



# Food & Home

A knowledge exchange project exploring disabled and older people's access to food in their own homes

# Contents

Executive summary	1
1. Introduction	3
2. Barriers to accessing food at home	6
3. Adaptations to overcome barriers to food access	14
4. Interventions	19
5. Legislative, policy and practice context of food support	26
6. Participation	32
7.Conclusions	37
8. Recommendations	38
References	42
Appendix 1: Evidence review methodology	46
Appendix 2: Key legislation and guidance since 2001	49

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# **Executive summary**

This report looks at the experiences of older and disabled people<sup>1</sup> in accessing food, with a focus on food preparation and eating at home; including food practices, service provision and policy responses. The research brought together existing evidence with new insights from policy makers, national stakeholders and disabled and older people themselves to increase understanding across five key areas.

(1) The key barriers older and disabled people face in accessing food at home Individual access to food is a complex issue with multiple drivers at play. The current evidence base mainly focuses on economic access to food, particularly for working age disabled people. This is undeniably an important driver. This report provides new insights in particular around barriers to shopping, preparation and eating and access to safe and appropriate foods, in addition to further evidence on the additional costs often faced by older and disabled people. Barriers to food access include access to safe and special diets, the role of labelling and packaging, digital exclusion, energy and preferences when preparing food and intersectional issues. An intersectional lens further highlights specific challenges related to race, ethnicity, gender, socioeconomic status as well as periods of transition such as retirement, change in household make-up or moving between informal and formal care. Groups that might be at particular risk of poor food access include those on low incomes, single people, people without children or informal carers, and people living with complex long-term conditions and dementia.

#### (2) The adaptations individuals make

There is limited research on the adaptation individuals make to ensure food access. Our findings add to the complex picture of food choices for disabled and older people. People's adaptations to ensure food access are highly individual due to diverse barriers and their own circumstances. Informal networks of support and family carers are crucial for some people. Many older and disabled people use partially prepared and ready to eat food to help overcome barriers. Adaptations can be both enabling for individuals to be able to prepare their own meals and access a nutritious diet, but can also involve compromises related to food quality, healthiness of food, level of control, ethics and costs.

#### (3) The support available to people in their own homes

The existing evidence base is unevenly spread across different types of interventions and there is no systematic mapping of the scale of the interventions available, including identification of areas where there is no or very limited provision, such as 'home from hospital' services, domiciliary care and personal assistants. This research identified key issues for services including the current impact of rising costs on service provision alongside the continuing acute pressures on social care services. Remaining meals delivery services are often in precarious situations. We also heard how domiciliary care workers are often

<sup>&</sup>lt;sup>1</sup> 'Disabled people' is used throughout to include all people covered by the social model of disability. This would include those with physical or sensory impairments, people with learning difficulties or disabilities, those with mental health issues, people with long term health conditions, D/deaf people and those who are neurodivergent.

hampered by inadequate training, underfunding, short and very short visits, late arrivals and substitutions. There are meals delivery services that are managing to survive and in some cases thrive in these difficult circumstances and emerging innovative delivery models. This varied and often inadequate level of provision directly affects disabled and older people's health and wellbeing and management of certain conditions.

#### (4) The legislative, policy and practice context of food support

Our analysis highlighted gaps and confusion in legislation and policy, as well as limited statutory responsibilities around food and nutrition that have resulted in a fragmented and variable response to ensuring food access for older and disabled people. There is a lack of understanding amongst policy makers, service commissioners, providers and other stakeholders of how adult social care assessments, care plans and self-directed support identify needs and support food access. Support providers are challenged in a policy environment that does not appear to consistently prioritise food access for older and disabled people. Food retailers are legally required to take some action to ensure older and disabled people can access their services, but this can be limited to legal requirements around physical access and assistance, without a full understanding of the different actions they can take for example in terms of the retail offer. Due to capacity, NGOs and provider representatives face challenges in working to highlight gaps in policy and ensure they are addressed.

#### (5) Participation of older and disabled people in policy-making

There is a growing commitment to participation within policy-making and research, including in areas related to food access. There are already some well-documented reflections on this. Our research provides some further insight into participants' experiences. There are disabled and older people who are highly motivated to share their experiences to try to improve policy and practice for themselves and others. There are also some who are sceptical of the extent to which they will be listened to and the chance of success in influencing policy and practice.

There are multiple opportunities for participation by disabled and older people. These can range from research and consultation to formal partnerships to advocacy and campaigning groups. The most successful examples are backed by a genuine commitment to participation, taking an approach centred on the social model of disability, adopting formal structures, resourcing organisations, particularly DPOs to convene spaces and crucially genuine willingness from policy-makers to listen and take action (or set out why action hasn't been taken). There is still a long way to travel before disabled and older people feel confident that they will be listened to and action taken on the basis of their experiences. It is also vitally important to consider the experiences and perspectives of disabled people when shaping policy and practice around live issues such as the consumption of pre-prepared food, ready meals, takeaways and ultra-processed foods.

#### **Recommendations for action**

Food access is affected by a complex range of issues. However, this complexity should not be used as a reason to avoid taking specific and meaningful action. The recommendations outlined at the end of this report are directed at a range of actors across government, industry, providers, NGOs and academia who can all play a valuable role in improving access to food at home for disabled and older people.

# 1. Introduction

In recent years there has been a proliferation of research into food insecurity in the UK context. Much of this has focused on the measurement of household food insecurity, lived experiences, and responses to economic barriers to food access including food banks and other community food initiatives (Lambie-Mumford et al, 2023).

Whilst there is an increasing body of evidence looking at place-based interventions and indicators, there remains a lack of research focused on home-based food support. This is a significant gap, given that food insecurity evidence and nutritional research shows that older people living in the community and households with an adult 'limited a lot by disability' are particularly vulnerable to food insecurity and malnutrition. Households with an adult 'limited a lot by disability' are over three times more likely to be experiencing food insecurity, compared to households with no one 'limited by a disability' (Food Foundation, 2023). At the same time, one in ten people over the age of 65 are estimated to be malnourished or at risk of malnutrition (The Malnutrition Task Force, 2021).

Research into food support during the COVID-19 pandemic highlighted the shortcomings in policy design for people who required support with food preparation and eating in their own homes during the pandemic, with **not enough consideration being given in intervention design to how people were managing in their homes**, or whether provision met dietary requirements (Lambie-Mumford et al 2023). Whilst recent analysis of household food insecurity data highlights the importance of household income as a determinant of food insecurity for both groups (Hadfield-Spoor M., et al, 2024), there is a lack of research looking at the specific dynamics and lived experiences of the relationship between everyday activities and food insecurity for people with long-term health conditions, impairments or disabilities (Lambie-Mumford et al, 2023). Case study research and data published by the food support sector highlights the need for home-based provision and a sharp decline in this provision in recent years, driven by public spending cuts and worsened by the COVID-19 pandemic (NACC, 2023). Together, this suggests that there could be a lack of understanding of home-based food support needs and at the same time, a decline in support available.

The two groups that this primarily affects are disabled and older people. This project focused on people living in their own homes for whom 'a physical or mental impairment affects their ability to carry out normal daily activities' (Equality Act 2010), with a particular focus on barriers to preparing and consuming food in their own homes. This primarily includes disabled adults and older people who are the largest group of people living with a disability, impairment or long-term health condition affecting their ability to carry out daily tasks. We have used a broad definition of older people as people aged 50+; while some people of this age would not consider themselves older at this point, we also heard how serious health conditions affect some people's ability to carry out daily tasks from this age. Our population is older than ever. For example, almost 40% of people in England are currently over 50, and almost 20% are over 65 (Office for National Statistics, 2022). These trends are expected to continue over the next 40 years, with the number of people aged 80 and over growing most rapidly (Office for National Statistics, 2024).

While we follow this Equality Act definition to explain the people this project focuses on, we have aimed to frame this project within the social model of disability, centring it on how people are disabled by barriers in society and not by their impairment or condition. Disability, impairments and health conditions are defined and deployed differently by different stakeholders and datasets, so we include this language to ensure we represent others' work clearly, including where their definitions appear to not be as consistent with the social model approach.

This is a small-scale project so while we have attempted to include experiences for people with a wide range of impairments or health conditions, we have not been able to provide a fully representative study across all disabled and older people.

There are an estimated 16 million disabled people in the UK, representing almost one quarter (24%) of the population. Disability prevalence is highest among pensioners (Kirk-Wade, E., 2023). There are over 26 million people in the UK who live with at least one long-term condition (LTC) and 10 million who have two or more (NHS England, 2018).

A further challenge to addressing barriers to food access for these groups is the fragmented nature of policy and service provision. Relevant areas of policy making sit across multiple national and local structures and services, creating a complex and often fragmented picture (Lambie-Mumford et al, 2020). We lack a comprehensive understanding of the different policies, services and practices that impact on food access for older and disabled people. Including state, voluntary and private sector actors. There has also been a decline in some services (NACC, 2023), and pressure on domiciliary care services with one workforce survey finding that almost half of providers (48%) reporting they cannot meet demand (Homecare Association, 2024). Meaning that we do not have a good overview of the landscape, and how it has been impacted by recent trends.

Linked to all of this, is also a lack of lived experience informing policy design (Lambie-Mumford et al, 2023). There is also an important opportunity to exchange knowledge and expertise on participatory policy research and design approaches and come to recommendations for good practice in including older and disabled people in policy and practice design (Perry et al, 2022)

# Aims and objectives

The project brought together existing evidence with insights from national stakeholders and people with lived experience of accessing food as an older or disabled person to:

- Identify the key barriers older and disabled people face in accessing food at home, the adaptations individuals make and the extent, and benefits, of support available to people in their own homes and gaps in support and the implications of these.
- 2) Explore how policy and practice across the four Nations does, or does not, assist organisations supporting food access for disabled and older people in their own homes, analyse the characteristics of specific examples where policy and practice support food access responses and discuss the influence of the wider context and other factors.

- 3) Gather examples of disabled and older people's participation in designing policy and/or practice in order to capture learning for future involvement activities.
- 4) Provide recommendations for future research, policy and practise for ways to improve access to food for disabled and older people in their own homes.

#### Methods

To meet these aims, our research project included:

- Systematic searches of academic and grey literature were undertaken in April 2023 and February 2024, which identified 48 pieces of academic literature and 31 grey literature items (please see Appendix 1 for details of the search strategy and analysis approach).
- 24 central government, local government, provider, Disabled People's Organisation (DPO) and NGO stakeholders attended at least one of our three stakeholder workshops or individual interviews between February and May 2024.
  - Workshop 1 focused on the key barriers to eating well that older and disabled people face and the main types of provision that is available to support people to eat well in their own home. We built on our overview of evidence to capture a comprehensive overview of disabled and older people's experiences of accessing food in their own homes, the extent of current responses and implications of this, as well as the gaps in support and the implications of this.
  - Workshop 2 focused on the key challenges facing services and providers supporting older and disabled people to eat well in their own homes. We built on our initial overview of the current evidence to explore how policy and practice across the four Nations does, or does not, assist organisations supporting food access for disabled and older people in their own homes, the characteristics of specific examples where policy and practice support food access responses, and the influence of the wider context and other factors.
  - Workshop 3 explored real-life examples of working with disabled and older people to involve them in designing policy and practice and captured learning for future involvement activities.
- Nine people attended four experts by experience meetings in April 2024. Attendees
  were recruited through DPOs, as experts by experiences of accessing food as a
  disabled or older person. Attendees discussed their own experiences of preparing
  and eating food at home as well as experience of shaping policy and practice (not
  necessarily in relation to food access), for example through lived experience panels.

# 2. Barriers to accessing food at home

This chapter explores the key barriers older and disabled people face in accessing food at home. Economic access to food is a major driver that has been explored extensively in other research, albeit with limited exploration of some of the additional costs around food for disabled people. This chapter therefore focuses on the relatively under-researched non-financial barriers to food access.

# Summary of existing evidence

# Food insecurity risk for disabled and older people

Individual access to food is a complex issue with multiple drivers at play. These drivers can be heightened for disabled and older people, alongside societal barriers linked to impairments, health conditions and other factors. Existing evidence on barriers to food for this group centres around economic access and experiences of food shopping.

Existing data highlight a much higher risk of food insecurity for disabled people and an increased risk of malnutrition for people over 65. Households with an adult 'limited a lot by disability' are over three times more likely to be experiencing food insecurity, compared to households with no one 'limited by a disability' (Food Foundation, 2023). 1 in 4 disabled people experiencing food insecurity were unable to get to a food shop and 1 in 8 were unable to get a food delivery (Food Foundation, 2023). 1 in 10 people over the age of 65 are estimated to be malnourished or at risk of malnutrition (The Malnutrition Task Force, 2021).

#### **Economic access**

Analysis of government survey data has shown that low income is a key driver of food insecurity amongst people with long term health conditions (Hadfield-Spoor M., et al, 2024). There is a higher level of poverty among disabled people, driven by low earnings, delayed and/or inadequate social security and sanctions (Biggs. H,. et al, 2023). Indeed, a 2023 report found that over two thirds (69%) of working-age people referred to food banks in the Trussell Trust network across the UK were disabled (Bull, R. et al, 2023). We know that income is a key driver of food insecurity and determinant of access to food for other at-risk groups (Food Foundation, 2023). However research consistently shows that Households which include a disabled person devote higher proportions of their household budget on energy bills and shopping for food and drink (Veruete-McKay, L. et al, 2023). Income also determines people's ability to store, cook and heat food.

Some of the existing research highlights the reasons behind the additional costs faced by disabled people or people with health conditions or allergies in accessing food at home. This can include having to buy adapted utensils, pre-chopped packaged food, speciality and free-from foods as well as increased cost of shopping for mobility issues, for example transport, car fuel, minimum spend for deliveries, food delivery costs, and not being able to shop around for more affordable options. Individual drivers for needing to make these adaptations

include energy deficits, cognitive or sensory overload, brain fog and so on (Connors. C. et al, 2022).

Importantly, employment, including full-time work, can be insufficient for working age disabled people to avoid food insecurity, whereas having savings and/or home ownership can close the gap in risk between disabled and non-disabled people over 65. (Hadfield-Spoor M., et al, 2024).

#### Non-financial barriers

Disabled people face disproportionate barriers to accessing products and services, including food. The ONS found that one quarter (25%) of disabled people reported difficulty accessing food, drink or toiletries versus one tenth of non-disabled people (10.5%) (Office for National Statistics, 2022). We know from small-scale research that a wider range of other issues impact on access to food for both disabled and older people, though the evidence base relating to working age disabled people's experiences is more limited when compared to research on older people's experiences (Dickinson et al, 2021; Food Foundation, 2023; Papadaki et al, 2024; Walker-Clarke et al, 2023; Whitelock et al, 2022). In published research to date, these barriers are often attributed to people's impairments or conditions, but still under-developed in the literature is an understanding of the additional challenges for people when support needs are not met with an adequate response, when they are unrecognised or hidden or when people 'manage' alone or with informal support.

As the dynamics of the relationship between disability, older age and food insecurity are under explored, it is important for us to look at them in more detail (Lambie-Mumford et al, 2023). There is evidence to suggest that older and disabled people face particular non-financial barriers to accessing food which impact on shopping, preparation and eating. A third of those 'limited a lot by disability' report not being well enough to shop or prepare food as a factor causing their food insecurity (Food Foundation, 2023). In 2021/22 two thirds (67.4%) of surveyed older adults living at home and receiving social care were using services that helped them with their food and drink needs/ outcomes (NHS England, 2022).

# Our findings

#### **Economic access**

Our findings echo and emphasise the importance of economic barriers to food access. Data highlighted the severe insufficiency of the social security system, the increased, and increasing, demand for food aid such as food banks. For some this presents a 'structural violence' against disabled people and a failure to implement international obligations related to human rights and disabled people.

'There is not enough money being paid in disability benefits to disabled people to cease this slide backwards this regression to use the United Nations human rights term... But actually what that means is that is structural violence being applied to

people and that's wrong. We shouldn't accept the structural violence of the state being applied to disabled people.' (DPO stakeholder)

Research participants also discussed the myriad of reasons behind disabled people's **additional costs** related to food preparation, as well as many other aspects of their lives. The recent **cost of living crisis** has also had a disproportionate impact on disabled people, further adding to this additional cost.

'Disabled people are facing even higher costs than normal than a non-disabled person. For example disabled people need equipment that needs charging all the time. They need high-cost equipment to get on with their lives. You need extra heat in and all this is a huge cost and it comes out of the disability benefits and the benefits which leaves very little for food that they're needing and also... So many more disabled people are in debt for basic things like electricity and food putting it on credit cards.' (Lived experience participant)

There are also additional costs for **people living alone** as groceries are often packaged in portion sizes for couples or larger households. Larger-sized portions are also priced more affordably. These larger portions can also increase food waste. Smaller portions would help to reduce waste and reduce costs.

'Everything seems to be designed for families or couples. So if you live on your own, it's too much for one person and then if you do go for a smaller amount or whatever it costs more so you're being penalised.' (Lived experience participant)

**Frozen food** is not necessarily an affordable option for people. Research participants highlighted this as a more recent change in relation to frozen groceries and meals.

'The price of frozen food isn't cheap anymore... A few years ago it used to be quite cheap. Look at their prices - it's extortionate now.' (Lived experience participant)

While **local shops** may be easier to get to for some, groceries can often cost more. Some disabled people need to use local shops as they can be closer to home, though the shops themselves can be less accessible. So this is another way that disabled people can face additional costs. Other disabled people that are able to will try to avoid shopping in local shops due to price.

'And sometimes you're having to shop in some of the more expensive shops because they're accessible.' (Lived experience participant)

The impact of food insecurity is well-documented. Our research highlighted a number of impacts, for example **reduced protein intake**.

'I get the sausages and beans tins, so I'm replacing it [more expensive protein] with that...I don't think it's a huge amount of protein. I'm probably eating less, a lot less.' (Lived experience participant)

For other people pressure on costs and food insecurity means that they **no longer host others to eat at home**. This can have a very significant impact in terms of people's social isolation, health and wellbeing.

### Access to shopping and food items

Covid-19 still presents a significant threat for older and disabled people at risk of severe illness, who are avoiding or limiting contact with others, especially in busier indoor spaces or public transport. This can severely reduce their autonomy and options, as well as increase costs in relation to food prices in the outlets they are able to use and transport costs were needing to use taxis.

'There are still people shielding because of the prevalence of Covid [...] If they haven't got access to the internet this becomes a real issue, or if home delivery spots are all filled up in their area, and there's no prioritisation now, then they've got real difficulties in accessing food unless somebody does it for them.' (NGO stakeholder)

**Consistent placement of goods** in stores helps people to shop independently. Moving items to a different location can make things much harder for some people and can put people off shopping in-store, instead switching to shopping apps or online shopping.

'When I go to Lidl near me and everything's always in a set place and I do find that far better for me. I know where things are. I can get what I want to get.' (Lived experience participant)

**In-store assistance** from people can be really important both on a practical basis and for providing social connection. For some people this tends to be a positive experience with staff offering support and conversation. However, there can be assumptions that this kind of help should only be provided for people with physical impairments or older people and it can be inconsistent in terms of whether support is available.

'If I ask for assistance from staff, I am at the mercy of the gods. Some will help without hesitation, some won't, it's not consistent if there are not enough people on tills, the shop floor etc.' (Lived experience participant)

Inaccessible packaging and labelling can present a major barrier for people. Some products use Braille labelling or NaviLens to make packaging more accessible for people with visual impairments, but generally text can be very small. There is also little consistency across brands. This text includes very important information such as ingredients, allergy information and cooking or heating instructions. In some cases, allergy information can be very prominent whereas instructions on how to heat or eat safely can be much harder to read. Packaging can also be difficult to open with some people giving up on eating something as it has proved too hard to open.

'If your eyesight isn't the best, which as you know may happen as you get older, and even for myself, some of the packaging, the writing is absolutely tiny. So, how are people going to read the ingredients list and make sure that that food is safe for them to eat whether they have an allergy or intolerance or even read the cooking

instructions to ensure that they are cooking everything correctly and reducing the risk of foodborne illness and things like that?' (Government stakeholder)

**Online shopping** can provide an alternative for some disabled people, and recommendations based on previous shops can help people. Research participants also raised a number of issues including uncertainty about the quality and shelf-life of products.

'Not all the stuff that they get is always good quality because it depends on the person who's picking it for them and the quality of the product that they put in the basket.' (Lived experience participant)

**Digital exclusion** remains an ongoing issue for disabled and older people. This covers access to equipment such as a computer or smartphone, the costs of equipment and internet connection and data costs, as well as ability to navigate online. We also heard about fears of internet scams and concerns about sharing personal data online for transactions.

'About 30 per cent of disabled people in Scotland don't have access to the internet and it does vary with age, obviously the older you are the less likely you are to have internet access. It's not just a matter of providing kit and a connection, lots of older people are reluctant to use it, feeling they can't manage their way around and things like that. When Glasgow Disability Alliance surveyed over 2,000 of their members during lockdown, 60% of them said they could not access information on the internet. So there's real issues there if the only source of information is the internet.'(DPO stakeholder)

### Access to safe and appropriate food

Many disabled and older people have **special dietary requirements**. This can be related to medical or health needs, but may also be about strict preferences to certain foods or brands for example for some autistic or neurodivergent people. This usually brings additional costs as these foodstuffs are likely to be more expensive with prices more vulnerable to supply disruption or market forces. Special food can also require specific storage, such as refrigeration, which can add to costs. These issues can be further compounded if people's food shopping is restricted in some way, for example if they can only use local shops or only shop online; choices may be limited or subject to minimum spends. The cost of food to meet dietary requirements can present a real challenge. This additional cost can also be compounded by a lack of choice to ensure people get a sufficiently varied diet.

'Something that we continually hear about from our insight gathering is that lots of disabled people will have specific foods that they either can't eat or have to eat for their own health reasons and that food can be, and often is, more expensive.' (Government stakeholder)

'It can get very expensive to be able to get a healthy diet when there are lots of things that you can't eat... It [the local area] really doesn't have a good selection of food overall and it's difficult for me to be able to get enough variety of food that I can actually safely eat.' (Lived experience participant)

We also heard about the difficulties when there is a clash between **cultural needs** and dietary requirements.

'I come from an Asian background. So curries are an everyday thing for us, but unfortunately my stomach can't handle them.' (Lived experience participant)

We also picked up on **anxiety and concerns about food supply**, including the impact of climate change, extreme weather and barriers to trading. Supply chain issues will disrupt how disabled people source food and therefore what they prepare and eat at home. Non-disabled and younger people are likely to be advantaged in how they navigate supply chain disruption. This can leave disabled and older people at a severe disadvantage.

'I think that if we do face supply chain challenges and I think we will then I do believe, unfortunately, that the strongest will survive and they'll push their way to the front and get what's needed, what's on the shelves and people who can't do that will suffer as a consequence.' (DPO stakeholder)

# Food preparation and storage

There are a whole range of factors that can affect people's **ability to prepare and cook food**, especially on a daily basis. This can include whether people are able to know what's in their cupboard, fridge or freezer or if they can access the hob, cooker or other equipment in a way that is safe, doesn't cause, or add to, pain or injury, over-exertion or fear of being in the kitchen alone especially when using knives or hot equipment.

'I think it really depends healthwise on a particular day. Some days I'll be able to maybe heat something up in the microwave... I don't think I've actually cooked a proper meal for three or four years. I can't really stand to chop things and that kind of stuff.' (Lived experience participant)

As with the population as a whole disabled and older people have variable knowledge and opportunities for preparing and cooking food in relation to their individual circumstances, which can include meeting specific needs they have. There are limited support options for people to develop this knowledge. People's desire to cook foods can also be strongly influenced by preferences and aversions, some of which may be linked to being autistic or neurodivergent, including hypersensitivity to food smells or textures.

'When people say things like staple food, I don't understand that concept... It's the anxiety of what goes together or how do you cook that? It's slowly learning about that from family, but it's quite overwhelming... I think it's kind of having those life skills and as the third sector shrunk I think as I was growing up, there used to be more opportunities like support groups or youth groups where people would cook together or sort of learn to cook.' (Lived experience participant)

'Preparing food from scratch took time and energy, and so they faced a dilemma of spending the little energy they had on preparing food that suited their needs or eating convenience foods like pre-chopped foods or ready meals - but then options can be

more expensive, more processed, less fresh, and more likely to contain allergens like dairy or gluten' (Government stakeholder)

# Eating

Research participants gave individual details on the role of physical factors, mental health and motivation to prepare and eat food. For some people food is a point of control and this can lead to a distorted relationship with food. Others may not have an appetite and/or may not feel or be alert to hunger while for others exhaustion including from cooking can kill their appetite. Some people's medication can affect appetite and motivation to cook as well as affect their ability to eat, for example due to a tremor and this may inhibit them from eating with others which can affect how and what they eat. People may also need assistance with toilet visits so they need to plan eating around these needs as well.

'When I was 15 and started mainstream school and struggled with my mental health, not eating was the only control I had, so I have a pretty bad relationship with food, apart from snacks and things which I have now tried to cut down.' (Lived experience participant)

'I just want to go and lie down. I'm hungry, but I just don't want to eat. So by the time I do get up from the couch and start eating, my food's gone cold. And there's nothing worse than cold chapati, absolutely disgusting. I'll eat it if it's hot, but once it's gone cold, I just can't stomach it. So a lot of the time I go to bed hungry and I really shouldn't because probably the only proper meal I have is the night-time meal so I can sleep.' (Lived experience participant)

Stakeholders identified a number of groups for whom there appears to be greater risk of food access issues. This includes a subset of people aged 50+ (so under pension age) who already live with significant health conditions combined with lower incomes, men with learning difficulties using food banks, and family carers who also have health issues alongside the person they are caring for. Key transition points can also have a profound impact on someone's access to food at home, including someone losing a partner or main family carer.

'What we have kind of come across as well in older people is if somebody is unwell, like a couple and one partner is unwell, and the partner is taking care of them and maybe that might be the first time they are ever making a meal and cooking for that person or if somebody becomes widowed and it usually does tend to be the husband who really struggles with preparing food for themselves. Because it could be the first time in 50, 60 years or whatever length of time and now they have to cook for themselves and they have no knowledge or no background whatsoever in that because everything used to be taken care of.' (Government stakeholder)

#### Discussion

The current evidence base mainly focuses on economic access to food for disabled people, with the additional costs, and barriers to accessing and preparing food only considered in a limited way in existing studies. There are a range of measures of health and disability used

across surveys and studies, which makes it difficult to build a robust picture of disabled people's experiences across evidence sources. Disability, impairments and health conditions are defined and deployed differently by different stakeholders and datasets. For example the FSA focuses on 'health condition' rather than disability or impairment (FSA, 2024) and the Food Foundation's survey data uses 'households with someone limited by disability' (Food Foundation, 2023). Research on older people's food experiences has covered shopping and food preparation, but there remains a limited approach to the conceptualisation and operationalisation of 'age' when it comes to food experiences, with research suggesting experiences of people aged over 50 with health conditions should be a key area of focus, and attention should also be paid to those in older age groups of 85+, as demographics in the UK change.

Our evidence provides new insights around barriers to shopping, preparation and eating faced by older and disabled people. The additional food costs faced by disabled people are significant and multi-faceted, including shopping for a single person, needing to purchase prepared or partially-prepared food, and meeting dietary requirements. Recent increases in food prices, especially of frozen food, has placed further pressure on budgets. Our evidence also suggests that more attention needs to be paid specifically to disabled people's access to safe and appropriate foods. Dietary requirements and preferences can result from hypersensitivity, adhering to medical diets, and preferences resulting from sensory issues. This can add to food costs, but inaccessible packaging and labelling can also pose significant risks. People's ability to shop and prepare food due to their health condition can be highly variable and can result in reduced choice, control and healthiness.

Our findings also highlight the importance of an intersectional lens to explore the dynamics of specific challenges related to race, ethnicity, gender, socioeconomic status as well as periods of transition such as retirement, change in household make-up or moving between informal and formal care. Intersectional dynamics are not well accounted for in existing evidence, and require further exploration. Groups that might be at particular risk of poor food access include those on low incomes, single people, people without children or informal carers, and people living with complex long-term conditions and dementia.

Potential solutions to some of the barriers faced by people can also have their disadvantages or flaws. For example, support with in-store food shopping can be variable, and many older and disabled people are still digitally excluded from online shopping. More systematic evaluation of interventions is required.

# 3. Adaptations to overcome barriers to food access

This chapter provides an overview of the adaptations individuals make to address barriers to accessing food at home.

# Summary of existing evidence

Disabled and older people are accustomed to adapting their behaviour in response to factors impacting on them, including access to food at home. It is important to note that adaptations can be empowering where they enable alternative ways to ensure access, but can also be driven by a lack of options and choice leading to a reduction in autonomy and forced compromises.

Adaptations to behaviour can include adaptations that people may make for themselves or someone they live with (or who informally cares for them) makes for them. For disabled people, they can include changes to the kinds of food purchased, including pre-prepared or partially prepared food (Food Foundation, 2023), the ways in which people do their shopping (for example online), use of adaptive equipment, or changes implemented by informal carers.

There have been examples of lunch clubs that have also provided take-home meals. However there is evidence that many closed during the pandemic lockdowns and have not reopened again (Gordon et al, 2022).

# Our findings

Adaptations to reduce or limit costs

Stakeholders told us about different ways that people are managing financial pressures and the impact of this.

We heard about people **not using or limiting their use of more expensive to run equipment**. Research participants talked about not using cookers, switching off or limiting the use of fridges and freezers and other equipment, as well as skipping meals. People can also rely on pre-prepared ready-to-eat or ambient food, reducing intake of chilled products such as milk. In Scotland, energy expenditure is higher on average, so this contributes to increased pressure on household budgets.

While helping people to manage costs, these decisions can also have significant implications on the type of food being consumed, food safety, whether medication is taken alongside food, condition management, ultimately affecting people's health and wellbeing and management of specific conditions such as diabetes.

People have opted for **cheaper to run equipment including microwaves and air fryers**. This can allow people to easily cook or heat meals or more easily assemble different

components of a meal. People told us about the importance of such equipment being accessible and easy to use, for example for people with visual impairments.

'I think a lot of people really diss the microwave but I think mine might be on the way out because it's not heating as much but microwaves [are] really good because you can get stuff like packets of rice and stuff which you don't have to [cook from scratch] and it's about adding things together and then you can get stuff from Iceland.' (Lived experience stakeholder)

'We've recently met with members about fuel insecurity and what's been coming through very strongly is because people cannot afford the energy costs of using the cooker, so it's not that they've not got a cooker. They have cookers. They just can't use them because of the cost of running them. So they're relying always on prepared food which is higher cost and just microwaving it if they need to heat food which they do in a Scottish winter, believe me. So...there's also higher fuel costs in Scotland generally and higher fuel costs for disabled people. So there's real issues around the ability to prepare food at home because of the fuel cost, yeah. And although that's beginning to end it's certainly been a big issue for the last two winters.' (DPO stakeholder)

Some disabled people may prepare **simple snacks or meals**, in some cases where it is not possible to cook more complex meals. In some cases people felt this was a nutritious solution, in other cases they thought that the level of nutrition was poorer.

'My wife buys bananas on a regular basis and when she's out I can go and enter the kitchen. The one thing I can prepare is bananas on a roll. We have a long bread roll. It's much easier to access for me. No cooking involved, they open up, stick the banana in and I'm good to go. Convenience foods, that's what I'm getting at as much easier, especially if there's no cooking involved.' (Lived experience participant).

#### Pre-prepared or ready-to-eat ingredients or meals

**Using pre-prepared ingredients, partially prepared meals and meal kits** is one key adaptation, which both helps people to access a good meal but can sometimes also be cost-effective. This can include pre-sliced fruit or vegetables, precooked items such as a ready-cooked chicken, sachets or meal kits, often purchased from supermarkets or sometimes companies such as Wiltshire Farm Foods.

'At one time you could buy a ready-cooked chicken. And that was quite an easy thing to do... It was actually cost effective because you bought a home chicken already cooked and the time you got home you could just serve that up with some boiled potatoes and some tinned vegetables and there's a meal and you could knock that out quite quickly because you're not cooking the chicken, all you're doing is boiling the potatoes and the veg.' (Lived experience participant)

'I was very upset because I couldn't seem to make a white sauce and then people think lots of people make white sauces out of packets, and just using the shortcuts you can use and I think there's a lot on [the] internet about people going on about

processed foods, but there's no shame and stigma. I think very few people cook from scratch. It's about using a combination of fresh ingredients and there's nothing wrong with tins and sauces and things because that's what they're there for.' (Lived experience participant)

However, in many cases pre-prepared food or meal kits can lead to additional costs or waste as they are designed for households of more than one and people felt that the food doesn't keep for as long.

'In the past they have prescribed things like HelloFresh, but often it's designed for two people, so I only eat half of it and then some of the stuff doesn't stay as fresh as the supermarket stuff.' (Lived experience participant)

**Ready meals** play a useful role for people. However we heard concerns about affordability and nutritional content.

'I have also ordered for someone with dementia and those companies that do sort of half ready meals that you put in the microwave. And they're quite expensive. There's 10 meals for 25 quid and something like this is very quick. Whereas, if you physically go to somewhere like Iceland you could get the same meals but a lot cheaper, so I'm not really sure either what the benefit is.' (Lived experience participant)

**Takeaways** can also provide an important option for people. They can be particularly helpful when people have limited mobility or ability to shop and come ready to eat. Deliveroo and Just Eat were two providers mentioned by participants. While there are benefits, we also heard concerns about nutritional value, choice, and cost, including more recent price increases. People were keen to impress on us that relying heavily on takeaways is not the treat that people might imagine it is.

'I mean because I have mobility problems, I could save a lot of money by walking the 200 yards to the takeaway, by ordering it over the phone and picking it up. I pay a £5 service charge just because I don't want the pain. What's the point of getting something that you're really looking forward to, then you get home and you're so pained by the walk home that you can't be bothered to eat it?' (Lived experience participant)

'So it's difficult seeing my money go on fast food, but sometimes I need to get takeout. I mean the best quality that I can get for a reasonable price, but it might sound fun to other people, but it's not when you have to eat it all the time because the partner I live with has health problems and he's sometimes just not well enough to be able to deal with cooking.' (Lived experience participant)

A particular issue was raised in relation to **being able to easily find food that meets dietary requirements** on delivery websites or apps.

'I get them from Just Eat which has become more difficult and that's actually something probably worth mentioning that they used to have a section called 'your favourites' where the places you went to regularly were stored in a list which meant

that I could find out what was safe for me and I could just keep a list of it there and now they no longer do that. So basically every time I have to go through and try and work out which places I can get safe food from.' (Lived experience participant)

While most references to takeaways were to formal outlets, we did also hear about **takeaway meals offered as part of lunch clubs** or similar provision.

'But as I said I go to this club that cooks your food on a Wednesday and they actually prepare takeaway food and they put them in the Chinese takeaway plastic tupperware things. And you can take that home and then I can just whack that in the microwave.' (Lived experience participant)

Discussion of healthy food also included people's consumption of **ultra-processed foods** (UPFs). Some expressed concerns about the consumption of this kind of food, but efforts to reduce UPF consumption must consider how their consumption by disabled and older people can be driven by ease of access and preparation, so any alternative must remain accessible to them.

'The current debate around UPFs risks developing policy solutions that do not take account of some disabled and older people's consumption of UPFs or make it genuinely possible for disabled and older people to adopt alternatives to UPFs, especially where they are unable to cook every meal from scratch.' (NGO stakeholder).

# Informal support

We heard from people whose **partners and/or family members** prepare food for them. People may also prefer to eat when someone else is at home in case of any choking or other incidents. People are also often part of informal support networks including groups of disabled people who offer mutual support to each other.

'I'm in the fortunate position that I'm married. My wife just doesn't let me anywhere near the kitchen.... I'm also fortunate that my two daughters live nearby. So if my wife's out and I need anything, I've got my two daughters I can rely on as well.' (Lived experience participant)

While this support is provided with good intentions, we did pick up on a **lack of control and choice** among some of the people we spoke to who were in this situation.

'I would also really prefer to be primarily vegetarian, but my partner will not go along with that. He's concerned apart from anything else about me getting enough nutrition when I can only eat a smaller number of calories. I think it's doable, but I'm not the one who's in control of the cooking process. So I'm limited on that. '(Lived experience participant)

# Discussion

People's adaptations to ensure food access are highly individual due to diverse barriers and their own circumstances. Some people are reducing or avoiding using ovens, fridges and freezers and foods that need that equipment, such as food that needs to be oven-baked or chilled. Alongside microwave use, we also picked up on an increasing use of air fryers due to relative ease of use, convenience and lower energy costs. Some people may be assembling meals using this equipment, rather than cooking from scratch. It is important that any equipment is accessible and easy to use, and for research to explore the impact of these changes on diet and health, particularly if people are also reducing use of equipment needed for medication or healthcare.

There is some limited existing literature on the use of pre-prepared meals and takeaways by disabled and older people. Our findings add to the complex picture of food choices for disabled and older people, and highlight the importance of availability of easy to prepare and pre-prepared foods, as well as delivery services. Rising costs of these foods, and the accessibility of online platforms can be barriers to these adaptations. More evidence is needed on the role these foods play, and how access to them for health can be supported by the food industry and government. It is vitally important to consider the experiences and perspectives of disabled people when shaping policy and practise around pre-prepared food, ready meals, takeaways and UPFs, to take account of the requirements of people who rely on foods that fall within these categories.

Disabled and older people are often limited in the options they can choose between, so are often not making genuine choices. This can result in people making a range of compromises related to food quality, healthiness of food, level of control, ethics and costs. Informal networks of support and family carers are crucial for some people. Even where a carer does most of the cooking, some people may still prepare or eat simple snacks themselves, but these can vary in nutritional value.

# 4. Interventions

This chapter explores the evidence around the formal support available to people in their own homes, beyond the adaptations discussed in the previous section.

# Summary of existing evidence

There are a number of food-based support interventions for people living in their own homes. Key interventions that exist include meals on wheels, food support from domiciliary care workers or personal assistants and food support when people are discharged home from hospital. Two thirds (67.4%) of surveyed older adults living at home and receiving social care were using services that helped them with their food and drink needs/ outcomes (NHS England, 2022)

These interventions sit in a wider context of other types of support including shopping support (in stores or through assisted shopping programmes), community meal provision (lunch clubs and shared meals), and access to community food aid (food banks, social supermarkets), as well as support from family or informal carers or the local community as discussed in the previous section.

There is **no consistent level of provision across all local areas**. This is driven by multiple factors including the multi-layered and fragmented policy and practise framework, variable availability of statutory and non-statutory funding, local decision-making and other factors including the state of the local voluntary community sector and local geography.

For example, the number of publicly funded meals on wheels type services for older and disabled people has declined significantly since 2016. As of 2023, such services are now available in only 29% of local authority or health and social care trust areas in the UK. The extent of provision varies widely across the four nations; there is a 62 percentage point difference between the number of local authorities and trusts funding a service in Northern Ireland and England. Higher per capita adult social care budget allocation in Northern Ireland, Scotland and Wales is partly credited for this difference (Provider stakeholder; Nuffield Trust, 2022).

Table 1. Number of local authorities and health and social care trusts funding a meals on wheels type services 2016 - 2023 (NACC, 2023)

	2016	2018	2023	Change 2016-23
Northern Ireland	100%	80%	80%	-20%
Scotland	75%	61%	61%	-14%
Wales	50%	45%	36%	-14%
England	43%	36%	18%	-25%
UK	48%	42%	29%	-19%

The average cost of the meal to the end user also varies hugely - between £1.90 and £7.33. There are also a myriad of delivery organisations with services provided in some cases directly by local authorities and trusts, but many are contracted out (NACC, 2023).

Alongside this decrease in funded meal services, the closure of day centres at the local level and the long waiting time for referrals for example, to community dietitians (Rand et al, 2024). There is little evidence on trends in food support provided by domiciliary care workers and personal assistants.

# Benefits of food support

Small scale studies on meals on wheels highlights some of the benefits from prepared meal provision for older people (Dickinson et al, 2022; Papadaki et al, 2022, Papadaki et al, 2023; Wilson, 2010):

- Maintaining independence and people's ability to remain in their own home
- Reducing social isolation
- Providing support and services beyond the meal itself such as welfare checks
- Reducing demands on more intensive support, as well as family carers

# Factors impacting on support services: challenges

There is variable academic evidence on the factors impacting provision of food support, but there is a significant amount of grey and anecdotal literature. Key factors identified include:

- Lack of understanding of the risk factors for different groups including older and disabled people (Lambie-Mumford et al 2023)
- Increasing food and operational costs of running services (NACC, 2023). The knockon impact of increasing costs also increasing the amount that people pay to ensure these services can remain viable (NACC, 2023)
- The wider pressures on public spending leading to depriortisation of non-statutory or preventative support (Papadaki et al, 2021; NACC, 2023)
- The very limited length of home care visits (Papadaki et al, 2021; Local Government Ombudsman, 2022)
- Limited training for care workers and undervaluing of their role in supporting good nutrition (Watkinson-Powell, A., et al, 2014)
- Variable and at times poor information about meals on wheels services (Roberts, R. et al, 2024)

# Impact of gaps in support

Worryingly, there is evidence of an increase in self-reported unmet needs related to food and drink. Analysis of older people aged 65+ using social care in the Adult Social Care Survey found an increase from 4.3% in 2011 to 8.1% in 2022 reporting unmet care needs related to food and drink (Rand et al, 2024).

# Our findings

## Cooking and preparing food

Cooking and preparing food present **opportunities for disabled and older people to have control and agency**, particularly where this may be challenging in other aspects of their daily life. For this reason it is important to consider how food support can ensure people have choice and control when receiving assistance of some kind and help some people to regain control where they may have lost this. For example, disabled people with a personal assistant (PA) can still direct food preparation while receiving support.

'Food is a great way to enable control to happen. Someone can direct their PA to cook a meal, and go shopping. The PA is their hands, people should be able to see what they have, need to buy, to be fully involved and in control. SDS should hand over control to the supported person...There are certain learnt behaviours which mean disabled people can be less assertive.' (NGO stakeholder)

**Meals delivery services** can use meals prepared in-house or meals that have been prepared by companies such as apetito. These meals are delivered to people as frozen or ready-to-eat. Research participants identified a range of issues for meals delivery, including the limited number of providers now available, the quality, or perceived quality, of delivered meals, the variable cost to the beneficiary of delivered meals depending on the level of subsidy provided, underestimates of need and decreased commissioning.

'Quality has gone down - the appearance, taste, quantity. Providers are struggling with rising costs and don't want to pass these onto services or people. So there are very few providers of plated meals to choose from. We have lost a lot of providers and demand has gone down as local authorities are not commissioning.' (Local government stakeholder)

A number of issues were identified in relation to **domiciliary care services**, including the time constraints on domiciliary care workers, the impact of care staff being delayed or not arriving at all and in some cases being substituted with care workers who do not understand people's food needs. This can result in people going without food. Care workers are often only able to reheat meals in the microwave due to the short time slot. In some cases we heard that the visit time can be as little as six minutes in reality, so even this task faces competing priorities. Indeed, a number of participants expressed that care workers were being put in impossible situations.

'They only have 15 to 20 minutes, they will not cook anything. There's a rule that they do not cook anything at all. They only microwave. They might make a cup of tea and that. So you can't order anything that requires any preparation.' (Lived experience participant)

'Social care services have become harder pressed budget-wise and contact times have been reduced. So particularly in the evenings, there is simply no time to prepare a meal... and what they get in the evening is a ready meal put in the

microwave and served to them within 15 to 20 minutes and that's it. So the quality of the food and all the additives that are in it, it's not good and so again there's real issues there.' (DPO stakeholder)

'We've had reports of disabled people relying on care and carers don't turn up. And of course people are sat there without any access to food in completely inaccessible settings that they can't really get out of.' (DPO stakeholder)

Flawed service provision can lead to apparently absurd situations, for example of people being served two meals in quick succession.

'Once went in to assess someone for home help and she was being given breakfast at 11:30 and then the next home health came in at quarter to 12 and served lunch to her.' (Lived experience participant)

There is often no or very limited **training for care workers on preparing food** beyond food hygiene. There are some initiatives to offer training for directly contracted care workers, but it is harder to reach independent providers to provide this.

'Care workers are expected to provide food with no training whatsoever. If someone goes to catering college, there's no care module and specific dietary needs are not included.' (Local government stakeholder)

We did also hear about some people's own hesitation or outright opposition to asking for social care support. This may be due to distrust of services in terms of what they actually receive or a feeling that they should be able to manage or don't want to ask for help.

'The one reason that I won't get social care is because I'm too proud.... I think that's probably a male thing, probably a Western Scotland male thing, but when I worked in Glasgow and the number of men that really needed assistance that would not accept it.' (Lived experience participant)

We also heard examples of the limitations of **nutritional supplements** where their consumption is not monitored and it can be assumed that a food access need has been met simply by prescribing them.

'Food first, supplement after. You do see fridges full of them, prescribed, but not monitored.' (Local government stakeholder)

# Impact of lack of support

Stakeholders are concerned about the **impact of unmet needs** related to food, this relates to both people's access to food, but also the lack of ancillary benefits such as social contact and regular welfare checks. This was highlighted in relation to closures of community services or groups, where people may have regular contact with the same people and concerns that at-home services do not always provide such regular contact with the same people. It should however be noted that we heard how some services, including meals delivery services, do try to send the same staff on a regular basis.

'But all that other stuff that comes with going to these centres is missing and not being replaced with anything. Sometimes obviously with the at-home food services, sometimes it is the same person that comes into your house, but often it can be someone new every single day, just because of how the services are run. So again, there's not that kind of continuity of that personal relationship.' (Government stakeholder)

There are also concerns that where food may be provided, **there is not enough support in place to ensure it is eaten**, that's to say 'getting from plate to mouth'. Challenges around this include physical difficulties, fear of choking while alone, lack of motivation, lack of appetite related to impairments, conditions or treatments. Therefore support required also varies accordingly and can include assistance, food preparation, encouragement and reassurance.

'One thing we fear...is people getting the food on their plate to their mouth because that's what's not happening. Social care and domiciliary care are coming in and preparing food, making sandwiches, but are not making sure that it's getting from the plate to the mouth.' (NGO stakeholder)

## Examples of policy and practice working well

A number of examples of policy and practice were shared during the workshops and interviews, as well as featured in the literature. Many initiatives aim to be inclusive and accessible to disabled and older people. In terms of targeted initiatives, there appear to be more initiatives specifically targeted at older people (who are likely to be living with a disability and or health condition), rather than disabled people of working age. These examples provide some sense of the variety and reach of initiatives. These examples are not based on formal evaluation evidence, rather they were examples that practitioners highlighted which we explored further.

#### Food support training for homecare and care home staff in Monmouthshire

One example cited by a local government stakeholder was that Monmouthshire Council developed a booklet and provided training to domiciliary care workers to provide effective food support. This work also aimed to promote the importance of food and drink among care providers. It has proved much easier to reach in-house care workers and much harder to reach care workers working for providers independent of the council. The Council has also worked with a newly built local care home which has its own kitchens. Staff and residents have Sunday lunch all together. Care staff were training to prepare and cook food. Residents can see and smell the food being cooked, which helps with their appetite.

#### Developing a new delivery model in Monmouthshire

This stakeholder also highlighted that Monmouthshire Council, with the support and funding of Cardiff University, has trialled a new model for preparing and delivering meals. The trial used a development kitchen, rather than a full kitchen, and an electric van to deliver meals. The trial used locally produced seasonal produce, as well as forgotten cuts of meat that can be used in stews and casseroles. The trial aimed to produce nutritional and appetising meals that would appeal to service users. The trial produced 200-220 meals a week for 30 people a day. The size of the development kitchen limited the scale of the trial.

# Subsiding meals on wheels in Fife to support service reach, foster viability and to prevent higher level needs

The NACC has showcased a number of meals on wheels services, including this service which delivers approximately 600 hot meals per day and 150 afternoon teas. Fife Council subsidises the service by about 30%. The Council values that the service provides people with nutritious meals, allows for regular welfare checks and supports people to remain in their own homes. The subsidy ensures the service is affordable for more people which helps to maintain the overall viability of the service. This also reduces the pressure on social care budgets, especially the need for residential care.

# Free meals deliveries for people receiving Universal Credit or Pension Credits in North Edinburgh and Leith

A DPO stakeholder referenced how Lifecare delivers two course hot meals to older and disabled people in the north Edinburgh and Leith areas. Deliveries usually take place twice a week. The charge is currently £7.15 for a two-course meal. There is no charge for people receiving Universal Credit or Pension Credits; this is funded by fundraising activities.

# Coordination and collaboration across the statutory and non-statutory sectors to ensure people can access food at home after hospital discharge

Sustain has gathered multiple examples from around the UK of health trusts, hospitals, councils, voluntary and private providers working together to identify food access needs and ensure support is in place for a patient's return home and for the longer-term as needed, this includes disabled and older people. However, this is highly variable with no consistent provision across the country.

There is also **emerging practice to rethink provision**. For example, the NACC is working with partners to develop new models for production and delivery of meals on wheels that are different to the traditional local authority commissioned services. This would explore models that use a central production unit to prepare meals for care homes and meals on wheels. This unit might be in a hospital or larger care setting or potentially community setting such as lunch clubs or local restaurants or pubs (Provider stakeholder).

#### Discussion

The existing evidence base is limited in terms of smaller scale studies, and a focus on certain interventions (for example meals on wheels provision). There is currently no systematic mapping of the different types of interventions available, or their coverage or scale, including identification of areas where there is no or very limited provision. Data that is available, for example data of adult social care service users is under-analysed despite clearly showing high levels of need for support with food. There is a modest but growing evidence base exploring meals delivery services, but detailed studies are often small scale. There is a real - and urgent - gap in research on support through home from hospital, domiciliary care and personal assistants.

As part of our research we heard about the current impact of rising costs on service provision alongside the continuing acute pressures on social care services. Remaining meals delivery services are often in precarious situations. We also heard how domiciliary care workers are often hampered by inadequate training, underfunding, short and very short

visits, late arrivals and substitutions. There are meal delivery services that are managing to survive and in some cases thrive in these difficult circumstances and emerging innovative delivery models. However, it appears that this work is disparate and there is certainly a lack of universal access to reliable and sustainable service provision.

The research also highlighted how provision of nutritional supplements can sometimes mean that 'real food' options are not considered first. Alongside this, there is particular concern about ensuring food is actually eaten. This is a vital component of food access support, highlighting how providing food or meals only is not sufficient for some people; they also need to be supported to eat meals. This could be reflected in data showing increasing levels of unmet food needs within social care support. More evidence is needed around the gaps which are emerging between support requirements and provision within social care and other services. Overall, the varied and often inadequate level of provision of food support is an important issue for policy and practice to address, given that it directly affects disabled and older people's health and wellbeing and management of certain conditions.

# 5. Legislative, policy and practice context of food support

This section explores the legislative, policy and practice context of food support and the key opportunities and challenges facing service providers, businesses, policy makers and practitioners.

# Legislation and policy

#### Legislative frameworks

Policy and practice designed to support disabled and older people with food needs is dispersed. This includes interventions to ensure people have an adequate income to access food and address the additional costs related to disability, as well as health and care responses. Responsibility sits at the UK, four nation and local authority or health and social care trust levels. Appendix 2 identifies key policy and practice responses produced across the four nations since 2001.

Policy and guidance around support to prepare and eat meals is included within legislation, guidance and standards. However, relative to hospital and residential care settings, there does not appear to be as much of an emphasis or special focus on this in relation to assistance, care and support for people in their own homes (Rand et al, 2024).

Across all four nations there appears to be a significant focus on addressing malnutrition in hospital settings, despite there being higher prevalence in the community (Elia et al, 2010). Governments in all four nations in the UK have taken a broadly similar approach to addressing malnutrition among older people. BAPEN tracked action on malnutrition by governments and other national bodies across the four nations up to 2018 and this presents a fairly consistent picture, even if some administrations have gone further than others (BAPEN, 2021).

Many different actors and providers are involved in provision of food support, including the NHS, local authorities, voluntary sector, not-for-profit, social enterprise and private providers. The table below sets out key actors and their roles.

Table 2: Overview of roles and responsibilities across sectors and scales

UK level government	<ul> <li>Human Rights Act (including the Right to Food)</li> <li>Equality Act and Public Sector Equality Duty (including reasonable adjustments that traders and service providers should put in place)</li> <li>Disability Living Allowance</li> <li>Personal Independence Payment</li> <li>Attendance Allowance</li> <li>UK Food Security Assessment (UKFSA)</li> </ul>	VCS, social enterprise and private sector providers and organisations  Work across these scales on delivery and advocacy:  • Advocacy, research and campaigning • Delivering commissioned services • Delivering non-commissioned services (charitably or self-funded) • Providing meals for other organisations to deliver	
Four nation governments	Policy and practice:		
Local authorities (in England, Scotland and Wales) and health and social care trusts (in Northern Ireland)	Implementation and local adaptation:		

# Statutory duties

The UK is a signatory to the Right to Food and social care legislation across the four Nations requires assessment of nutrition needs. However, a lack of focus on food needs at home, limited statutory duties and an inadequate application of human rights law lead to a lack of prioritisation of food needs at home and provision of assistance, care and support. Assistance that is currently provided is vulnerable to budget cuts due to insufficient statutory underpinning. There is a gap in ownership of the issue at national and local government levels.

'...although there is a Right to Food, I don't think that anyone from national government down through Scottish Government and local authorities actually takes responsibility for making sure that food gets to the people that really, really need it and that's a gap.'(DPO stakeholder)

'I have seen examples of good practice... of food delivery to older and disabled people. One of the problems I think is though that if you were to ask a local authority whether they had a statutory duty to commission such services, they would probably say no. And that makes it difficult when there's budget cuts to find to make the budget balance, those services are often the ones that then are reduced or just not funded at all. So there remains a real problem. It's like welfare rights, it's not a statutory duty for a local authority to provide a welfare right service. So again they're often first to be cut or reduced in scale when budget cuts are announced, so yeah some local authorities are very good and others much less so.' (NGO stakeholder)

'Access to food is everyone's human right and there's not policy around it and there's no ownership of it, government's not taking ownership.' (Local government stakeholder)

While each nation's social care legislation requires social services departments in local authorities or trusts to assess and meet eligible care needs, including ensuring people can access nutrition, there is no specific statutory duty beyond this that directs the types of food provision and support that should be available. This leads to inconsistency across local authorities and trusts. There is also a lack of information and difficulty accessing information.

'There is no responsibility at the moment. Lots of departments will say it's the local authority, but there is no statutory responsibility. Local authorities will focus on what is statutory, and local authorities say it's not their responsibility.' (Provider stakeholder)

# Food supply

National government attention is focused on food supply at a national level and income support, rather than in-home support services which government considers to be a local concern. Indeed the UK Food Security Assessment (UKFSA) is very much focused on food supply chain resilience, ability to purchase food and consumer confidence. **The lack of a clear statutory duty on food access leads to a gap both in terms of responsibility and response**.

'From a national government perspective, it seems that there is more of a focus on foods that can be bought, like supermarket food and stuff like that, rather than athome food services, so I think and that might be because people centrally don't see as you know, it seems like it should be a local authority focused area, but obviously for local authorities, it's not for them, so I think there is has been identified there is a gap.' (Government stakeholder)

# Policy makers and practitioner perspectives/challenges

A more general lack of easy **collaboration between national governments and local authorities** is also thought to hamper joined-up responses including to food needs, whether related to adult social care needs or at the point of hospital discharge.

'The links between the LGA [Local Government Association] and all the local authorities with central government is quite complicated. So even from our view of [a UK government department], if we want to reach the local government network, it's really hard to actually find those contacts and really hard to actually get anything, any sort of communication going. I think that's another key piece that's missing is that link between central government and local government and getting those links between them. I think when you are discharged from hospital, it's so overwhelming anyway, but if you have a clear pathway of things that are open to you then you can see ok these are the decisions I need to make and this is when I need to make those decisions. Just making that kind of pathway super clear, but again going back to what our first discussion was I don't know who has responsibility for that. I think there's so many gaps in that process that sounds like a good idea to address, but actually really hard to implement.' (Government stakeholder)

#### Gaps in national policy-making can create variability in responses at the local level.

For example in Scotland support for food shopping is not considered as eligible as part of the free personal care entitlement (which does include other aspects of care and support and beyond 'personal care' itself). As in other parts of the UK, charities in Scotland have taken on the shopping support role in some areas, supported by different levels of statutory or charitable funding.

It is also unclear if self-directed support, personal budgets and direct payments, which are intended to ensure needs are met in an individualised way, enable people to better meet their needs around preparing food and eating.

'Access to self-directed support varies by local authority as well within Scotland. So some local authorities are good at promoting it and providing it as an option, others much less and still any favour either in house or commissioned care support, rather than giving somebody a budget of their own. And that obviously affects how the person can choose to spend the money on what they believe are their greatest needs.' (NGO stakeholder)

**Devolution** has allowed for some services to be more protected and supported than in other nations.

'Advantages of the funding model for devolved administrations, more campaigning and evidence has helped to protect services in these other three nations, rather than England.' (Provider stakeholder)

#### The role of other actors

Legislation and policy provide the context for other actors including providers of support, NGOs, DPOs and food retailers.

Among service providers, **responsibilities around food support** are also unclear, this can impact on a range of aspects of service delivery including standards, training and operational procedures.

'Domiciliary care managers are not clear on their responsibilities and how to recognise if there's a problem. Nobody actually knows what guidelines we should be following, as it's not clear. There's no policy that says they have to know how to feed people, whereas moving and handling is a given. It's just as bad for someone to eat something they are allergic or intolerant to. This can be as bad as a medication error which would be a reportable incident and have to be investigated. This is just as serious but not seen that way.' (Local government stakeholder)

The impact of a lack of clear responsibilities can hit hard for individuals, for example those **living in rural areas**.

'If they've not got a family member, they reach crisis before any help is available. People living alone end up in crisis before being recognised as having a problem. They are hard to reach, we don't know they're there and don't know they need help. Because they're rural people living remotely, they're less likely to be flagged by neighbours. It could be people living in very nice houses in the middle of nowhere, who are suddenly in hospital. The house is well maintained, but they're not eating well, not getting to shops and not coping. Is that a health problem? Not sure whose job it is to look?' (Local government stakeholder)

Stakeholders shared that many local authorities and trusts looked to NGOs and local community groups to provide access to food at home during the peak of the Covid-19 pandemic. This required a slackening of the normal rules and regulations surrounding commissioning, but worked well in many areas as the NGOs (including DPOs and groups supporting older people) and local community groups had greater knowledge of the barriers facing older and disabled people and also better intelligence on which groups needed support and the type of support that might be required such as special dietary needs due to health conditions or cultural needs.

The **role of DPOs and NGOs** to campaign and advocate for effective policy is hampered by gaps and confusion in policy. Organisations have limited capacity to research and campaign on these food access issues. Most recently the cost of fuel has had to be a priority for such campaigning, especially given many disabled people can have higher energy costs. This may give the incorrect impression that there is not a significant issue around food access.

During concerns about a no-deal Brexit in 2019, Sustain tried to unpick where responsibility for food access sits and ensure that there was a clear sense of responsibility particularly in relation to people at higher risk of food supply disruption, including older and disabled people. (Sustain, 2019). The Government's response was that:

'Local authorities do not have a general duty to provide food but have duties to provide food to particular groups in particular circumstances, including schools and care settings.' (UIN 281010, 2019)

Sustain's conclusion at the time was that if someone receives meals in a care home, hospital, prison or school, their food supply might be secure, but this is not guaranteed

(Sustain, 2019). This lack of certainty would appear to be particularly the case for those living in their own homes.

**Food retailers** are subject to the Equality Act in terms of ensuring older and disabled people have access to goods and services and consumer regulation in terms of labelling and packaging. Alongside following legislation and regulations, some retailers have also developed a range of voluntary initiatives to support access, including in-store assistance and 'quiet' shopping hours (Equality and Human Rights Commission, 2019).

#### Discussion

Gaps and confusion in legislation and policy, as well as limited statutory responsibilities around food and nutrition have resulted in a fragmented and variable response to ensuring food access for older and disabled people.

There may be value in focusing on the extent to which social care assessments and support plans do identify and meet needs related to food and nutrition, as these responsibilities are on a statutory footing. This also applies to whether self-directed support is operating effectively to enable people to meet food needs.

Support providers, whether in the voluntary, social enterprise or private sector are challenged in a policy environment that does not appear to consistently prioritise food access for older and disabled people.

Food retailers are legally required to take some action to ensure older and disabled people can access their services, but this can be limited to legal requirements around physical access and assistance, without a full understanding of the different actions they can take for example in terms of the retail offer.

Due to capacity, NGOs and provider representatives face challenges in highlighting gaps in policy and ensuring they are addressed.

# 6. Participation

This section explores examples of disabled and older people's participation in designing policy and/or practice in order to capture learning for future involvement activities.

# Summary of evidence

In recent years there has been an increase in involving people with lived experience of an issue within research, including in projects on related topics including Food vulnerability during COVID-19 and Covid Realities (Food Exp CV19 Panel, 2021; Patrick, R., et al, 2022). There is however a gap in evidence of the impact of participation both in terms of disabled and older people's experiences and the benefits for policy and practice.

Examples of older and disabled people's participation

There are a range of real-life examples of working with disabled and older people to involve them in designing policy and practice. A number of organisations support standing panels of disabled and/or older people to help shape policy and practice. There are also regular fora or meetings of representatives of Disabled People's Organisations which can also meet to discuss policy and practise with a view to influencing them. In reviewing recent examples, they can often be primarily characterised as campaigning or advocacy outside statutory organisations, formal partnership agreements with statutory organisations or research.

# Our findings

Participants shared some of the reasons behind their **motivation** to get involved in opportunities for engagement or participation. This included a need to speak up on behalf of those less able to do so and to ensure that disabled people's voices were included in discussions.

'Want to campaign on behalf of people who don't have a voice, [there are] so many inequalities, I want to help influence for people who are very vulnerable.' (Lived experience participant)

'So it's become so difficult and it's important that disabled people along with disabled people's organisations are sat at these tables with ministers and prime ministers. We need to let them know the difficulties in the widening inequalities and the suffering that disabled people are having.' (Lived experience participant)

Participants did share some **positive experiences** of participation. This included individual benefits such as having opportunities to share experiences and opinions and learning about other people's experiences. As well as feeling that they were genuinely being listened to , that feedback was being acted on, for example in relation to the grocery boxes provided to people shielding from Covid-19, and being consulted in advance of decisions being taken, rather than being consulted too late in a decision-making process. There was a sense that this has improved in terms of engagement with local government and the Scottish

Government, but there was less confidence in being listened to by the government in Westminster.

'It was a real insight into how poverty is different here than in rural areas. Difficulties I wouldn't have thought of if I hadn't been on that panel. Like missing a bus that runs once a day and all the additional costs, they have to buy oil, hundreds of pounds in one go. Being part of the panel gave me an insight into other people's lives and a basis to share what I was going through and know there are other people out there. Can't talk to neighbours about issues. It's a safe space for me. I got to speak to policy makers, decision-makers.' (Lived experience participant)

However, a significant number of participants did also express **scepticism**, **disillusionment and fear** around participation. Examples included not feeling listened to or there being a genuine commitment to participation, suggestions being watered down, decisions being made outside of evidence, as well as being over-consulted.

'They then put their thoughts together to the Scottish government and then some guy in the Scottish Government, a civil servant, makes a decision on what he puts forward to the minister. And so when you start off with really good values and points, by the time it gets to the minister, they're all watered down.' (Lived experience participant)

Participants also highlighted a **lack of equality**, **access or information and respect** that would enable genuine participation.

'Not always very accessible to do. I want to do more of it. It's hard to know who to get in touch with, how to go about things.'(Lived experience participant)

Participants identified **opportunities for future engagement and participation**, for example regular engagement by supermarkets to generate regular feedback.

'So in many ways, it would be a good idea if they communicated regularly and maybe they had a forum for their supermarkets or supermarkets in general in an area and invite people to join. Even if it was just once a month people could talk about, they could ask them about a certain promotion that didn't work or something like that or what they thought of a promotion. I think that would actually be quite helpful.' (Lived experience participant)

During our workshops, we identified a number of **challenges for participation**, particularly for disabled and older people.

- Engagement with rural or more isolated areas is increasingly possible via online meetings, however not all disabled people have access to the internet.
- Face-to-face meetings with a group of strangers in unfamiliar settings are not always a good option for neurodivergent and autistic people.
- Involvement can be particularly challenging to deliver for some impairment groups such as people with low energy levels or for whom attending events can consume a lot of their available energy.

- Navigating some tension between access requirements for different groups, for example what colours and lighting levels to use
- Consultation fatigue, which is compounded by disabled people saying that they are seeing things getting worse rather than better
- Locally-supported ideas and innovations being hampered or even undermined by Westminster in terms or funding and/or policy

#### Examples of participation in Scotland and Greater Manchester

Workshop 3 included presentations from Inclusion Scotland and Greater Manchester about the work they do to support participation of disabled people in policy making.

#### Inclusion Scotland

Inclusion Scotland aims to involve disabled people either directly or indirectly to influence policy, bringing them in contact with decision makers. They focus on involvement of disabled people during national level consultations, for example from the Scottish Government, NHS and Police Scotland and less so on local authorities as their member DPOs do more of the local authority work themselves. They aim to ensure Ministers, MSPs and Scottish Government officials attend workshops involving disabled people, so that they can hear directly the lived experiences that they have.

When social security benefits, particularly disability and carers benefits were being devolved to Scotland, Inclusion Scotland argued very strongly and successfully for the creation of lived experiences panels. This presented a real step forward for inclusion of disabled people in policy development. Sometimes people share their evidence in private sessions due to the nature of what they want to say. This ensures that MSPs still hear from these people.

'We also got opportunities to have face-to-face meetings with ministers and put our questions to ministers and try to have conversations and have a close link that way as well, which I thought was really great. We really gelled as a group and it became a safe space for all of us to share our views and I think after a couple of sessions, we really did realise that it was a safe space where we could share all our views. And it really did encourage me to go further with what I like to do and that's voice my opinions and talk about matters that affect me and other disabled people.' (Lived experience participant)

Inclusion Scotland is also funded to facilitate a people-led policy panel aiming to co-produce the reform of social care in Scotland meeting regularly with Scottish Government officials. Members are disabled people and unpaid carers who are able to directly share their experiences and ideas with officials.

Inclusion Scotland has also started a parliamentary intern scheme that placed young disabled people as interns with MSPs. This aimed to benefit the young people in terms of experiencing high level policy making first hand. It also gave MSPs insight into the barriers faced by disabled people as their own interns faced barriers coming to work and taking part on an equal basis.

Inclusion Scotland has also supported people to be part of the Poverty & Inequality Commission's Experts by Experience Panel. This was made up of 20 people. The panel met a few times a month and tackled issues such as the cost of living, benefits, housing and energy costs. The Panel recommended changes to the Scottish Government and held meetings with Ministers. The panel provided a safe space for people to share their experiences and views. This helped to inform policy but also helped individuals to connect and better see that there were others going through similar experiences and challenges.

#### Greater Manchester Disabled People's Panel (GMDPP)

During the first election campaign, the Mayor of Greater Manchester committed to supporting the action in the disabled people's manifesto to establish the GMDPP as a place to consult directly with disabled people on policy. 16 DPOs from across Greater Manchester's 10 boroughs are part of the panel. The Greater Manchester Coalition of Disabled People is funded to run the panel. There are panels for other groups too such as LGBTQ+ people, women and girls, faith and belief, race, older people and young people.

'Actually I would say always the initiatives that have improved people's lives come from disabled community and the organised disabled people's movement and organisations. We haven't got time to go through history, but often people kind of think maybe charities did it or maybe a bill in Parliament emerged. Those are all down the line of disabled people actually agitating for that. So the first thing about this panel and the work we've done, it came from disabled people and disabled people's organisations. The system itself does not know enough about the people it rules over to do the right thing; initiative is always needed by the community.' (DPO stakeholder)

For the Coalition, it is very important that a DPO is the convener of this panel; it is not convened by civil servants, local government people or the Combined Authority. This allows the Panel to have 'one foot in the system and one foot in the community' and fulfil the role of a critical friend.

Greater Manchester Coalition of Disabled People is also part of the DPO Forum England. This came out of meetings during the pandemic. The attendees found the meetings really useful, whether there was a minister attending or not. DPOs use the meetings to connect, share information and hear from guest speakers showcasing good or innovative practice, as well as engage with politicians and policy-makers

The Coalition is also involved in the proposed Social Care Commission for Greater Manchester (an element of the Greater Manchester trailblazer devolution deal). This aims to develop a roadmap for social care that can support independent living, free at the point of need. This should develop proposals for action in Greater Manchester which will also hopefully influence and push agendas at the national level.

#### Discussion

There is a growing commitment to participation within policy-making and research, including in areas related to food access. There are already some well-documented reflections on this, and our research provides some further insight into participants' experiences.

There are disabled and older people who are highly motivated to share their experiences to try to improve policy and practise for themselves and others. There are also some who are sceptical of the extent to which they will be listened to, and the chance of success in influencing policy and practice. Participants raised the issue of consultation fatigue. This can be particularly pronounced when people are asked to participate in processes to explore individual or compartmentalised issues, such as fuel or food poverty, accessible housing or transport, access to health and care or income or social security, rather than be part of a process that considers the multiple issues affecting them in the round. This highlights the need for policy makers and practitioners who establish these processes to work towards, evidence and communicate putting people's advice into practice, as well as explaining back to participants where this hasn't happened. It is also incumbent to consider whether sufficient evidence already exists to support action, without placing further requests on people with lived experience.

There is evidence of improvements in mechanisms for listening to and responding to disabled and older people, and there are multiple opportunities for participation by disabled and older people. These can range from research and consultation to formal partnerships to advocacy and campaigning groups. The most successful examples are backed by a genuine commitment to participation, taking an approach centred on the social model of disability, adopting formal structures, resourcing organisations, particularly DPOs to convene spaces and crucially genuine willingness from policy-makers to listen and take action (or set out why action hasn't been taken). There is still a long way to travel before disabled and older people feel confident that they will be listened to and action taken on the basis of their experiences.

### 7. Conclusions

#### Conclusions

There are **multiple and multifaceted barriers** to disabled and older people accessing food at home. However, these barriers can be identified, explored and addressed by policymakers, researchers and practitioners. Any policy and practice solutions should be considered in relation to real life experiences of disabled and older people.

**Adaptations to behaviour** by older and disabled people to ensure access to food can include a combination of preferences, necessity, compromise and choice. A range of enablers support people's adaptations. Action across research, policy and practice can address specific gaps in understanding including in relation to pre-prepared food, readymeals, takeaways and informal support.

Provision of **interventions** to ensure food access for older and disabled people is patchy, as is the evidence assessing practice and impact. Recent cost increases have placed further pressure on existing provision.

**Legislative policy and practice** contain multiple gaps including a lack of statutory duties to ensure food access. Responsibility and ownership of the issue is not taken on in a clear way by statutory organisations.

There is a growing focus on **participation** of older and disabled people in policy making and shaping practice. While there are positive examples of people's experiences, there is still a lot of work to be done to genuinely listen to older and disabled people and for them to feel that their experiences are shaping policy and practise for the better.

#### 8. Recommendations

This research has explored the multiple challenges to access to food at home for older and disabled people, as well as opportunities to better understand and respond to these challenges. In response to the key issues raised in the research, these recommendations aim to prompt meaningful action at different levels and across different actors to ensure older and disabled people have equitable access to food in their own homes. For ease, we have divided recommendations by actor, there is therefore some repetition.

### National governments and governmental agencies

- Develop a clear understanding across governments, local authorities, health and care trusts, health services and other agencies of responsibilities to ensure older and disabled people's access to food at home.
- Ensure adequate incomes for disabled and older people, in order to protect economic access to food for these groups.
- Work with local authorities, trusts and researchers to understand the scale of food support currently provided by adult social care and health services as well as unmet need and limitations or gaps in support.
- Include supporting access to food home as part of adult social care reform, development of 'National Care Services' and funding allocations, including providing sufficient funding for homecare visits to be long enough for staff to prepare nutritious meals where this is an assessed need.
- Gather insight on the accessibility of food labelling for older and disabled people, including for those with allergies and preferences and requirements related to health, disability, impairment or neurodiversity and take action to respond to opportunities to improve labelling.
- Provide advice and reassurance for older and disabled people to feel confident in using online food shopping and delivery apps.
- Ensure planning for future supply chain disruption ensures access to food for older and disabled people, including meeting dietary requirements and other specific needs and preferences. Communicate these plans to older and disabled people and their organisations to provide reassurance.
- Support the development of emerging and innovative food provision to update, share good practice and safeguard provision for the long-term.
- Foster a sustainable funding environment for NGOs and DPOs working on food access issues.
- Work with researchers and the food industry to get a better understanding of the use and implications of reliance on prepared foods and online food purchasing.
- Ensure policy related to consumption of pre-prepared food, ready meals, takeaways and ultra-processed foods (UPFs) takes into account the perspective of older and disabled people and provides realistic alternatives.
- Ensure there are clear frameworks and funding to support and follow best practice in disabled and older people's participation in policy making.
- Monitor the impact of means-testing of Winter Fuel Payment on access to food and support uptake of Pension Credit and Winter Fuel Payment by those who are eligible.

Local government (local authorities in England, Scotland and Wales and health and care trusts in Northern Ireland)

- Analyse barriers to access to food at home for older and disabled people identified through adult social care needs assessments and the current response to identified needs in care plans, including self-directed support, and identify any limitations or gaps.
- Work with in-house services and independent providers to offer food preparation training for domiciliary care workers beyond food hygiene. This should include preparing meals within time available as well as how to feed people, how to boost their nutrition and hydration, how to fortify food and how to ensure people can eat and that food gets from 'plate to mouth'.
- Provide food preparation training for disabled and older people to attend alongside their personal assistant or regular care workers.
- Ensure homecare visits are sufficient to allow for preparation of nutritious meals where this is an identified need.
- Support existing local provision of food support, including opportunities to update and expand their offer, maximise referrals and safeguard provision for the long-term.
- Work with other statutory, community and private sector partners to support the development of emerging and innovative provision, including central processing unit models.
- Provide sustainable support for NGOs and DPOs working on food access issues.
- Help local community meals providers to also provide takeaway meals for people to eat on other days.
- Lead, or be an active partner with, 'home from hospital' services to maximise access to food support.
- Ensure professionals in contact with older and disabled people are able to share information on easy-to-prepare, nutritious and enjoyable meals and snacks.
- Support genuine participation mechanisms for older and disabled people and their organisations over the long-term, learning from and adopting existing good practice.

### Non-statutory funders

- Prioritise support for DPOs, older people's organisations and NGOs to understand, respond to, and campaign on food access needs among older and disabled people
- Support activities to develop, sustain, evaluate, and learn from food access initiatives benefiting disabled and older people.

Community, social enterprise and private sector providers of support

- Provide food preparation training for domiciliary care workers beyond food hygiene.
  This should include preparing meals within time available as well as how to feed
  people, how to boost their nutrition and hydration, how to fortify food and how to
  ensure people can eat and that food gets from 'plate to mouth'.
- Ensure food support is given due importance and time.

- Consider opportunities to offer takeaway or ready meals from services such as care homes or hospitals, including learning from emerging CPU models.
- Encourage older and disabled people accessing support to participate in opportunities to shape policy and practice.

#### Food and equipment industry

- Consider all aspects of accessibility for older and disabled people, not only physical accessibility.
- Ensure consistent approaches to in-store shopping support for customers.
- Maintain and expand provision of ready-to-eat nutritious and enjoyable food.
- Minimise price premiums for people buying smaller amounts of food to meet the needs of older and disabled people who live alone and to reduce food waste.
- Maintain affordable frozen food offer, including nutritious and enjoyable ready-meals or partially-prepared food.
- Offer and proactively promote options for affordable protein.
- Ensure pricing structures minimise additional costs for people accessing special diets.
- Ensure allergy information is easy to see in store and online and customers can filter by dietary requirements or preferences.
- Reduce the minimum spend and delivery charge for home deliveries for older and disabled people.
- Consider opportunities for playing more of a role in meal delivery for older and disabled people.
- Develop accessible and easy to use food preparation and cooking equipment which is easy for all to use, not just older and disabled people.
- Develop opportunities to regularly and meaningfully engage disabled and older customers and take action in response to insights gathered.

# Disabled People's Organisations and older people's organisations (subject to available funding)

- Evidence people's food access needs and map current local responses, limitations and gaps.
- Consider opportunities to develop food preparation courses for disabled and older people and their personal assistants or regular care workers.
- Work with informal carers to foster choice, control and independence when preparing food for others.
- Share information on easy-to-prepare, nutritious and enjoyable meals and snacks.
- Champion food access support and campaign about gaps in local areas.
- Develop relationships with local statutory partners to build genuine collaborative participation in policy making.
- Develop links with local food partnerships, alliances and networks to ensure they are inclusive of older and disabled people.

#### Researchers

- Build on existing research to ensure a comprehensive understanding around food access for older and disabled people, including areas of unmet need.
- Explore under-researched areas including access to safe and special diets, the role
  of labelling and packaging, digital exclusion, skills, motivation and preferences when
  preparing food, intersectional issues, adaptations, including the role of partially
  prepared foods, use of equipment and support from informal carers or mutual aid
  networks, support provided through home from hospital services, domiciliary care
  and personal assistants.
- Consider opportunities to conduct research with professionals who visit people at home such as occupational therapists, district/ community nurses, nutritionists, dieticians and community dietetics service.
- Explore how much food access needs are currently picked up by adult social care assessments, care plans and self-directed support.
- Ensure genuine participation for older and disabled people in research projects, by carefully planning participation opportunities from the start and in partnership with older and disabled people and their organisations. Frame research and language within the social model approach, focusing for example on older and disabled people's choice, control, independence, avoiding centring research on deficits. Use consistent language and markers to ensure comparability across individual research projects. Take a diverse and intersectional view of ageing and disability to ensure a wider understanding of disabled and older people's needs.

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## Appendix 1: Evidence review methodology

The aim was to review existing evidence relating to the experiences of older and disabled people in accessing food, with a focus on food preparation and eating at home; including food practices, service provision and policy responses. The review was conducted in April 2023 and updated in February 2024.

The review focused on food-based support and did not cover provision of nutritional supplements or food fortification. It focused on people living in their own homes only, rather than residential or hospital care where meals are provided. This scope does include people living in assisted or supported living without daily access to meals provided.

The review also assessed the extent of evidence of environmental sustainability considerations within practical food access initiatives. This is to understand the extent to which interventions are framed within the wider food system and efforts to improve and future-proof interventions.

#### Scoping review and search conducted in April 2023

- 1) Search tools to identify research
  - Google Scholar, Google
  - Sage, JSTOR, ProQuest Academic Complete
  - Scopus, PubMed, ProQuest Sociology

#### 2023 Search terms

Population	Elderly adults; elderly people; older adults; older people; adults over 75; adults over 80; adults over 85; pensioners; disabl* disabled (disability); geriatric; later life; ageing; homebound; housebound
Problem	Food, diet, nutrition  (Additional terms if needed: Access to food; food access; access to nutrition; health; diet; nutrition; malnutrition; nutritional risk; nutritional outcome; food safety; Loneliness; isolation)
Interventions	Meals on wheels; meal delivery; home-delivered meals; home-delivered meal programme; mealtimes; meals; frozen foods; ready meals; frozen meals; ready to heat; meal kits; lunch clubs; luncheon clubs; shared meals; communal meals; shopping delivery; shopping support; home from hospital; home help; domiciliary care.  (Additional terms if needed: Care; community care; adult social care; day care; social services; home visits; home care services; prevention; hospital discharge; rehabilitation)
Sustainability	Sustainab*; procurement; plant-based; vegetarian; low carbon
Author	Wendy Wills; Angela Dickinson; Angeliki Papadaki;

#### **Searches**

- 1 population + problem
- 2 population + intervention
- 3 population + intervention + sustainability
- 4 authors (cross referenced on the previous returns)

#### Inclusion and exclusion criteria

- Global comparable countries for defining problem/ categorisation and UK only for interventions
- Relevance to topic and review aims
- Empirical standard: minimum that evidence is based on data (no commentaries or editorials)
- Publication date from 2010 onwards
- Use both keyword and subject heading searches to ensure comprehensive

#### **Reviewing this literature**

Records were recorded in a spreadsheet split between academic and grey literature and categorised by population and 'problem' search terms. Interventions were recorded using the primary terms in each item (e.g. 'meals on wheels' or 'meals delivery' or 'delivered meals').

#### **Analysis**

Included research was reviewed thematically, in relation to the key areas of focus in the study. These were: key barriers older and disabled people face in accessing food at home, the adaptations individuals make and the extent, and benefits, of support available to people in their own homes, and gaps in support and the implications of these.

#### Policy and practice mapping

This was informed by the search returns and grey literature sources and was supplemented with Google searches for specific policies, as well as reviewing BAPEN's list of key policies up to 2021 (BAPEN, 2021) to map the policy and practice landscape.

#### Update to the evidence review conducted in February 2024

This had three elements:

- Updating our needs and interventions literature search
- Updating our policy and practice mapping
- Searching for literature on participatory engagement and case study examples.

We also asked stakeholders to alert us to any literature we should review.

#### Home-based food support need and interventions search terms

	Elderly OR older adults OR older people; adults over 75; adults over 80; adults over 85; pensioners; disabl* disabled (disability); geriatric; later life; ageing; homebound; housebound
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Problem	AND				
	Food, OR diet, nutrition, eating, food insecurity, malnutrition				
	(Additional terms if needed: Access to food; food access; access to nutrition; health; diet; nutrition; malnutrition; nutritional risk; nutritional outcome; food safety; Loneliness; isolation)				
Interventions	OR				
	Meals on wheels; meal delivery; home-delivered meals; home-delivered meal programme; mealtimes; meals; frozen foods; ready meals; frozen meals; ready to heat; meal kits; 'home from hospital'; home help; domiciliary care; adaptation; adjustment; equipment; social care				
	(Additional terms if needed: Care; community care; adult social care; day care; social services; home visits; home care services; prevention; hospital discharge; rehabilitation)				
Participation	OR				
	Participation; participatory; involvement; engagement				

#### **Searches**

- 1 population + problem
- 2 population + intervention
- 3 population + intervention + sustainability
- 4 authors (cross referenced on the previous returns)

#### Inclusion and exclusion criteria

- Global comparable countries for defining problem/ categorisation and UK only for interventions
- Define relevance to working definition above
- Empirical standard: minimum that evidence is based on data (no commentaries or editorials)
- Publication date from 2023 onwards
- Use both keyword and subject heading searches to ensure comprehensive

#### Reviewing this literature

Returns were added to the spreadsheet to avoid duplicates. Research was reviewed using the same thematic approach and also included a theme around disabled and older people's participation in designing policy and/or practice.

#### Policy and practice mapping

We returned to websites to check whether there were any updates to the policy and practice context.

# Appendix 2: Key legislation and guidance since 2001

#### **UK level**

- The Human Rights Act 1998
- International Covenant on Economic, Social and Cultural Rights (ICESCR)
- Welfare Reform Act 2012 and the Social Security (Personal Independence Payment) Regulations 2013, The Welfare Reform (Northern Ireland)
  Order 2015, The Social Security (Disability Assistance for Working Age People) (Consequential Amendments) Order 2022
- Agriculture Act 2020: UK Food Security Assessment (UKFSA)

#### Four nations

#### Policy and practice:

- Funding for social care and health
- National strategies and action plans
- Standards and Inspection
- Commissioning guidance
- Practice guidance
- Public health and food safety guidance

England	Northern Ireland	Scotland	Wales
National Service Framework for Older People (DH,	Health and Personal Social	The Community Care and Health	Nutrition in community settings. A
2001)	Services Act (Northern Ireland) 2001	(Scotland) Act 2002	pathway and resource pack for Health and Social Care
Improving Nutritional Care: A joint Action Plan from the	2001	Age, Home and Community: A	Professionals, the Third Sector,
Department of Health and Nutrition Summit	Quality Standards for Health and	Strategy for Housing for	Care Home Staff, Relatives and
stakeholders (DH, 2007)	Social Care: Ensuring Good	Scotland's Older People: 2012 -	Carers (Welsh Government, 2011)
	governance and best practice in	2021 (Scottish Government,	
Food, Nutrition and Hydration and Social Care online	the HPSS (DHSSPSNI, 2006)	2011).	Social Services and Well-being
training (Skills for Care, 2008) No longer available		Health and Social Care	(Wales) Act 2014
online.	Promoting Good Nutrition – a	Standards: My support, my life	
	strategy for good nutritional care		

QS24: Nutrition support in adults (NICE, 2012)

Care Act 2014

<u>Guidance – Commissioning Excellent Nutrition and Hydration 2015 – 2018</u> (NHS England, 2015)

Home care for older people (NICE, 2016)

QS 136: Transition between inpatient hospital settings and community or care home settings for adults with social care needs (NICE, 2016)

Helping older people maintain a healthy diet: a review of what works (Public Health England, 2017)

Skills for Care core and mandated training includes Food Safety, Nutrition and Hydration (Skills for Care, 2019)

<u>People at the Heart of Care Adult Social Care Reform</u> White Paper (DHSC, 2021)

Care and support statutory guidance (DHSC, 2023)

for adults in all care settings in Northern Ireland (DHSSPSNI, 2011)

Wellbeing - Eating and drinking (Scottish Government, 2017)

Coming out of hospital (Care Information Scotland, last updated April 2023).

The Scottish Government consulted on a new Health and Social Care Strategy for Older People and developing plans for a National Care Service and responded to this in October 2022.

Health and Care Standards included Standard 2.5 Nutrition and Hydration (Welsh Government, 2015)

Health and Care Quality
Standards 2023. (NHS Wales
Executive, 2023)

Hospital Discharge Guidance (Welsh Government, 2023)

#### Local authority or health and social care trusts

#### Implementation and local adaptation:

- Assessing needs
- Providing or commissioning services including meals on wheels
- Providing or commissioning adult social care, including domiciliary care workers
- Providing direct payments/ personal budgets/ self-directed support for personal assistants
- Market shaping



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