research in practice

Social Work with Carers

Practice Overview

1. Introduction

On Census Day 2021 (21 March 2021) there were approximately 4.7 million unpaid carers in England, who provide continuing help and support to a relative, partner or friend. There were approximately 120,000 young carers aged between 5 and 17 years.

The Care Act 2014 gives carers a legal right to an assessment of their needs (regardless of how much care they provide) and suitable support to help them in their role as a carer. Social workers play a central role in ensuring that carers receive advice, information and help. This Practice Overview sets out some of the main considerations around social work practice with carers. It covers:

> Ethics

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- > Law and policy
- > Capabilities
- > Evidence from research, practice and lived experience.

The aim of the Practice Overview is to provide a concise picture of good practice with carers.

The main audience is social workers and those who support them in practice, for example supervisors, managers and people in professional development roles. The overview is also valuable for carers and those who support them, and for people working in other roles in social care and health.

The review focuses on carers of adults, including young carers.

2. Methodology

Social Work Practice With Carers: An Evidence Scope (Citarella 2016) was completed for Research in Practice's web resource on social work with carers. The scope was based on a pragmatic literature review. In 2023, a further review was undertaken to identify updates in ethical and capability frameworks, updates in law and policy, and new evidence from 2016 to 2023.

The Evidence Scope was rewritten as a Practice Overview to reflect the emphasis on ethics, law and policy, and capabilities as well as evidence.

This overview is not exhaustive but aims to provide a picture of key elements of good social work practice with carers. It goes alongside the Research in Practice site, commissioned by the Department for Health and Social Care. This provides further resources and signposting.

3. Language

Carer: Carers UK's website says that "A carer is a person of any age who provides unpaid care and support to a family member, friend or neighbour who is disabled, has an illness or long-term condition, or who needs extra help as they grow older."

Young carer: A young carer is a carer under 18.

Social worker: A social worker in England is someone who has completed a social work qualification and is registered with the regulator, Social Work England.

Other definitions can be accessed from the Think Local, Act Personal Care and Support Jargon Buster

4. Ethics

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"Social work is a practice-based profession and an academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work. Underpinned by theories of social work, social sciences, humanities and indigenous knowledge, social work engages people and structures to address life challenges and enhance wellbeing." (IFSW 2014)

The IFSW Global Social Work Statement of Ethical Principles (IFSW 2018) highlights ethics that apply to social work with carers, as to all social work:

- > Recognition of the Inherent Dignity of Humanity
- > Promoting Human Rights
- Promoting Social Justice, including Access to Equitable Resources, and Challenging Unjust Policies and Practices
- > Promoting the Right to Self-Determination
- > Promoting the Right to Participation
- > Treating People as Whole Persons
- > Professional Integrity.

In England, the professional association for social workers, BASW, owns the Code of Ethics for the profession (BASW 2021). The code highlights the importance of social workers working to enable people, in partnership, as change agents: "In its various forms, social work addresses the multiple, complex interactions between human beings, their social situation and their environment. Its mission is to enable all people to develop their full potential, enrich their lives, and safeguard people who may be at risk of harm. Social workers work in partnership with others to find solutions and achieve positive change. As such, social workers are change agents in social and civil society as well as in the lives of the individuals, families and communities they serve."

The Code of Ethics describes ethics in practice, all of which apply to social work with carers:

- 1. Developing professional relationships
- 2. Assessing and managing risk
- 3. Acting with informed consent, unless required by law to protect that person or another from risk of serious harm
- 4. Providing information to people affected by social work decisions
- 5. Sharing information appropriately
- 6. Using authority in accordance with human rights principles
- 7. Empowering people
- 8. Challenging the abuse of human rights
- 9. Being prepared to whistleblow
- 10. Maintaining clear and accurate records
- 11. Striving for objectivity and self-awareness in professional practice
- 12. Using professional supervision and peer support to reflect on and improve practice
- 13. Taking responsibility for their own practice and continuing professional development
- 14. Contributing to the continuous improvement of professional practice
- 15. Taking responsibility for the professional development of others
- 16. Facilitating and contributing to evaluation and research.

5. Law and policy

The Brief Guide for Carers (Bishop 2016) provides a plain English description of the law:

The rights set out in the Care Act apply to adult carers (over the age of 18) and young carers (aged under 18) who are caring for someone over 18... When a professional is assessing a carer's needs and those of the person they care for, the Care Act says that the circumstances of the whole family should be taken into consideration so that the support a family receives is as joined up as possible... The assessment will look at the carer's physical, emotional and mental well-being, and what support might be needed to maintain it.

The Care Act 2014 states that "The general duty of a local authority, in exercising a function under this Part (Care and Support) in the case of an individual, is to promote that individual's well-being" (Part 1, section 1). This means work with carers under the Care Act is ultimately undertaken to promote well-being. The Care Act 2014 statutory guidance (DHSC 2023) states that assessment: 'should not just be seen as a gateway to care and support, but should be a critical intervention in its own right' (6.2).

Carers must be assessed where it appears that they may have needs (including if those needs are future needs), regardless of the level of needs or their financial resources. Carers may be assessed even if they are providing care as paid or voluntary work (DHSC 2023).

Assessment involves looking at the carer's needs for support, the impact of these on their areas of well-being, outcomes they want to achieve, and what will help them to achieve these (Part 1, section 9 and section 10). This should include consideration of the duties of:

- > Preventing, reducing or delaying needs (Part 1, section 2)
- > Promoting integration of care and support (Part 1, section 3)
- > Providing information and advice (Part 1, section 4).

The duty on the local authority (required by s9(4)(a) and s10(5)(c) of the Care Act 2014) is to make judgements concerning the impact of assessed needs on well-being, which is set out in s1(2). For carers, this includes the sustainability of the caring role. The Care Act 2014 emphasises the importance of the carer choosing who should be involved in their assessment and being involved in the assessment of the person they are caring for (Part 1, section 9 and section 10). A local authority may carry out a carer's assessment with another agency (Part 1, section 12).

Following the assessment, there is an eligibility determination (Part 1, section 13). For carers, eligibility focuses on not being able to achieve specified outcomes and/ or the consequences or impact of providing care for an adult, that result in a deterioration of the carer's "*physical or mental condition*". (The decision on eligibility for someone with a carer is made without reference to what the carer is willing and able to do, though care and support planning will include consideration of what the carer is doing.)

Carers whose needs are going to be met by the local authority will then move onto the next stage of care and support planning, including finalising a financial assessment for any financial contribution.

A young carer is defined in section 96 of the Children and Families Act as a person under 18 who provides or intends to provide care for another person of any age. The Children and Families Act 2014 and the Care Act 2014 placed a legal duty on local authorities from 1 April 2015 to identify young carers and carry out both a needs assessment and a transition assessment to consider the impact on the child and whole family. They build on the requirements set out by the Children's Act 1989

In 2021, the Government set out their vision for adult social care in England in their White Paper *People at the Heart of Care.* In this vision, they included statements which they would like unpaid carers to be able to say in the future.

- > I am supported to provide care as I wish and do so in a way that takes into account my own access to education, employment, health and wellbeing
- I have a life outside of caring and I am able to remain connected to the people who matter to me
- I know my needs are equally recognised and my goals and aspirations are respected and fulfilled
- > I have the right information and advice to be able to make informed decisions
- I have access to appropriate support that suits my needs, including respite care and carers breaks.

In April 2023, the Government published *Adult social care system reform: next steps to put People at the Heart of Care* (DHSC 2023). This is a plan for adult social care system reform for 2023 to 2025. The plan includes:

- > An evaluation of support provided to unpaid carers
- > A requirement for local areas to outline plans to support carers and report on these
- > Care Quality Commission inspection of how local authorities are supporting carers.

Wider policies that impact on carers are to: increasingly join up health and social care; improve digital social care records; improve outcomes monitoring; and make assessments more accessible.

6. Capabilities

The capabilities for social workers in England are set out in the Professional Capabilities Framework (BASW 2018). All of these apply to social work with carers. Carers are specifically mentioned in terms of:

- Values and ethics I ensure my practice is underpinned by commitment to working in partnership with, and listening closely to, people who use services, carers, families, communities and networks, wherever possible.
- Rights, justice and economic wellbeing I promote strengths, agency, hope and selfdetermination in people using services, carers, families and communities and support them in raising their own challenges and finding solutions to inequality, social injustice and rights violations.
- Knowledge I value and take account of the expertise of service users, carers and other professionals and seek their feedback on my practice/role.
- > Skills and interventions I actively support, initiate and co-produce community groups and networks for the benefit of people using services, carers and families.

The Knowledge and Skills Statement for social workers working with adults highlights particular capabilities for this area of social work (DH 2015). It says that "social workers need to apply a wide range of knowledge and skills to understand and build relationships, and work directly with individuals, their families and carers to enable and empower them to achieve best outcomes." Carers should be enabled, through person-centred practice, partnership work, systemic approaches and outcome-based work to: have their expertise recognised; exercise choice and control and; determine and achieve the outcomes they want for themselves. Social workers must balance competing interests of service users, their families and their carers, and manage the emotions and expectations of service users and carers.

In the Professional Standards (Social Work England 2019), social workers are expected to: work with people and see them as part of the families, communities and networks they live in; and to draw on and strengthen these relationships to promote, maintain and enhance the wellbeing of people. (Standards 1.2 and 1.4)

The National Institute for Health and Care Excellence published a quality standard for *Supporting adult carers* (NICE 2021). The elements of the standard are:

- Carers are identified by health and social care organisations and encouraged to recognise their role and rights.
- > Carers are supported to actively participate in decision making and care planning for the person they care for.
- > Carers having a carer's assessment are given the opportunity to discuss what matters most to them, including their own health, wellbeing and social care needs, and work, education, or training.
- > Carers are regularly given the opportunity to discuss with health and social care practitioners the value of having a break from caring and the options available to them.
- > Carers are offered supportive working arrangements by workplaces.

The Practice Framework and Handbook for strengths-based working (DHSC 2019) sets out how to do strengths-based practice with adults. The resource emphasises that strengthsbased conversations should involve carers in discussions about what the best steps are for all, with a focus on each person's wellbeing. Carers say that they want social workers to build a relationship with them, help them see things more clearly and to plan. Strengths-based working includes:

- > Recognising expertise and not imposing your way of thinking on carers' lives
- > Being flexible in your approach in order to have meaningful conversations
- > Working with people to identify together the best next- step for them utilising all the strengths and resources they currently have or may have access to.

The resource provides reflective questions to support practice.

7. Evidence

Evidence to 2016

Social Work Practice With Carers: An Evidence Scope was completed by Vic Citarella in March 2016. This was based on a practical literature review. The central messages in Social Work Practice With Carers: An Evidence Scope (Citarella 2016), which remain highly relevant, are:

- > A lot of the materials prepared and circulated by carers organisations and service providers are useful for social work practitioners.
- > Social workers should keep abreast of local resources and services for carers. They should know where to refer carers for specialist knowledge and information.
- Carers should be treated as expert partners by social workers. However, the social worker must know what should happen (the process), the law, the duties and powers, and people's rights.
- > It is a social work task to 'keep an eye on the ball' of who the 'service user' is and the possible conflicts of interest with the carer. Whole family approaches may require co-working, a separate social worker for the carer or the involvement of an advocate.
- > The interface between social workers working with adults and those working with children involve the same families, carers and young carers. Effective personal transition for the carer should not be impeded by organisational issues.
- The role of the social worker as care coordinator seems readily accepted in multidisciplinary settings in the community – less so in health settings/hospitals. There is a systems leadership role emerging for social workers that could be of benefit to carers in their communities.

- > The tendency to segment social work roles and tasks, particularly in work with older people, means that carers may have to relate to different non-social workers for assessments (including their own), care plans, support and reviews. This can shift the coordination responsibility onto the carer and create risk of breakdown.
- > The NHS and health commissioners are alert to the needs of carers when commissioning health services but less so to the role of social work.
- > Carers can make effective trainers of social workers and the carer experience should be integrated into the curriculum.
- > There is a risk of stress and burnout in social workers who are themselves carers.
- > The applicability of theory and research on relationships attachment, loss, transition, lifecourse and resilience for example - can be useful for enhancing understanding of carers.

Overview of caring 2023

The UK Census 2021 (Office for National Statistics 2021) asked "Do you look after, or give any help or support to, anyone because they have long-term physical or mental health conditions or illnesses, or problems related to old age?" On 21 March 2021, there were approximately 4.7 million carers in England. There were approximately 120,000 young carers (aged between 5 and 17 years) in England. The proportion of usual residents aged 5 years and over, who provided any amount of unpaid care in England was 8.9%, down from 11.3% in 2011. Comparisons between 2011 and 2021 data showed:

- A decrease in the proportion who provided 19 hours or less care a week (from 7.2% in 2011 to 4.4% in 2021)
- > An increase in the proportion who provided between 20 and 49 hours of unpaid care a week (from 1.5% in 2011 to 1.8% in 2021)
- > The proportions of people who provided 50 or more hours of unpaid care a week remained similar (2.7%).

The State of caring 2022 report (Carers UK 2022) was based on a survey of around 8000 carers in England. Of these:

- > 80% were female; 27% considered themselves to have a disability; 3% described themselves as Black, Asian or from a mixed/multiple ethnic background and; 4% identified as lesbian, gay or bisexual, with 1% choosing to self-describe
- > 3% were aged 0-34, 11% 35-44, 24% 45-54, 34% 55-64, 19% 65-74 and 9% were aged 75 and over
- > 18% also had childcare responsibilities for a non-disabled child under 18
- > 41% of current carers were in employment: 21% worked full time, 16% part-time and 4% were self-employed; 26% were looking after the home/family/dependents fulltime; 26% were retired; 5% were unable to work due to a sickness or disability; 1% were unemployed/ looking for paid work
- > 31% had been caring for 15 years or more, 14% for 10-14 years, 23% for 5-9 years, 28% for 1-4 years and 3% for less than a year
- > 45% cared for 90 or more hours each week, 15% for 50-89 hours, 24% for 20-49 hours and 16% for 0-19 hours
- > 74% cared for one person, 19% for 2 people, 4% for 3 people and 2% for 4 or more people.

The main issues in the report were:

- > 25% of carers said they were cutting back on essentials such as food or heating, and 77% said saw the rising cost of living as a major challenge.
- > 63% said they were extremely worried about managing their monthly costs.
- > 21% said their physical health was bad or very bad and 30% said their mental health was bad or very bad. 29% said they felt lonely often or always.
- > 41% of carers hadn't taken a break from their caring role in the last year.
- > 36% said that not knowing what services were available was a barrier to accessing support.
- > 25% of carers said they had undertaken a Carer's Assessment. 19% said that they had not requested a carer's assessment as they didn't think it would be beneficial.
- Carers who had an assessment said that the following things were not properly considered: 33% the need to take regular breaks from caring; 32% their ability to maintain relationships with friends and family; 31% their ability to have time to themselves; and 31% what to be put in place in case of an emergency.
- > Carers from a Black, Asian or minority ethnic background and Lesbian, gay and bisexual carers were less likely to have an assessment. The older a carer was, the more likely they were to have an assessment.
- > 71% of carers stated that seeing themselves as a family member or friend was a barrier to identifying as a carer. Carers from underrepresented groups were also more likely to feel that services didn't meet their needs.
- > 31% had never used sitting services, 34% had never used other breaks services, 30% had never used NHS funded care, 28% had never used day services, and 29% had never used care homes for short respite breaks.
- > Only 13% said they were confident that they would have the practical support they need in the next 12 months.
- > 32% said they would be worried about the consequences of making a complaint about a social care service.
- > Carers rated their life satisfaction at an average of 4.7, significantly lower than the UK average of 7.5.

The Personal Social Services Survey of Adult Carers in England 2021-22 (NHS Digital 2022) surveyed 43,525 carers, who had been assessed or reviewed in the previous year. It found that:

- > 79.6% of carers aged 75 and over cared for someone also aged over 75.
- > 50% cared for someone with a physical disability, 39% for someone with a long-standing illness and 35% for someone with dementia.
- > The majority of cared-for people with a physical support need were aged 65 and over, and the majority of cared-for people with a learning disability support need were aged under 44.
- > 47% of carers did not use information and advice.
- > 13% of carers reported the person they care for used services that allowed them to take a break for more than 24 hours, and 10.5% in an emergency or at short notice.
- > The proportion of carers who felt they have as much social contact as they want, with people they like decreased from 32.5% in 2018-19 to 28% in 2021-22.
- > 36% of carers that are extremely dissatisfied with the support or services did not receive any support or services during the COVID-19 pandemic.
- > The percentage of carers that always felt involved or consulted in discussions dropped from 27.4% in 2018-19 to 22.6% in 2021-22.
- For carers that always feel involved or consulted, 63% per cent are very or extremely satisfied with the support or services received. For carers that never feel involved or consulted, 9% are very or extremely satisfied.

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Impact of social work

Manthorpe and Moriarty (2016) highlighted that few studies discuss social work with carers. They found evidence of inconsistent social work support for carers. Brimblecombe et al (2018) carried out an evidence synthesis. They also found limited evidence of impact but identifed a wide range of potentially effective interventions to support carers. Evidence was strongest for formal care services for people with care needs (so-called 'replacement' or 'substitution' care); flexible working conditions; psychological therapy, training and education interventions; and support groups. It seemed that a combination of interventions could be most effective for many people.

Implementation of the Care Act 2014

Research on the implementation of the Care Act 2014 found gaps in the support provided to carers compared with the duties set out in the legislation (Fernandez et al 2020). The number of carer assessments fell from approximately 450,000 per year in 2009/10 to just over 350,000 per year in 2017/18. Carer-related expenditure by local authorities decreased by 6% in the first year following the Care Act's implementation, although overall social care expenditure increased by 3% in cash terms. Support to carers was concentrated on those providing the most care. An increasing proportion of carers received information or advice, rather than support services. There was a reduction in satisfaction with adult social care support.

Researchers concluded that the policy ambitions of the Care Act were undermined by budgetary constraints. This was corroborated by in-depth interviews in 2017-18 with stakeholders in three English local authorities (Marczak et al 2021), which found that, when faced with financial constraints, carers were viewed as a resource and replacement care was limited by needs thresholds and financial assessments. However, the Care Act was seen as making progress in highlighting carers' needs and the importance of their wellbeing.

Research on Care Act implementation in four local authorities (O'Rourke et al 2021) found that signposting carers to third sector services, alongside limited resourcing of the sector, meant that more carers might be in contact with social care but fewer would receive substantive support. However, carers could find voluntary or community services more acceptable or trusted. They also could be a place where staff could specialise in carer support. However, carer support workers were often not registered professionals such as social workers and the emphasis could be on quantity of assessments rather than impact.

The outsourcing of support for carers to the third sector also created complexity for carers trying to find out about services. A study (Willis et al 2021) looking at online information found that websites varied dramatically in quality and there were issues with links and signposting on some. Nonetheless, online support enabled information to be shared more widely and some organisations provided training or IT support for carers to enable them to make online connections.

Integration

Research (Ward et al 2019) on integration found that carer support needs a whole system approach and to be proactive. Social care needs to work with health and the third sector to provide good support. This should be co-produced and include the voice of carers fully. There needs to be a commitment to involve carers from minoritised groups.

Carers often act as system navigators for complex systems that are not joined up. This adds to the stress and burden that they experience. The system needs to have navigation built into it, rather than relying on carers (Funk et al 2019). A study looking at navigation for carers of people living with dementia (Robertshaw and Cross 2019) found that the concept of integrated care was viewed positively but needed to be comprehensive and take account of individual needs.

Experiences of carers

Research points to the positive effects of caring for older people (Pysklywec et al 2020). These arise from the impact of relationships:

- > Firstly with oneself: personal growth; gaining expertise; and life purpose
- > Secondly with the care recipient: closeness; satisfaction and; appreciation
- > Thirdly with others: from new or stronger relationships with other close people.

Older carers of adult children with a learning disability face worries about the future and require support to plan and manage (Deville et al 2019). Older carers from minoritised ethnic groups may experience particular barriers arising from cultural expectations and culturally insensitive care (e.g. Herat-Gunaratne et al 2020). Older men who are caring may experience particular issues with loneliness due to loss of social networks that their partner took the lead on, unwillingness to access support, desire to be independent or seeing caring as feminine (Willis et al 2020).

Working age carers, including former carers, face barriers accessing employment. Major barriers include: lack of trusted respite provision; low confidence and self-esteem; lack of employer understanding or employment opportunities and; lack of social capital to draw on for support (Ambition for Ageing 2020). These issues particularly affect older carers.

Carers, who live at a distance from the person they are supporting, experience particular challenges (White et al 2020). There are practical concerns around travel time and financial demand, as well as emotional issues about not being able to check in face-to-face. Distance carers undertake a range of support and can feel positive about caring. The availability of a more local network and of technology to maintain contact and carry out tasks helped to sustain the role but these are fragile support factors.

Carers of young people approaching and entering adulthood and, therefore, experiencing transition from children's to adults' services often had a poor experience (Contact et al 2020). Issues arose from lack of coordination, limited information and poor communication between practitioners. Parent carers experienced lack of involvement or their contribution not being valued and, in a survey of 578 parent carers, only 37% felt that practitioners were supportive of the young person and their wishes.

Examples of support for young carers highlight the importance of involving young carers in the design of services, joint work between children's and adults' services and other agencies, working with schools, and building capabilities in this area including in the use of digital technology to provide support (LGA 2018). Young carers may miss school and are more likely to have an illness or disability. They are more likely to come from a minoritised ethnic group or experience poverty. Young carers provide support with practical tasks, emotional support and one quarter of them provide nursing care. They report feeling angry and feeling lonely. It is essential to provide easy ways for young carers' voices to be heard, and for them to access support through any agency that they come into contact with, including schools and health services (LGA 2018). Black, Asian and Minority Ethnic young carers are less likely to receive support, due to barriers arising from culturally inappropriate information, lack of engagement with their communities and understanding of cultural needs or fear of involvement (James 2019).

Research with carers of people living with dementia found that they extract meaning from caring based on the reciprocity and their previous relationship (Cherry et al 2019). The experience of caring depends on how the carer can maintain a sense of self and social connectedness. Important areas to support carers with are: social links; psychological resilience; physical health; quality of life and external support (Parkinson et al 2017). Carers of people living with dementia can prioritise the person's peace, participation, happiness, independence and safety over their own wellbeing (Hale et al 2020). Contact from others, information and quality support helped to avoid carers losing their sense of self and agency. Carers also benefit from good quality provision to enable a break from caring, however suitable services are lacking and arranging short breaks can be challenging, due to lack of clarity about who the support is for and how it is funded (Allen et al 2020).

Family carers of people living with hereditary illnesses, such as Huntingdon's experience specific stress arising from the fear of prevalence within the family and genetic risk (Parekh et al 2017). Carers of people with alcohol or other drug problems experience long-term stress and report missed opportunities for support including palliative care. End of life discussions may not happen and lack of identification or support for carers can continue after death. Open discussion about substance use and its impact is needed, alongside practical and emotional support to enable relationships to be as open as possible (Wright et al 2018).

Support for people caring for someone at end of life starts with recognition and needs assessment (Marie Curie and Macmillan Cancer Support 2018). Support needs to be coordinated with good communication and information. Respite and replacement care should be available. Particular attention is required around finances and carers will need the offer of bereavement support. Turner et al (2016) also highlight the need to recognise carers, who may not identify as carers, who are caring for their partners in later life and end of life. Caring until death can be seen as part of the commitment to their partner and support may not be sought.

Health and social care professionals (Isham et al 2021) identified the potential for caregiving stress to lead to carers becoming overwhelmed or acting in a potentially abusive way. Carers can also experience violence or intimate partner abuse. There is a need to look at physical safety and welfare, and also psychological or spiritual wellbeing. There is a balance between risk aversion and underestimating impact. It can be difficult to ask about safeguarding, and issues can be linked to or excused by cognitive changes. The history of the relationship and the circumstances leading to someone taking on the caring role are important to understand, along with stressors such as finance or social isolation. Practitioners emphasised the importance of relationship-based support to raise issues sensitively and balance competing needs.

Carers of people, who are not eligible for means-tested support, often take on a main role in organising care (Ward et al 2020). This leads to practical and emotional demands, and stress. Carers experienced pressures from the complexity of the system, including around financial help, and the need to manage care workers and, sometimes, to look after them. Having care workers could lead to strain in the home for carers who lived with the cared for person. Carers also had anxiety about issues with future planning. The authors concluded that better information and support for carers is needed.

Covid-19

Research on carers' experiences during the Covid-19 pandemic (Onwumere et al 2021) highlights firstly that there were 4.5 million new carers. Carers faced issues around access to their loved ones if they did not live with them, and anxiety and loss from not seeing them. In shared households, carers experienced additional responsibilities and pressure, including from services closing or cancelling support to avoid infection. Carers of people who depend on predictability for wellbeing, such as people with autism, experienced particular difficulties. A shift to online interactions was difficult for people who face digital inequality and also limited what carers felt able to share with professionals due to privacy issues. Social inequalities, including financial insecurity, social isolation or poor housing and neighbourhoods, compounded difficulties that carers faced.

Social care service changes and closures led to loss of control, uncertainty and worry (Giebel et al 2021). There were particular stressors around the loss of medical input, and the need to monitor, provide additional emotional support and manage income difficulties, and more limited ways for carers to manage stress (Walters and Petrakis 2022). However, carers did find opportunities to have greater agency and develop self-efficacy. Strategies such as gaining knowledge and connection, including online, helped (Walters and Petrakis 2022). Online support for carers increased during the pandemic (Willis et al 2021) and enabled social connection, self-help, counselling and online learning. Some organisations supported training and IT kit for carers.

Social workers who are carers

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Research on working conditions for social workers highlights that stress is affected by the homework interface, including whether someone is a carer (Ravalier et al 2022). Working conditions and wellbeing for social workers worsened during the pandemic, from a situation of already being significantly affected by stress.

Carer involvement in social work education

Research looking at ten years of carer involvement in social work education (Stanley and Webber 2022) found that, despite limited evidence about outcomes, all stakeholders were positive about the perceived benefits of service user and care involvement. Students reported insight and learning that led to questioning of their own knowledge. They gained understanding about the skills that would enable them to empower others.

Carers (and service users) reported benefits for themselves and their students. There is some, limited evidence of changes in attitudes by students, and increases in capabilities and confidence.

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