Call for evidence Adult Social Care Committee
Lifting the veil: Removing the invisibility of adult social care
Friday 27 May 2022

This response is provided by members of the ESRC-funded Centre for Care[1]. It also draws on our recent work in the Sustainable Care programme[2]. In preparing it we consulted with charitable organisations, care workers, unpaid carers, and experts by experience in the Sheffield region. We thank them for their time in contributing to this response.

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The Centre for Care is a research-focused collaboration between the Universities of Sheffield, Birmingham, Kent and Oxford, the London School of Hygiene & Tropical Medicine, the Office for National Statistics, Carers UK, the National Children's Bureau, and the Social Care Institute for Excellence. Funded by the ESRC (Economic & Social Research Council) as one of its flagship research centres, it works with care sector partners and leading international teams to provide accessible and up-to-date evidence on care – the support needed by people of all ages who need assistance to manage everyday life.

Led at the University of Sheffield by Centre Director Professor Sue Yeandle and Deputy Director Professor Matt Bennett, our work aims to make a positive difference in how care is experienced and provided in the UK and internationally by producing new evidence and thinking for policymakers, care sector organisations and people who need or provide care.

In studying care, we focus on ways of improving wellbeing outcomes and on the networks, communities and systems that support and affect people's daily lives, working closely with external partners.

In preparing this evidence, we consulted with local residents including unpaid carers, recipients of care and care workers. These consultations enabled us to gain a deeper understanding of the priorities and everyday experience of care recipients and carers. In this submission, people with lived experience of care combine with academic research to make a compelling need for changes in the current ASC system.

We would like to acknowledge and thank the local people and organisations who gave their time and insights to enable us to prepare this response.

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[2] Economic & Social Research Council (award ES/P009255/1, Sustainable Care: connecting people and systems, 2017-21, Principal Investigator Sue Yeandle, University of Sheffield).

Summary

In this submission, we have responded to all three Sections of the inquiry

Section 1: The invisibility of adult social care and its consequences

There is a lack of public awareness about adult social care (ASC) that is born out of:

- An unwillingness to think about a time where social care is necessary
- Fear based on negative news stories
- Stigma related to being in receipt of care
- Carers not identifying as a carer
- Insecure migration status

In addition, carers we consulted felt social care was deliberately kept hidden to constrain demand and reduce costs to local authorities and government. The risk of such invisibility is that carers and care recipients are not receiving the support they need.

The invisibility reduces the chance for ASC to fulfil its' purpose, defined by the Care Act 2014, to 'help people to achieve the outcomes that matter to them in their life'. This was particularly the case where people needed only a small amount of care (4-6 hours a week) which care agencies could not fulfil. Also, for unpaid carers who had to stop work as care was inconsistent, poor quality and complex to navigate.

Invisibility could be reduced by a campaign that celebrated social care and the skills of the people who worked in it. This would show a different side to media stories about care scandals and potentially increase the public affection for ASC in line with that for the NHS.

Section 2: Better support for unpaid carers

Self-identification can be difficult, as many carers do not recognise their role as 'caring'; this underscores the importance of identification by health professionals and their role in signposting carers to support. A NICE Guideline (NG150) on Carers, published in 2020, offers detailed guidance for local authorities and NHS organisations. If widely used, this would lead to substantial improvements in support for carers.

Unpaid carers need support from employers to remain or re-join the workforce. However, without good quality social care for the person cared for maintaining employment can feel impossible.

The main priority for carers is good quality, long term support for the person they care for. Instead, they feel ignored by service providers, required to fight for support and left navigating complex and inaccessible information.

Section 3: Putting co-production at the heart of care

Despite an increased focus on involvement and co-production in contemporary ASC, much of this is experienced as tokenistic or episodic. Typically, lived experience is not valued as highly as traditional forms of policy analysis and research. However good practice examples do exist for example the Disabled People's Commission run by The London Borough of Hammersmith and Fulham

Many key issues about the development of choice and control were addressed in the Care Act 2014. Failings in the implementation of that Act have been a key disappointment of recent years. It is vital that future developments in ASC respond to this context of failed implementation and learn lessons from it.

1) The invisibility of adult social care and its consequences

1.1 One of the fundamental challenges facing adult social care is that it is 'invisible'. Do you agree? What do you think explains this?

Yes. Researchers and the carers we consulted agree there is a lack of public awareness about care; some felt this comes from not wanting to acknowledge a possible future need for care, or fears related to negative news stories and scandals. Another reason may be people's reluctance to plan for an uncertain, and sometimes feared, future.

Adult social care (ASC) also lacks the visibility and public affection of the NHS, with care work seen as "an extension of domestic work", not a distinct, skilled profession.[3] Research shows many people do not understand the difference between health and social care and often revert to talking about health even when specifically asked about social care.[4] Reasons for this include the complexity of social care funding and the lesser use of, and familiarity with, social care compared to the NHS.

David (SACMHA, a charitable organisation supporting the health and social care needs of people of African and Caribbean descent) described social care as *"frayed into little businesses"* and lacking the cohesion of the NHS.

Discussions with carers also revealed distrust in engaging with social care providers, particularly social services, for fear of losing control and privacy. Some families where a young person is caring fear children may be removed from their parents. Carers for adults can worry that a loved one may be offered unsuitable care or placed in an Assessment and Treatment Unit, from which they may never return home. These anxieties can prevent families seeking help.

Carers must also balance their own concerns with their loved one's wishes; some people needing care refuse support, feeling there is stigma involved in having a social worker. (In one study, 44% of carers of working age not using services attributed this to the person cared for not wanting this[5].) Lisa's daughter with autism did not want her to contact social services on her behalf:

"You can't go back on it, and think 'Oh god, I've got a social worker in my life'" (Lisa, carer).

This invisibility can have especially negative impacts on Black, Asian, Minority Ethnic and Refugee (BAMER) communities due to cultural assumptions. Carers attending a local African Caribbean community group described an expectation to *"take care of their own"* (African Caribbean carer), and assumptions that older people will wish to return to their country of birth and to be cared for there.

Insecure migration status is also a barrier to accessing support, and the recent placement of immigration officers in some local authorities, reportedly resulting in people lacking leave to remain deciding not to access services and not getting support they need.[6]

Caring for someone in another country is a further layer of invisibility in the ASC system that is mostly ignored in policy and by employers in the UK and internationally. Carers in this situation need to

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[3] Laugier S. (2021) Paradoxes in the invisibility of care work, *Philosophical Topics*, 49(1): 61-79.

[4] Sussex, J., Burge, P., Lu, H., Exley, J., & King, S. (2019) Public acceptability of health and social care funding options

[5] Yeandle, S. et al (2007) *Carers, employment and services in their local context*, London: Carers UK.

[6] Barton, J. & Grierson, J. (2022) 'Immigration officers placed in 25 local authorities by Home Office FoI reveals', *The Guardian*, 1 May, https://www.theguardian.com/uk-news/2022/may/01/immigration-officers-local-authorities-home-office-foi-embedded

coordinate caring from afar and to navigate time differences; they are often unable to take the leave they require from paid work to attend to caring duties. Transnational carers are also not routinely included in conversations with service providers about the care their loved one needs.[7]

The invisibility of social care is further compounded by evidence that many carers do not recognise their own role. When people do not identify as a carer, it is likely they do not realise help may be available to them or to those they support.

Along with the fears and anxieties that exist within families that keep ASC hidden, carers, experts by experience and community groups we consulted felt local authorities and the Government want to make care opaque and difficult to access to constrain demand and reduce costs, leaving families and friends to pick up the caring. Coreen (carer) felt people were left to *"just get on with it".*

Experts by experience described complex, densely written forms without guidance or easy-read versions that seemed deliberately off-putting and difficult to navigate:

"If you had no-one to help you, do it you couldn't do it" (Puja, expert by experience).

"Families don't have time to wade through convoluted forms" (Stuart, carer).

Some carers and experts by experience we consulted described giving up trying to access support and somehow 'coping' as a family, thereby maintaining the invisibility of care.

1.2 What are the key changes that need to be made to reduce the invisibility of adult social care?

In our discussions, carers and experts by experience called for a campaign to raise the profile of ASC and the care workforce. The disparity in esteem between health and social care was frequently raised. Care workers noted that during the Covid pandemic, NHS staff received pay rises and adequate PPE while care workers relied on church donations:

> *"We feel like we are worker ants being trod on"* (Coreen, care worker).

Carers felt it would be useful to have a campaign that celebrated social care and the skills of the people who worked in it. This would show a different side to media stories about the cost of ASC and care scandals. Elsewhere, such campaigns have been effective in increasing public understanding and recognition. When planning its major reform of disability services, Australia ran a campaign to build public support:

> 'The Every Australian Counts campaign that advocated for the new funding scheme was a broad-based movement that harnessed public support for the National Disability Insurance Scheme through media campaigns and targeting of key politicians to make a public commitment to the proposed new system …The campaign's title was expressive of its key message: that people with disabilities should be treated as full citizens …The Australian approach drew on something else: an appeal to universality and risk assurance, which was not evident in the English case.'[8]

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[7] Sethi, B. (2022) Negotiating culture, geographical distance and employment: The lived experiences of European transnational carer employees. *Wellbeing, Space and Society*, 3.

[8] Needham, C. & Dickinson, H. (2017) 'Any one of us could be among that number': Comparing the policy narratives for individualized disability funding in Australia and England. *Social Policy & Administration*, 52: 731–749

Carers also need to be visible and recognised across all services. This requires a joined-up health and social care services approach that enables carers to be identified and offered support. Our 'Carers Count' campaign (2021) offers an example of messaging to support carer recognition.[9]

1.3 How does this invisibility reflect the experience of social care for people who draw on care and support and their carers, and how is this experience different depending on the age range and particular circumstances of those who draw on care and support and their carers?

The risks of maintaining such invisibility are great. It results in carers and care recipients being unaware of their rights, and lacking information about the support available. It maintains the imbalance in the esteem in which the NHS and ASC are held and enables bad practice to remain hidden while good practice is not celebrated. It creates a culture of fear in which families are afraid to ask for help, as their only knowledge of ASC is negative. Some people we consulted were convinced social care remains hidden as it is in the interests of local authorities and the Government to keep it that way. Failing to make ASC visible enables these suspicions and the stigma surrounding social care to thrive.

1.4 How would you define the purpose of adult social care? How does the invisibility of adult social care get in the way of achieving this purpose?

Some (not all) local authorities clearly explain the purpose of ASC. Current examples include:

> Derby City Council: *Adult social care provides personalised, practical support for people over 18. It supports them to live their lives the way they want. It preserves dignity and keeps people independent. People who need care should have the choice, flexibility and control to live their lives the way they want. The Government, local councils, and service providers all have a duty to make sure this happens.*
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> Sheffield City Council: *Our vision for Adult Social Care is that 'everyone in Sheffield lives in a place they can call home, in communities that care, doing things that matter to them, celebrated for who they are - and when they need it, they receive care and support that prioritises independence, choice, and recovery'.*

In the Sustainable Care research programme, Needham and Hall analysed ASC in the four UK nations reviewing policy documents (1997-2022) and conducting interviews in England, Scotland, Wales and Northern Ireland. Some documents described social care as a list of formal interventions (e.g. one document stated, *'[Social care] comprises a number of services, ranging from residential and nursing care homes and the provision of aids and adaptations to domiciliary or home care support'*.[10] Elsewhere care was defined more expansively as a means to other ends: '*seeing friends; caring for our families; and being part of our communities'*[11] and '*Social care support is the means to an end, not an end in itself. The end is human rights, wellbeing, independent living and equity, as well as people in communities and society who care for each other*'.[12] In the last decade, the role of social care in

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[9] https://circle.group.shef.ac.uk/carers-count-the-importance-of-census-data/

[10] Prepared to care? Modernising adult social care in Northern Ireland, Commissioner for Older People for Northern Ireland (2015).

[11] HM Government (2012) Caring for our future: reforming care and support.

[12] Scottish Government (2021) Independent review of Adult Social Care in Scotland.

promoting wellbeing has become a recognised policy priority in all four nations.[13] It is formally defined in England in the Care Act 2014,[14] where wellbeing includes outcomes such as physical and mental health, dignity, protection from abuse, control, relationships, participation in activities and the community as well as social, emotional and economic wellbeing, with local authorities having a 'general duty' to promote wellbeing. The Care Act 2014 stresses: 'The core purpose of adult care and support is to help people to achieve the outcomes that matter to them in their life'. The Centre for Care strongly supports this expansive account of social care.

In reality, to those who receive and deliver ASC, care can feel like a set of tasks to be delivered that are not person-centred, flexible, or appropriate. The invisibility of social care enables poor levels of support to persist, as there is no widely shared understanding of what social care should and could deliver. Several people with learning disabilities in our discussion groups were currently receiving no support, despite an assessment of need that showed they required a small amount of support (about 4 to 6 hours a week) to live the life of their choosing. In reality, local care agencies could not provide this. Some in our group said they now rely more on family and friends or are attempting to support themselves. One person, who relied on support for paying bills and administrative tasks, described the considerable negative impact on their life:

> *"I've fallen through a hole"* (person with autism).

Carers felt the focus of social services on tasks failed to recognise the emotional support required to support a person:

> *"The package they offer, it's very limited. They ask, 'What do you do for this person?', but it's not only task based. … They ask, 'Can they sit and eat?', but it's not that simple. When you fill in forms, it's just about tasks"* (carer).

People from BAMER communities pointed out that the support offered may not feel culturally appropriate. David's mother now needs residential support:

> *"But there were no black staff and no other black users. It's an issue if you want recognition e.g., the food you're used to".*

Our recent research shows that culturally inappropriate care is likely to be exacerbated by migration rules that deem care workers unskilled. Barring non-UK workers from coming to the UK as care workers is likely to reduce the ethnic diversity of care staff.[15]

Whether the purpose of ASC is as expressed in the two local authority examples cited above, or understood as human rights, wellbeing, independent living, and equity, it is currently falling well short, with too many people left without support due both to inadequate funding and/or staff and the inflexibility of the offer. The invisibility of the system means this is not recognised. In the absence of appropriate services, families and friends have no option but to attempt to bridge the gap, often with huge costs to their own wellbeing, health, finances, and life chances.

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[13] Hamblin, K. (2019) Adult social care and wellbeing policy in the four nations of the UK, Sustainable Care Paper 1, CIRCLE, Sheffield: University of Sheffield.

[14] HM Government (2014) Care Act 2014.

[15] KIlkey, M., Ryan, L., Lorinc, M. & Tawodzera, O. (2020) Care 'in' and 'out' of place: the experiences of ageing migrants, Sustainable Care Findings Report, CIRCLE, Sheffield: University of Sheffield.

1.5 To what extent does the definition of the purpose of adult social care differ for younger and for older adults? How can future reform of the adult social care system best address these differences?

The younger people we spoke to in our discussion groups were seeking support that is flexible and 'light touch'. Many felt the current system could not provide the support they wanted, resulting in some having no support at all. One disliked the word "care", preferring "support". He felt a change in the narrative was needed, from a passive description of receiving care to an active description of accessing support.

Our research in the past decade with older people facing multiple challenges – sight and hearing impairments, mobility challenges, cognitive decline – shows they too want things set out in the Derby CC and Sheffield CC statements[16]. They value social connections, being treated as individuals, and recognised for who they are and all they have done in the past and want personalised support that can sustain them until the end of their lives. Many younger disabled people want an ASC system that enables them to work, travel, have families, enjoy age-appropriate social activities, and develop their skills, relationships, and interests. People who are very old or who are experiencing complex illness or declining physical and mental capacities may have different goals, but still need an ASC system that offers respectful, empowering, relationship-based support.

Differences in what people need are best addressed (as has been official policy in England for several decades) via a personalised approach. There are cost differentials in providing 'task-based' and 'relationship-based' support, but (compared to the much higher costs of improvements in healthcare, involving development of new drugs and clinical techniques) these are relatively small. Funding good, life-enhancing care, as opposed to poor, minimum standard care, should be a positive choice and is well within the nation's collective means.

1.6 What are the key challenges that people who draw on care and support and carers will face in the future, which are not factored into current assumptions related to the social care system, for example the fact that some families will age without children to care for them? How are these challenges different for younger and for older adults who draw on care? What should be done now to address them?

Increased mobility (both within and between nations), alongside trends towards smaller families, means we cannot assume people will have family nearby to care for them. Families today are more geographically dispersed; this, along with other demographic factors, will increase the demand for social care as fewer family members live close enough to provide proximal/daily support.

Due to UK immigration rules, young asylum seekers entering the UK will struggle to get family reunification visas, meaning there could also be an increase in people entering the country without family members who can care for each other.

There is still little support at transition points, particularly from Children's to Adults' Services. Carers we spoke to who cared for someone with a lifelong condition described a massive decrease in support as their loved one moved to Adults' Services:

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[16] See Publications - Aktive Project Living Innovation Program - ALIP and Hamblin, K., Koivunen, E.-R. & Yeandle, S. (2016) *Keeping in Touch with Technology: Using telecare and assistive technology to support older people with dual sensory impairment*, Sheffield: University of Sheffield.

> *"Where it (the service) struggles most is when they hit the eighteen mark, there is nothing out there"* (Lisa, carer).

Lisa described how her daughter, in her twenties, has one activity a week - playing football - but apart from this has no support or activities to attend. Her daughter wants to be independent, but without support this feels impossible. Lisa, along with other carers and disabled people we spoke to, fears what will happen when family are no longer able to care. Over-reliance on unpaid care, without adequate support, may result in families pushed into crisis requiring more support from ASC in the future.

1.7 How can other public services (such as the NHS) play their part in tackling the invisibility of adult social care?

Our research, and the experiences shared in our discussion groups, show that recognition of carers by GPs and the wider NHS is vital for joined-up services and for reducing the invisibility of care. This has been known for some time, but while some GPs and NHS services show good awareness of carers and respond proactively[17] [18], this goal is far from being achieved everywhere. Good practice includes recognising carers and recording this on a patient's notes, consulting carers if the person they care for is in hospital and signposting carers to accessible services. These practices and the support that hospitals and other NHS providers can provide have been found in past research to be crucial[19].

Research findings and our groups' lived experience make it clear, however, that without adequate social care, there is only so much NHS services can do: without appropriate ASC services that can respond promptly, signposting is not enough. The carers we spoke to wanted the health and social care systems to be more joined-up. Research suggests that integrating health and social care is important but not a panacea. Further alignment of vision, purpose and resources for ASC is also needed to achieve the wellbeing goals for all that were explicit and centre-stage in the Care Act 2014 that remains England's core ASC legislation.

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[17] https://www.england.nhs.uk/publication/supporting-carers-in-general-practice-a-framework-of-quality-markers/

[18] Wigfield, A. & Wright, K. (2012) https://www.sheffield.ac.uk/polopoly_fs/1.546414!/file/Supporting-Carers-in-general-practice.pdf

[19] Yeandle, S. & Wigfield, A. (eds) (2011) *New approaches to supporting carers' health and well-being: evidence from the National Carers' Strategy Demonstrator Sites programme*, Leeds: CIRCLE, University of Leeds.

2 Section 2: Better support for unpaid carers

2.1 What, in addition to the support that has already been pledged by the Government, would be the most effective thing that could be done to raise the profile, as well as to improve the identification and support of carers? What examples exist to demonstrate that better identifying and supporting of carers leads to better outcomes for those for whom they care

Self-identification can be difficult, as many carers do not recognise their role as 'caring' and see themselves as simply doing what is needed for their family member or loved one. All too often this results in carers lacking support they need. It underscores the importance of identification by health professionals and their role in signposting carers to support. Research has shown that support (from health professionals, social workers, and carers' organisations) at key moments makes a real difference:

- *prior to hospital discharge* of the person cared for (e.g., someone treated for stroke, heart attack, hip fracture)
- *at point of diagnosis* (e.g., Alzheimer's/Parkinson's disease, other dementias, terminal illness)
- at key *stages during the caring journey*:
    - as the disease or disability of the person cared for progresses
    - when caring for someone at the end of life (and following bereavement)
    - during the carer's own life course (e.g., starting work/education, retirement, changes in household composition or in family/partnership status)

A NICE Guideline (NG150) on Supporting Adult Carers was published in 2020. This offers detailed and comprehensive practical guidance for local authorities and NHS organisations. If widely used, it would undoubtedly lead to substantial improvements in support for carers.

To increase identification, Carers UK, with whom we have collaborated on many studies, also recommends:[20]

- A national public health campaign, aimed at increasing awareness, recognition, and support for carers and about care more generally, so that carers can identify themselves and know how to access support and advice.
- Development of education, information, and training for a range of frontline professionals to increase knowledge and signposting of carers
- A new duty on the NHS to identify carers, to ensure they are routinely identified and that their health and wellbeing is promoted.

Participants in our group discussions agreed that national campaigns were needed to raise awareness and that being a carer should be recorded in patient records, with this information shared across all services and flagged during appointments. This would help health and social care providers to see that the person was a carer, understand the responsibilities they have that could affect their health and wellbeing and guide them to support. Large-scale studies have shown the benefits of short, flexible carer support programmes for carers in many different circumstances[21].

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[20] Carers UK (2016) Missing out: the identification challenge.

[21] Yeandle, S. & Wigfield, A. (eds) (2012) *Training and supporting carers: national evaluation of the 'Caring with Confidence' programme*, Leeds: CIRCLE, University of Leeds.

2.2 How can carers who wish to do so be better enabled to stay in work or re-join the workforce? What needs to change to achieve this?

In 2019, the Sustainable Care team worked with Carers UK on the likelihood of being a carer in adult life[22]. Analysis of longitudinal data showed that two-thirds of adults have at some point in their lives been the carer of someone who was sick, disabled, or who required support in old age: 7 in 10 women and 6 in 10 men. Women are more likely to care earlier in life than men (on average by age 46, eleven years earlier than men). These findings indicate that caring features especially strongly in women's lives and that they are especially likely to be caring at ages when they would expect to be in paid work. Caring often affects their participation in paid work and reduces their lifetime earnings, with wider gender equality implications. Being a carer is an important reason why women are more likely than men to experience low income in later life, including after their caring role has ended.

In 2020, Sustainable Care researchers published *Supporting working carers: How employers and employees can benefit*[23]*,* based on a representative survey of working carers in England and Wales:

- 44% of working carers reported finding it difficult to combine their paid employment and caring responsibilities. An estimated 1.6 million carers were struggling to combine work and care.
- Half of working carers felt their caring responsibilities affected their job. Most working carers had experienced difficulty in concentrating at work because of their caring responsibilities.
- 30% of working carers had reduced their hours of work because of their caring role. 36% had refused a job offer or promotion, or decided against applying for a job, because of their caring responsibilities.
- 39% of those who had not discussed their caring role at work said this was because they did not believe anything would change. 22% said it was 'not the sort of thing that people talk about where I work', implying that they were employed in a workplace that cannot be regarded as 'carer-friendly'.
- The most frequently mentioned form of employer-provided support was being able to use the telephone, or private time for private calls (available to 24% of working carers).
- Among working carers who indicated that no forms of support were available to them, paid care leave was the most commonly desired form of support, followed by flexitime and the ability to work at home on some days.

Yeandle and Buckner[24] have described ways carers can be supported to remain in work, including through:

- Support and flexibility in the workplace (e.g., flexible working, work from home options)
- A framework of rights and entitlements in employment, welfare, and social care systems (supporting them to make choices about providing care without putting their own health, financial wellbeing, or social support at risk)
- Carers' leave (with financial support) in a variety of appropriate circumstances.

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[22] Zhang, Y. & Bennett, M. (2019) Will I care? The likelihood of being a carer in adult life, Carers UK.

[23] Austin, A. & Heyes, J. (2020) Supporting working carers: how employers and employees can benefit, research report, London: CIPD and University of Sheffield.

[24] Yeandle, S. & Buckner, L. (2017) Older workers and caregiving in England: the policy context for older workers' employment patterns, *Journal of Cross-Cultural Gerontology*, 33: 303-321.

Learning from international policymaking in eight countries, including the UK, informed Yeandle's report for the German Government [25] (for its policy review of supporting carers of older people to remain in work [26]) and her 2020 review paper for the European Commission on work-care reconciliation policy[27].

Sustainable Care Innovation Fellow Dr Mandy Cook explored support for carers in a variety of workplaces and sectors, recommending the following as good practices that employers can adopt:[28]

1. Introduce paid carer's leave
2. Ensure workplace interventions to support carers are sustainable
3. Employ work-based communication campaigns to make employees aware of carers legal rights and existing support
4. Employ flexible working opportunities such as working from home
5. Train line managers, to raise awareness about caring responsibilities. This can also assist identification of carers.
6. Develop a Carers' Policy and include carers in generic policies to ensure support for carers is fully embedded in the organisation
7. Offer practical support, such as ensuring carers have access to a parking place and allowing carers to keep their phone with them.

Employers need to offer support and flexibility for carers. The highly successful employer forum *Employers for Carers* exemplifies this and many case studies of organisations taking this approach have been produced[29]. Remaining in employment relies on good quality social care support for the person cared for. Without this, maintaining employment can feel impossible. This is the experience of Stuart (carer participating in our discussions) and his family. Because his father-in-law's support was of poor quality and unreliable, his wife left her employment to ensure *"consistency and quality"* of care, resulting in a significant drop in their household income.

2.3 What are the key priorities for carers in terms of their own support, wellbeing, and resilience? How and where can these best be provided?

For the carers we spoke to, the key to their wellbeing was the right support for the person they cared for; long-term, well-planned care that would enable them to feel confident, less stressed, and able to manage their own needs. To them, good support included tailored respite services, a named contact

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[25] Yeandle, S. (2017) *Work-care reconciliation policy: legislation in policy context in eight countries*, background paper for German Federal Ministry for Families, Senior Citizens, Women & Youth (Bundesministerium für Familie, Senioren, Frauen und Jugend).

[26] See https://beobachtungsstelle-gesellschaftspolitik.de/f/72c67e304b.pdf and German government website https://www.bmfsfj.de/bmfsfj/meta/en/older-persons (in English): "*In September 2015 … an Independent Advisory Committee for the Reconciliation of Care and Work was set up. (It) addresses matters relating to work-life balance, accompanies the implementation of relevant regulations and discusses their effects. Every 4 years, it submits a report to the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth, which may include recommendations for action. In addition to detailed insights and assessments of studies, the report includes recommended action on further developing the topic of "work-life balance".*

[27] Yeandle, S. (2020) Thematic Discussion paper, Peer Review "Work-Life Balance: promoting gender equality in informal long-term care provision", European Commission, D-G Employment, Social Affairs and Inclusion.

[28] Cook, M. (2020) *Support for employees who combine paid work with unpaid care*, Parts 1 to 4, Sustainable Care Policy and Practice Brief, http://circle.group.shef.ac.uk/sustainable-care-publications/.

[29] For examples see part 2 of Yeandle, S. (2017, cited above), co-authored with M. Starr and K. Wilson; also, Yeandle (2020) (cited above), pp. 13-16 which provide examples and further references.

and services that were easy to access. In our group discussions, carers described times when telephones went unanswered, and messages were not responded to. Some said that services felt adversarial rather than supportive, with carers needing to fight for support:

> *"You shouldn't have to fight and fight and fight. It's hard work and you do get worn out"* (Lisa, carer).

Stuart (carer) described the damaging nature of delays and obstructions, when the person needs care, but services are impossible to access or withdrawn, and the carer is doubly exhausted: first by caring and second by fighting for a service. Without a named social worker or care coordinator, navigation of services falls to individual carers, exacerbating stress and time pressure. In some cases, despite an assessment of need, no services were accessed as the carer did not know what was available and what they were entitled to:

> *"It's great to ask questions, but what if you don't know what questions to ask? The pathway to get what's needed needs to be accessible and simple"* (David, SACHMA).

Well-resourced, reliable, person-centred services for those they cared for were vital for carers' wellbeing. This included long-term support, rather than services that were constantly being changed and restructured:

> *"I would really like to know that there's something I can access over the next 20 years. Things to be put in place before things that age brings, such as dementia"* (Liz, carer).

Carers spoke about access to longer term funding; several mentioned Carers' Allowance being 'withdrawn' on receipt of the state pension as an extra burden and a cause for concern[30].

2.4 To what extent do carers make use of alternative forms of support, such as the voluntary community? Is there any scope for them to draw on those assets more and how might they be enabled to do that? Are there examples where this happens successfully now?

Many of the carers we spoke to used community groups for support. Not all of these were specifically focussed on being a carer; some were community groups for people in particular ethnic groups, others for a particular condition (e.g., autistic spectrum disorders). Carers found these groups provided support, social opportunities, and information, and could be a 'one stop shop' where carers could access information and the expertise of people who could help them find available support. Research shows that co-locating services does not offer a 'silver bullet' for integrating services, but can provide a basis for joint working, and can reduce the burden carers face in coordinating multiple services[31].

Helen (worker at Sheffield Young Carers and herself a carer) described an initiative involving a WhatsApp group for support group members that had decreased isolation and provided peer support. It was particularly busy on Christmas Day when lone parents may otherwise have been isolated or overwhelmed.

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[30] 'Eligibility' for Carer's Allowance remains after reaching state pension age, but the benefit is not payable as it is treated as an 'overlapping benefit' with State Retirement Pension. This issue has been controversial but unresolved for decades and was explicitly addressed, with recommendations made, in the House of Commons Work and Pensions Committee's 4th Report of Session 2007-08, 'Valuing and Supporting Carers' (Vol. 1).

[31] Lalani, M. & Marshall, M. (2020) https://onlinelibrary.wiley.com/doi/pdfdirect/10.1111/hsc.13211, *Health & Social Care in the Community,* 30, e388-396.

2.5 How valued and respected are carers in the overall adult social care system and what are the consequences of failing to value and respect them?

Dr Rachael Black's PhD thesis, based on a study of carers of people with learning disabilities[32] provides further evidence that some carers do not feel respected by the system. Some described feeling judged by services, viewed with suspicion, and forced into fighting mode - if they were consulted at all. Too often, carers felt they were deliberately ignored or avoided. To ensure their loved one received the best support, they had needed to use tactics such as using terminology matching that used by social care staff and emphasising the hardest aspects of caring (which left some feeling disloyal to the person cared for).

Carers in the study knew that services are supposed to collaborate with them, as equal care partners, but felt this was not a genuinely collaborative relationship, describing it as ‘tokenistic’ and ‘condescending’. These experiences left some carers feeling highly stressed by interactions with service providers, fearful of losing services they rely upon, or obliged to ‘fight’ for further support. This took a psychological toll and placed barriers between carers and the ASC system.

Carers in our discussion groups described needing to be *“pushy parents”* or a *“guerrilla parent”* to get the support their relative needed. They pointed out that some carers would be unable to do this (such as those for whom English is an additional language or who have no family to speak up for them) and that this will result in individuals and families missing out on care and support they need.

2.6 What can be done to make sure that social care professionals recognise the expertise of carers and value them as full and equal partners in care, who are included as part of the whole team, so that there is greater synergy between paid and unpaid care?

Our team’s long experience of researching care and caring and doing so in collaboration with agencies across the whole of ASC, has shown us that there is nevertheless good practice in this area, from which much could be learned. Long-standing examples of good support for carers that takes this approach include the work of Action for Carers Surrey, whose website includes services for ASC professionals which could serve as valuable examples for others to adopt or learn from: Training for professionals | Action for Carers. Hertfordshire County Council also offers support that has been recognised as exemplary: see, for example, their accessible fact sheets: Adult social services factsheets | Hertfordshire County Council. Examples of good and innovative practices are also described in Yeandle and Wigfield’s report of the national evaluation of the Department of Health-funded ‘Demonstrator Sites’ programme, that explored multi-agency cooperation in providing carers with health and wellbeing support in 25 sites across England.[33]

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[32] Black, R. (2018) The experiences of family carers of people with learning disabilities: a participatory action research study. PhD thesis, University of Sheffield.

[33] Yeandle, S. & Wigfield, A. (eds) (2011) *New approaches to supporting carers’ health and well-being: evidence from the National Carers’ Strategy Demonstrator Sites programme*, Leeds: CIRCLE, University of Leeds.

2.7 Why is the current care system so difficult to access for carers? What needs to be put in place so that carers can simply understand what is available to them as a right and discretion, and the person they support? Do you know of good practice examples? How can these examples be expanded more widely across the system?

Among those we consulted in spring 2022, both unpaid carers and people with lived experience of care and support described the information they were expected to understand and respond to as highly inaccessible. This felt frightening, as completing forms incorrectly or providing the wrong information could result in care being denied or removed. Their experience was that there was no support or guidance for navigating this complex information, leaving them trying to make sense of it, often on top of other responsibilities such as childcare responsibilities or paid work. Much of the information relied on being able to use computers:

> *"Everything is targeted at people who can use a computer, if you can't use it, then you're doomed."* Andrea (care worker and carer).

Carers who had been supported to understand and complete forms said this felt like 'good luck' rather than a feature of the system. The notion of 'competent individuals' working in a system that was 'not fit for purpose' came up in several of our discussions. People found the system difficult (some said impossible) to access, unless you were lucky enough to find someone who could help.

Lisa described coming across a local community group while conducting her own internet searches that has provided her with peer support and some information but felt 'lucky' to have met the group, and still needs to contact several different organisations in an attempt to get her daughter support. Accessing the current system requires *"energy and tenacity"* (Liz, carer) to contact a wide range of providers, wait for responses and then be placed on long waiting lists. Accessing services was experienced as a 'drain' and an effort that relies on the energy of carers.

3) Putting co-production at the heart of care

3.1 To what extent are the voices of people who draw on care and support and carers shaping the design and delivery of social care, irrespective of their age or circumstances? If these voices are not sufficiently heard, what is the impact of this on those who draw on care and support and carers?

Despite an increased focus on involvement and co-production in contemporary ASC, much of this is experienced as tokenistic or episodic. Typically, lived experience is not valued as highly as traditional forms of policy analysis and research.

This is something the IMPACT (Improving Adult Care Together) ASC Evidence Implementation Centre (co-funded by the Health Foundation and the Economic and Social Research Centre) was set up to change. Members of our team are closely involved in this work, in which new models of delivering evidence-based improvements in ASC, based on three kinds of knowledge - conventional published research, 'practice wisdom' and 'lived experience' – are being piloted in 2022, prior to full implementation 2023-2027. IMPACT has already established five 'Assemblies' across the UK to debate and inform its development, and to consult on promising examples of positive ways forward. Our own new Centre for Care is also built on principles of co-production and meaningful, respectful collaboration with a wide spectrum of ASC partners.

From past experience, however, we know there can be clashes between norms of scientific rigour and the inclusivity agenda.[34] Glasby and Beresford note that "the lived experience of service users" is too often overlooked in favour of more "objective" evidence.[35] For us, the key to effective co-production within ASC lies in valuing the lived experience of people with support needs and carers equally to professional know-how and expertise, and in engaging meaningfully in co-production at all stages of the academic research we undertake.

3.2 It is often difficult for people who draw on care and support and carers to exercise choice and control if they do not know what good support looks like or what kinds of care and support might be available. What information and support could be helpful to address this and how could it be made available more easily?

Many key issues about provision of information and the development of choice and control were addressed in the Care Act 2014. Failings in the implementation of that Act have been a key disappointment of recent years. It is vital that future developments in ASC respond to this context of failed implementation and learn lessons from it. Our analysis of this implementation failure (for the Department of Health and Social Care) based on a review of research projects relating to the Care Act[36] found that while the Care Act 2014 was 'implementation ready',[37] it has had only partial success in actual implementation. This needs to change. There may also be useful lessons to learn from

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[34] Allen, K., Needham, C., Hall, K. & Tanner, D. (2019) Participatory research meets validated outcome measures: Tensions in the co-production of social care evaluation. *Soc Policy Admin*. 53: 311– 325.

[35] Glasby, J. & Beresford, P. (2006). Commentary and Issues: Who knows best? Evidence-based practice and the service user contribution. Critical Social Policy, 26(1), 268–284

[36] Burn, E. and Needham, C. (2021) Implementing the Care Act 2014 – a synthesis of project reports on the Care Act commissioned by the NIHR Policy Research Programme, University of Birmingham.

[37] Peckham, S., Hudson, B., Hunter, D., Redgate, S. and White, G. (2019) Improving choices for care: A strategic research initiative on the implementation of the Care Act 2014.

experience in Wales, where the 'Track the Act' approach (to comparable legislation there) provides an example of how legislative intentions and their outcomes can be assessed.

3.3 We recognise that people with long-term conditions require different support at different points in their lives and that transitions, such as a change in health needs, moving from children to adult services, leaving education, starting a job, or moving home, can be particularly challenging. Can you describe the key moments of transition from your experience? How have the formal processes worked during these periods of transition? What could or should have been in place to make these transition moments easier?

We make some comments on this, based on our prior research, in Section 2 (1). Transitions and trajectories in care are the focus of one of the new Research Groups we are currently establishing in the Centre for Care (2021-26), and we will report new findings in this area as this work evolves.

3.4 What does truly co-produced care look like for younger and for older people with differing challenges and needs? Have you got any good examples to share?

The London Borough of Hammersmith and Fulham offers one positive example. It ran a Disabled People's Commission, led, and designed by people with lived experience of care. This produced significant change in the council's approach to ASC (website: https://www.lbhf.gov.uk/councillors-and-democracy/resident-led-commissions/disabled-people-s-commission.)

A different example is provided by Caroline, expert by experience and trainer, who used her direct payment to purchase a tricycle, enabling her to take her children to school and save money (she had previously been paying off a mobility scooter). To find a suitable tricycle, she had to travel around the country. Subsequently she worked with a cycling champion to set up Cycling for All, an organisation to enable people to try cycling, loan tricycles and take part in fitness activities. Cycling for All has now been running inclusive all-ability cycling in Sheffield for over 10 years. Caroline identified an unmet need and established an organisation that has a hugely positive impact in disabled people's lives.

3.5 How can we design care and support arrangements which work both for the person drawing on care and support and for those who care for them?

Caroline also described her early experiences of direct payments (DPs). She was able to use the funds to reward friends who provided care, such as buying a meal for those who collected her children from school while she attended an appointment. She felt trusted to spend the money creatively to meet her own needs, those of her children and of those providing her care. This is not now allowed, and she no longer feels trusted or empowered by DPs to live the life of her choosing. Being able to use the funding flexibly met her needs and those of her support network. This is an example of a support arrangement that worked previously that has been halted. Consulting with disabled people and their carers can yield examples of services and solutions that have worked before.

3.6 How can people who draw on care and support and carers both be involved in the planning of future services?

A key aspect of care delivery in the future will be digital care and technology-based support. However, there are risks associated with implementing care technologies. Research highlights the importance of co-production and co-delivery in rolling out technology-based solutions in care. There is a lack of understanding about how people, particularly older people, access technology; when they are involved in co-design it can lead to better-adjusted design and increased feelings of ownership[38]. Without this, cheaper 'off the shelf' technologies may be implemented (e.g., Alexa that may not be fit for the required purpose)[39]. Involving people who draw on care and support and carers in developing and implementing technology is crucial for responsible and ethical roll-out of care technologies.

Mary (expert by experience and Disability Champion) described her *"magic wand"* moments when she first saw disabled people not as recipients of care but as actors in delivering support to their peers. She described a potential buddying system where she could impart her knowledge, for example around computers, and get support from others in areas where she struggled, for example, getting shopping. She also wanted to support others by delivering mutual support. Disabled people told us they do not just want to plan care that they 'receive', but to develop systems in which they themselves are providing support and empowering others.

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[38] Fischer, B., Peine, A. & Östlund, B. (2020) The Importance of User Involvement: A systematic review of involving older users in technology design. *Gerontologist*. 60: (7): e513–e523

[39] Wright, J. (2021) The Alexafication of Adult Social Care: Virtual assistants and the changing role of local government in England. *Int. J. Environ. Res. Public Health*. 18: 812.