May I give you a lift? Car sharing and disabled people

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Contents

Setting the scene

Introduction

It is commonplace for one citizen to offer another citizen a ride in their car. These informal, often spontaneous arrangements enable people to help one another and open up social events to non-drivers and people who don't own a car. They help people get to work, to socialise with their friends, to have a drink, to share an outing together. They reduce costs, pollution and congestion on the roads, in some places shortening journey time by giving access to High Occupancy Vehicle (2+) lanes[1]. They point to the future, in which driverless cars may be used as a service, rather than individually owned[2].

Many people who rely on health and social care services, and especially those who live in care homes miss out on these everyday social transactions. Getting out would do them good. An outing has a much greater value than simply attending something, receiving a service or purchasing an item. As a recent report illustrated, it is important to think about the opportunity it affords to see life, to feel connected and so to gain in wellbeing and combat the sense of loneliness and boredom. As one commentator observed:

> *One particular shopmobility scheme allows up to 20 older people to visit local shops on a specific weekday. It is routinely fully booked one week ahead. However, it is common for only five or fewer of the passengers to return with shopping bags. Many of the others use the service because they value the interaction, the ability to leave their house and enjoy fresh air, to enjoy a cup of coffee and a bite to eat at a local supermarket*.[3]

We wonder why informal lift sharing seems to be a rarity in UK care homes. Perhaps staff feel obliged to provide transport themselves and so they increase demands on the public purse, rather than support people to accept a lift from a neighbour or a friend. If anyone mentions lift-sharing, some staff may assume this means other people using the same health or social care service, rather than ordinary citizens. When planning a trip, do they suspect that their employer would discipline them for offering a lift to a member of the public? Would they insist on seeing a certificate from the Disclosure and Barring Service to prove that neither the driver nor the passenger has a criminal record of robbery or hostage taking? Some worry about liability in the event of an accident. These anxieties result in citizens using health and social care services being denied opportunities to offer or receive a lift.

This paper is not about getting around[4]. We shine the spotlight on lift-sharing as an opportunity for disabled people[5] to enjoy social connections with neighbours and friends beyond the disability community[6]. By asking about lift-sharing with the general public, we accuse the health and social care system of creating a benevolent ghetto in which the body is cared for and moved around, but the person is held back from engaging with other citizens. Lift-sharing is almost unthinkable in many services because it is too hard to imagine that the person might have existing friends outside the

service or the potential of making new ones. On those rare occasions where informal lift-sharing does happen, staff are afraid to talk about it openly for fear that it will come to the attention of a bureaucrat and get closed down. This paper looks for ways to bring this everyday exclusion to an end so that people who receive health and social care support can be part of the community too, offering and accepting lifts like anyone else.

In the USA, a movement called 'Free Range Kids'[7] has stood against the over-regulation of children's lives. Grossly inflated views of the real level of risk lock down children's lives in a futile attempt to keep them safe by denying them opportunity, and Free Range Kids challenges this fear-fuelled rhetoric. In March 2018, Utah[8] became the first State to pass a law that protects families who opt for 'free-range parenting'. Perhaps the UK needs to think about creating systems that support free-range adults.

A few facts and figures

- Some 21% of households in the UK did not have access to a car in 2017, rising to 63% of those in the poorest ten percent of the population[9].
- The Department for Transport is promoting travel by disabled people by spending £2 million on developing Changing Places toilets in motorway service stations and £300 million on making railway stations more accessible[10].
- After retirement, the number of trips taken by older people falls by a fifth, but an increasing proportion of these trips are by car, and, until the age of 85, they have, on average, more social outings and shared journeys than citizens of working age[11]. When disability intervenes, this social life is impaired, and people tend to become much more isolated immediately prior to admission to the care home. This means that residents may hope to pick up the active social life that they enjoyed after retirement, especially as the care home is now removing the burden of domestic chores. Residents' expectations will then be tempered by the routines and practical arrangements of the care home and informed by working staff who may have a much narrower social life than that enjoyed until recently by the resident.
- Half of disabled older people utilise lifts from friends or family[12]. Disability may impair the ability to use public transport, rather than the ability to drive or ride in a car. When an older person is contemplating the decision to give up driving, they are more likely to do so if they have strong social networks that increase the opportunity for informal ride sharing[13].
- In a convenience sample of 751 care staff who were asked, 'Would you offer a lift to the person that was not a clear part of the care plan' two thirds of them (63%) answered 'No, never' or 'probably not'[14]. In a survey of 1702 care staff, 34% were never or almost never aware of a resident being taken out of the home for their enjoyment[15].
- Many care home providers are in financial difficulties, with more than 100 providers going out of business in 2018[16].
- A 2019 survey asked 500 care home providers to respond if their residents ever went out of the home with a friend, rather than with a staff member, registered volunteer or relative. Only four providers responded[17].

- Nearly 30 years ago someone remarked that 'Typical rural travel surveys have shown 7-8% of all trips to be lifts, compared to 10-16% by public transport and 57-70% by household car. Over 50% of rural car owners routinely give lifts.'[18] More recent data may be available[19].
- People who are detained in secure forensic settings are entitled to 'access to the outdoors' and 'information, signposting and encouragement to patients where relevant to access local organisations for peer support and social engagement such as: voluntary organisations; community centres; local religious/cultural groups…'[20] We might consider whether there is a justification for subjecting people living in care homes to more restriction than this group, especially where it is applied covertly.

Human Rights and human feelings

Article 8 of the Human Rights Act 1998 protects a citizen's right to a private and family life, and this includes the right to forge friendships and other relationships, to engage in social, cultural and leisure activities and to participate in society. Article 19 of the Convention on the Rights of Persons with Disabilities addresses the right to live independently and be included in the community. In particular,

> *States Parties… recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that…*
>
> *Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community.*[21]

The explanatory note that was approved and published by the United Nations explains that persons with disabilities should have access to all services offered to the public and to support services offered to persons with disabilities to enable them to be fully included and participate in all spheres of social life. These services include access to transport[22].

The Mental Capacity Act 2005 insists that a person has capacity to make their own choices unless it can be shown that this is otherwise, and that they must not have their freedom restricted without due cause and process. Therefore, even where people are living under Deprivation of Liberty Safeguards, they still must have their freedom of choice honoured and upheld in every possible area of life.

The Department of Health guidance *Positive and Proactive Care*[23] makes it clear that steps should be taken wherever possible to eliminate restrictive practices so that people using health or social care settings can enjoy the same opportunities as other citizens. Restrictions must be minimised, proportionate to the risks involved and individualised to the person concerned. The routines adopted by many health and social care providers that have the effect of banning informal lift-sharing for almost everyone are therefore unjustifiable and a denial of human rights. In particular, when most free citizens negotiate the giving or receiving of a lift, they do not ask for sight of insurance documentation, MOT or DBS certificates prior to getting into the car and so care staff have to make a clear case for adopting a more restrictive practice. Simply declaring that the person is a care home resident or subject to a DoLS is insufficient.

Alongside the need to uphold human rights stands a need to recognise the range of human feelings that are associated with informal lift-sharing. It feels good to help another person, and social exchanges help people to feel known and connected to others. When staff and care systems prevent informal lift-sharing, they reinforce the stereotype that disabled people are takers and not givers, that they only ever need the help of others; that they have no way of contributing. They label people as vulnerable.

Informal lift-sharing is an act of trust in which the driver chooses to place faith in the passenger to act appropriately, and the passenger chooses to undertake the journey and hopes it will be safe. Whilst driving has declined in the last quarter of a century[24], it is still strongly associated with feelings of safety, freedom and independence, feelings which may deter some people from offering other citizens a lift.

Indeed, the feelings associated with car sharing and with asking for and offering a lift are complex and highly personal. One driver is reluctant to offer a lift because her car is so messy, while another would rather offer a ride to a relative than to a neighbour; one passenger would not notice the driver exceeding the speed limit, while another would spend the whole journey anxiously pressing an imaginary brake pedal. Some people are happy to accept a regular lift, while many prefer to ration the lifts they accept in order 'not to be a nuisance'[25], especially when the outing is a social occasion, rather than a visit to hospital[26]. Some even see the passenger as a scrounger who has refused to engage in responsible citizenship and now expects others to take care of their needs, while the passenger themselves may feel ashamed of their lack of car ownership.

For some, their car is portable territory[27] and driving is a private activity, just as some travellers will wish to keep the purpose of their journey confidential and not explain why they are visiting the hospital, Trans Unite or Cats Protection. The distance between the origin and destination of a journey may be a nuisance, wasting time, costing money and polluting the planet, but for others, the journey itself is an enjoyable outing, a positive stimulus and a source of happy memories, as well as a distinguishing marker between the idyllic retreat of home and the social context of the destination[28]. The very act of movement, of locomotion, is the way in which we humans connect our inner and outer worlds, make sense of our context and make our way in the world[29]. If the traveller finds themselves obliged, by reason of encroaching disability or other life changes, to give up driving and begin using mass transport – a public bus, train or community transport - this dramatic change is loaded with symbolic meanings.

As always in these matters, staff and other mediators need to clarify their own emotional response and then set it aside as they listen to the person they support.

> *Dorothy and James got to know each other at the local meetings of Paxton Green Timebank. One evening, they both wanted to go to the North Africa themed evening at the Town Hall, where they would have the chance to drink Moroccan tea and learn about Islamic culture. James is a car owner/driver and was kind enough to offer to collect Dorothy from her care home and take her home again afterwards. They both had a great evening.*

Deprivation of liberty

Before we begin a discussion of how to protect people who lack mental capacity, we must restate the person's fundamental human rights. A care home resident who has capacity has the right to make and enact their own decisions and cannot lawfully be prevented, even if those choices are

unwise, as clearly stated in the third principle of the Mental Capacity Act 2005. The 'right to a life in the community' protected under article 5 of the Human Rights Act 1998 means Interacting with citizens beyond the care home. Any care home resident who has the mental capacity and wishes to go out and ride in someone else's car cannot be stopped any more than a person living in their own home can be deprived of an opportunity to seek or give lifts.

A citizen may be lawfully deprived of their liberty by the state through imprisonment, detention under the Immigration Act 1971, the Mental Health Act 2007, or actions taken by the Court of Protection or under the Mental Capacity Act 2005. People living in care homes may find themselves subject to restraint or restriction, and, where this is substantial enough, the person should be protected by the Deprivation of Liberty Safeguards (DoLS). The aim of the safeguards is to balance necessary restrictions exercised in the best interests of the person with maximum freedom and they apply to people living in care homes and hospitals who are unable to give consent to their care arrangements where those arrangements effectively deprive them of their liberty. DoLS are classed as standard or urgent authorisations and are always time-limited. DoLS are anticipatory, established for both compliant and non-compliant persons, in order to protect the individual's rights, whether the person is testing them or seems entirely content with the restrictions. The UK government is seeking to replace DoLS with Liberty Protection Safeguards[30].

There are over 400,000 people living in residential social care in England, of whom around one fifth are subject to DoLS[31], and the processing backlog means that, all settings together, there are more than 100,000 people with uncompleted DoLS applications across[32]. This leaves 80% of care home residents who are not protected by these safeguards but who may be subject to liberty-restricting measures that are insufficient to justify the application of the DoLS. Whether the person is protected by DoLS or not, the Mental Capacity Act always requires care providers to act in the person's best interests and insists on the least restrictive option being considered[33].

Some readers may think it absurd to include people subject to DoLS in a discussion about informal lift-sharing, as the likelihood of this actually happening are slight. In contradiction to such a view, this group are included in the discussion to show that opportunities should be offered even here, and so residents should not be excluded from the opportunity to share a ride, whether they are subject to DoLS or not.

We can think about the DoLS process in three steps. First comes the assessment of eligibility. Lady Hale set this out in her 'acid test', referring to supervision and control, and freedom to leave, of which more below. These are broad issues that describe the whole of the person's life, to which we must add some specific items that increase the likelihood that the person will be eligible for DoLS. These might include, for example, the person being given covert medication or being physically restrained 'for a non-negligible period of time'. Second, scrutiny. Once the DoLS in in place, it brings the whole of the person's care plan under its scrutiny and review mechanism. Thirdly, impact. When a DoLS is in place, it does not authorise the care home to transfer all power away from the person but is decision and context-specific and must relate to the particular areas where restraint or restrictions are to be applied in order to keep the person safe and meet the expectations of the care plan. We must ask if the right to a life in the community appears in the care plan and how it will be accomplished.

Many people protected by the DoLS need 'continuous supervision and control'. This does not automatically mean that they must have constant line-of-sight supervision, can never be left alone, or must need help with absolutely everything. Rather, they might be left on their own for short periods, and will need assistance with many, but not all activities of daily living. They may go out.

Furthermore, there is no expectation that all the supervision must be provided by staff – relatives or friends may also contribute[34]. The law acknowledges that a precise definition is not possible or practicable and so each case needs to be looked at in the round.

In addition to continuous supervision and control, people protected by DoLS are 'not free to leave'. Such a person may not go and live somewhere else on a permanent basis and they would need permission and/or help to go out for a temporary period. The deprivation of liberty does not rest on the individual being non-compliant with restrictions, but the case for the safeguards is reinforced if the staff refuse the person's request to leave, deny them the opportunity (such as by locking a door) or arrange for them to be returned to the care home against their will[35]. None of these things prevent the person who is subject to DoLS going out.

Indeed, in a landmark case[36], the European Court of Human Rights specifically ruled on this matter in relation to people who were deemed to be detained, but occasionally took unescorted trips into the community with the permission of the manager of the residential care setting. No doubt some people could find their way to a nearby and familiar venue but would get lost if taken beyond this safe horizon. The decision was clear – people subject to DoLS may make unescorted outings into the community. There appears to be a dearth of literature on positive unescorted outings, in contrast to resources on absconding, AWOL and people judged to be 'missing from care'[37].

However, in most cases, people who are subject to a DoLS will go out with an escort if they go out at all[38]. Indeed, in explaining the DoLS to care home managers, the Social Care Institute of Excellence actively encourages these outings:

> *"Managers will review and promote access to activities provided in the home, access to the garden or the local shop, to public facilities and to family outings or visits."*[39]

The driving force of the Mental Capacity Act 2005 is the person's best interests, but within this, there is a requirement to consider the least restrictive option. Care planning for people subject to a deprivation of liberty should include the ways in which people are assisted to maintain contact with their family and friends, which, as SCIE explain, may include, for example, an 'occasional visit to the pub'. SCIE goes on to assert, 'preventing contact with family members and friends may be a breach of a person's human rights.'

From a more positive perspective, the DoLS can include specific conditions that can be attached to an authorisation. This would require a care home to enable a specific activity, that might include accessing activities in the community or nurturing existing relationships which are important to the person.

On a few occasions, sadly, the person's relatives or friends may wish to cause harm to the person, and so contact with such people needs to be restricted in the person's best interests. This can be achieved through an application to the Court of Protection, rather than through the DoLS process[40]. It is important to note that, while it is acceptable to use restriction and restraint to protect the person from known harm, preventing them from accessing the community because of a vague fear of 'stranger danger' or of 'something going wrong' is not.

Challenge #1

Under what circumstances might someone who is subject to Deprivation of Liberty Safeguards safely enjoy unescorted or unstaffed leave from the care home?

Seeking solutions

Long term car ownership

We begin with a solution that may be more applicable to disabled people who live in the community, rather than substantial numbers of people who live in residential care settings. It is included for reasons of completeness and because there may be some people for whom it is relevant.

In this option, the disabled person owns their own vehicle and chooses to offer an informal lift to a friend or neighbour. Perhaps the solution for some people is simply to acquire a car and, in so doing, achieve personal mobility, gain the ability to offer another citizen a lift, and obtain a range of symbolic benefits. The automobile is highly symbolic in Western society and represents the values of decisional autonomy (the ability to decide where and when to travel), self-reliance (the freedom to undertake a journey without being beholden to others) and altruism (the resources to help others)[41].

From a historical perspective, the 'invalid carriage' was the first attempt to provide a modern transport solution at scale to meet the mobility needs of disabled persons. The first of these was manufactured by Invacar Ltd from 1948 to 2003, when it was withdrawn from use due to safety concerns. Significantly, the Invacar was a single seater vehicle[42], carrying even fewer people than the motorcycle from which it was adapted. So, whilst we may have taken the invalid carriage off the road, we have not taken it out of our heads, and health and social care staff continue to book vehicles on the assumption that the person has no family, no friends, no neighbours and no wish to show kindness by helping anyone else, so will not need any extra seats[43].

The Invacar was replaced by the Motability scheme that enables disabled people to lease a car in exchange for their mobility allowance. The Motability rules indicate that the car 'will only be used for the benefit of the disabled customer', a phrase that might be interpreted to prohibit informal lift sharing. Fortunately for our purposes, Motability define 'benefit' to include giving a lift to friends and family[44], as 'benefit' includes the opportunity to be a good neighbour, to participate in community life and to demonstrate kindness and generosity.

So those who have taken on a Motability lease and own a car may offer lifts to friends and neighbours, as well as people who share their interest in a community activity or membership group. Indications are that welfare benefit reform is removing entitlement to a Motability car from some claimants[45], thus reducing the proportion of people able to benefit from this scheme.

Short term car hire

A second option for acquiring the use of a car (which may then be used to offer an informal lift to a friend, neighbour or acquaintance) is to hire one. Conventional cars can be hired from commercial hire companies, such as Enterprise, Hertz and Europcar, while car clubs offer non-profit options. Wheeliz is a website that matches people who own adapted vehicles and are willing to rent them out with people who need to hire one for short periods. This enables people who are dependent on specialised transport to travel abroad.

It is unlikely that the insurance conditions appertaining to short-term car hire prevent an authorised driver offering a lift to a neighbour or a friend, but this could be checked rather than assumed. Where care staff or their administrative colleagues are making arrangements for short-term vehicle hire, this should be checked so that staff are clear about whether the hire conditions permit the staff and residents to offer a lift to a member of the public.

Vehicles owned by the care provider

Some care homes and day centres operate their own vehicles to enable their residents and attendees get around. This means that they could contribute to community life by offering neighbours and friends a lift from time to time. Indeed, in one organisation, this is commonplace, and outings frequently welcome relatives, volunteers and friends on board. Of course, since one of the most important spurs to community participation is to find an activity companion[46], the ability to offer a lift can make all the difference between engaging in the activity or abandoning it. The opportunity for disabled passengers to connect with the general public is further enhanced when volunteers are permitted to drive the vehicle, of which more below on the section on community transport.

In contrast, staff from another part of the same organisation believed that offering a ride to neighbours and friends was prohibited due to either the terms of the vehicle insurance, or the organisation's own rules that had, they presumed, been shaped by a fear that the relative, friend or member of the public might have an accident and litigate against the organisation.

Challenge #1

Do any care providers have a written policy that restricts the uses of their vehicle to staff and people using their service and prevents any other person riding in the vehicle? What are the reasons given for this restriction?

Many care providers are moving away from large, specialised vehicles and choosing instead ordinary, unmarked transport, perhaps with subtle adaptations that avoid drawing attention to the passengers and so dodging the amplification of stigma[47] that might otherwise occur. Maintenance costs for ordinary vehicles may also be less and potential drivers may be more willing to take on the task.

Staff using their own car for work

Some staff working in care settings have agreed to use their own car whilst at work and for work purposes. Employers may apply any rules they wish on what staff do with their cars during worktime as long as they meet their obligations under the Health and Safety at Work Act 1974. Insurance is discussed separately below.

Challenge #2

What are the rules governing care staff using their own vehicle in work time? Can they transport people using their services? What about including a member of the public in the journey?

Taxis

Some disabled people are unable to own a vehicle themselves and so depend upon adapted taxis or other licensed vehicles (of which more below). Cars seating eight or fewer people and offered for hire or reward are required to obtain a PSV permit if the vehicle is hired as a whole, rather than an arrangement by which each passenger pays an individual fare[48]. Commercial taxi companies are required to make reasonable adjustments to enable disabled people to use them and this is a condition of the license. The specific adjustments that are required to obtain a taxi licence are set out by the local authority, so details will vary from one area to another and the local authority will

sometimes reduce the license fee for disability-friendly vehicles. These are more likely to be hackneys as they are wheelchair accessible and many have induction loops, intercoms and accept service dogs in the vehicle. All taxi drivers in the UK are required to obtain an enhanced background check with the Disclosure and Barring Service[49].

As was mentioned above in relation to car ownership, consideration should be given when booking a taxi to the need to transport relatives and friends as well as the person themselves. The additional cost of a slightly larger vehicle is the price of community inclusion. Online systems have been proposed to enable taxi users to rideshare, thus reducing cost, pollution and compensating travellers for the marginal increase in journey time where applicable[50].

Challenge #3

Does anyone have a story in which a care provider sets up a taxi for a person they support and they then offer a lift to a member of the public?

A particular pattern of behaviour emerges when citizens share a taxi with someone who can reclaim the cost from their employer. One view is that, while the travel claim should not show an inflated price, the additional passenger only needs to pay the margin and the bulk of the journey cost can be covered in the claim.

Can a disabled passenger riding in an adapted taxi offer their neighbour a lift to the shops or a U3A[51] meeting? It is a commonplace thing for other citizens who drive to take a diversion to pick up a friend or take them home after an event, as any parent knows when they arrive to collect one child and end up taking three home! Where the diversion is short, drivers are rewarded with a word of thanks, while it is a social convention to offer a contribution towards the cost of fuel for longer trips, such as to the airport. When hailing a taxi for the drive home after a concert, informal groups coalesce and negotiate amongst themselves how to pay the charge showing on the meter.

Challenge #4

There is a difference between a pre-arranged lift booked between friends who know one another, and a spontaneous arrangement where the connection is more tenuous and may even be mediated by a third party. Should informal lift-sharing be confined to pre-planned occasions or be limited to people who have capacity or who are accompanied by staff?

For many car owners, it is their pleasure to offer a neighbour a lift, and the marginal cost of that additional journey or diversion is their gift, a way to strengthen community ties and contribute. Those who rely on taxis have the freedom to be similarly altruistic.

Community transport

Non-profit transport providers often run adapted minibuses, known generically as Community Transport and specifically as Dial-a-ride, Easylink or Ring and Ride services, and these have been the subject of recent research[52] and Government interest[53], with many organisations belonging to the Community Transport Association[54]. They are designated as private hire vehicles and licensed under Section 19 and section 22 of the Transport Act 1985, with arrangements enabling them to complement commercial and public transport services rather than compete with them. Some Community Transport Associations also run a Community Car Scheme for people who are unable to use public transport.

The regulations allow some providers to operate what some have dubbed a 'stigmobile'[55] that segregates disabled people from the rest of the community, but most of the options that form Section 19 permits allow providers to carry relatives, friends and members of the public as well, as shown below.

> Class A - members of the body holding the permit.
>
> Class B - persons whom the body exists to benefit, and persons assisting them.
>
> Class C - disabled persons (as defined in the Disability Discrimination Act 1995) or persons who are seriously ill and persons assisting them.
>
> Class D - pupils or students of any school, college, university or other educational establishment and staff or other helpers accompanying them.
>
> Class E - persons living within a geographically defined local community, or group of communities, whose public transport needs are not met other than by virtue of services provided by the body holding the permit.
>
> Class F - any other classes of persons specified in the permit.

Challenge #5

There is no legislative definition of assistance or support in Section 19 permits, but do individual Community Transport providers specify the nature of the assistance or support that helpers must offer to eligible passengers?

The two phrases 'persons assisting them' and 'helpers accompanying them' are not further defined in the legislation, so we may assume that it could include both practical help, such as assisting the disabled person to get on to the vehicle, alight or remain calm while aboard, or emotional support, such as companionship and encouragement. Thus, a member of the public cannot ride independently, but if they are assisting an eligible passenger, then they may ride too. This is a natural opportunity for informal lift-sharing, and there is no reason why the support and assistance needs to be one-way, so the member of the public may benefit in some other way from the shared journey, as well as helping the disabled passenger.

Passengers pay individually a small amount towards the running costs, share the ride with other passengers who may be travelling to a different destination and take a route selected by the driver to allows people to be dropped off in turn in the most efficient manner.

Car sharing or carpooling schemes

There are several websites that help people find a car sharing partner either regularly or for a single trip. Some, like Liftshare[56] are social enterprises, while others may be commercial organisations. GoCarShare and BlaBlaCar, Europe Carpooling and Waze Carpool are active in the UK, with some offering international journeys. Some cities and nations have found these arrangements (especially Uber and Lyft) to be disruptive of traditional markets and so have sought to regulate or even prohibit them, and the negative press associated with these views may have tarnished the car-sharing concept.

Li and colleagues[57] identify five distinctive components of such arrangements:

- Dynamic - Ridesharing allows drivers with spare seats to establish links with users who seek on-demand ridesharing.
- Independent - Drivers are not employees of ridesharing companies.
- Cost-sharing - The costs incurred by the trips are shared by participants.
- Non-recurring - Trips tend to be one-way
- Automated matching - A computer system helps riders and drivers find each other.

DeLoach and Tiemann[58] studied the preferences of people involved in a carpool in the USA and found that people preferred to carpool for a regular journey with someone who shared similar characteristics to themselves – similar race, sex and job level. They often take turns to drive. Where people share similar characteristics and feel that they are already part of a community (perhaps as fellow employees of a large company or members of the same community organisation), software such as RideConnect can be used to match up drivers and passengers within that group.

Where online software is used to link a driver with a passenger and to complete the financial transaction, both passengers and drivers are safer[59] than they would be in a traditional taxi where the temptation of cash is carried in the vehicle and where neither knows the identity of the other. In addition, passengers using online rideshare services rate the quality of the experience immediately after the experience and so it is easy for the computer system to link this feedback with the specific driver or passenger, thus collecting early warning data about potentially dangerous persons.

People who spend a lot of time at home may enjoy the chance of an outing, and a car sharing trip simply to visit another place for a few hours may be a welcome change. They provide for occasions when more than one passenger rides in the vehicle, so there is no reason why a person and a support worker couldn't take up this opportunity. Car sharing schemes do not need a licence from the local authority.

Challenge #6

Does anyone have an example of a person who is supported by health or social care services using a car sharing scheme?

Public transport

The use of public transport by disabled people is just beyond the remit of this paper, as it has the potential to be a shared journey rather than a lift share. Furthermore, the person with whom the journey is shared is important. There may be merit in a care home resident sharing the ride with a staff member (perhaps a travel trainer), with a support worker or with another resident of the care home, but the full potential for community connections is not achieved unless the journey is shared with a member of the public.

> *At a supported living service in Liverpool, one resident needs the reassuring presence of a staff member to help him get on the correct bus. They finally worked out the best arrangement. They go to the bus stop together but do not interact when other passengers are waiting nearby. When they get on the bus, they choose separate seats and onlookers would consider them to be strangers to one another. This leaves the person free to interact with other passengers or use the bus semi-independently.*

In addition of providing a means of getting around, public transport provides opportunities for social interaction. While for most of us, riding on public transport is something we do alone or with a friend, rather than to make a friend, there are exceptions. This is illustrated by Rachel Simon's memoir[60] of spending a year with her sister riding the public transport system and meeting the

friends she had made there. In contrast, research has found that people who experience high levels of anxiety sometimes find crowded public transport so exquisitely stressful that they never use it[61], while for others, a well-planned journey can alleviate these difficulties[62]. Informal lift-sharing may be a workable solution for them.

> *Paxton Green Timebank arranged a shared meal at Dem, the local Turkish restaurant. Staff at Magnolia House care home encouraged their residents to participate but did not go themselves. One member of the Timebank who had previously got to know two of the residents arranged to meet them at the care home and then the three of them got on the number 67 bus to Dem. Four other residents booked a taxi and travelled together.*

Second, people who regularly use public transport walk further and faster than car users, and so derive health benefits[63].

Third, pensioners in the UK have been offered free bus travel since 2008, and, while this policy is very popular with the public, it may have made people reluctant to pay for transport. As Luxembourg is set to remove all charges from bus, tram and train travel from summer 2019, there will be ample opportunities to see the impact that this has on the environment as well as on other forms of transport. It may turn out to be one of the reasons that the fee charged by Community Transport providers is resented by some passengers. For the individual passenger who needs an adapted vehicle, charges can work as a tax on disability – which, for some, will be offset by disability-related welfare benefits.

Fourth, services that support learning disabled adults and young people sometimes offer a training programme[64] to equip the person with the skills they need to ride on public transport. For example, York spends around £45,000 per annum on a team of travel trainers that work with a new group of 25 young people each year to establish their independence in using public transport. If one young person moves from taxis to the bus, there are lifetime savings to the public purse as well as a significant quality of life improvement for the person themselves. The Council estimate that this programme yielded a net saving of over £200,000 in its first three years of operation[65].

Some of these programmes teach the student to only accept a lift if it is pre-planned and approved by a parent or carer, while others, such as *Clever Never Goes*[66] recognise that spontaneous offers are made from time to time, and the person needs to learn to assess the offer and assert their decision in each situation. From a developmental perspective, playgroups do not release a child in their care into the hands of an adult unless that adult is on a previously approved list issued by the primary carer of the toddler, while in contrast, adults frequently make a spontaneous and positive response to an informal offer of a lift. Individual travel training programmes therefore position themselves on this spectrum, between the extremes of defaulting to pre-arranged authority on the one hand or equipping the person to make their own assessment on the other[67].

Assessing and managing risk is a natural part of everyday life, and public transport forms part of this ordinary community. Drivers employed on public buses are subject to the Basic DBS check and have a simple duty of care towards the safety and comfort of their passengers[68], usually limited to drawing the vehicle to the side of the road and calling for emergency services, as set out in the operating procedures issued by the employer. In contrast, drivers of school buses, and presumably other specialist transport that is dedicated for use by children or vulnerable adults, must undergo an Enhanced DBS check which includes a check of the barred lists – the most thorough check available[69].

Hitchhiking

At this point, some readers will find it difficult to go on, as the very idea that a person who uses care services might hitchhike seems patently absurd. So why does it appear in this paper? Hitchhiking provides the most vivid example of many features that appear in more subtle ways of informal lift-sharing. Its unpredictability helps us see how our attitude to many forms of travel is shaped by our need for reliability[70]; its perceived riskiness is emblematic of our fear of strangers on the bus or in the carpool. So we jump aboard this part of our survey and see what we can learn which will challenge our thinking about all kinds of informal lift-sharing.

Hitchhiking has a long history[71] but has declined in recent decades due to faster roads, more widespread car ownership and a reduced tolerance for risk, partly fuelled by horror movies such as the *Texas Chain Saw Massacre*. In some parts of the world it remains an entirely legitimate means of transport and is even encouraged. Resources are available to help with risk assessment[72], although actual risk levels are very low[73] and there is evidence to suggest that passengers and drivers adopt a range of distinct strategies for managing the social implications of being strangers yet physically close and unable to move for a sustained period[74]. These resources may well be applicable in other forms of informal lift-sharing.

Some hitchhikers relish the independence of the journey and choose to travel alone, partly for the joy of meeting the people who offer them a ride. Perhaps this sense of freedom, which is at its most potent in hitching, is also a driving factor in going out and walking or spontaneously using public transport:

> *One of our nursing home[75] residents has retained independence and regularly heads out on his own. He has keen interests and has access to organised daytrips but seems to prefer doing it all himself. He regularly walks five miles into the town centre and often uses the bus and the train. Care staff recognise and support his independence, and he is welcome to venture out without any assistance.*

Hitchhiking brings together strangers through the spontaneous decision to respond to a request by stopping and picking someone up, and this makes it almost the most informal type of lift-sharing of all. A variation occurs in the moment when a driver notices someone they recognise walking or standing at a bus stop and stops to offer them a ride. This seems to be more likely when the driver recognises that they have something in common with the other[76]. In that situation, the recipient is merely invited to acquiesce, rather than the more active signalling to request a lift that is employed by the hitcher. Whilst the *Clever Never Goes* campaign[77] seeks to train pre-teen children never to accept a spontaneous, unplanned lift, and notes that child abduction by a non-parent is an unlikely but real risk, much informal and spontaneous lift-sharing continues to take place in communities.

Perhaps most significantly, hitchhiking highlights the elements of novelty, unpredictability and adventure[78], contrasting with the routine of a familiar journey that one is obliged to undertake. The hitcher does not know for certain whether they will get a lift at all, and if they do, exactly where they will be dropped. Creativity and problem-solving is required, perhaps to complete the last leg of the journey. It is exactly this unpredictability that lends savour to the trip[79], that delights in serendipity when the right driver offers a lift to just the right place, that engenders a sense of triumph on arrival, and that fills hitchers with a sense of appreciation for the kindness of strangers. These enriching emotions are not often found in the guts of the care staff, who are likely to feel a different set of emotional responses. Perhaps most importantly for our present discussion, such adventures form

memories that can be drawn on in later years as corporeal travel is, at least in part, replaced by imaginative mobility[80].

> *Jim has both learning disabilities and mental health challenges and is supported by a care team. At the start of their working relationship, they quickly discovered that Jim likes to get on a bus or a train and travel a long distance before getting off. He would often phone the office for help with finding his way back. Staff gradually learnt that Jim is a resilient person and likes to travel, sometimes hundreds of miles. That means he needs help on the phone at odd times of the day and night and sometimes spends a night sitting in the buss station rather than sleeping in his own bed. He is content with paying that price in exchange for the feeling of freedom he experiences. Staff have gradually learned to be content with it too[81].*

As Mahood[82] has declared, hitchhiking is counter-cultural, representing a rejection of society's dominant narrative, which is sometimes dubbed 'project fear'. Even back in the 1960s, when hitchhiking was commonplace, many young people hitched in joyful defiance of their parent's wishes[83]. Does a paternalistic care system object to these passions associated with escape, adventure, uncertainty and delight, especially when seen in the people it supports? How might care homes create a positive environment that includes opportunities for unpredictability, adventure, the kindness of strangers and delight?

Studies of social support often favour close friendships over casual acquaintances, recognising that substantial help is exchanged between friends who care about each other over years or even decades. But weak ties are valuable too[84], and both the grateful hitcher and the solitary driver benefit from sharing the journey with a raconteur who listens well. These ephemeral social connections enrich the lives of the participants - and may well suit some people with mental health issues or autism more than long term and emotionally demanding friendships. In passing, we note that travellers whose life is overloaded with social encounters may enjoy their journey precisely because it is an opportunity to be private, whether that means wearing headphones and listening to music on the bus, reading a book on the train or looking out of the car window.

These considerations point to several issues, as listed below:

- Informal lift sharing involves both risk and the public attitude towards risk, which are often quite different. Risk assessments should be based on evidence[85], not popular myth.
- When informal lift-sharing occurs, both the driver and the passenger engage in a complex negotiation involving the request, the offer, agreement and acknowledgement. Sometimes a third party mediates by asking the driver and the passenger what they would like before bringing them together. The voice of people using health and social care services must be clearly heard in these situations.
- Informal lift-sharing demands that a sophisticated etiquette be observed between driver and passenger. Some people using health or social care services may benefit from being explicitly taught these skills. We might go on to consider the merits of 21st century travel training, which could include a range of car-sharing options as well as the usual elements of how to understand and safely use public transport.

Systems, rules and processes

Where may I park?

Disabled people may apply for a Blue Badge which allows them to park on-street close by their destination. A non-disabled person may drive or be a passenger in the disabled person's car, but the badge must only be used for the benefit of the disabled person. For example, if a disabled driver and their non-disabled neighbour were parking on-street to visit a shop, the blue badge may be used if the disabled person is going into the shop while the other remains in the car, but may not be used if the disabled person is remaining in the car – the non-disabled person must walk the usual distance from the public parking place[86]. The owners of the land used for off-street parking set their own rules.

Hospital car parking is a particularly contentious type of off-street parking which may be of interest to our topic, as care home residents may wish to give or receive a lift to a hospital appointment, be dropped near the entrance, share parking fees or reduce overcrowding in parking areas. It is free in most hospitals in Scotland and Wales, while hospital Trusts in England may charge if they wish and they raise more than £200 million per annum doing so[87]. The Government has recommended[88] that car parking fees be waived for certain groups (including disabled people, frequent attenders, carers and visitors of patients undergoing an extended stay in hospital), but one in eight hospitals in England have rejected this advice and even charge disabled people and Blue Badge holders. Where concessions are available, they may apply to only some patients and some of their companions, such as those who are recognised as 'medically necessary'[89]. At some hospitals, fees are rising rapidly[90].

Of the many consequences flowing from these practices, we note that imposing parking charges may shift journeys away from informal arrangements to staffed or formal volunteering schemes where charges can be reclaimed.

Car insurance

Staff have proper concerns that practical matters of liability and insurance be covered in respect of road journeys, just as with a range of other activities. This short section thus addresses the question of vehicle insurance and considers how it might affect the offer or acceptance of a lift.

In setting the scene, it may be noted that many, but not all insurance companies have signed a common undertaking not to charge higher rates for customers who help charities, voluntary organisations, clubs and societies by becoming a volunteer driver[91]. So it is not a given that insurance companies will be unhelpful.

Challenge #7

Does anyone have an example of a person who is supported by health or social care services putting a neighbour or friend on their car insurance?

A disabled person who has an adapted vehicle but does not drive it themselves will add the name of their driver on to the insurance. This is straightforward when the driver is a staff member or a vetted and approved volunteer. But there is no reason why they should not submit the name of a friend or neighbour as an additional driver, and it is hard to see how health or social care staff could legitimately gatekeep that arrangement if it is what the disabled person wants, they have mental capacity to make that decision and the friend is willing.

Paying for the journey

A lift-sharing passenger may contribute towards the cost of a journey, as long as the amount is no higher than the HMRC rates[92] so that the driver does not make a profit from the trip. Otherwise, the arrangement falls into Public Service Vehicle licensing regulations and may also fall foul of insurance rules. Where ride sharing is a free or low-cost affair, then passengers are sometimes expected to thank the driver and perhaps offer a small gift such as flowers or a cup of coffee to show their appreciation.

Direct payments have been offered by local authorities as an alternative to the direct provision of some care services since 1997[93]. From 2012, a few 'trailblazer' Councils[94] were permitted to offer Direct Payments to care home residents, either as full payments, covering the cost of residential care and any other eligible need, or part payments made to fund additional activities or services, with the cost of residential care being covered separately. The most recent declaration from Government has been that all English Councils will be able to offer Direct Payments to people living in care homes from 2020[95]. Evaluation of the trailblazer sites showed that these payments were sometimes used to fund community access and activities[96], which might, we suppose, include transport.

A pertinent aspect of these arrangements occurred where the resident used the Direct Payment to employ their own support worker, perhaps on a part-time basis, to assist them in undertaking a community activity. It is interesting to note that the researchers found that some care home staff were worried about these arrangements, believing that they had both power and responsibility to vet such appointments and that the regulatory body would hold them liable for anything that went wrong. This is a clear example of over-reaching their role which may have parallels with the approach of some care homes who feel obliged to vet friends, acquaintances and volunteers before such persons can be 'permitted' to engage with the resident for whom they feel so responsible.

Employer's rules

Employers and organisations that engage volunteers have responsibility for them under the Health and Safety at Work Act 1974. As a result, they usually issue instructions to their staff regarding the use of their own car during work hours. They may refuse the employee permission to use their car at all during work hours, or to carry passengers or transport goods. If they give the employee permission to use their car for work purposes, they will insist on seeing evidence that the driver has insurance cover for business use and the vehicle is taxed and is in a roadworthy condition as shown by an MoT certificate where required. The driver will be expected to keep the vehicle well maintained and to only drive when they able to do so safely. The employer may expect to be notified of any driving offences.

It has been noted that volunteer drivers are often older persons and the UK Driver and Vehicle Licensing Agency does not require additional age-related tests of eyesight or health for older drivers.

Risk assessment and safeguarding

Perhaps the biggest risk is that people will be denied their human rights by a health and social care system that illegally restricts the opportunities available to the people they claim to support. Ordinary citizens conduct their own informal risk assessment before getting into someone else's car and generally do so without the aid of DBS checks or written assessment documents.

People using health and social care services are often supported by a staff member, who may be obliged to carry out a formal risk assessment. Other commentators have criticised the residential care sector for promoting safety by denying opportunity and these voices have called for the adoption of positive risk-taking in place of defensive practice[97]. But before a risk assessment can be carried out, there is a need for a good understanding of what constitutes a life worth living. In a recent systematic review[98] of the evidence, Hilary Graham and colleagues found that older people highly value the opportunity to get out, to relieve the tedium of spending all day and all night in the same building. Indeed, they valued the journey itself for the pleasure and stimulus of a change of scenery and for the social contact afforded to travellers on the journey. Getting out is quite as important as getting there.

There is a widespread assumption that public transport, taxi companies and community transport providers are safe, partly through the local authority's licensing system. Examples of health and social care staff promoting informal car sharing are rare and hard to find.

A particular worry for some people is that informal lift-sharing might lead to abuse, and particularly financial abuse if the disabled passenger contributes to journey costs or the disabled driver takes a diversion for the benefit of a member of the public. Services need to separate out ordinary kindness from abuse and promote the former whilst tackling the latter. This ordinary kindness is illustrated by the following example:

> *My friend is long-term unemployed and does not run a car, but rather systematically receives free lifts to church events. Several times a week, most weeks, she is receiving a lift from one member of the community or another. This is not abuse or exploitation, but rather ordinary social cohesion in an intergenerational, diverse community where people help one another at different stages in the lifecourse*.

Challenge #8

Do any organisations use a risk assessment protocol that includes travel arrangements where members of the public could be involved? This would need to be a risk management approach that contemplated the possibility of informal lift-sharing rather than just prohibiting it.

In assessing risk and generating a safety plan, generalised and specific risks must be managed in a proportionate way. During an outing, for example, there is a risk of being knocked down by a drunk driver and there is the risk of meeting an abusive ex-partner. Ordinary citizens would adopt road safety habits[99] for the former and perhaps time their outing to avoid the latter. Neither risk would be used to make a case for never going out. Risks should be considered, but then positively managed so that the person's rights are upheld – the right to privacy; to a life beyond the service; to a life in the community free of surveillance.

Disclosure and Barring

Changes in the UK regulations for checking criminal offences were made in 2012 that reduced the proportion of the adult population covered by these rules from 17% to 10%. The Safeguarding Vulnerable Groups Act 2006 defines regulated activity in respect of vulnerable adults in Schedule 4, part 2[100] and this is further clarified by advice issued by the Disclosure and Barring Service (DBS)[101, 102]. The DBS sets out where an 'Enhanced DBS with an adults' barred list' check is required. This guidance has a bearing on informal lift-sharing.

	DBS rules	A guess at the underpinning principle	Consider the following
1	Concern any adult who is in receipt of social care work. However, members of peer support groups, even if the group is directed or supervised by a healthcare professional, are not in regulated activity[103].	Focus on **social care interventions** not social care money**.** Some people who receive health or social care are particularly at risk and so fall within the scope of these rules, if the activity meets the additional conditions below.	Being aware of an activity, including it in a Care Plan and even supervising it does not necessarily make it a regulated activity, as only health or social care interventions are included.
2	Assisting, providing, training, prompting or supervising personal care - eating, drinking, toileting, washing, bathing, dressing, oral care or the care of skin, hair or nails.	**Essential personal care** delivered to a person who receives health or social care services is a regulated activity. This must be a substantial part of the person's role[104], and the scope of the regulation is confined solely to the place where the person is living[105].	A visiting manicurist who offers optional sessions in a day centre is not undertaking regulated activity[106]. Nor is a volunteer who prepares and serves a meal to the person in their own home, unless they assist the person to eat it[107].
3	Assisting an adult with managing money, paying bills and shopping or with their affairs if they lack capacity	Checks are needed to protect the person against **financial abuse.** Helping someone plan their shopping is not undertaking regulated activity[108].	Relatives who take on a Power of Attorney do not need a DBS check, as they are trusted by the person to act responsibly.
4	Health and social care appointments[109]. Trips for pleasure are excluded from regulation[110].	**Places** known to provide health or social care services are expected to be safe.	Offices and community centres may be funded by health or social care but visiting them is not regulated activity[111].
5	As above	**Supervised intervention.** The health or social care appointment must be for the purpose of assessment or actively promoting independence, rather than as a leisure activity.	An artist running an art group in a day centre would be an unregulated social activity, while a specialist session run or supervised by an art therapist would be a healthcare intervention and so a regulated activity.
6	Conveying adults to, from or between health care, personal care and/or social work services who can't convey themselves because of their age, illness or disability.	**Journeys to hospital.** People are considered vulnerable when receiving health or social care interventions and this is here extended to the journeys to and from such appointments. Regulation does not cover a friend or neighbour providing transport to hospital[112].	Attending an activity that is part of the social prescribing scheme is not a health or social care intervention[113], unless it takes place in a social care or healthcare building and is directed or supervised by a healthcare professional.

	DBS rules	A guess at the underpinning principle	Consider the following
7	Conveying adults in a specialised vehicle for the purposes of health treatment.	The **vehicle** is specially designed for the provision of treatment	Vehicles that provide everyday transport are exempt from regulation by the CQC[114].
8	Conveying adults on behalf of an organisation, as 'personal, non-commercial relationships' are excluded[115] .	A **driver** acting on behalf of an organisation is in a position of trust has substantial power over their passengers – to choose where to take them, to compromise traffic safety and to be in private.	Bus drivers do not need an enhanced DBS check[116]. Friends do not need DBS unless they are driving the person on behalf of a group[117].
9	Conveying adults, even if they are accompanied by someone caring for them.	**Escort**. Could this mean that 'someone caring for them' means a relative (who may be equally vulnerable) rather than a health or social care worker?	Volunteers do not need an enhanced check if they are under the day to day supervision of a person who is checked. Volunteer escorts are not closely supervised.
10	The regulated activity is happening on more than 3 days in any period of 30 days or at least once a week on an ongoing basis.	**Frequency**. Activities that, if done very frequently, would require regulation are also included if they are infrequent but occur often enough to increase concerns about safety.	The requirement for low frequency contact may reduce risk but it also inhibits positive social connections.

This table suggests the following conclusions. Informal lift-sharing is not a social care intervention by a social care worker, so is not regulated. It is not essential personal care, so is not regulated. It does not involve handling finances, so is not regulated. It is not a trip to hospital or a social care appointment, so is not regulated. It is outside the place where the person lives, so it is not regulated. It is not a trip to hospital in an ambulance, so it is not regulated. It is based on informal friendship rather than receiving a service from a formal group or organisation, so it is not regulated.

On closer inspection, the rules make a distinction between regulated activities in which the employer is legally required to seek a DBS check, activities for which the employer is eligible to seek a DBS check and those for which it is an offence to seek a check[118]. There are some situations where employers have discretion and bear responsibility for seeking advice, making their own risk assessment and perhaps deciding (i) whether a particular activity requires a DBS check; and (ii) whether to engage a person whose DBS check identifies offences.

Challenge #9

Has anyone tried to obtain more clarity about the boundary between regulated activities and informal community participation so that care recipients can easily engage in an informal life beyond the service?

The rules regulate activities undertaken by employees and volunteers but do not regulate ordinary citizens engaged in informal contact with others in the community[119]. There is anecdotal evidence

that staff working in care services may not be well informed about how DBS regulations actually work[120].

Furthermore, Section 59 of the Safeguarding Vulnerable Groups Act 2006[121] specifically asserts that a person is vulnerable '*in the context of the setting in which they are situated or the service they receive'*, which shows that the term must not be used globally, but is context-specific, like the notion of mental capacity. Just because they are designated as a vulnerable adult in one place, and therefore the people who support them are engaging in regulated activities, that does not mean that they are necessarily vulnerable or subject to regulation in other parts of their life. The person's informal life should not be automatically placed under the aegis of the service and subject to the stringent regulations associated with regulated activities. Rather, the person has a human right to a private life in the community, free of restraint.

For example, imagine a resident in a supported living setting wants to attend church each week and is capable of riding on the public bus, but needs a care worker to accompany them to do so. The worker should use public transport to promote independence, and participation in the church community promotes social inclusion. The person can pay for their own bus ticket without triggering concerns about financial abuse and they do not need personal care on the journey or at the church. Bus drivers do not routinely have an enhanced DBS check[122] but are conveying the person and their support worker and may do so more than three times in 30 days. A rigid reading of the DBS rules might prohibit this perfectly reasonable activity, but this is surely not the intention. Stopping good lift-sharing is not a very effective way of stopping bad lift-sharing.

Challenge #10

Has anyone converted the various scenarios described in official documents explaining DBS checks into a questionnaire with which to find out if frontline health and social care staff know the difference between regulated and unregulated activities? This would test the hypothesis that folklore beliefs about DBS checking are creating unduly restrictive conditions for care home residents.

Volunteer drivers

The world of volunteering makes a distinction between formal and informal volunteering. In theory, this is a simple way of distinguishing the two types, as signing up as a volunteer driver, receiving your badge and going on duty to carry a patient to the hospital in a journey that has been pre-booked through the Red Cross is clearly formal volunteering, while informal volunteering might be spotting your neighbour walking back from the shop with a heavy bag and stopping to give them a lift.

Formally recognised volunteers working with a constituted organisation are likely to be subject to similar restrictions as are applied to paid staff. They will be expected to produce evidence of a valid, current Driving Licence, a current Comprehensive Insurance Certificate and where necessary, an MOT.

Local Area Coordination

Local Area Coordinators working in the UK are often employed by the Council's adult social care service, partly with the aim of linking people with their local community using asset-based approaches[123]. As they are intentionally working to link the formal social care service with the

informal community, their work is directly relevant to our theme. One Coordinator called Richard described introducing Andy to Sue. They became natural friends, and Andy gave Sue a lift in his own car on several occasions. At the same time, Richard notes that his own practice whilst at work is to rarely offer a lone person a lift. Several observations arise from this scenario, as set out in the following paragraphs.

Where would Sue be safest from a physical perspective? We might say that she would be safer riding with Richard because he is DBS checked and his activities are supervised, while Andy is unknown and unmonitored, although most citizens are recognised as safe. In contrast, she is vulnerable if Richard abuses the trust associated with his position, which could be said of any paid worker who engages in one-to-one interactions. Risk must be assessed as a combination of severity and likelihood, so Richard might be the safer prospect, although in both cases, the risk is small.

Where would Sue be safest from an emotional perspective? Car journeys can be intimate spaces, where the combination of proximity, privacy and lack of eye contact create a unique opportunity for talking and disclosure, as anyone with teenage children will admit. Sue may find that a shared car journey creates a space for sharing confidences that leads to a feeling of closeness. Such feelings may be welcomed by Andy but would be inappropriate in the working relationship with Richard.

Where would Sue be clearest about her working relationship with Richard? By ensuring there is always a chaperone, he reduces the risk of Sue misunderstanding the nature of the relationship between them. Very often Local Area Coordinators meet people at their most vulnerable, and a kindness or offer of help could easily be misconstrued.

Where would Sue be most independent? From the outset, the Local Area Coordinator avoids any activity that could lead to dependency, preferring instead to arrange circumstances that lead to empowerment, independence from the worker and mutual interdependence with other citizens in the community. While an occasional lift from the Coordinator may introduce someone to a new activity, it must not become an expected service. Moreover, if the person has the means and capability to use public transport or other independent travel arrangements, this will be favoured over travel arrangements that involve staff.

Where would Richard be safest? It is rare that confusion, distress, misunderstanding or malpractice lead to malicious or misguided allegation against a worker, but Richard will protect himself against this hazard by ensuring others provide lifts or a chaperone is present.

Like many other Local Area Coordinators, Richard does not necessarily take on the full responsibility for how connections will develop in the future once he has introduced people to one another. This is a distinctive approach in several ways, of which the following are perhaps the most significant for our discussion. First, each Local Area Coordinator spends a great deal of time getting to know the person, their story, family, friends and immediate community, and so becoming well placed to consider whether potential introductions will be a good fit. We might hope that staff working in residential care settings know the residents well too.

Second, Local Area Coordinators work alongside people for extended periods of time, often dipping in and out of their lives as required, which means that there are no time limits on the working relationship that people enjoy, unlike the ‘refer, assess, intervene, discharge’ approach taken by many health and social care services. This provides a continuing connection with the people concerned and so enables any safeguarding or other concerns to be addressed as they arise. Third, while Local Area Coordinators honour confidences shared with them, they often hear news of other people in their community which they can then follow up where necessary. These three elements enable Richard to meet his duty of care by conducting a well-informed risk assessment and agreeing a safety plan with the person regarding the proposed introduction between the person and a member of the general public.

This approach, which has some similarities to community work and community development[124], stands in stark contrast to the approach taken in lots of care homes where there seems to be an assumption that, if staff facilitate an introduction between someone for whom they have a duty of care and another citizen, they are forever liable for the long-term consequences of that introduction. The care home worker may fear that if anything should go wrong at any point in the future, they themselves, the staff member who made the introduction, will be blamed. This fear is not soundly based and has the effect of denying the resident their human rights.

Timebanks

Timebanks form a second example that inform our discussion and provide some useful pointers to the way forward. Timebank members are regarded as engaging in informal arrangements between citizens rather than regulated activities and therefore are not subject to DBS checks[125]. Furthermore, the Disclosure and Barring Service has asserted that brokers can facilitate these arrangements without their activities leading to the activity being redefined. Depending on their role, Timebank Brokers themselves may need a DBS check and Timebanks UK can manage the application process.

Challenge #11

Timebanks do not need a DBS check, so how do they manage risk when children or vulnerable adults are involved?

The example of Timebanks may help with those lifts that are privately arranged by individual citizens among themselves without being centrally coordinated by the organisation where people meet. Someone can, for example, attend a church service, meet other parishioners there and negotiate their own lift in a private conversation at the back of the church, without this being seen as a formal arrangement that is the responsibility of the church. This is the decision of the Disclosure and Barring Service as we have seen and it extends to permit the Timebank Broker to facilitate such an informal arrangement between citizens, so in our parallel example, the vicar can make an announcement that people offering and needing lifts should congregate at the door - and even pair up drivers and passengers without this becoming a formal situation in which the church is regarded as providing a transport service. It is worth noting that this is a decision of the Disclosure and Barring Service, so insurance companies, local authorities or other gatekeepers might respond differently, but it provides a reference point.

Key people

Good neighbours

We have yet to secure an example of a person using health or social care services being supported to take up the offer of a lift from a friend, relative or neighbour, although these practices are surely commonplace. Once located, we need to find out what checks are undertaken, if any, and compare this with the informal arrangements that ordinary citizens make among themselves.

Care planning

Do people living in a care home have a life beyond the service? In order to gain some perspective on the potential for informal lift-sharing, we need to revisit the practice of care planning and particularly consider its edges. The person-centred planning movement over the past twenty years has encouraged us to investigate the person's whole life, while here, we will search out the aspects that close the door to workers. The care plan is not global and there are aspects of the person's life that are properly beyond the scrutiny of the care team.

When I am creating my own life plan, I may wish to include a wide range of aspects of my life that are relevant to me, but I will also have a category for private matters that are none of anyone else's business, or that are shared with chosen confidantes and definitely not shared with staff. My human rights include the right to a life free from surveillance, so staff nosiness and arbitrary interference in my life is outlawed.

Workers must respect my right to privacy and so their intervention plan (what an individual worker or team will do) and their coordination plan (how different workers or teams will cooperate with one another to maximise their positive impact in my life) will be smaller than my life plan, and will explicitly recognise that there are some areas of my life that are none of their business.

Workers can collect data about me if it can be shown to deliver health gain, protect me from abuse or prevent terrorism. Beyond this, workers have no right to collect, store or process this personal information. The decision to collect and use data must be person-centred and context-specific and cannot be a blanket rule that applies to all. Introducing video surveillance into all care home bedrooms in one place in response to the prosecution of a care worker in another place fails this person-centred test and so is a breach of the right to privacy. Putting a video camera in my bedroom because I have been victimised before could be an acceptable and proportionate response.

It is acceptable to collect, record, use and store data if it can be shown to deliver health gain. We can interpret 'health' widely and so in social care we might interpret that as (i) promoting independence; (ii) encouraging contribution; and (iii) supporting an inclusive life, but these things must be endorsed as explicit parts of a care plan. If the information staff glean from me is not directly relevant to delivering the care plan and promoting my 'health', then staff have no business recording or reporting it. Rather, it is part of my private life.

Similarly, a good assessment tool helps the worker select relevant issues that relate to their task and avoid impertinent intrusions into my life. When I go to see my dentist, for example, she asks me if I clean my teeth, but must not ask whether I clean my house.

Record keeping

Before concluding our reflections on care planning, we need to pause and reflect on the detective work that is sometimes part of an assessment. Frontline staff often collect snippets of information and record them so that a more qualified professional can search out patterns and formulate explanations for the person's behaviour. In this situation, any future intervention is wasted if this information is not collected and shared - and legislation in 2015 has placed a legal duty on health and adult social care staff to share information when it will facilitate care for an individual[126]. Of course, one of the reasons for sharing information with other team members is that some explanations do not arise until observations from several perspectives are combined. But there is still a need to show that the specific surveillance and data collection is a legitimate and proportionate response to delivering the care plan, and that it is the least restrictive option.

It is also acceptable to collect, record, use and store data if it can be shown to protect me from abuse. Staff may have a role in the background, rather like parents with children when friends visit.

They may be listening out for sounds of a quarrel or the creaking of a bed, but they do not insist on sitting in the same room throughout the visit. They do not chaperone their child on every outing but may confirm that she is home at the appointed time. The risk of abuse is managed in a flexible way, constantly balanced against the right to privacy, and adjusted in the light of prior experience and the unique characteristics of the individual. So with adults in care settings – residents have the right to a private life beyond the service.

The role of care staff and the impact of services

Some people receiving health and social care services are so isolated that they have no friends beyond the service. Everyone they know is either a staff member, another person using the service or a close relative. This level of isolation means that it is hard to conceive of the person building new social connections that eventually become robust enough for informal lift sharing to begin. Perhaps staff should work on overcoming this intense segregation and isolation by facilitating introductions, inviting members of the public into the care setting, building alliances with community groups and linking residents with their neighbours who lived close by the care home.

Others are isolated because their support needs make community participation difficult. Their wheelchair does not fit on the bus or in an ordinary car, they need a Changing Places toilet but none are available locally, they need specialist help when eating a meal and they do not use words to communicate, impairing ordinary exchanges with other citizens. It is hard to see their potential contribution to the wider community. Perhaps staff should develop the potential for the person to offer a lift to someone else, try it out and see if the person seems content with this.

Perhaps the most significant barrier of all is the staff who are so preoccupied with their own work that it is too big a stretch for them to think about the person's life beyond the service, and so they assume that the question means no more than 'should I offer an informal lift to my clients?' But the challenge that lies at the heart of this paper concerns informal lift sharing between the person using health or social care services and a member of the general public. Perhaps staff should seek ways to support the person to build relationships in the community rather than merely surviving in service-land.

Conclusion

This review has suggested that informal lift-sharing has many benefits as it enables access to community, promotes independence, supports friendship and community participation, facilitates contribution and enhances choice. Despite these obvious benefits, a range of factors mean that informal lift-sharing is rarely enjoyed by care home residents – misunderstanding of the law and the regulatory framework, a lack of practical solutions and risk management systems, and defensive attitudes, such as over-protection and a reluctance to engage in positive risk-taking. If the right approach was taken by managers and care staff, transport providers and community groups, there is no reason why care home residents should not enjoy informal lift-sharing with neighbours, friends in the local community.

Austerity politics have a stranglehold on health and social care services and so care homes are staffed to a level where they can keep the body alive, but there is barely enough time left to nurture

the soul. Staff have few opportunities for conversations with residents, high vacancy rates and agency staffing levels disrupt long term relationship building. Getting out of the building is rare. This makes informal lift-sharing with friends and relatives the only way that many residents will get out, the only way they will exercise their human right to a life in the community and the only way that they will be able to contribute to wider society. Responsible, rather than reckless solutions to the problems of informal lift-sharing must be found that promote contribution rather than confinement.

What is the status of this paper?

Most of the documents we read are finished pieces of work, carefully crafted and edited in private before being shared with anyone else. This is a different kind of paper – it was shared online here from the first day, when the initial handful of ideas were incomplete, poorly phrased and tactless. The work has been edited many times, and on each occasion a revised version has replaced the earlier material online. This process is still under way, and so this paper may still be lacking crucial concepts, evidence, structure and grammar[127]. As readers continue to provide feedback[128], further insights will be used to update it, so please contact peter.bates@ndti.org.uk with your contributions[129].

It is one of a suite of documents that try to open up debate about how to empower disabled people and share decision-making in health and social care services – in research, implementation and evaluation.

This way of writing is risky, as it opens opportunities to those who may misunderstand, mistake the stopping points on the journey for the destination, and misuse or distort the material. This way of writing requires courage, as an early version can damage the reputation of the author or any of its contributors. At least, it can harm those who insist on showing only their 'best side' to the camera, who want others to believe that their insights appear fully formed, complete and beautiful in their simplicity. It can harm those who are gagged by their employer or the workplace culture, silenced lest they say something in a discussion that is not the agreed party line. It can harm those who want to profit from their writing, either financially or by having their material accepted by academic journals.

In contrast, this way of writing can engage people who are not invited to a meeting or asked for their view until the power holders have agreed on the 'right message'. It can draw in unexpected perspectives, stimulate debate and crowdsource wisdom. It can provide free, leading edge resources.

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[1] Washington DC has had 3+ lanes since the 1970s and these quickly created informal carsharing arrangements similar to hitchhiking as would-be passengers wait at specific locations and drivers stop to pick them up, thus becoming eligible to use the HOV lane. At December 2018 there were over 20,000 members of the online forum Slug Lines, that serves this informal community. See http://www.slug-lines.com/Index.htm.

[2] See Mobility as a Service (known as MaaS) or Demand Responsive Transport in which online booking systems merge different forms of transport to provide a seamless journey https://en.wikipedia.org/wiki/Mobility_as_a_service.

[3] The response of the Community Transport Association in Scotland to 'A Connected Scotland: Tackling social isolation and loneliness and building stronger social connections' (April 2018).

Available at https://ctauk.org/wp-content/uploads/2018/11/A-Connected-Scotland-CTAs-Response.pdf.

[4] There is a strong link between mobility and getting out and about on the one hand, and feelings of wellbeing on the other. See Ziegler F & Schwanen T (2011) I like to go out to be energised by different people': An exploratory analysis of mobility and wellbeing in later life Ageing and Society 31(05):758 – 781. DOI: 10.1017/S0144686X10000498.

[5] Some readers may prefer the term people with disabilities here, but this paper is all about the ways in which people are shut out of ordinary social interactions and disabled by a care system that denies them opportunities.

[6] KeyRing described a situation where a disabled driver that they support kindly offers a lift to a disabled passenger who also is supported by KeyRing. However, the focus of this paper is on lift-sharing between a person using health or social care services and a member of the general public.

[7] See https://letgrow.org/ and http://www.freerangekids.com/.

[8] https://www.deseretnews.com/article/900013224/utah-governor-signs-law-legalizing-free-range-parenting.html.

[9] See https://www.ons.gov.uk/peoplepopulationandcommunity/personalandhouseholdfinances/expenditure/datasets/percentageofhouseholdswithcarsbyincomegrouptenureandhouseholdcompositionuktablea47. The national.travelsurvey@dft.gov.uk has data that may yield information about informal lift-sharing, but it would take 'a significant amount of work to produce new analysis' on this and would require a licence to do so (personal correspondence 26/11/2018). See their statistics at https://www.gov.uk/government/collections/national-travel-survey-statistics also http://discover.ukdataservice.ac.uk/catalogue/?sn=5340 also http://doc.ukdataservice.ac.uk/doc/5340/mrdoc/pdf/5340_nts_user_guidance_1995-2016.pdf also https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/632910/nts-technical-report-2016.pdf also https://www.gov.uk/government/organisations/department-for-transport/about/statistics. The following report asserts that there is little robust evidence on lift-sharing, even for formal arrangements, such as Uber or BlaBlaCar, and less on informal lift-sharing - https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/673176/young-peoples-travel-whats-changed.pdf.

[10] https://www.gov.uk/government/news/more-service-stations-to-become-fully-accessible-as-government-fund-opens

[11] All these data are cited by Meurer J et al (2014) *Social Dependency and Mobile Autonomy – Supporting Older Adults' Mobility with Ridesharing ICT.* Available at http://www.wineme.uni-siegen.de/paper/2014/p1923-meurer.pdf.

[12] People with disabilities aged 65+ are more likely to use lifts from friends and family, and to use taxis; 36% of people without disabilities in this age group use lifts from friends or family, compared with 54% of people with disabilities. See page 7 at https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/647703/disabled-peoples-travel-behaviour-and-attitudes-to-travel.pdf

[13] Coughlin, J.F. (2001) Technology and the Future of Aging *Journal of Rehabilitation Research and Development* 38, 1.

[14] The other options were 'Yes, definitely' (8%), 'Probably' (25%) and 'Probably not' (25%), No never (305 = 41%). Data was collected by the author from health and social care staff met in the course of

work between 2010 and 2014. See Bates P, Lymbery M & Emerson E, (2013),"Exploring boundary attitude", *The Journal of Adult Protection*, Vol. 15 Iss: 1 pp. 26–36. DOI: http://dx.doi.org/10.1108/14668201311299890.

[15] Cooper C, Marston L, Barber J, Livingston D, Rapaport P, Higgs P, et al. (2018) Do care homes deliver person-centred care? A cross- sectional survey of staff-reported abusive and positive behaviours towards residents from the MARQUE (Managing Agitation and Raising Quality of Life) English national care home survey. PLoS ONE 13(3): e0193399. https://doi.org/10.1371/journal.pone.0193399.

[16] See https://www.theguardian.com/society/2019/mar/11/over-400-care-home-operators-collapse-in-five-years-as-cuts-take-toll.

[17] CQC maintains a register of care homes in England and the author accessed this at https://www.cqc.org.uk/search/site/spreadsheet%20of%20care%20homes?sort=default&distance=15&mode=html&f%5B0%5D=ds_created%3A%5B2019-01-01T00%3A00%3A00Z%20TO%202020-01-01T00%3A00%3A00Z%5D&f%5B1%5D=im_field_registration_status%3A6585&f%5B2%5D=bundle%3Aprovider on 1 March 2019, selected the year '2019' and 'providers of registered care homes' and downloaded the database as an Excel file. Using the column headed 'Specialisms/Services', he deleted all services that did not include accommodation for persons who require nursing or personal care. The result was a dataset of 1405 providers. The database gave the website address of each provider, so some of these were checked. Sites were selected to meet the following criteria: (i) the link given by CQC worked (a surprisingly large proportion of links were broken); (ii) the site indicated that the provider ran at least one registered care home; (iii) the provider was not a local authority; (iv) an email address was readily visible on the website. Online forms were not used, as this would have entailed more work and provide no record of the message having been sent. (v) Where websites gave a separate email address for each home that they managed, the first was chosen. The list was frequently re-sorted during the process, and providers were selected quite at random, sometimes by jumping to a different part of the spreadsheet to give some variety. For each email address identified, a copy of the standard email message below was sent to the provider. Duplicates were removed and any undelivered emails were replaced by another provider from the list. This continued until 8 March when a total of 500 email messages had been sent (35% of the total number of eligible providers). A further 497 websites had been checked and excluded. The email message that was sent to the provider read as follows: *Hello. If care home residents go out at all, they are usually escorted by a member of staff – either a care home staff member or a worker from another part of the Health and Social Care system. This might be a nurse, a paramedic, a social worker or an advocate. Then there are occasions when a resident might get a trip out with someone else. This might happen in various ways: (i) Residents might go out with a Registered Volunteer, such as the driver of a Community Transport or hospital car service, or a volunteer who is registered with a Befriending Team. (ii) Residents might go out with a relative who has come to visit them; (iii) Residents might take informal trips out with a member of the public, such as when a resident has been attending church for many years, and another parishioner picks them up and gives them a lift to the morning service and home again. In this example, the parishioner is not engaged as a formal driver by the church, but is simply acting as a longstanding friend, fellow worshipper and good neighbour. The arrangement is entirely informal. We all need informal friends in our lives as well as paid officials, so it would be worrying if care home residents are missing out on option 3 above. However, it seems really difficult to find examples. Is anyone in your care home enjoying outings with an informal friend who is just a member of the public? I'd love to hear from you on this if you could spare a moment.* Notice that this email message simply asks about outings, so a walk would count, rather than narrowing the search by asking specifically about lift-sharing. By 9 March, only 2 homes had responded.

[18] Nutley, SD (1990) *Unconventional and community transport in the United Kingdom.* See https://books.google.co.uk/books?id=k5rrC4nYek8C&pg=PA273&lpg=PA273&dq=informal+lift+giving&source=bl&ots=q8KBWXgdkS&sig=tRKhFYVAUp6pYHBK1hfpH17BdNU&hl=en&sa=X&ved=2ahUKEwi7lJPfkN_eAhXLAMAKHXa_C0cQ6AEwCnoECAEQAQ#v=onepage&q=informal%20lift%20giving&f=false

[19] See https://www.tandfonline.com/doi/abs/10.1080/09669582.2017.1401633.

[20] See https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/quality-networks/secure-forensic/forensic-standards-qnfmhs/qnfmhs-standards-for-forensic-mental-health-services-2nd-edition-2017.pdf?sfvrsn=3b7e16ba_2 standards 84 and 103.

[21] See https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-19-living-independently-and-being-included-in-the-community.html.

[22] United Nations (adopted 27 Oct 2017) Committee on the Rights of Persons with Disabilities *General comment No. 5 (2017) on living independently and being included in the community*. Available at https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GC/5&Lang=en

[23] See https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/300293/JRA_DoH_Guidance_on_RP_web_accessible.pdf.

[24] More people have a driving licence and access to a car, but fewer trips are being taken and young people are less likely to drive than they were in previous decades (more urban living, more concern about the environment, costlier lessons and insurance, harder driving test). https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/729521/national-travel-survey-2017.pdf.

[25] A consistent finding in Graham et al's evidence synthesis was reluctance to rely on family and friends and a preference for alternative forms of transport that supported independence. See See Graham HM, De Bell S, Flemming KA, Sowden AJ, White PCL & Wright K (2018) Older people's experiences of everyday travel in the urban environment: a thematic synthesis of qualitative studies in the UK *Ageing & Society*. DOI: 10.1017/S0144686X18001381.

[26] Musselwhite shows how travel meets primary needs (such as travel to work or to medical appointments), secondary needs (social and emotional activities) and tertiary (aesthetic needs, such as visiting a garden or walking amongst beautiful architecture. Some non-essential journeys are dubbed 'discretionary travel'. See Musselwhite C (2017) Exploring the importance of discretionary mobility in later life *Working with Older People,* Vol. 21 Issue: 1, pp.49-58, https://doi.org/10.1108/WWOP-12-2016-0038.

[27] Michael O'Regan, "Alternative Mobility Cultures and the Resurgence of Hitchhiking," in Fullagar S (ed) (2012) *Slow Tourism: Experiences and Mobilities* Bristol, UK: Channel View Publications, p134.

[28] Parkhurst, G., Galvin, K., Musselwhite, C., Phillips, J., Shergold, I., Todres L. (2014). Beyond transport: understanding the role of mobilities in connecting rural elders in civic society. Chapter 5 in Hennesey, C., Means, R., Burholt, V., (Eds). *Countryside Connections: Older people, Community and Place in Rural Britain.* Policy Press, Bristol, 125-157.

[29] Agich GJ 'Respecting the autonomy of old people living in nursing homes' Chapter 10 in Morrison EE (ed) (2009) *Health Care Ethics: Critical issues for the 21st century* 2nd edition. Sudbury, Massachusetts: Jones & Bartlett Publishers.

[30] Cathy Brewin is an occupational therapist who started an NIHR Clinical Doctoral Fellowship in April 2018 with the goal of developing an assessment tool that could help OTs in their task of protecting the liberty of people with dementia under the emerging LPS arrangements.

[31] A count of the number of individuals with granted DoLS applications in 2017-18 found 83,070 living in residential social care in England (see https://digital.nhs.uk/data-and-information/find-data-and-publications/supplementary-information/2019-supplementary-information-files/individuals-with-granted-dols-applications-by-cqc-location-category). There are 457,515 beds in residential social care homes in England (at January 2019, see https://www.cqc.org.uk/sites/default/files/2%20January%202019%20Latest%20ratings.xlsx) so, assuming that all the beds are occupied, this gives a ratio of 18% of residents who are subject to DoLS. An alternative estimate suggests that there are 415,000 people in care homes in the UK (ONS. Changes in the older resident care home population between 2001 and 2011. In: Statistics OfN, editor. 2014) and England forms around 88% of the UK population, which increases the percentage of residents who are subject to DoLS to nearly 23%. Hence the estimate given in the body of the paper of around 20%. Ratios will be different in other categories of care, change over time and averages will mask local variations.

[32] As of 31 March 2018, there was a backlog of 125,630 uncompleted DoLS applications – see https://www.communitycare.co.uk/2019/01/11/government-issues-deprivation-liberty-definition-bid-provide-clarity-practitioners/.

[33] See Department of Health (2014) *Positive and Proactive Care: reducing the need for restrictive interventions* – available at https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/300293/JRA_DoH_Guidance_on_RP_web_accessible.pdf.

[34] Some DoLS are authorised to oversee a care plan comprised of 'continuous supervision and control' which are made up of some supervision provided by staff and the rest provided by relatives or others. There is no formal advice that specifies the identity of the supervisor.

[35] See https://www.lawsociety.org.uk/Support-services/documents/Deprivation-of-liberty---chapter-3---cheshire-west/.

[36] Stanev v Bulgaria.

[37] See http://library.college.police.uk/docs/APPREF/Protecting-Vulnerable-Missing-Adults-Framework-FINAL.pdf.

[38] One contributor to this paper indicated that they believed that some care homes treat all DoLS authorisations as meaning that the person may not go out of the care home unless staff accompany the person on this outing, and even outings with relatives are prohibited. This is not lawful.

[39] See https://www.scie.org.uk/mca/dols/practice/care-home . The same point was made in P (Scope of Schedule A1) (30 June 2010) (Unreported) (Mostyn J) - 'it was understandably in P's interests that he should have access to society in the community and 'escape' the confines of the care home.' See page 107 of the Law Society *Deprivation of Liberty: A practical Guide.* Available at https://www.lawsociety.org.uk/support-services/advice/articles/deprivation-of-liberty/

[40] See https://www.39essex.com/cop_cases/sr-v-a-local-authority/.

[41] It is interesting to note that altruism did not appear in the analysis of research papers conducted by Graham and team. See Graham et al (2018) op cit.

[42] Bert Greeves built the first Invacar in 1948 for his cousin, adapting a motorcycle and using a lawnmower engine. They ran the business together until 1976 and Greeves received an MBE for his services to disabled people. The fastest model could do a maximum speed of 82mph. Simon

McKeown, Director of the Invalid Carriage Register, (www.invalidcarriageregister.org) explained that these early carriages were one seater and it wasn't legal to carry passengers, although some people did, hidden from view, but this carried serious risks and loss of the vehicle etc. (personal correspondence 28 Nov 2018).

[43] My friend Rob sometimes drove his Invacar with two of his sons sitting on the floor by his feet, who were instructed to duck down if he shouted 'Police!' The extra ballast helped to stabilise the invacar on icy roads, reinforcing the metaphor that travelling with others is better than driving alone.

[44] Motability confirm that, '*If our customer wishes to offer lifts to friends and family, we would be more than happy for them to do so, and this would not be a breach of any terms and conditions. The only time we would be concerned would be if a nominated driver offers to give their own friends and family a lift in the Motability car, as our Customer would not be benefiting from these journeys.*' (personal correspondence 21 December 2018).

[45] Pat Higgins was moved off Disability Living Allowance on to a Personal Independence Payment and lost her entitlement to her motability car. See https://www.mirror.co.uk/news/uk-news/disabled-woman-isolated-alone-after-14040495.

[46] Stathi A, Gilbert H, Fox KR, Coulson J, Davis M, Thompson JL (2012) Determinants of Neighbourhood Activity of Adults Age 70 and Over: A Mixed-Methods Study *Journal of Aging and Physical Activity*, Vol 20, Issue 2, Pages:148-170 DOI: 10.1123/japa.20.2.148.

[47] Goffman E (1963) *Stigma: Notes on the management of a spoiled identity* Harmondsworth: Penguin. Also Wolfensberger W (ed) (1972) *The principle of normalisation in human services* Toronto: National Institute on Mental Retardation.

[48] See https://www.gov.uk/government/publications/section-19-and-22-permits-not-for-profit-passenger-transport/section-19-and-22-permits-not-for-profit-passenger-transport.

[49] A standard check was required until March 2012, but an enhanced check is now mandatory – see https://webarchive.nationalarchives.gov.uk/20130315224447/http://www.homeoffice.gov.uk/publications/about-us/parliamentary-business/written-ministerial-statement/crb-taxi-drivers-wms/.

[50] See Sonule N, Khatib MS & Shaikl F (2018) Implementation of real-time taxi *sharing International Journal of Trend in Scientific Research and Development* Vol 2 issue 3, pp891-895. Available at http://www.academia.edu/36981661/Implementation_of_Real-Time_Taxi_Ride_Sharing

[51] On 21/3/19 I emailed Rodney Buckland at U3A if they could find examples of informal lift-sharing.

[52] See http://www.powertochange.org.uk/wp-content/uploads/2017/06/Research-Report-7-Transport-DIGITAL.pdf

[53] Some local authorities offered non-profit transport providers reduced licence fees and then invited them to tender for the provision of commercial routes. The lower licence fee gives them an unfair competitive advantage over commercial transport providers. Removing this unfairness could destabilise the market and result in a reduction of transport options, specifically for disabled people and rural communities. See https://publications.parliament.uk/pa/cm201719/cmselect/cmtrans/480/48003.htm#_idTextAnchor004.

[54] See https://ctauk.org/.

[55] This incisive term was coined by Maggi McElroy. It particularly refers to vehicles that are emblazoned with logos of the company and credits to the donors of the vehicle. Such coachpainting may reduce car parking fees and help the donor feel good when they see the vehicle, but it

engenders feelings of indebtedness in the passengers and attracts potentially stigmatising attention from onlookers. See more on this topic at http://peterbates.org.uk/home/garden-shed/painting-the-minibus/

[56] Email inquiry sent to Liftshare 29/11/2018.

[57] (2018) The Governance of Risks in Ridesharing: A Revelatory Case from Singapore *Energies* 11, 1277 Doi:10.3390/en11051277.

[58] Stephen B. DeLoach and Thomas K. Tiemann, (2012) Not Driving Alone? American Commuting in the Twenty-First Century *Transportation* 39, no. 3, p4.

[59] Feeney M (2015) *Is ridesharing safe?* CATO Institute Policy Analysis number 767 (Jan 27, 2015).

[60] Simon R (2002) *Riding the bus with my sister* New York: Plume.

[61] Posner R, Durrell L, Chowdhury S & Sharp R (2018) *Mental Health and transport* TRL Ltd. Available at https://trl.co.uk/sites/default/files/Mental%20health%20and%20transport_0.pdf.

[62] Advice for people with autism on negotiating public transport is available at https://network.autism.org.uk/knowledge/insight-opinion/supporting-independent-travel.

[63] Mark G Davis MG, Fox KR, Hillsdon M, Coulson JC, Sharp DJ, Stathi A & Thompson JL (2011) Getting out and about in older adults: the nature of daily trips and their association with objectively assessed physical activity *International Journal of Behavioral Nutrition and Physical Activity*2011**8**:116. https://doi.org/10.1186/1479-5868-8-116

[64] Independent travel training may include supporting the learner to create a personalised I Spy book to take on a regular bus journey so that they can gradually learn to recognise where they are and when to get off the bus. See an example syllabus at http://ccea.org.uk/sites/default/files/docs/curriculum/area_of_learning/learning_life_work/thematic_unit-into_independance/ks3-sld-going_places.pdf

[65] See http://apse.org.uk/apse/index.cfm/members-area/briefings/2017/17-23-home-to-school-transport-services-for-send-children-reducing-costs-and-enhancing-outcomes-part-1/

[66] Clever Never Goes is a travel safety programme designed by the charity Action against Abduction. It is designed for children at primary school and seeks to replace the outdated Stranger Danger approach. Even in primary school, children can make some contribution to the process of staying safe and have a role alongside parents and professionals in risk assessment and management. In 2019, the charity will be working on a similar programme for teenagers that shifts more of the responsibility for risk assessment from the parent to the young person themselves.

[67] Advice requested from organisations that provide independent travel training - Pure Innovations (8/12/18).

[68] See https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/377669/national-standard-for-driving-buses-and-coaches.pdf.

[69] See http://hub.unlock.org.uk/wp-content/uploads/A-Z-of-specific-job-roles-and-eligibility-for-criminal-record-check.pdf.

[70] People love to own a car because it gives them autonomy and the ability to act spontaneously – to simply get in and go. See Meurer J et al (2014) *Social Dependency and Mobile Autonomy – Supporting Older Adults' Mobility with Ridesharing ICT.* Available at http://www.wineme.uni-siegen.de/paper/2014/p1923-meurer.pdf.

[71] See https://en.wikipedia.org/wiki/Hitchhiking

[72] See http://hitchwiki.org/en/Hitchhiker%27s_safety.

[73] See Julian A. Compagni Portis (2015) *Thumbs Down: America and the Decline of Hitchhiking.* Wesleyan University B.A. Thesis https://wesscholar.wesleyan.edu/cgi/viewcontent.cgi?referer=https://en.wikipedia.org/&httpsredir=1&article=2428&context=etd_hon_theses#page=44.

[74] Hagen sets out the etiquette of lift-sharing and describes several types of driver behaviour (reticent, conversational, preoccupied) and passenger behaviour (sleeper, talker, busy bee, mouse and sideliner). Carol Hagen (2007) *Slugging in the fast lane: a study of transient nonintimate relationships through public and private space.* PhD dissertation. Available at https://www.researchgate.net/profile/Carol_Hagen/publication/33935171_Slugging_in_the_fast_lane_a_study_of_transient_nonintimate_relationships_through_public_and_private_space/links/00463536a14645c6bb000000/Slugging-in-the-fast-lane-a-study-of-transient-nonintimate-relationships-through-public-and-private-space.pdf. Email sent to Carol at Westat 7/12/18. See also Laurier, E., Lorimer, H., Brown, B., et al. Driving and 'Passengering': Notes on the Ordinary Organization of Car Travel. *Mobilities* 3, 1 (2008), 1–23. Available at https://www.research.ed.ac.uk/portal/files/8456101/PDF_Passengering_Mobilities2.pdf. Also Sherlock, K. Revisiting the concept of hosts and guests. *Tourist Studies* 1, 3 (2001), 271–295.

[75] The resident lives in a nursing home managed by Your Health Ltd.

[76] David S. Alcorn (1975), Who Picks up Whom: The Fleeting Encounter between Motorist and Hitchhiker *Humboldt Journal of Social Relations* 3, no. 1 p 58.

[77] The campaign is being run by the charity Action against Abduction, who provide both data and campaign work on child kidnapping and abduction. They note the distinction between attempted and completed acts and the difference between such crimes occurring and those reported to the police, offences perpetrated against children and adults and parental versus non-parental perpetrators, while the police only record the kidnapping or abduction if it is the most serious crime that occurs in each event.

[78] Elijah Wald (2006) *Riding with strangers: a hitchhiker's journey.* Chicago: Chicago Review Press.

[79] S. Franzoi (1985) Personality-Characteristics of the Cross Country Hitchhiker *Adolescence* 20, no. 79. Available at http://raspunicum.de/misc/Franzoi_Personality_Hitchhike.pdf.

[80] Zeigler F and Schwanen T (2011) "I'd like to go out to be energised by different people"': an exploratory analysis of mobility and wellbeing in later life *Ageing and Society*, vol 31, no 5, pp 734-57.

[81] Account from Alastair Minty.

[82] Mahood L (1960) *Thumbing a ride: Hitchhikers, hostels and counterculture in Canada.* Vancouver: UBC Press.

[83] Mario Rinvolucri collected data from 1000 hitchhikers via questionnaire and interview. See Rinvolucri M (1974) *Hitchhiking.* Available at http://hitchwiki.org/en/index.php?search=Rinvolucri&go=Go&title=Special%3ASearch.

[84] Granovetter MS (1973) The Strength of Weak Ties *American Journal of Sociology* Vol. 78, No. 6 (May), pp. 1360-1380.

[85] There is a paucity of quantitative research. A study of hitchhiker-related crime was carried out in California in 1973. Hitchhikers were no more likely to be involved in crime than the general population. Women were more at risk than men, but the ratios matched those for crime in the general population. On average, one hitcher was a victim of crime per 2500 trips and one driver was a victim per 6500 trips. Hitchhiking with a buddy reduced the risk of being victimised by a factor of

six. See California Highway Patrol *California crimes and accidents associated with hitchhiking.* Available at http://bernd.wechner.info/Hitchhiking/CHP/body.html.

[86] See https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/638526/blue-badge-rights-responsibilities.pdf

[87] See the House of Commons Debate Pack at http://researchbriefings.files.parliament.uk/documents/CDP-2018-0026/CDP-2018-0026.pdf.

[88] See Government advice on hospital car parking concessions at https://www.gov.uk/government/publications/nhs-patient-visitor-and-staff-car-parking-principles.

[89] The Healthcare travel Costs Scheme is available for eligible appointments, patients and carers where the carer is judged to be 'medically necessary' by the patient's healthcare professional. Simply visiting a friend or relative in hospital does not qualify. See https://www.nhs.uk/using-the-nhs/help-with-health-costs/healthcare-travel-costs-scheme-htcs/.

[90] Commentary at https://www.bbc.co.uk/news/uk-46687272. Data is at http://hefs.hscic.gov.uk/DataFiles.asp.

[91] The undertaking and a list of insurance companies who have made this commitment can be found at https://www.abi.org.uk/globalassets/files/publications/public/motor/2017/10/abi-guide-to-volunteer-driving---the-motor-insurance-commitment.pdf.

[92] This is the HM Revenue and Customs Approved Mileage Payment Allowance, available at https://www.gov.uk/government/publications/rates-and-allowances-travel-mileage-and-fuel-allowances.

[93] Section 33 of the Care Act 2014 provided for exceptions to this, which meant that people living in long term residential care are not eligible for a direct payment unless they live in a designated 'trailblazer' Council area. The specific local authorities that do have permission to offer direct payments to people living in residential care are granted this opportunity through regulation 6 and schedule 2 of the Care and Support (Direct Payment) Regulations 2014 (SI 2014/2871).

[94] There were 14 trailblazer Councils at the start of the project, but one withdrew at the end: Cornwall, Gateshead, Hertfordshire, Hull, Lincolnshire, London Borough of Enfield, London Borough of Redbridge, Milton Keynes, Norfolk, North Lincolnshire, Nottinghamshire, Staffordshire (withdrew), Stockport, and Surrey. See https://www.scie.org.uk/about/partnership-projects/direct-payments-in-residential-care.asp and http://www.legislation.gov.uk/uksi/2016/167/pdfs/uksiem_20160167_en.pdf

[95] The plan is to eventually permit all local authorities to make this offer as part of the implementation of Part 2 of the Care Act 2014. The first implementation date was 2016 - see https://www.communitycare.co.uk/2016/01/27/direct-payments-residential-care-delayed-2020/. Then the Rt Hon Alistair Burt, Minster of State for Care and Communities, wrote to all trailblazer sites on 8th January 2016 to defer this, and to explain that direct payments in residential care will be an option for all local authorities in England to take up from 2020.

[96] See https://blogs.lse.ac.uk/healthandsocialcare/2017/02/22/direct-payments-in-residential-care/ and the full report Ettelt S, Wittenberg R, Williams L, Damant J, Lombard D, Perkins M & Mays M (2017) *Evaluation of Direct Payments in Residential Care Trailblazers Final report* Policy Innovation Research Unit (PIRU) Department of Health Services Research & Policy London School of Hygiene and Tropical Medicine. Some of the direct payments were used to pay for the resident to attend day care in another care home, and other outings were to access community amenities. Sometimes the Direct Payment paid transport and admission charges for a support worker as well as the resident.

[97] Croft, J (2017) Enabling positive risk-taking for older people in the care home *Nursing and Residential Care* Vol. 19, No. 9. Published Online: 12 Aug 2017. https://doi.org/10.12968/nrec.2017.19.9.515. We might consider that eliminating restrictive practices is not just a matter of establishing formal acceptance for a particular activity; it also requires procedural solutions that enable the activity to be enacted. In a stark example from another field, a man was formally assessed as having capacity to engage in sex but any potential partner was required to present a clean DBS certificate in advance. Thus the principle was established, but the procedural impediments effectively prohibited the activity itself. See http://www.bailii.org/ew/cases/EWCOP/2014/973.html.

[98] Graham et al (2018) op cit. This study team recommended that a review should be carried out on the travel needs and experiences of older people living in care homes, but have no plans to conduct such a review (personal correspondence 8 Jan 2019).

[99] Dr Sarah O'Toole at UCL is conducting research on road safety for children and for people aged 7-25 with learning disabilities or autism, as well as learning about the role of parents. See https://www.ucl.ac.uk/civil-environmental-geomatic-engineering/people/dr-sarah-otoole.

[100] See https://www.legislation.gov.uk/ukpga/2006/47/schedule/4.

[101] See at https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/739152/Regulated_Activity_with_Adults_in_England.pdf.

[102] See https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/758275/ENGLISH_-_DBS_Checks_in_Sports_-_Working_with_Adults.pdf

[103] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216900/Regulated-Activity-Adults-Dec-2012.pdf. DBS confirmed on 13 December 2018 that the guidance in this leaflet is still valid and current (personal email correspondence).

[104] This conclusion is drawn from the direction concerning first aiders. DBS explain that an employee in a shop who takes on the role of First Aider is not undertaking regulated activity because they are employed for another purpose. We might infer that a person running a U3A group is engaged to teach French to members and this is the main purpose of their role. If one member happens to use health or social care services, the French teaching does not immediately become regulated activity. See https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216900/Regulated-Activity-Adults-Dec-2012.pdf

[105] CQC (2015) *The Scope of registration* page 19 defines the types of personal care which result in a duty to register as a provider of regulated activity. This includes the following statement 'The regulated activity of personal care consists of the provision of personal care for people who are unable to provide it for themselves, because of old age, illness or disability, and which is provided to them in the place where those people are living at the time when the care is provided.' Available at https://www.cqc.org.uk/sites/default/files/20151230_100001_Scope_of_registration_guidance_updated_March_2015_01.pdf

[106] In sheltered housing complexes, the housing and support provider may let out some space in their building to a hairdresser, formalising the arrangement with a contract that specifies liability. Residents then choose to use that service or an alternative at their own discretion.

[107] This point also shows that point 1 in the table must refer to only some people receiving adult social care, as many meals at home services are subsidised by the Council's social care budget. The

focus in this point is not on the source of the funding, but on the nature of the help that is given to the person. The guidance refers to spooning food into the person's mouth, which suggests vulnerability, while receiving a meal at one's front door speaks of independence. See https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216900/Regulated-Activity-Adults-Dec-2012.pdf.

[108]

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216900/Regulated-Activity-Adults-Dec-2012.pdf.

[109] https://www.resourcecentre.org.uk/information/disclosure-and-barring-service-dbs/#who%20must

[110]

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216900/Regulated-Activity-Adults-Dec-2012.pdf.

[111] While the DBS rules provide a list of 'specified establishments' in its guidance regarding children, there is no such list for adults, so a place-based approach is not fully warranted.

[112]

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216900/Regulated-Activity-Adults-Dec-2012.pdf.

[113] Visitors to health and social care settings who are providing activities are not regulated unless they are providing health care which is 'directed or supervised by a health care professional'. See https://www.unison.org.uk/content/uploads/2013/07/Briefings-and-CircularsDisclosure-and-Barring-Factsheet3.docx

[114] CQC (2015) *The Scope of registration* page 48 explains which transport services require to be registered as providers of regulated activities, as follows, 'Services are captured by this regulated activity where they involve a vehicle that was designed for the primary purpose of transporting people who require treatment. Transport services provided in vehicles that have a different primary purpose (such as taxis, volunteers using their private cars, or mortuary vehicles and Dial-A-Ride vehicles) are not captured in this regulated activity.' Page 49 adds 'Our view is that this regulated activity will normally cover routine, planned patient transport related to treatment.' Available at https://www.cqc.org.uk/sites/default/files/20151230_100001_Scope_of_registration_guidance_updated_March_2015_01.pdf

[115]

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216900/Regulated-Activity-Adults-Dec-2012.pdf.

[116] http://hub.unlock.org.uk/wp-content/uploads/A-Z-of-specific-job-roles-and-eligibility-for-criminal-record-check.pdf.

[117] https://www.resourcecentre.org.uk/information/disclosure-and-barring-service-dbs/#who%20must.

[118] If an individual knowingly asks for a DBS check for a post which is not included in the Exceptions Order 1975 to the Rehabilitation of Offenders Act 1974, they would be in breach of Part V, section 123 of the Police Act 1997. It is not known whether there have been any convictions under this section.

[119] CQC (2015) *The Scope of registration* page 16 provides a list of arrangements that are exempt from registration as providers of regulated activities. This list includes the following, 'Any health or social care activity carried out by a carer for a member of their family or someone in a personal relationship, where the care is provided in the course of that family or personal relationship for no

commercial consideration. A family relationship can include people treating each other as if members of the same family, so long as they are living in the same household. A personal relationship means a relationship between or among friends, including family friends.' Available at https://www.cqc.org.uk/sites/default/files/20151230_100001_Scope_of_registration_guidance_updated_March_2015_01.pdf

[120] For example, during the discussions that informed this paper, the author was told by one person that the definition of regulated activity was established by the Care Quality Commission, rather than the Safeguarding Vulnerable Groups Act 2006 and the DBS. This same individual believed that care home managers had a duty to obtain DBS checks for anyone who came into the home and interacted individually with residents, which is contrary to the specific advice issued by DBS.

[121] See http://www.legislation.gov.uk/ukpga/2006/47/notes/division/18/3.

[122] See http://hub.unlock.org.uk/wp-content/uploads/A-Z-of-specific-job-roles-and-eligibility-for-criminal-record-check.pdf.

[123] See http://lacnetwork.org/. Also Broad R (2015) *People, Places, Possibilities* The Centre for Welfare Reform.

[124] There are differences too, particularly the extent to which community development is issue-based, while Local Area Coordination is relationship-based.

[125] Statement from DBS Policy Team, November 2018: 'From the information provided about Timebank communities and the activities being performed, these individuals would not appear to be eligible for a standard or enhanced DBS check as it is highly unlikely that they will meet the criteria required to be in regulated activity or work with adults. It would appear that people enter into these communities and perform activities as part of a personal arrangement, with the Broker facilitating the arrangements.' (Statement obtained by Janet Compton).

[126] The Health and Social Care (Safety and Quality) Act 2015 inserted sections 251A, B and C into the Health and Social Care Act 2012 – see http://www.legislation.gov.uk/ukpga/2015/28/contents/enacted. These sections make no reference to the right to privacy under the Human Rights Act, but they do indicate that information may be withheld if the person objects to it being disclosed.

[127] As a result, the author assumes no responsibility or liability for any errors or omissions in the content of this paper. The information contained is provided on an "as is" basis with no guarantees of completeness, accuracy, usefulness or timeliness.

[128] Contributions and challenges to elements of this discussion have been kindly offered by the following people, who bear no responsibility whatsoever for the contents of this paper – Sam Clark, Chris Craig, Jo Croft, Richard Davies, Judy Downey, Brian Frisby, Nick Harding, Brian Herbertson, Iona Loffman, Fiona Marshall, Simon Mckeown, Kate Mercer, Abdullah Mosaid, Geoff Newiss, Julie Pointer, Power to Change, Carol Robinson, Narinder Sandhu, Phil Sharp, Jan Shortt, Sam Smith, Ben Troke, Chris Ward, Janice Wiseman, Neil Woodhead and Kirsty Youngs. The following people have been invited to comment: Nicki Baker, Sarah Bird, Jane Carrier, Carol Clifford, Madeline Cooper-Ueki, Lee Harrison, Jemma Kelly, Liftshare, Bill Love, Barbara Mitchell, NHS Digital (inquiry ref NIC-257494-F1B8T), Rachel Posner, Power to Change and Tito Samra.

[129] This document was begun on 17 November 2018. Undated or early versions should be replaced with the most recent, available here.