RE-IMAGINING CARE:
Disruptive change is essential to alleviate the crisis
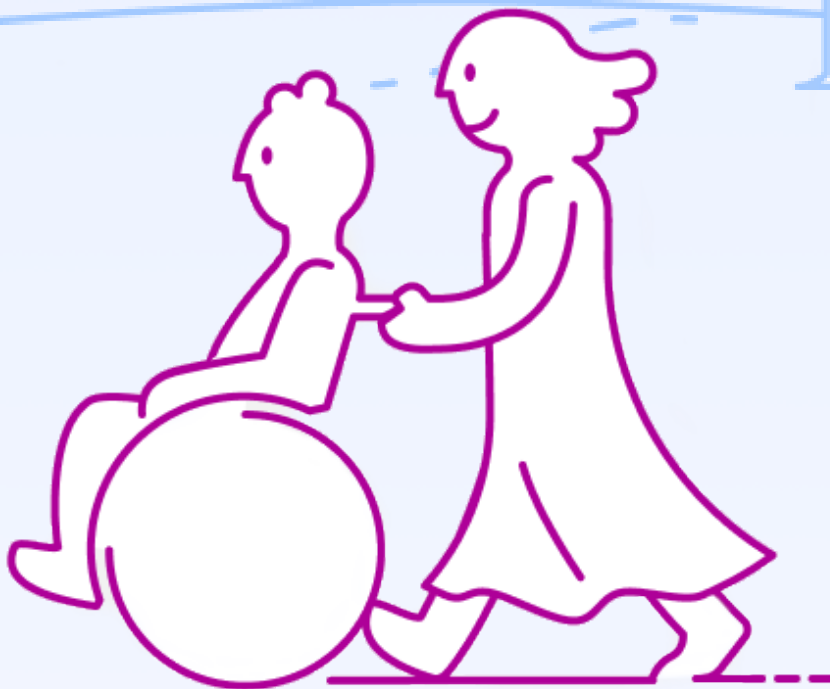
2023

Hi Carer

Re-Imagining Care

TABLE OF CONTENTS

Re-iminging Care

INTRODUCTION
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The Health & Care Crisis

The UK is currently facing a crisis in health and care provision. With healthcare workers stretched to their limits, and a significant lack of careworkers, many people are finding themselves stuck in hospital when they are medically ready to leave but unable to do so.

Just last month it was revealed that of the 20,302 people per day are ready to be discharged but only 37% left hospital. This often leads to poorer health outcomes and an emotional toll for those affected, and at a cost of £303 per patient per day (Allen 2021) this means a **daily cost** of £3.88m to the NHS.

But there may be a solution. What if we could harness the power of technology to provide people with more control over their own care arrangements? What if a disruptive change allowed us to
 re-envision how care is organised and delivered in the UK?

It's time for a conversation about how we can implement innovative processes that will allow everyone involved – patients, carers, family members, healthcare providers and beyond – to benefit from a new way of arranging care provision in the United Kingdom.

It's time to use disruptive change in the care sector to alleviate the crisis in the NHS.

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THE ISSUE

Thousands of people are in hospitals ready to be discharged yet are unable to do so because there aren't enough workers to provide homecare services they need. This shortage creates worryingly long waiting lists and puts strain on carers as they struggle to keep up with demand.

The main cause is well documented, there are simply not enough people in the care sector meaning that older and/or disabled people are unable to get the care needed. NHS Delayed Transfers of Care (bed-blocking) due to Social Care delays, costs the NHS C.180m p/a (Allen 2021).

Just 1.5m people work in the sector supporting 14.6m (Kirk-Wade, 2022) people who have a disability, with 34.4% workers leaving the sector last year. The aging population means more people with disabilities and means we must recruit 500k+ workers to one of the lowest-paid occupations in the UK within 8 years (SfC, 2021).

Ultimately, we must increase the availability of carers and enable them to be paid a more sustainable rate.

Delayed Transfers of Care due to Social Care Delays, cost the NHS c.£180m p/a.
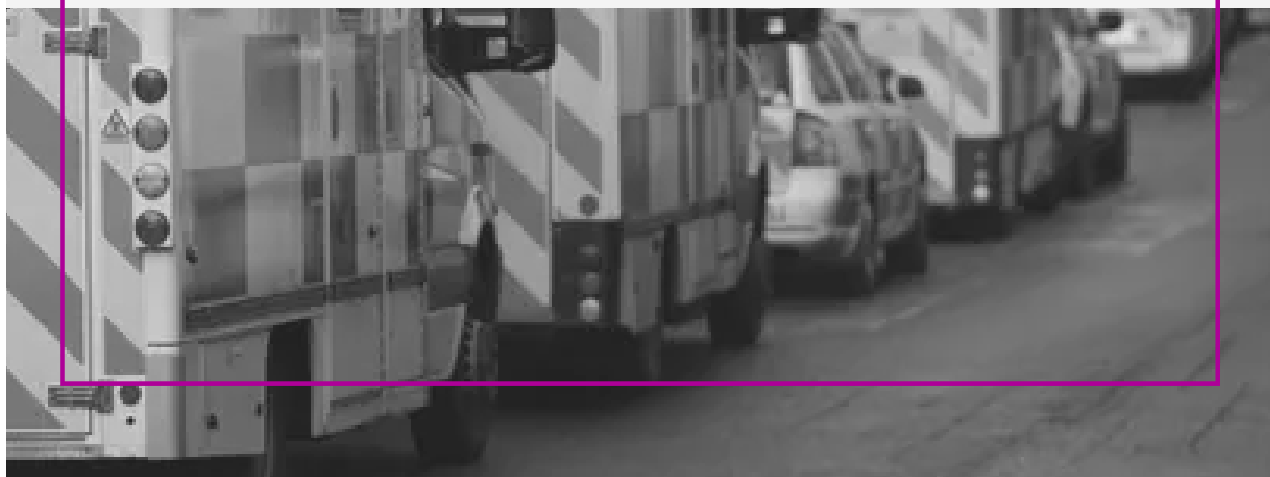
WHO NEEDS CARE

There are 14.6m people in the UK with a disability.

Representing 22% of the total population.

42% OF PENSIONERS HAVE A DISABILITY

As would be expected the number of people with a disability increases with age, 42% of adults over the State Pension age have a disability.

5.7M CLAIM DISABILITY BENEFIT

5.7 million people claim an extra cost disability benefit in Great Britain, representing 8.7% of the total population (Kirk-Wade 2022 - Government Research Briefing)

LESS THAT 1/2 PEOPLE WHO REQUEST IT GET FUNDED CARE

King's Fund 2021 states that 838,530 adults receive publicly funded long-term social care. This is approximately only 43% of people who request it.

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WHO NEEDS CARE

"The trend of population aging has continued, with more people than ever before in the older age groups. Over one-sixth (18.6%, 11.1 million) of the population in 2021 were aged 65 years and over, up from 16.4% (9.2 million) in 2011. The size of the population aged 90 years and over (527,900, 0.9% of the population) has increased since 2011, when 429,017, 0.8%, were aged 90 years and over." (ONS 2022 – Census 2021).

In the UK, 5.7M+ people receive disability benefits (Kirk-Wade, 2022). 1.5 million people have unmet care needs (Age UK, 2019), and self-payers spend £10.9 billion on care each year (National Audit Office, 2018). Of an estimated 4.5 million unpaid family carers (Kingsfund, 2022), 2.6 million have given up work to care for family members (Carers UK, 2019).

There are 1.5 million care workers, 58% (870K) of which are female (SfC, 2021).

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ASSESSING NEED

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Creating meaningful care and support begins with understanding the individual, and what they need and want to live the most fulfilling life possible. Individuals need to understand their level of need, their strength, and their possible support network to enable them to prevent deterioration, get support, and achieve life-goals.   Different organisations assess need differently, most aiming to be inclusive and emphasise "person-centered" values, yet generally, their attention lies with the realm their funding touches, for example, healthcare or personal care.

Recently, comprehensive, holistic needs assessments have been increasingly accepted as a highly beneficial practice in the area of cancer management (spearheaded by Macmillan Cancer Support). The NHS Constitution has formally highlighted the importance of putting the person at the centre of their own care. Unfortunately, due to competing budgets, even when presented with an opportunity to explore the extent of an individual's needs, there is often little that can be done with these answers.

Local Authorities (LAs) face a challenging reality. LAs with care responsibility must ensure that any adult with an appearance of care and support needs receives a proportionate, person-centred, strength-based assessment. This includes examining people's needs; how these impact their wellbeing, and the outcomes the person wishes to achieve. However, all of this is 'couched' in terms of care. Despite attempts (via language used on websites) to dissuade people from seeking assessments without clear and significant signs of care need, ADASS reports that over 500,000 individuals are still waiting for assessments.

More alarming is that almost two-thirds of LAs in England are forced to triage assessments, only responding in cases involving abuse or neglect, intended hospital releases, or short-term residential care. This sobering statistic makes it evident that current methodologies are failing to address the ever-increasing needs of individuals requiring support. It is simply unrealistic to expect LAs to adequately assess circumstances holistically, when dealing with an ever increasing backlog of critical and substantial care requirements.

The Care Act 2014 offers provisions that allow assessments to be carried out in different ways, with delegated or supported self-assessments. In examining various LA Care Assessment Proforma's, all require a skilled worker to help an individual to describe their needs and wants in such a way that the resulting information would be useful. To support Local Authorities in their monumental care responsibilities, we need to radically rethink the way needs, and subsequent provisions are assessed. We must put individuals (and their families) in the driving seat of assessing their own needs not simply have them as passengers on the journey.   We can utilise advances in technology, to enable individuals to examine their own holistic needs through supportive strength-based simple questioning. Creating a basis for them to create their own support/care package, forming the basis for evaluation by LAs/assisted self-assessments where required. In doing so, it will not only benefit those directly involved but also save valuable local authority resources.

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THE SUPPORT CIRCLE

Successive Prime Ministers have made efforts to facilitate the empowerment of individuals and communities, such as Tony Blair's 'Giving Age', Gordon Brown's Council for Social Action, and David Cameron's 'Big Society'. Evidence of the potential for people to come together in order to benefit one another has been especially visible during Covid-19, when restaurants transformed into delivery services and neighbours provided shopping services to each other.

Nevertheless, effective empowerment does not amount to telling people to support one another without providing the tools necessary to do so. People often genuinely make offers to lend a helping hand in times of adversity (this is particularly the case when someone has a life-changing diagnosis/treatment or a sudden hospital stay), families want to help aging relatives, but the complexity of coordination between multiple parties can make it easier for the burden of responsibility to fall on a single individual.

Preventing decline in people needing care, and preventing carer burnout is critical in reducing reliance on state-funded support. In response to this, we must make active attempts to provide resources designed to truly assist, rather than further handicap individuals and their communities. We need to give people the tools so that they can assess their own needs, have a resulting cohesive plan which informs them of support that might be available, and enables them to share out tasks between willing friends, family and neighbours.

£10.9bn is spent by self-payers on care (National Audit Office, 2018), and there are an estimated 4.5 million family carers (Kingsfund, 2022) (2.6 million of whom have given up work because of their caring duties (Carers UK, 2019)). Unfortunately, most existing care planning tools are only accessible by care businesses – not individuals. The care planning tools also only focus on paid support not unpaid. This must be remedied if we wish to put individuals and their families in control, providing them with the necessary resources to efficiently manage their own care circle. Such care circles may well include professional paid-for assistance, but it should be created at an early stage to prevent decline, and make the most of the immense generosity that is available in the community.

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CREATING A PACKAGE

For those who self-pay for care and the millions of people not eligible for or not utilising the assistance provided by their local authority, the task of obtaining and managing an ongoing programme of care is immense.

Where someone does not meet the eligibility criteria for care the local authority must give written advice and information about what can be done to meet or reduce the needs; and what can be done to prevent or delay the development of needs for care and support, or the development of needs for support, in the future." (Care Act 2014).   There is no requirement to provide any further support, or tools to help people get and manage their own care and support, just a letter with some advice.

Self-payers, those not eligible for support and those with temporary/transient need (ie those with a recent cancer diagnosis) all need help to create their own plan.

Every plan is unique to the individual and their circumstances, often including help with household tasks, ensuring bills are paid and finances managed, administering medication, bathing, dressing, feeding, as well as keeping them safe when out and about or at home, the needs can also include gardening, helping with pets etc.

The complexity of coordinating multiple people in a care circle and the varying time requirements (e.g. mealtimes, medication doses, socialisation, clubs) can appear insurmountable. Nonetheless, technology provides an ideal solution for intricate issues: artificial intelligence (AI) and machine learning (ML) could take personal inputs and refer to what has been successful for others to create an individualised programme of aid with tasks assigned to various people to meet their specific needs.

Currently, care providers are taking advantage of programmes that produce customised care packages and assign visits and jobs to paid caregivers, thus optimising time while ensuring duties are executed. In some cases, family members may keep track of the visits/tasks completed. Yet, none of these solutions consider activities beyond paid care services or allocate tasks to an extended support system. To this day there is no direct access for individuals to input and manage their own programme/resources.

We need to create and give access to individuals, through the use of technology which takes the individual needs and wants and combines this with the support available in the support circle (paid and unpaid), which logically creates a plan and assigns tasks to enable the individual to be supported.

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PROVIDING CARE

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The escalating cost of living is putting extreme pressure on care agencies that are already stretched to the limit by inadequate financial uplifts from local authorities. The situation has become dire, with only 1.5 million people employed in the sector providing support to over 14.6 million individuals with disabilities. 34.4% of those workers left last year. The aging population means we must recruit 500k+ workers to one of the lowest-paid occupations in the UK within eight years (Kirk-Wade, 2022; SfC, 2021).

We cannot simply recruit more carers, it is an industry where a third of the workforce left in the past year, many go to work in supermarkets and shops as the pay is greater and the conditions better. It is horrifying to think that it's better to stack beans than it is to provide care to the vulnerable.

It's clear the system is reaching breaking-point. We need to be creative in how care is provided via paid carers as well as through circles of support. As well as recruiting people to care agencies, care homes and as healthcare assistants, we need people who want to support individuals in their local area.

There are a variety of different organsitaions, in other industries, that have appeared over the years that have resulted in market disruption. Uber, not only resulted in more taxi drivers overall in a city but found that 49.7% of drivers had another job, thereby expanding the market (Berger 2017, TechJury 2023). Similarly, sites like Fiverr, UpWork and Etsy (63% started as 2nd Job, Wallstreet Zen, 2022) all provide tools for individuals to take on additional paid roles outside their main employment. These tools differ from the way care agencies work, in that the control is in the hands of the person carrying out the task. We need a platform for care that enables individuals providing care and those needing care to make arrangements directly.

The Care Quality Commission (CQC) strictly regulates the provision of personal care, therefore requiring all agencies to be registered and monitored. Registration is an extensive process that demands the implementation of various policies and training. Initially, the CQC's guidance allowed single workers who were not responsible for the activities of other personnel to provide care without being registered under the CQC; however, this directive has now been revoked, further decreasing the workforce in the care sector. It is beyond dispute that the regulation of care is necessary, yet it is the level of requirement that merits scrutiny. Consequently, it is imperative that urgent discussion is had over this change in scope, as well as the question of whether family members or friends providing care services unpaid are also subject to registration.

We need to ensure the safety of vulnerable people whilst providing a mechanism that means that individuals can provide care to people in their local area. Giving realistic levels of regulation vs the ability to enable the maximum numbers to provide care.

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MANAGING CARE

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Once all the needs are established, a support system is put in place and paid carers are found, the issue of effectively managing the continued provision of care becomes critical. In order to manage complex rota plans, ensure data privacy and record-keeping and provide information to various carers attending a client, care businesses have turned to technology. They have systems to manage payments, contracts and safeguarding lone-workers. Sadly, this technology is not available for those arranging their own care and support—leading to a choice between paying more to an agency to cover the necessary aspects or trying to figure it all out on their own in hopes of saving some money.

The difference in what individuals who are buying care pay versus what those providing the care receive is stark; with the average care worker earning £9.50 per hour (Skills for Care, 2022), and someone purchasing care through an agency typically spending between £15 - £30 per hour and an average rate of £18 - £20 (UK care guide, 2023).

Introduction agencies have made strides in bridging the carer gap, yet there are other viable solutions. Technology has advanced and could be created to provide those who require care (and their families) greater autonomy in managing the provision.

Individuals need the tools to create rota's, assign and track care tasks, let families know that carers have arrived/left, manage journals, hold contracts and manage invoices/payments. Being able to use a tool to do this themselves will enable more competitive pay for carers, thereby encouraging more people into the sector. It will allow those receiving care to take control.

We need to create the tools to enable them to take this forward.

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NEXT STEPS

With an aging population, a rising demand for care workers and dwindling resources, this problem has become increasingly urgent and requires a proactive approach.
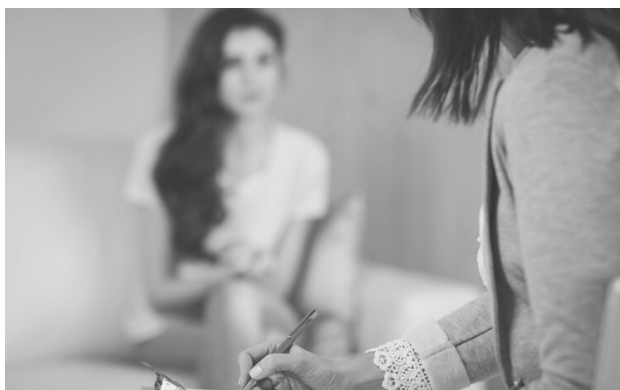
ASSESSING NEEDS

Empower individuals to assess and 'own' their own needs

- Strength-based, holistic
- Enable them to share it with relevant agencies

SUPPORT CIRCLES

Tools for the individual/family to manage

- Family/friends
- neighbours and community
- Paid carers/care agencies

CARE PROVISION

Tools to enable the individual (family) to manage

- Ongoing care arrangements
- Administrative elements
- Payments

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CONCLUSION

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The present system of drawing upon social services and other traditional sources of care is no longer dependable and leaves those who need assistance with long delays and uncertainty. Now, more than ever, we must focus our energies on those willing to innovate groundbreaking solutions that can challenge the classic form of care and equip people with a variety of ways to better plan and manage their own care efficiently and effectively.

We need to create tools that ease the burden on Local Authorities, and the NHS, enabling thousands of people currently stuck in hospital whilst waiting for suitable care provision to be identified, to leave hospital safely.

To enable individuals to gain control over their own care provision we must reduce the complexity associated with determining care and overall needs, hiring/paying/employing carers, scheduling tasks, and safeguarding, thereby reducing the cost to enable competitive pay whilst lowering the threshold for those receiving care to take the reins.

Technology, including Artificial Intelligence (AI), Machine Learning(ML), Internet of Things (IoT), Near Field Communication (NFC) and Global Positioning Systems (GPS) all offer remarkable potential that must be fully exploited to streamline the managerial and operational tasks that keep people from organising their own care, as well as those providing care to them.

HiCarer is devoted to giving people access to the tools they need to make this vision a reality.

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