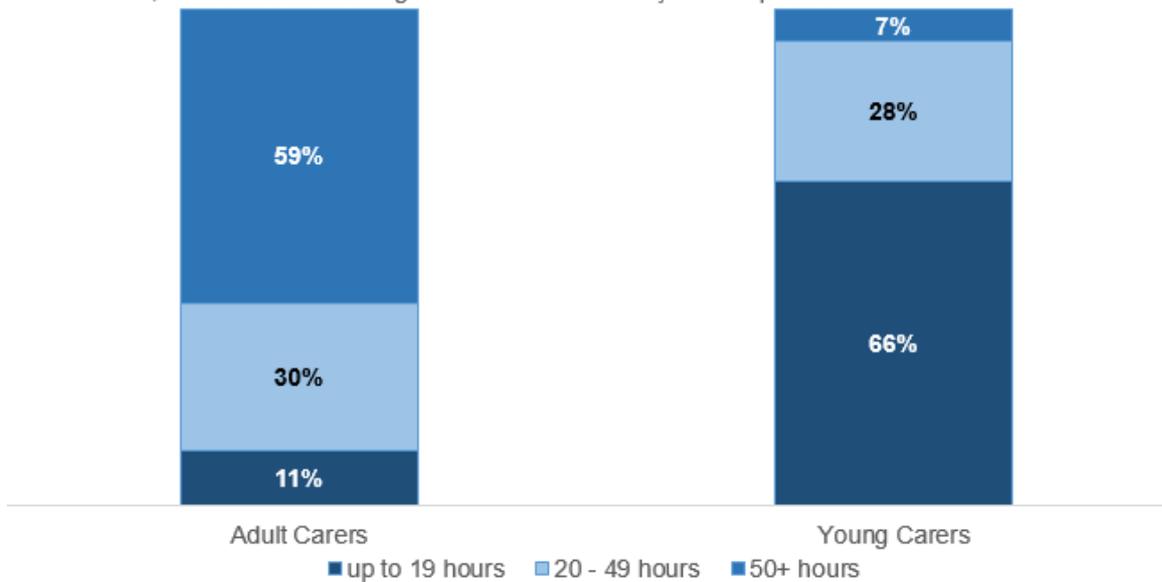
In 2020-21, 17% of carers for whom information on intensity of care was available spent less than 19 hours per week providing care compared to 14% in 2019-20. This is around a third of the proportion (56%) reported in Scotland's Carers, but again may suggest that people with more intense caring roles are more likely to seek support from local services and so be included in the Carers Census.

Figure 3 shows that the intensity of care provided varied between adult carers and young carers. In 2020-21, 66% of young carers spent less than 19 hours a week providing care compared to 11% of adult carers. This difference was also observed in the 2019-20 data and likely reflects differences in the capacity for, and the appropriateness of, higher levels of caring between adult carers and young carers.

Figure 3. Most young carers provided up to 19 hours of care per week on average in 2020-21

Source: Carers Census, Scotland, 2019-20 and 2021

Based on 17,150 records containing information on intensity of care provided



Impact of Caring on Carers

Providing care and support to family members, friends and neighbours can have multiple impacts, both positive and negative, on a carer's life.

The data shows that, while the areas of carers' lives impacted by providing care were similar in 2019-20 and 2020-21, there was an overall reduction in the proportion of impacts reported. This is contrary to anecdotal evidence of carers reporting negative impacts due to the pressures arising from the Covid-19 pandemic, and the resulting limitation of services and support. The reduction reported here may be due to the fact that only carers who were being actively supported by local services were included in the Carers Census.

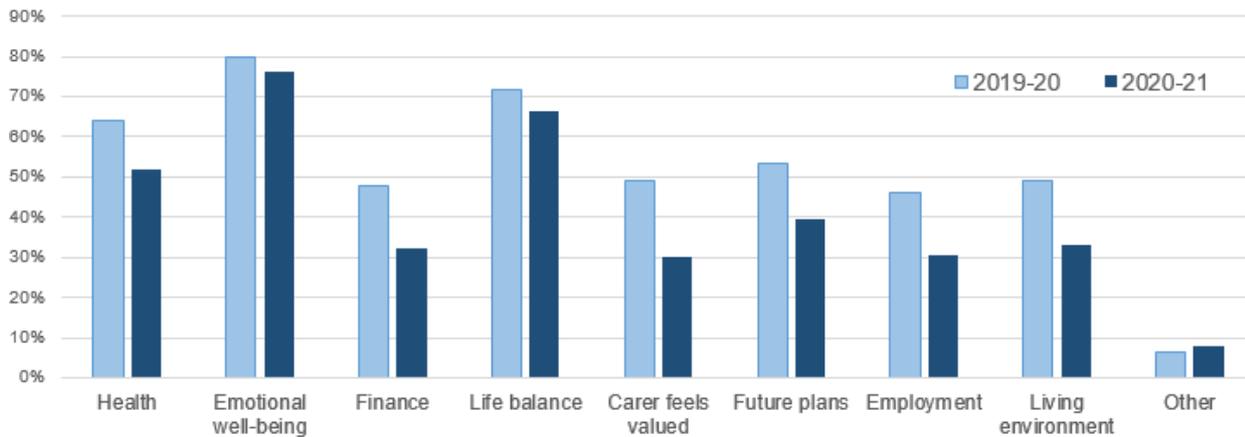
There were 13,650 records with information on the impact of the caring role in 2019-20 and 11,490 records with this information in 2020-21. There was little change in the proportion of carers experiencing an impact on emotional well-being and life balance between 2019-20 and 2020-21. In both years, impact on emotional well-being was the most commonly reported (80% in 2019-20 and 76% in 2020-21). This was followed by impact on carers' life balance, with 72% reporting this in 2019-20 compared with 67% in 2020-21.

As seen in Figure 4, the biggest reduction was observed for carers who reported that their caring role made them feel valued. In 2019-20, the data indicates that 49% of carers felt valued for providing care but this fell to 30% in 2020-21. There were also noticeable reductions in the proportion of carers recorded as experiencing impacts on their finances, employment and living environment between 2019-20 and 2020-21 (all -16%).

Figure 4. The most common impacts experienced by carers due to their caring role were on their emotional well-being and life balance

Source: Carers Census, Scotland, 2019-20 and 2020-21

Based on 13,650 records from 2019-20 and 11,490 records from 2020-21



Note: Carers can be impacted by caring in many ways, so individual categories will not sum to 100%.

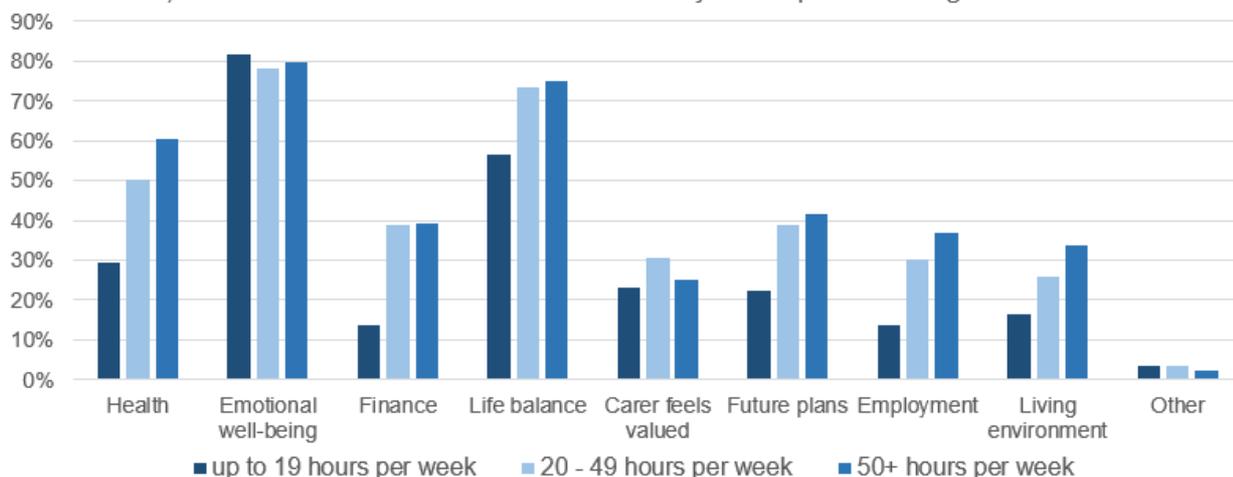
The data for both 2019-20 and 2020-21 also suggests that adult carers and young carers were impacted differently by their caring roles. In 2020-21, adult carers were more likely than young carers to experience impacts on their health (56% compared to 27%), finance (34% compared to 20%) and future plans (43% compared to 19%). These differences were slightly more pronounced in 2019-20. Young carers were more likely to experience an impact on their emotional well-being due to their caring role than adult carers in both years. In 2020-21, data suggested that 89% of young carers experienced an impact on their emotional well-being, compared to 74% of adult carers.

The impacts of providing care varied depending on the average number of hours of care provided per week. The data suggests that the more hours of care a week provided by carers, the more likely they are to experience impacts on their health, employment and living environment. For instance, in 2020-21 29% of carers providing up to 19 hours of care per week experienced an impact on their health compared to 60% of those caring for 50+ hours a week. This is shown in Figure 5.

Figure 5: In 2020-21, carers were more likely to experience impacts on their health, employment and living environment as the intensity of their caring roles increased

Source: Carers Census, Scotland, 2019-20 and 2020-21

Based on 8,690 records with information on the intensity and impact of caring



Note: Carers can be impacted by providing care in many ways, so categories will not sum to 100%.

While it may be expected that the impact of caring would vary a great deal depending on the relationship with the cared for person and the reason for caring (e.g. cared for person’s dementia, learning disability etc.), this did not appear to be the case.

Some situations seemed to lead to more carers experiencing impacts overall; for instance, people caring for a person on the Autism spectrum or a learning disability appeared to be more likely to experience impacts due to their caring role. Also, people caring for a child or grandchild appeared to be less likely to experience impacts due to their caring role than people caring for a parent or grandparent. However, no group appeared more likely to experience particular impacts of caring as a result of their relationship to the cared for person.

In 2019-20, the data suggests that people who lived with the person they were caring for were much more likely to experience impacts due to their caring role – particularly on their finances (57% compared to 37% of carers not living with the person they provide care for) and living environment (58% compared to 38% of carers not living with the person they provide care for). However, these differences appear to have reduced greatly in 2020-21. Again, this may be due to the effects of the Covid-19 pandemic and the changes to people’s everyday living situations.

3.4 Support Plans, Needs and Support Provided

The analysis in this section is based on those carers for whom information was available. Data completeness for the information in this section was fairly low overall, which should be taken into consideration when interpreting the results.

Adult Carer Support Plans (ACSPs) and Young Carer Statements (YCSs)

Under the Carers (Scotland) Act 2016, all carers have the right to a new ACSP or YCS based on their personal outcomes and needs for support. As systems to collect and record this information are still being implemented, some data providers were unable to return variables on ACSPs and YCSs for 2019-20 and 2020-21.

Out of the 31,760 individual carers in the 2020-21 Carers Census, information related to ACSPs and YCSs (including date of offer or request, whether the plan was completed or not and whether or not the plan was incomplete) was present for 66% of records. This information was also available for 59% of records in 2019-20.

Of those records where there was information available in 2020-21, and so an ACSP or YCS must have been offered or requested, the data showed that 41% of carers had a completed ACSP or YCS and for 47% their ACSP or YCS was recorded as incomplete. This means that the plan was offered or requested but not finished. For 6% of these records with an incomplete support plan this was because the plan was declined by the carer and for 12% a plan was deemed to be not appropriate.

Table 4: Percentage of ACSPs or YCSs completed or declined by end of 2020-21

	ACSP or YCS completed	ACSP or YCS incomplete
Adult Carers	41%	46%
Young Carers	41%	51%
All Carers	41%	47%

Note: Based on 20,950 records with information relating to ACSPs and YCSs in 2020-21.

The figures above include all instances of where there was some information on support plans available. When looking solely at records where there was information on the date the plan was offered, the data shows that there was a 28% reduction in the number of completed ACSPs and YCSs between 2019-20 and 2020-21. This is likely a result of the Covid-19 pandemic and the subsequent emergency legislation passed in order to ease pressures on local services.

Carers' Support Needs

Carers can have multiple support needs; including short breaks or respite, counselling or emotional support, or assistance with benefits.

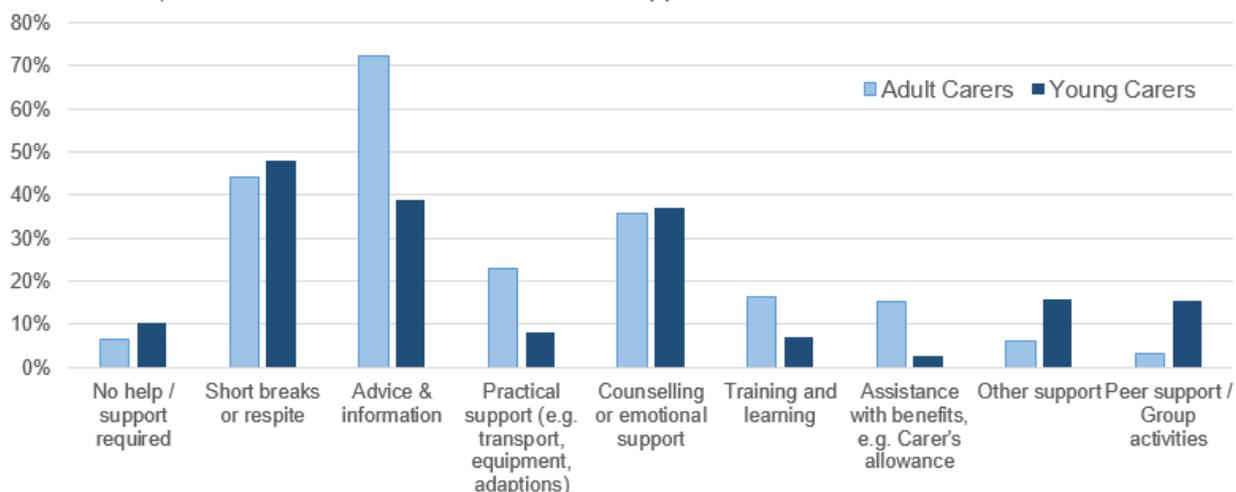
Based on the 9,090 records for which information on carers' support needs was available in 2020-21, around two-thirds were recorded as needing advice and information and just under half were recorded as needing short breaks or respite. This is very similar to 2019-20.

The data suggests that support needs vary between adult carers and young carers, as shown in Figure 6. In 2020-21, adult carers were more likely to be recorded as needing advice and information (72% compared to 39% of young carers) and practical support

(23% compared to 8% of young carers). This is broadly similar to 2019-20. Young carers were more likely to be recorded as peer or group support (16% compared to 3% of adult carers) in 2020-21.

Figure 6. Adult carers were more likely than young carers to need information and advice and practical support in 2020-21

Source: Carers Census, Scotland, 2019-20 and 2020-21
Based on 9,090 records with information on carer support needs



Note: Carers can have multiple support needs, so individual categories will not sum to 100%. Other support needs include recreation, well-being and support for the person being cared for.

The data suggests that carers' needs seem to vary slightly depending on the reason for cared for person requires care. For instance, people caring for someone with a learning disability appear to be slightly more likely than people caring for other groups to require short breaks or respite. Also, the data indicates that people caring for someone with dementia or on the autism spectrum seem to be more likely to be assessed as needing advice and information. The data also shows that people may be more likely to need advice and information or counselling or emotional support if they are caring for a parent or grandparent.

Support provided (or intending to be provided) to Carers

Carers may be provided with multiple types of support to meet their needs and to help support their caring role. A carer can be provided with support without needing to have an ACSP or YCS in place.

Based on the 18,320 records in 2020-21 for which information on support provided (or intending to be provided) to carers was available, 85% of carers were provided with advice and information in 2020-21 and 29% were provided with short breaks or respite. This is similar to 2019-20, where 77% of carers were provided with advice and information and 29% were provided with short breaks or respite.

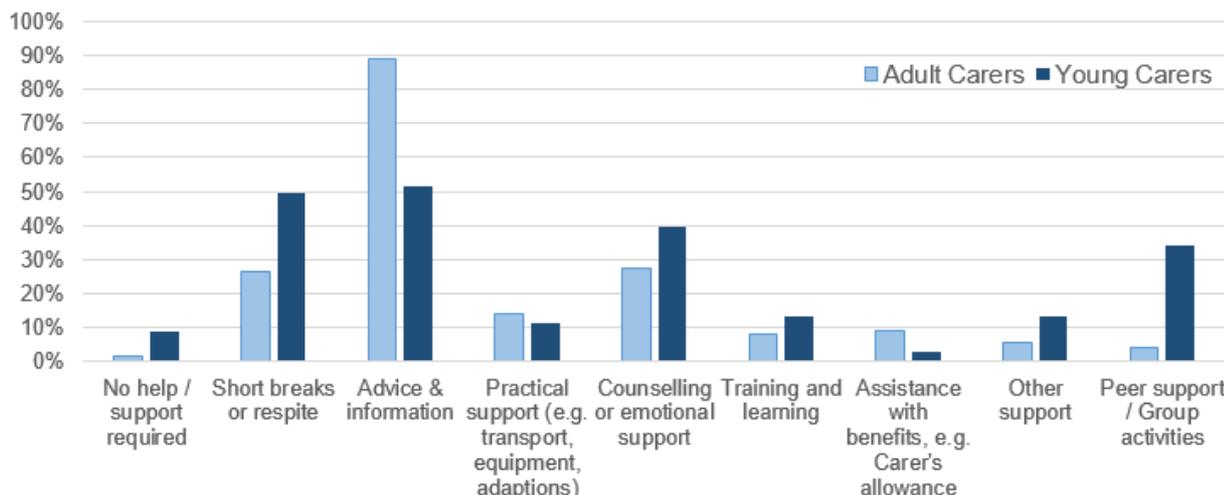
The data suggests that there were differences in the support provided to adult carers and to young carers, as shown in Figure 7. Young carers were more likely to be provided with short breaks or respite (50% compared to 27% of adult carers) and peer or group support (34% compared to 4% of adult carers). This may reflect the different support needs for young carers. The same pattern was observed in 2019-20. Adult carers were more likely to

be provided with advice and information (89% compared to 52% of young carers in 2020-21).

Figure 7. Young carers were more likely to be provided with short breaks or respite and peer/group support in 2020-21

Source: Carers Census, Scotland, 2019-20 and 2020-21

Based on 18,320 records with information on type of support provided



Note: Carers can be provided with more than one form of support, so individual categories will not sum to 100%. Other support provided includes recreation, well-being and support for the person being cared for.

Based on the 7,250 records in 2020-21 where information on both support needs and support provided (or intending to be provided) was available, the data suggests that nearly everyone who was recorded as needing advice and information (98%) was provided with this support. The data also indicates that 4 in 5 people who needed short breaks or respite (83%), or practical support (79%), was provided with that support. This is similar to 2019-20.

4. Cared For Person Information

The relationship between carers and the people they care for can be complex. Carers can provide care to more than one person and cared for people can receive care from more than one carer. Based on those de-duplicated records for which there is also information on the person being cared for; in 2019-20 20,740 carers provided care for one person while 2,540 carers provided care to two or more people. In 2020-21, 19,540 carers provided care for one person and 2,860 carers provided care for more than one person.

The information in this section is based on the number of individual cared for people who received care and support from the unpaid carers discussed in Section 3. This includes 25,140 cared for people in 2019-20: 24,010 cared for people who received care from one carer and 1,130 who received care from more than one carer. In 2020-21, there were 24,260 cared for people: 22,820 receiving care from one carer and 1,440 receiving care from more than one carer.

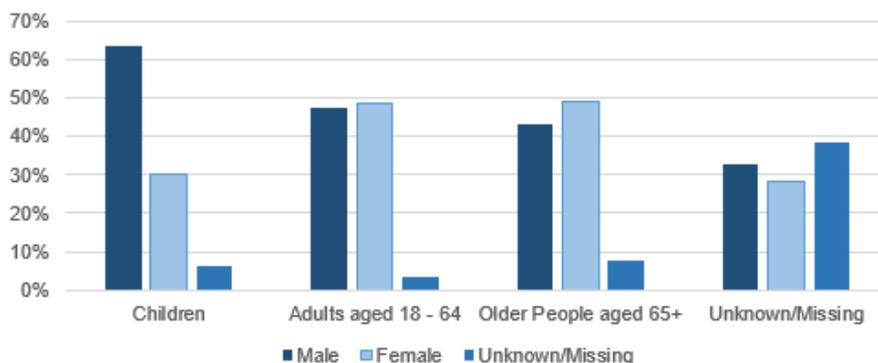
4.1 Age and Gender

In 2020-21, 20% of cared for people in the Carers Census were children. 30% were working age adults and 41% were older people aged 65+. This is similar to 2019-20.

There was a similar proportion of male and female cared for people overall and a similar proportion of male and female adult cared for people in both years. However, as seen in Figure 8, this differed for children being cared for by an unpaid carer. In both 2019-20 and 2020-21, 63% of children being cared for were male compared to 30% who were female.

Figure 8. Around 3 in 5 children being cared for by an unpaid carer were male in 2020-21

Source: Carers Census, Scotland, 2019-20 and 2020-21



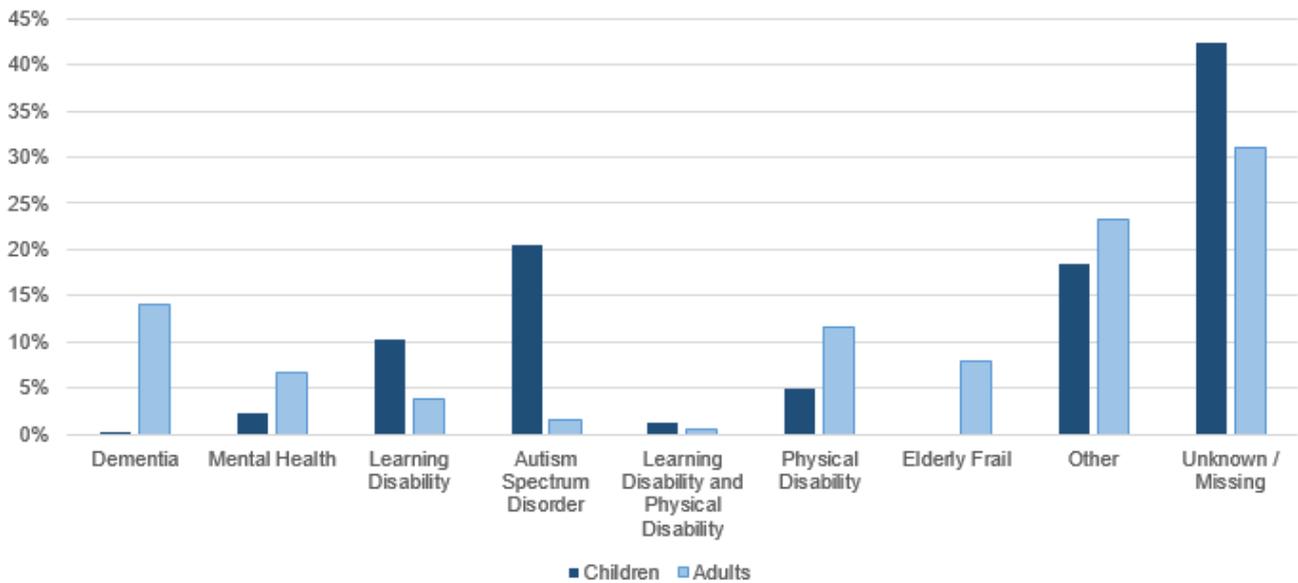
4.2 Main Client Group

A person's main client group, such as mental health or physical disability, is the main reason a person requires care and support. Cared for people can have more than one client group but for the purposes of this analysis, only the main client group for each cared for person is considered.

In 2020-21, the most common main client group overall and for adult cared for people, apart from 'Other', was Dementia (14% of adult cared for people) followed by Physical Disability (12% of adult cared for people). However, the most common main client group for children receiving care from an unpaid carer was Autism Spectrum Disorder (21%). This is similar to 2019-20.

Figure 9. Around a fifth of children being cared for by an unpaid carer in 2020-21 were in the Autism Spectrum Disorder client group

Source: Carers Census, Scotland, 2019-20 and 2020-21



5. Background Information

5.1 Data Quality

As mentioned in Section 1.1 of this publication, the figures presented in this report are taken from the 2019-20 and 2020-21 Carers Census returns. Some data providers were still implementing new systems to collect and record the required data during the collection period. As a result, there are a number of data quality issues that have been identified which we hope to improve upon for future publications. Care should be taken when interpreting the results included in this report.

The main data quality issues identified are:

- There are gaps in coverage across Scotland. Data returns were received from around 70% of data providers, but not all areas were equally represented. For instance, some areas have data from multiple services whereas others have data from either statutory social work or from the third sector.
- Information could not always be returned on all of the carers who met the criteria for inclusion in the Carers Census since the data was not always available. Therefore, the figures presented in this report will be an undercount of the true number of carers being supported by local services.
- The completeness of the returns received varied widely. Some providers were only able to return more basic information such as demographic variables due to lack of data availability. Therefore, some of the analysis presented in this publication (mainly in Sections 3.3 and 3.4) is based on a smaller number of carers for whom information was available.
- Identifiers such as date of birth, gender and datazone were missing for nearly a fifth of the records submitted. As a result, these records were removed through the de-duplication process and so not included in the final analysis (See Section 2 for more information).

These issues are mainly due to lack of available data and the fact that it is taking time for providers to implement systems to accurately collect and record the required information following a significant change in practice. It is expected that these issues will improve as time goes on and systems develop further. In the meantime, we will continue to work with data providers to continue to improve the quality of the data.

5.2 Future Improvements

As well as improving the general data quality, we have also identified other improvements that we plan to implement for future publications. These include the proposed improvements set out below:

- For future publications, we intend for the de-duplication process to be carried out by National Records of Scotland who will be able to link the Carers Census data to Scotland's population spine. The population spine contains the personal identifiers of everyone in the Scottish Census and should allow us to obtain an accurate number of individual carers being supported by local services in Scotland. However, this will be dependent on accurate identifiers being submitted for each carer.

- As data quality improves, we expect to be able to include local area breakdowns in future publications in order to look at the differences in how the Carers (Scotland) Act 2016 has been implemented across Scotland.

We would welcome any feedback on this report in order to help us improve future publications. If you have any comments or suggestions, please e-mail SWStat@gov.scot.

Data under Development

This is the second publication of the Carers Census. The data collection systems and quality assurance processes necessary to collect and process the data are still being developed. The statistics shown here, therefore, are data under development and should not be considered as National or Official Statistics.

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How to access background or source data

The data collected for this 'Data under Development' Statistics Release may be made available on request, subject to consideration of legal and ethical factors. Please contact SWStat@gov.scot for further information.

Complaints and suggestions

If you are not satisfied with our service or have any comments or suggestions, please write to the Chief Statistician, 3WR, St Andrews House, Edinburgh, EH1 3DG, Telephone: (0131) 244 0302, e-mail statistics.enquiries@gov.scot.

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