#### **Divisions Affected -**

Public Health; Adult Social Care; Children's Services

# HEALTH AND WELLBEING BOARD 16 March 2023

# REVIEW OF SUPPORT TO UNPAID CARERS Report by Karen Fuller

#### RECOMMENDATION

- 1. The Health and Wellbeing Board is RECOMMENDED to
  - A. Develop and publish a new All-age Unpaid Carers Strategy for Oxfordshire, based on priorities expressed by carers of all ages
  - B. Align workplans across Health, Education and Social Care to the refreshed All-age Unpaid Carers Strategy for Oxfordshire so that all services have procedures in place to identify and support unpaid carers, regularly review procedures, and seek ways to support and include carers
  - C. Develop and keep updated a central public repository of information for carers so that carers and those supporting/advising them can easily find support
  - D. Support the establishment of the overview arrangements necessary to ensure improvements are achieved across the system

## **Executive Summary**

2. Local Authorities and Health organisations have statutory duties to support unpaid carers of all ages (see Background, below). The Survey of Adult Carers in England 2021/22 showed that, nationally and in Oxfordshire, unpaid carers' satisfaction levels against all measures had fallen. Census 2021 showed that although the number of unpaid carers overall has fallen, the hours of care each generally provides has increased since Census 2011.

An action group set up to resolve carers' reported issues and to engage more widely with carers found that many issues reported involved the wider Health, Education, Social Care and voluntary sector organisations, and especially communication between organisations. Carers and those supporting them found information hard to find. The issues reported followed the same themes as those reported in the national survey. The existing Oxfordshire Carer Strategy 2017-20 contained out of date information, particularly regarding young carers, and required refreshing; the adult carers' main priorities remained the same. A review of support to young carers and engagement started later and

is ongoing, and the emerging themes mirror those of adult carers. Many improvement actions have been completed and work continues.

A review of support to adult carers in Oxfordshire was carried out, including listening to carers' stories and concerns through various methods, and agreeing goals and outcomes with them. Services for carers were evaluated to gauge whether they supported carers' three main priorities, which showed that more work is required, particularly to avoid carers having to constantly retell their stories.

Our findings showed that adult carers' priorities remain unchanged, that carers and those who support/advise them have difficulty finding information and support, and that organisations need to find ways of joining up to support carers. These findings are reflected in the recommendations above. Approval to develop the strategy was supported by Adults DLT (6/3/23) and Joint Commissioning Executive (9/3/23).

## 3. **Background**

The Care Act 2014 gives adult carers the right to receive support from their local authority if they have eligible needs. The Local Authority has a duty to assess carers when they come to their attention, provide carers with support to meet their needs according to national eligibility criteria, and a duty to provide information and advice, to promote wellbeing and to prevent people needing support, where possible. Young carers are those under 18 years old with caring responsibilities. Their rights to be assessed come mostly from the Children's Act 1989 and the Children and Families Act 2014, and as part of the whole family approach. The Health and Care Act 2022 places a duty on NHS Hospital Trusts to involve carers in discharge planning, ensuring that carers are involved in choices about discharge.

The Council's Strategic Plan 2022-25<sup>1</sup> states 'Support carers and the social care system' as one of its nine priorities. The Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board states in its Master Strategy Document<sup>2</sup> its ambition that carers experience a level of support that is seamless and consistent, including better access to support in a crisis, and that the health and wellbeing of carers is improved.

Oxfordshire County Council's Carer Strategy has been in place since 2017. Since its publication, the Covid-19 pandemic<sup>3</sup> and cost of living crisis<sup>4</sup> have impacted the population, with unpaid carers being particularly adversely affected financially and in terms of their wellbeing. The impact of the pandemic was reflected in the results of the Survey of Adult Carers in England

<sup>&</sup>lt;sup>1</sup> Our strategic plan 2022 - 2025 | Oxfordshire County Council

<sup>&</sup>lt;sup>2</sup> 7412dde8ee3fd572bf249ae0cb8058c2\_Master\_BOB\_Strategy\_Document\_Draft\_vFINAL2.pdf (amazonaws.com)

 $<sup>\</sup>underline{https://www.ons.gov.uk/people population and community/health and social care/social care/articles/coronavirus and the social impacts on unpaid carersing reatbritain/april 2021$ 

<sup>4</sup> https://www.economicsobservatory.com/how-is-the-cost-of-living-crisis-affecting-unpaid-care

(SACE) 2021/22<sup>5</sup> (which itself had been postponed for a year due to the pandemic) and showed lower performance than the previous survey across the five ASCOF indicators below, both nationally and in Oxfordshire.

- Carer reported quality of life
- I have as much social contact as I want with people I like
- Overall satisfaction of carers with social services
- The proportion of carers who report that they have been included or consulted in discussions about the person they care for
- The proportion of carers who find it easy to find information about services

The typical carer in Oxfordshire is a woman aged 65+ years living with the cared for person, providing 100 hours or more of care a week, and has been caring for over 5 years. This includes help with dealing with care services/benefits, personal care, making medical and other appointments, arranging transport and attendance with the cared-for person, collecting prescriptions, shopping, companionship, keeping an eye on them and other practical help including dealing with crises at short notice.

The main source of data about unpaid carers in Oxfordshire comes from the census. At the time of writing, data from Census 2021<sup>6</sup> is being released. This tells us that both nationally and locally although the number of unpaid carers has reduced - in Oxfordshire to 52,674 from 61,000 in 2011 - the number of hours of care they are generally providing has increased.

In Oxfordshire the provision of unpaid care from 1-19 hours has decreased by 32%. However, there has been a 43% increase of people who provide 20-49 hours of unpaid care, and a 24% increase in those who provide 50+ hours of unpaid care. Again, this reflects the national trend.

Proportionally, Oxfordshire's residents provide fewer hours of weekly unpaid care than the rest of England and Wales.

The proportional rate of the population over 5 years old that provides:

	No care	•	20-49 hours	50+ hours
		unpaid care	unpaid care	unpaid care
		per week	per week	per week
Oxfordshire	92.3%	4.3%	1.3%	2%
England &	91.1%	4.3%	1.8%	2.7%
Wales				
Difference	+1.2	0	-0.5	-0.7

Source: Census table TS039

 $\frac{https://app.powerbi.com/view?r=eyJrIjoiNzI5ZDdmM2YtMDRiNC00MTY0LThIZjItYTE5ZjA3YTkxYWU4IiwidCI6IjUwZjYwNzFmLWJiZmUtNDAxYS04ODAzLTY3Mzc0OGU2MjlIMiIsImMiOjh9$ 

<sup>6</sup> Census | Oxfordshire Insight

<sup>5</sup> 

Oxford has the lowest proportion of the population who provide unpaid care across Oxfordshire. The population of Oxford which provide any weekly unpaid care is 2.20%. This is below the Oxfordshire average of 2.53%

Provision of unpaid care	Value	% of population
Cherwell	11,597	2.5%
Oxford	10,290	2.2%
South Oxfordshire	11,225	2.7%
Vale of White Horse	10,595	2.7%
West Oxfordshire	8,967	2.7%
Oxfordshire	52,674	2.5%
England and Wales	4,989,016	2.9%

Appendix 1 contains links to supplementary research and information. Annex 1 contains details of carers services currently provided in Oxfordshire

## 4. Response to the results of the Survey of Adult Carers in England 2021/22

The survey (SACE) was sent out in October 2021 to 1,600 carers registered with Oxfordshire County Council, of whom 465 (29.1%) responded. Interim results released from the survey in February 2022 showed:

- 62% were satisfied with the support they received; 16% were dissatisfied and 22% were neither satisfied nor dissatisfied
- 13% of carers said they had no time to do things they value or enjoy and 19% felt they were neglecting themselves; 19% felt socially isolated and 24% felt they had no encouragement or support in their caring role
- 20% reported that they had had to visit their GP as their health had been affected by their caring role
- Since 2012/13 there is a declining and statistically significant trend in the percentage of adult carers who have as much social contact as they would like (from 41.6% to 26.7%)<sup>7</sup>
- Nearly three quarters provide personal care (72.4%)

It was not clear from the comments that all carers actively wished to take on the role, but rather that they felt that they had to. Appendix 2 contains carers' comments from responses.

A task group was formed comprising staff from the Commissioning, Adult Social Care, Finance, Customer Service, Direct Payment Advice, Quality Improvement and Quality Assurance Teams at the County Council and partners from the voluntary sector: Age UK Oxfordshire, Carers Oxfordshire, Dementia Oxfordshire, and Oxfordshire Specialist Advisory Service. The group devised an action plan to resolve issues raised in respondents' comments in the survey.

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<sup>&</sup>lt;sup>7</sup> Public health profiles - OHID (phe.org.uk)

Progress on this work has been reported at People Overview Scrutiny Committee by the Interim Corporate Director of Adult and Housing on 12 January 2023. A summary of the work reported is in Annex 3; Annex 2 contains completed actions.

## 5. Carers Strategic Review

The work to this point showed that unpaid carers and those supporting them found it difficult to find information about services available, partly because multiple agencies were involved in their delivery and communication between those agencies was inconsistent, as indicated by 'communication' being the most referenced theme by carers. It was not possible to easily establish what was available to unpaid carers across all systems and where the gaps lay.

A stakeholder group was set up (with members from the County Council, Carers Oxfordshire, Rethink Mental Illness, Oxfordshire Family Support Network, Be Free Young Carers, Oxfordshire Parent Carer Forum, Age UK Oxfordshire, Dementia Oxfordshire, Oxford Health, Oxford University Hospitals, Buckinghamshire Oxfordshire and Berkshire West Integrated Care Board, Oxford City Primary Care Networks Social Prescribers and unpaid carers) to refresh the current Oxfordshire Carers Strategy and review services for unpaid carers. Adult carers were asked whether the three main priorities below from the current Oxfordshire Carer Strategy were still important to them, and for their experiences as carers. Lead Commissioners, Operational and Quality Improvement Leads across Health and Social Care, and voluntary organisations involved with supporting unpaid carers were asked to evaluate their services against the priorities and to provide stories of difference.

**PRIORITY 1:** To identify carers and effectively support them, improving their health and wellbeing and providing opportunities for a break from their caring role.

**PRIORITY 2:** To safeguard the most vulnerable carers who need more support to look after themselves, particularly during times of change and transition.

**PRIORITY 3**: To encourage and enable carers to have an active life outside their caring role, including fulfilling their education, employment, and training potential.

#### 5.1 **Services evaluation**

Each of the questions within each service evaluation was rated as to how the service met the priorities above: Green – clear evidence, Amber – partial evidence or Red – no evidence. Overall, the evaluations rated - Red: 36.6% Amber: 22.1% Green: 41.3%. The gaps were predominantly around follow-up of referrals made to other organisations; identifying 'hidden' carers and/or exploring/recording reasons for not wishing to be identified as a carer; and lack of recent or planned initiatives or improvements for carers to services.

An area in which most services rated well or had identified changes they needed to make was in ensuring carers did not have to retell their stories at each contact, about which carers have reported frustration. However, few of the services shared systems causing carers to have to reiterate when referred or signposted to another service.

#### 5.2 **Engagement with Unpaid Carers**

Carers Oxfordshire carried out engagement work to facilitate and widen carer involvement in the review of the Oxfordshire Carers Strategy and services for unpaid carers, focusing on carers aged 18+, caring for adults and/or children; engagement with young carers is being undertaken separately by the Engagement and Commissioning (Start Well) Teams.

Contributions were collected from: attendance at the Carers Oxfordshire 'Listening Event', online surveys, direct media such as email and Zoom, visits to small groups including those in more rural areas, and individual telephone conversations.

Carers unable to use the online options were encouraged to use telephone or post options to have their voice heard. Oxfordshire County Council's survey was also made available in the top five most-translated languages in the county (Polish, Sudanese Arabic, Brazilian Portuguese, Kurdish Sorani and Spanish). To increase the reach to carers, Carers Oxfordshire worked with Oxfordshire County Council, Dementia Oxfordshire, Age UK Oxfordshire, Oxfordshire Family Support Network and Oxfordshire Parent Carer Forum. To date circa 300 adult carers have contributed and engagement continues.

Common themes recurred through the evidence submitted from the groups and studies outlined above. Whilst these themes are all distinct, it is important to note that they are interrelated. This was particularly clear during the first carers voices event where carers were separated into groups that were allocated a theme to discuss their experiences around yet <u>found it difficult to</u> discuss one theme in isolation.

Based on responses received to date, the themes remained consistent with the national survey responses. They have been re-worked below to show goals and outcomes required to meet statements describing what carers say is important to them. It is important also to facilitate a means of measurement and accountability.

#### 5.3 Goals and outcomes agreed with carers

#### Having a quality of life should not be lost because you are a carer.

- Having a break from your caring role is essential.
- Different options for respite are important i.e. day care, family days out.
- Improved provision and access to residential respite.
- Access to support when at work or studying.
- Wellbeing opportunities need to be increased e.g. counselling.

#### Services, provision, and support needs to improve.

- Better communication including carers being listened to, responded to and involved.
- A joined-up approach between services. (NHS, Social Care and the voluntary and community sector)
- Quality of care needs to improve. (Timeliness, access to services e.g. GPs)
- Increased specialist service provision and training for services (SEND provision & Adult Social Care).

## Information & advice needs to be easily accessible.

- Information is available when needed.
- Available in different formats and languages.
- Easily understandable and accurate.
- In one place.
- With explanations of services.

#### Carers should be valued

- Treated as partners/experts in supporting the cared for person.
- Involved in decision making and planning.
- Understood and acknowledged for the important contribution they make to society.
- Provided with increased support to manage caring role. (Carers Assessment, Support Plans, Direct Payment).
- Recognised as having their own diversities, disabilities, abilities and needs.

#### Strategy priorities must be measurable and reported on.

- Effective, meaningful measures.
- Reporting back on strategy progress and outcomes.
- Transparency.
- Communication.

#### 6. **Monitoring progress**

To deliver the improvements required, the following are necessary:

- developing a common framework/strategy;
- 2. agreement from all of the partners to the strategy to implement within their own organisations the aligned workplans;
- 3. monitoring and review or progress against agreed areas for improvement overseen by the Health & Wellbeing Board in partnership with experts by experience.

#### 7. Conclusions

The review indicates the priorities within the strategy remain unchanged for adult carers, however, the current strategy does not include how to implement required changes, nor having a central source of information, nor how organisations can join up. Additionally, for young carers, the services have

since been brought in-house. For all of these reasons, a new All-Age Unpaid Carers Strategy is required, to:

- Achieve the system engagement and commitment to meet the needs of unpaid carers across health and social care throughout Oxfordshire.
- Ensure the outcomes developed in the strategy form part of how we monitor implementation and impact across health and social care settings. Focusing on simplicity, consistency, value for money and accessibility.
- Set expectations that individual organisations either develop or adapt unpaid carer service plans in line with the strategy when it is concluded.

It is clear from all engagement with adult carers that they cannot concentrate on their own wellbeing while they have concerns about the person/people they care for, so unpaid carers must be included and engaged in all services relating to the person/people they care for.

The review of the young carers' offer began at a later stage than that for adult carers and will require more time for review, analysis and planning and would inform the refreshed All Age Unpaid Carers Strategy for Oxfordshire. Emerging themes from engagement with young carers tend to mirror those of adult carers in that they do not necessarily identify as carers, are unsure of what support is available for them, and do not find information easy to find.

## **Corporate Policies and Priorities**

8. Carers are identified in our strategic policies including the Oxfordshire Joint Health and Wellbeing Strategy, the Council's Corporate Plan, and NICE quidelines.

## **Financial Implications**

9. There are no new or additional implications. Improvements required will come from the current allocated funds available to the Health & Social Care system. Through the review we have identified pockets of good practice and development of the proposed strategy seeks to strengthen integration between organisations.

## **Equality & Inclusion Implications**

10. An equalities impact assessment will be completed as part of the delivery of the final strategy.

## **Risk Management**

11. A stakeholder group has been developed to identify and mitigate risks of non-compliance with statutory duties. Unpaid carers including young carers, Health partners, voluntary sector and District Council colleagues are actively engaged in the development of the proposed strategy.

#### **Consultations**

12. Plans have been developed to ensure wider public engagement is sought prior to the publication of the final strategy, details of which will be reported at that time.

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Annex: Annex 1 - Carers services in Oxfordshire

Annex 2 - Completed actions Annex 3 - Summary of Action Plan

Appendix 1 - Supplemental information & Research

Appendix 2 - Carers' Comments

Background papers: Nil

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