

# How should we think about “unmet need” in social care? A critical exploratory literature review

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**March 2023**



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## Summary of findings

This critical exploratory literature review was conducted between June 2022 and March 2023. It draws on over 100 conceptual/theoretical and empirical sources, including government documents, ‘grey’ literature and academic literature. The review aimed to explore and critically evaluate: a) how academic literature conceptualises need and unmet need in social care, b) how unmet need is defined and understood in policy and practice within the Scottish context, c) what is known about the unmet needs of people who receive (or not) social care support. The review has a particular focus on disabled adults. As unmet need in social care for disabled adults is under-researched, the review balanced systematic approaches with exploratory approaches, critically evaluating the literature throughout.

The key findings are as follows:

- Approximately one in every four people being supported by social care services in Scotland in 2020/21 was aged under 65. In 2020-21, £2.3bn was spent on social care for those aged over 65 in Scotland, and £1.5bn on those under 65. Far more people in Scotland receive home care than live in care homes.
- Accurately identifying and measuring unmet social care needs in Scotland implies defining what is meant by unmet needs in adult social care. The Independent Review of Adult Social Care (IRASC) (Scottish Government, 2021a) does not do this, and this review takes on this challenge.
- There is no statutory definition of unmet need in social care in Scotland. There is ongoing debate at theoretical, policy and practice level of what unmet need is. Not defining “unmet need” or having a very narrow view of “need” at a social care policy level creates a risk of inconsistent and inaccurate recording of unmet needs, with huge potential for under-recording.
- Most evidence on unmet need comes from older people using social care. This constrains our understanding of unmet needs for disabled adults through the lifecourse. It also restricts our understanding of the unmet needs of disabled people in all their diversity. Nevertheless, even narrow activity-based measures suggest that over half of older people in England with care needs have unmet needs for support (IPSOS Mori, 2017: 4). In Scotland, the 2021/22 Health and Care Experience Survey (Scottish Government 2022b) of a representative population sample found that 2.5% of respondents had not had any help or support with everyday living, but felt they needed it - a total that does not include those who received some, but insufficient, support. The survey also found that disabled people, notably those with impairments that limit them ‘a lot’, are the social group with highest unmet social care needs.
- Unmet social care needs could be described as “*care poverty*” (Kroger, 2022). “Care poverty” describes where people in need of care do not receive any support or have insufficient support from either informal or formal sources. In “care poverty”, care becomes seen as a vital, non-material resource necessary for well-being in the same way as economic resources in poverty research.
- Different perceptions of need, definitions of unmet need, operational, organisational, and structural barriers, power structures, geographical inequalities, how the roles of

informal and formal carers are construed, and global crises such as austerity and Covid-19 with related financial pressures, all affect interpretation of unmet need. These limit the accuracy of needs assessments, and raise questions of fairness and of whose 'voice' matters.

- Disability studies, the social model of disability, and the work of the disabled peoples' movement demonstrate the need to foreground the voices, views and lives of diverse disabled people. Disabled people are structurally disadvantaged, but within that are as diverse as any other social group, experiencing multiple types of inequality and different types of intersectional unmet social care needs.
- Disabled people need to be fully involved in co-designing social care so that it accurately reflect their complex realities, intersectional identities, and aspirations through the lifecourse. Disabled People's Organisations (DPO) amplify the collective voice of disabled people and can independently inform disabled people about social care, human rights, and independent living options. Involving disabled people and DPOs will enable a more holistic approach to social care assessment and support, and overcoming power imbalances in expression of care and support needs will achieve more accuracy in measurement of unmet needs.
- The dominant interpretation of unmet need has been lack of service provision regarding activities of daily living and independent activities of daily living (ADL/IADL). These are narrow and individualised, and pre-date the social model of disability and contemporary notions of independent living as long endorsed by the Scottish Government, NHS, COSLA, and by IRASC (Scottish Government, 2021a and 2021b). ADL/IADL are an outdated model for how Scotland should be thinking about unmet needs in social care. They also pre-date Scotland's National Performance Framework (NPF). It is long overdue for Scotland to measure unmet social care needs based on how life is actually lived by disabled adults through the lifecourse, in social contexts and inter-dependently, with rights and aspirations, and with reference to independent living outcomes.
- IRASC (Scottish Government, 2021a, p.9) defines independent living as follows, which aligns with Scotland's NPF outcomes:

Independent living means people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. It does not mean living by yourself, or fending for yourself. It means having rights to practical assistance and support to participate in society and live a full life.

- IRASC also notes that social care should be about: *“supporting people to achieve their outcomes, to have a good life and reach their potential, including taking part in civic life as they themselves determine”* (Scottish Government, 2021a, Recc. 39). Scotland's principal social care delivery legislation notes that Self-directed support *“is intended to support, promote and protect the human rights and independent living of care and support users in Scotland ... delivered in a way that supports choice and*

*control over one's own life and which respects the person's right to participate in society.*" (Scottish Government, 2014b, p.4).

- To achieve independent living outcomes for all Scotland's adults that need social care first requires identifying and measuring the unmet care needs of three groups. Those who need social care but receive none; those who receive some social care but need more; and those who need their social care to be amended in order to achieve independent living. **'Unmet needs in adult social care' in Scotland should therefore be defined as: (a) the number of adults in Scotland that need any, more, or amended, social care to enable them to achieve and sustain independent living, and (b) the range of those unsatisfied care and support needs.** Or, to put it another way, the number of adults that need some, more, or different social care to be able to live life 'in all its fullness'<sup>1</sup> in Scotland, and the range of those unsatisfied care and support needs.
- There is a need for detailed and consistent record keeping of unmet needs during needs assessment. Not only in relation to existing services but with a focus on the person's inter-dependent and social needs and *"supporting people to achieve their outcomes, to have a good life and reach their potential, including taking part in civic life as they themselves determine"* (Scottish Government, 2021a, Recc. 39). This is the basis for accurate measurement of social care needs, which in turn is the necessary foundation for Scotland to fulfil disabled adults' social care needs in relation to independent living.
- More accurate needs assessment and record keeping for individuals requires consistent aggregation and analysis at local authority level in order to create accurate locality data to identify unmet social care needs and so to better inform priorities for social care-related policy at local level.
- To fulfil the National Care Service aim to tackle regional and Scotland-wide levels of inequality requires nation-wide aggregation and analysis of unmet social care needs. To our knowledge, there is no independent body (a) to evaluate the quality of needs assessment across local authorities, (b) to support social care services with the transition to accurately and consistently recording and measuring unmet social care needs in relation to independent living, or (c) to strategically co-ordinate, analyse, interpret, and respond to unmet needs data as they emerge across Scotland, ensuring these are tied to independent living outcomes, and tackling inequalities through the process. There is a need for such a body to drive through accurate evaluation of unmet needs in adult social care in the context of independent living. The body should involve disabled people, Disabled People's Organisations and social care user groups in the process.

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<sup>1</sup> Fiona McQueen, Chief Nursing Officer for Scotland 2015-2021, speaking at 'Global Shocks' event on social care, University of Glasgow, 24 October 2022.

## 1. Introduction

In Scotland, recording unmet needs in social care is proposed in the Independent Review of Adult Social Care (IRASC) (Scottish Government, 2021a) as part of its strategic goal of reforming social care to improve outcomes for people and communities. IRASC Recommendation 5 states: *“Where not all needs can be met that have been identified as part of a co-production process of developing a support plan, these must be recorded as unmet needs and fed into the strategic commissioning process.”* It adds: *“responding to unmet need for social care supports ... should be the priority for financial solutions”* for social care (Scottish Government, 2021a: 42).

This implies two separate - but related - activities. First, a Scottish approach to accurately identifying and measuring unmet needs in adult social care, so that these can be fed into the strategic commissioning process. Second, a Scottish approach to allocating resources to respond to those unmet needs. This literature review addresses the former activity. **Accurately identifying and measuring unmet needs implies defining what is meant by unmet needs. IRASC does not do this, and this review takes on the challenge.** Not defining “unmet need” or having a very narrow view of “need” at a social care policy level creates a risk of inconsistent and inaccurate recording of unmet needs, with huge potential for under-recording. Audit Scotland (2022: p14) note that inconsistent recording makes it problematic to *“assess the level of unmet need and therefore what more is required to deliver a person-centred, human-rights approach to social care”*.

Scotland has an established National Performance Framework.<sup>2</sup> This sets out core values, aspirations and outcomes to indicate Scotland’s success as a nation. The purposes of the NPF encompass increasing the wellbeing of people living in Scotland, and reducing inequalities and giving equal importance to economic, environmental and social progress. The NPF outcomes include that people:

- live in communities that are inclusive, empowered, resilient and safe.
- are creative and their vibrant and diverse cultures are expressed and enjoyed widely.
- are well educated, skilled and able to contribute to society.
- are healthy and active.
- respect, protect and fulfil human rights and live free from discrimination.
- tackle poverty by sharing opportunities, wealth and power more equally.

Public policy and practice at all levels should align with the NPF goals. IRASC argues that investing in social care helps Scotland to achieve all the purposes of the NPF (Scottish Government, 2021a, p.20). In IRASC, social care should be about: *“supporting people to achieve their outcomes, to have a good life and reach their potential, including taking part in civic life as they themselves determine”* (Scottish Government, 2021a, Recc. 39).

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<sup>2</sup> <https://nationalperformance.gov.scot/what-it>, accessed 21 Feb 2023.

In line with these goals, the intent of Scotland's principal social care legislation, Social Care (Self-directed Support) (Scotland) Act 2013 (Scottish Government, 2014b, p.4) is that:

Self-directed support, alongside many other policies, is intended to support, promote and protect the human rights and independent living of care and support users in Scotland. It aims to ensure that care and support is delivered in a way that supports choice and control over one's own life and which respects the person's right to participate in society.

The concept of independent living is fundamental to a contemporary understanding of unmet needs in adult social care in Scotland. IRASC (Scottish Government, 2021a, p.9) defines independent living as follows, which again aligns with the NPF outcomes:

Independent living means people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. It does not mean living by yourself, or fending for yourself. It means having rights to practical assistance and support to participate in society and live a full life.

IRASC notes that this definition has been adopted over many years by the Scottish Government, COSLA, the NHS and the disabled people's independent living movement.

To achieve independent living outcomes for all Scotland's adults that need social care first requires identifying and measuring the unmet care needs of three groups. Those who need social care but receive none; those who receive some social care but need more; and those who need their social care to be amended in order to achieve independent living. **'Unmet needs in adult social care' in Scotland should therefore be defined as: (a) the number of adults in Scotland that need any, more, or amended, social care to enable them to achieve and sustain independent living, and (b) the range of those unsatisfied care and support needs.** Or, to put it another way, the number of adults that need some, more, or different social care to be able to live life 'in all its fullness'<sup>3</sup> in Scotland, and the range of those unsatisfied care and support needs.

To arrive at the above definition, this critical exploratory literature review draws on government documents, 'grey' literature and academic literature, exploring "unmet need" in adult social care with a focus on the Scottish context, and seeking evidence on disabled adults through the lifecourse. The literature on unmet need in social care has generally focused on support for older people with what are commonly known as 'activities of daily living'. This follows a broader pattern of social care discussion by governments and other commentators focusing on older people. This minimises the experiences of disabled adults of working age. However, approximately one in every four people being supported by social

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<sup>3</sup> Fiona McQueen, Chief Nursing Officer for Scotland 2015-2021, speaking at 'Global Shocks' event on social care, University of Glasgow, 24 October 2022.

care services in Scotland in 2020/21 was aged under 65.<sup>4</sup> In 2020-21, £2.3bn was spent on social care for those aged over 65 in Scotland, and £1.5bn on those under 65 (Fraser of Allander, Aug 2022, p.4).<sup>5</sup> And far from the news-grabbing stereotype, far more people in Scotland receive home care than live in care homes.<sup>6</sup>

In sum, this review aims to explore and critically evaluate: a) how academic literature conceptualises need and unmet need in social care, b) how unmet need is defined and understood in policy and practice within the Scottish context, c) what is known about the unmet needs of people who receive (or not) social care support. The review has a particular focus on disabled adults. The review brings in a disability studies lens, which incorporates social model of disability and independent living principles, supported by the Scottish Government and IRASC, and consistent with the purposes, values and outcomes of the National Performance Framework. A disability studies lens allows the review to highlight three themes. First, the intersectional identities and diversity of impairments of disabled adults. Second, the wider inequalities that shape human needs, as established in social policy literature. Third, the inter-dependent lived experiences that constitute meaningful quality of life for disabled people, as for every other citizen. Finally, the review touches on the power of the care system and paid carers, and the role of informal carers, and how these also influence unmet needs. **Synthesising this evidence, the review argues for a Scottish approach to identifying unmet social care needs for disabled adults through the lifecourse. This approach should integrate principles of the social model of disability, independent living and human rights, and reflect the purposes, values and outcomes of the National Performance Framework.** The review concludes that it is vital to broaden out narrow, activity-based interpretations of unmet need, in order to enable accurate measurement by reflecting how life is actually lived by disabled adults, in social contexts and inter-dependently. The review incorporates a list of key findings.

## 2. Method

This review was conducted between June 2022 and March 2023.<sup>7</sup> To understand unmet need in adult social care in Scotland, we sought both conceptual/theoretical and empirical

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<sup>4</sup> There were also more females than males in the 65 plus age group, contrasting with slightly more males than females in the under 65 group. Approximately 1 in 25 people of all ages in Scotland (231,925 people) were reported as receiving social care support and services in 2020/21. <https://www.gov.scot/publications/national-care-service-people-access-adult-social-care-unpaid-carers-scotland/pages/3/>, accessed 17 Jan 2023.

<sup>5</sup> The two largest areas of expenditure in 2020-21 were on care homes (£860m) and home care (just under £700m) (Fraser of Allander, Aug 2022, p.4).

<sup>6</sup> In 2021/22 approximately 93,280 people received home care and 130,130 people had an active community alarm and/or telecare service (some in receipt of both). There were approximately 33,353 residents in care homes as of 31st March 2021. <https://fraserofallander.org/wp-content/uploads/2022/08/Annex-A-Summary-of-Scottish-Government-research-and-analysis-of-the-NCS.pdf>, accessed 17 Jan 2023.

<sup>7</sup> Review conducted by Nafsika Zarkou (Ph.D. candidate, University of Glasgow) and Dr Richard Brunner (Research Associate, University of Glasgow). Comments on drafts were kindly provided by Prof Nick Watson and Dr Charlotte Pearson (both University of Glasgow), and Tressa Burke and Sophie Lawson (both Glasgow Disability Alliance). Any errors are the responsibility of the authors. The review was conducted as part of the GDA 'Future Visions for Social Care' project 2022-23, funded by the Scottish Government. Nafsika Zarkou's contribution was funded by University of Glasgow.



evidence, including academic literature (book chapters, journal articles, and systematic reviews), grey literature (NGO reports, charities' reports, care sector blogs, and carers group articles), and policy-related documents (UK and Scottish Government reports, independent reviews, briefing papers, guidance documents, and factsheets). Initial inclusion criteria were: a) documents from the year 2000 onwards, b) information on unmet need focused on social care, c) data from the UK and Scotland, d) focus on disabled adults, including intersectional identities and different impairment types, and including literature on unmet needs and transitions (child/adult and adult/older person). As exclusion criteria we set a) data on children (under 16 years) and b) gerontology literature. However, as most research and conceptualisation on unmet need has been conducted in relation to older people, some key literature in relation to older adults is included.

As unmet need in social care for disabled adults is under-researched, our review balanced systematic approaches with exploratory approaches, critically evaluating the literature throughout. Our initial search terms were: "unmet need", "social care", "Scotland" which predominantly yielded results relating to social care needs for older people, social policy, needs assessments and self-directed support, and social care reform in England and Scotland. We could find no systematic review on unmet need in social care conducted in Scotland, only systematic reviews focused on unmet health needs. Adding the term "disab\*" to "unmet need", "social care" and "Scotland" our search yielded results regarding the integration of the health and social care sector, the support needs of disabled people, independent living, and free personal care in Scotland. It became clear that the needs of disabled people in Scotland were not obviously connected to the concept of unmet need in social care. We therefore decided to expand our search by searching "disab\*", "Scotland", "lived experiences". This reinforced that disabled people in Scotland experience unmet needs which do not become visible in the social care literature.

We identified seven key readings on unmet need in social care and to these we added all relevant reports, policy documents and academic articles, including the experiences of disabled people. *"Exploring unmet need"* (Godfrey and Callaghan, 2000) offered a nuanced analysis on the vague concepts on need and unmet need and how these are understood differently in policy and health and social care. Vlachantoni's (2019) work on unmet need on older people gave a perspective of unmet needs in social care are by using an 'activities of daily living' approach, the most used in social care policy and practice. Expanding the concept of unmet need in older people's social care, Kröger (2022) highlights the interplay of individual and social factors that lead to unmet care needs. To focus on the contemporary Scottish context, we paid attention to IRASC (Scottish Government, 2021a) and the *"Social Care briefing"* (Audit Scotland, 2022). Analysis using a disability lens highlighted the narrow understanding of need and unmet need garnered by the activities of daily living approach, considering disabled adults' lives in the full, and accounting for intersectionalities, diverse impairments and inequalities, our review was also informed by two key reading on thinking of need holistically; Dean's (2020) *"Understanding Human Need"* and Tronto's (2010) *"Creating Caring Institutions"*. Building on these readings we conducted this critical exploratory review.

### 3. Unmet need in adult social care

#### A. Conceptualising need and unmet need

##### Need

The concept of “need” is central to social policy and identifying and meeting social needs are key functions of the welfare role of the state. Questions on how needs are defined, assessed and prioritised, and which needs are considered fundamental for the state to meet and to what extent, are issues that governments attempt to answer and regulate through policies, legislation, eligibility rules, allocation of funding and related activities.

Theories of “need” have tried to conceptualise and define needs from a variety of perspectives (see. Maslow, 1954; Bradshaw, 1972; Plant, 1985). Much debate in social policy though, occurs in terms of *the basic levels* below which an individual is in real need (Mitton and Liddiard, 2011). Basic levels are translated to the minimum support a state should offer to individuals to meet human needs for security, education, work, health, and wellbeing (Platt, n.d.). However, these ‘objective’ understandings very often contrast with how individuals subjectively understand their own needs, and have further been expanded by consideration of human flourishing, meaning and quality of life beyond ‘basic needs’ (e.g. Dean, 2020). This is the political struggle over the recognition of needs, or what Fraser (1989) calls a “*needs interpretation process*”.

In social policy, definitions of need shape the politics of welfare and ultimately are “*rationing devices: they determine who gets what*” (Mitton and Liddiard, 2011). Public Health Scotland (2021) offers a definition of need as “*the capacity to benefit from services*” arguing that “*this definition keeps the focus of needs assessment on interventions that can produce real benefits, and on identifying people who could benefit from receiving those interventions*” (2021, para.4). However, this de-links needs from rights, and the notion of ‘real benefits’ both avoids definition of what ‘benefit’ means, and risks inequality bias in favour of those with maximum ability to self-advocate. More widely, PHS argue that needs assessment in both health and social care services should give information on “*the level of need for public services, the extent of unmet need, the pattern of supply and effectiveness of current services, how to work towards meeting a need, how to use resources in the most effective and efficient way*” (2021, para.6). This begs the question of how unmet need should be defined.

However, research shows that ‘need’ has been an unclear concept for practitioners in both health and social care, with no clear framework to assess need (Parry-Jones and Soulsby, 2001, Cameron, 2006). This conceptual uncertainty, in addition to balancing user-defined need against fixed eligibility criteria in framing decisions, has been an issue of real conflict for practitioners (Abendstern et al., 2008). Responding to IRASC (Scottish Government, 2021), Slasberg and Beresford (2021) argue that, in reality, social care assessment is assessing for eligibility as to whether a need can be met or not by existing social care services, resulting in a “*bureaucratic, obscure and professional-centric process*” (Slasberg

and Beresford, 2021). Assessing for eligibility means that the person's needs, however defined, are not at the centre of the process; rather, focus is placed on the person's capacity to meet local criteria for service provision. In Scotland, this also leaves inequities in what is meant, for example, by 'critical and substantial' (Scottish Government/COSLA, 2009) across local authorities, linked to available local resources for social care. To actualise IRASC's recommendation that needs assessments must be 'co-produced' (IRASC, Recommendation 5, see above), Slasberg and Beresford (2021) argue that new processes will be required to support disabled people to think through self-assessment of their needs and support requirements. This would enable people to have choice and control, with social workers ensuring realisation of rights, local authorities ensuring that "*self-assessments make the best use of resources so the person can have the best quality of life their circumstances allow*" (Slasberg and Beresford, 2021), and the Scottish Government ensuring equity in levels of need met across localities.

To the above factors, the COVID-19 pandemic should be added, a period that changed understandings of need, of basic levels of support and ways that support should be provided, driving much improvisation and innovation in social care (Pearson et al, 2022), notably by the third sector (Cullingworth et al, 2022).

The ambiguities in how need is assessed and recorded relates in turn to how unmet need is also defined, understood, and measured.

### Unmet need

Unmet care needs have historically been researched in relation to older people, predominantly understood as functional limitations and basic physical needs, culminating in an influential definition by Williams et al. (1997, p. 102): "*Unmet need occurs in long-term care when a person has disabilities for which help is needed, but is unavailable or insufficient*" (Kroger, 2022: 16-17). There are two archetypes of approach to evaluating whether or not care needs have been met (Kroger, 2022: 38): subjective self-reporting, and 'objective' measures. However, both are flawed: the first, whilst enabling user voice, contains potential self-reporting bias, notably underestimation; the second always imperfect due the 'interpretational' character of social care needs (Kroger, 2022: 48-49). Objective and subjective can also be combined (Godfrey and Callaghan, 2000), but for Kroger, neither is appropriate due to the influence of wider contextual factors (2022: 49-51).

In the literature, unmet need has been paired with various terms, in further attempts to define and measure it: "*under-met*" (Curry, et al., 2020; Glasby et al., 2021, NHS Confederation, 2021), "*hidden*" (Dunatchik et al., 2019), "*low*" vs. "*high*" (Millenaar et al., 2018). It has also been in interplay with other terms such as "*unmet demand*" (Cuthbert and Cuthbert, 2002; Dickinson et al., 2007; Scottish Government, 2021), "*unmet wants*" (Weber, 2021), and "*perceived need*" (Cohen-Mansfield and Frank, 2008). This interplay can be interpreted as efforts to define unmet need from different perspectives, for example, assessing need from a professional's perspective against the care receiver's perspective and seeking to get beyond binaries of met/unmet, and towards degrees or extents.

However, the ‘activities-based’ approach to evaluating need/unmet need in social care has historically been the most widely used in social care and adopted by governments (Dunatchik et al., 2016; Feldon, 2019). These are typically interpreted as Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL)<sup>8</sup>, concepts stemming from the 1960s (Kroger, 2022: 17) - prior to the disabled peoples’ movement, the social model of disability, and principles of independent living. ADL/IADL holds a deceptive clarity but continues to result in wide interpretations of ‘how many’ or which activities need to be unmet, and to what extent, to be interpreted as an unmet need for care and support (Kroger, 2022: 18-19). These constraints are also noted by Ipsos MORI, (2017: 10) in their England-focused unmet needs study, which pinpoints further ambiguities:

... the way in which need for care and ways of meeting those needs are defined affect the level of unmet need. Even with a relatively constrained set of survey data, multiple assumptions had to be made in defining and analysing unmet need. These included what level of difficulty with ADLs, IADLs and mobility should be considered to indicate a social care need, whether adaptations and aids could be considered to meet needs, whether unpaid care from family and friends can be considered as meeting needs or whether, in some circumstances, intensive care from family indicates an unmet need for help.

In line with this, and further exploring the ‘activities-based’ approach, Vlachantoni (2019), again in the context of older people, argues that the conceptualisation of unmet need is more than the mere opposite of having one’s need met. Vlachantoni differentiates between an “*absolute*” approach to conceptualising need, that is not receiving *any* support (see also Vlachantoni et al. 2011; Low et al. 2014), and a more “*relative*” approach which focuses on people who may perform daily activities with some difficulty or only with help (see also Maplethorpe et al., 2015). In an earlier paper, Vlachantoni et al. (2011: 73) find several large-scale datasets inadequate to fully understanding unmet need in England, while finding that “*the level of unmet need is significant regardless of the ADL or IADL used to indicate need*” and concluding “*There is significant unmet need for social care among older people, regardless of the specific question asked or the specific dataset used*” (2011: 74). They also (2011: 73) note the under-representation in population surveys of those older people who may be those most in need or the most vulnerable groups, in particular, those with dementia, complex needs, and communication difficulties. We might add those in greatest poverty and greatest isolation: some of those in Scotland with the highest unmet needs may not participate in surveys and may be invisible to statutory services. However, there will also be disabled adults through the lifecourse who have unmet low support needs, but do not

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<sup>8</sup> ADLs are activities relating to personal care and mobility inside the home that are basic to daily living. They include activities related to personal hygiene, dressing, eating, maintaining continence and getting around indoors. IADLs are activities which, while not fundamental to functioning, are important aspects of living independently. They include basic communication skills, transportation, shopping for groceries and clothing, housework, meal preparation, managing medications, managing personal finances. (Ipsos MORI, 2017: 22).

recognise their needs, do not ask for support, are not visible to services, are not eligible, or are not recognised in surveys.

Vlachantoni et al (2011 and 2019) note that the conceptualisation of need involves the consideration of a person's physical, mental and emotional circumstances, and these may be affected in turn by the person's demographic and socio-economic characteristics. Further, unmet need relates to the amount and nature of support received by a person with needs, as well as the extent to which such support is satisfactory from that person's perspective, so unmet need includes those who may receive support but are unsatisfied by it. They visualise unmet need by using two scales (2011: 65), conceptualising unmet need as being the point at which *"the report of difficulty with particular tasks (need) meets the lack of support received by the older person"* (2019: 660). Although their work offers a less individualistic approach to ADL/IADL, their data is constrained to older people, and they fail to acknowledge that demographics and socio-economic gradients apply not only to individuals, but also to regions/localities. Social policy research has long identified a socio-economic gradient to functional limitations and (unmet) care needs, overlooked by taking a micro-level, activities-based focus (Kroger, 2022: 20). In response, Kroger has argued for the concept of *"care poverty"*, seeking *"to capture how non-coverage of care needs indicates the presence of social inequalities"* (Kroger, 2022: 26), whilst maintaining attention on the micro-level of care needs. This is expanded on below.

Studies on older people with mental health conditions or palliative care needs further problematise the conceptualisation of unmet need (see Ventura et al., 2014; Dautzenberg et al., 2016). Wider critiques of ADL/IADL also come from feminist scholars arguing that its narrow understanding misses gendered inequalities in informal and formal caring at a societal level (Kroger, 2022: 19).

So, there are multiple limits to current approaches to assessing the 'unmetness' of care needs, including the overly-individualised and over-simplified 'activities-based' approach to assessing need; the problem of people with high or low unmet needs through the lifecourse that are not visible to services or recognised in surveys; and the present-day issue in Scotland that unmet needs also need to account for the extent to which social care supports people to maintain and sustain independent living, so living life 'in all its fullness', and reflecting the National Performance Framework. Nevertheless, even narrow activity-based measures suggest that over half of older people in England with care needs have unmet needs for support (IPSOS Mori, 2017: 4). In Scotland, the 2021/22 Health and Care Experience Survey (Scottish Government 2022b) of a representative sample of the population found that 2.5% of respondents had not had any help or support with everyday living, but felt they needed it - a total that does not include those who received some, but insufficient, support. The survey also found that disabled people, notably those with impairments that limit them 'a lot', are the social group with highest unmet social care needs (Scottish Government, 2022b: 9).

The various conceptualisations of need and unmet need show that how we do - and how we should - think about unmet need in social care for disabled adults through the lifecourse in

Scotland is an open question, as there is ongoing debate at a theoretical, policy and practice level (Godfrey and Callaghan, 2000; Vlachantoni et al., 2011; Charles, 2016; Sandman and Hofmann, 2019) and most empirical research focuses on people over 65. **The evidence suggests that how unmet need in social care is defined is significant (a) in terms of how best to record and measure unmet needs accurately so that social care commissioning can successfully respond to and satisfy unmet needs for disabled adults in Scotland (Scottish Government, 2021a), and (b) for recognition of disabled people’s human rights, independent living, wellbeing and potentials, and (c) in order to address wider inequalities.** To progress this further, in the next section we examine how unmet need has so far been interpreted in Scottish social care policy.

## B. Unmet need in policy and practice

### *(i) The concept of “unmet need” in Scottish social policy and official documents*

Although the term “unmet need” is widely used in social policy documents and publications, there is no statutory definition of the term. There is no reference to individual unmet need in the Care Act 2014 (England) or the accompanying care and support statutory guidance (Feldon, 2019). Similarly, we could locate no statutory definition of unmet need within Scottish policy for social care.

Scotland’s attempts at social care reform have been based on three innovations: self-directed support (Scottish Government, 2013), health and social care integration, and the Carer’s (Scotland) Act 2016. We found no reference to “unmet need” in the following key pieces of Scottish legislation and policy, included in the *“Review of Care Service Definitions: Challenges and Recommendations”* (Scottish Government 2021c) that provided the Scottish Government with evidence about how care service definitions reflect current and future needs: Health and Social Care integration: progress review (2019)<sup>9</sup>, Health and Social Care Integration - Localities: Guidance (2015)<sup>10</sup>, Self-directed Support Strategy 2010-2020: Implementation Plan 2019-2021 (2019)<sup>11</sup>, Health and Social Care Standards: my support, my life (2017)<sup>12</sup>. The term “unmet need” was also not referenced in other key social care policy documents, namely: Regulation of Care (Scotland) Act 2001<sup>13</sup>, Adult Support and Protection (Scotland) Act 2007<sup>14</sup>, Social Care (Self-Directed Support) (Scotland) Bill (as introduced-2012)<sup>15</sup>, Self-Directed Support guidance documents (Scottish Government 2014a and 2014b), Healthcare Framework for Adults Living in Care Homes: My Health – My Care – My

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<sup>9</sup> <https://www.gov.scot/publications/ministerial-strategic-group-health-community-care-review-progress-integration-health-social-care-final-report/documents/>

<sup>10</sup> <https://www.gov.scot/publications/localities-guidance/documents/>

<sup>11</sup> <https://www.gov.scot/publications/self-directed-support-strategy-2010-2020-implementation-plan-2019-21/documents/>

<sup>12</sup> <https://www.gov.scot/publications/health-social-care-standards-support-life/documents/>

<sup>13</sup> [https://www.legislation.gov.uk/asp/2001/8/pdfs/asp\\_20010008\\_en.pdf](https://www.legislation.gov.uk/asp/2001/8/pdfs/asp_20010008_en.pdf)

<sup>14</sup> [https://www.legislation.gov.uk/asp/2007/10/pdfs/asp\\_20070010\\_en.pdf](https://www.legislation.gov.uk/asp/2007/10/pdfs/asp_20070010_en.pdf)

<sup>15</sup> [https://archive2021.parliament.scot/S4\\_Bills/Social%20Care%20\(Self%20directed%20Support\)%20\(Scotland\)%20Bill/Bill\\_as\\_introduced.pdf](https://archive2021.parliament.scot/S4_Bills/Social%20Care%20(Self%20directed%20Support)%20(Scotland)%20Bill/Bill_as_introduced.pdf)

Home (2022)<sup>16</sup>, Learning/intellectual disability and Autism: Transformation Plan (2021)<sup>17</sup>. It is notable that ‘need’ is cited innumerable times in these documents, as the policies seek to meet need and improve the way in which they are doing that. But what to do about, how to define, or how to quantify unmet need, remains a silence.

Nonetheless, we found that the term “unmet need” was referenced in some guidance, reports, and other official documents, namely: Carers (Scotland) Act 2016: statutory guidance<sup>18</sup>, Coronavirus (COVID-19): living with dementia in care homes<sup>19</sup>, Annual social care costs: FOI release<sup>20</sup>, Mental health statistics<sup>21</sup>, and Social care support reform: summary of discussion paper responses (2019)<sup>22</sup>. However, none offer a definition, and discussion is somewhat general, sometimes at interplay with the concept of unmet demand, and paired with discussions around budgeting, cost containment, and funding (see also, Development of the 12<sup>th</sup> Standard for Good SDS – discussion sessions<sup>23</sup>). While “unmet need” is referenced six times in IRASC (Scottish Government, 2021a) this still lacks definition beyond being needs identified through a co-produced support plan that are not met and which must be recorded and fed into the strategic commissioning process (ibid. Recommendation 5).

So, there is no established definition of unmet need in social care in Scotland, and while at a policy level there is some discussion on unmet need, this is very patchy. Not defining “unmet need” or having a very narrow view of “need” at a social care policy level creates a risk of inconsistent and inaccurate recording of unmet needs, with huge potential for under-recording. Audit Scotland (2022, p.14) note that this makes it problematic to “*assess the level of unmet need and therefore what more is required to deliver a person-centred, human-rights approach to social care*” – consistent with the commitments made in IRASC (Scottish Government, 2021a). However, the IRASC report itself takes a very narrow view of unmet need when seeking to quantify unmet need. Using an adjusted comparison of the numbers of people using social care in 2018-19 compared to 2009-10, IRASC found that social care use had fallen by approximately 36,000 people. The report concludes, with

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<sup>16</sup> <https://www.gov.scot/binaries/content/documents/govscot/publications/advice-and-guidance/2022/06/health-care-home-healthcare-framework-adults-living-care-homes/documents/healthcare-framework-adults-living-care-homes-health-care-home/healthcare-framework-adults-living-care-homes-health-care-home/govscot%3Adocument/healthcare-framework-adults-living-care-homes-health-care-home.pdf>

<sup>17</sup> <https://www.gov.scot/binaries/content/documents/govscot/publications/strategy-plan/2021/03/learning-intellectual-disability-autism-towards-transformation/documents/learning-intellectual-disability-autism-towards-transformation/learning-intellectual-disability-autism-towards-transformation/govscot%3Adocument/learning-intellectual-disability-autism-towards-transformation.pdf>

<sup>18</sup> <https://www.gov.scot/publications/carers-scotland-act-2016-statutory-guidance-updated-july-2021/>

<sup>19</sup> <https://www.gov.scot/publications/coronavirus-covid-19-living-with-dementia-in-care-homes/>

<sup>20</sup> <https://www.gov.scot/publications/foi-202100218597/>

<sup>21</sup> <https://www.gov.scot/news/mental-health-statistics/>

<sup>22</sup> <https://www.gov.scot/binaries/content/documents/govscot/publications/consultation-analysis/2019/06/summary-report-discussion-paper-responses-analysis-responses-joint-discussion-paper-scottish-government-cosla-building-national-programme-support-adult-social-care-reform/documents/social-care-support-investment-scotlands-people-society-economy-summary-report/social-care-support-investment-scotlands-people-society-economy-summary-report/govscot%3Adocument/social-care-support-investment-scotlands-people-society-economy-summary-report.pdf>

<sup>23</sup> <https://www.sdsscotland.org.uk/development-of-the-12th-standard-for-good-sds-discussion-sessions/>

some caveats, that addressing unmet need for those “*who do not currently have access to social care support and for whom it would be beneficial*” would cost approximately £436m (Scottish Government, 2021a, p.91). Analysing this, Fraser of Allander note that this is “*unlikely*” to be a full reflection of unmet need (August 2022, p.7), more a measure of the impact of austerity, noting that unmet need requires including those with social care needs who are not currently eligible for social care, but may become eligible through future reforms.<sup>24</sup> The IRASC figure risks implying that in 2010-11 all social care needs were met. What it misses is the contemporary need to measure unmet needs as the social care that is required to enable all disabled adults to be able to maintain and sustain independent living, or (Scottish Government, 2021a, p.9):

... people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community... It means having rights to practical assistance and support to participate in society and live a full life.

Taking a narrow view of “need” undermines the ability to accurately estimate the true social care needs of the nation, and then to be able to assess at both local and national levels the actual investment required to meet unmet social care needs (Stalker et al. 2015). Achieving an accurate measure will allow Scotland to develop the most effective and efficient policy and practice levers to meet contemporary unmet needs. In contrast, not having a conceptually sound understanding will result in the lack of an empirically sound picture of the levels and types of unmet need for social care, and also detriment the quality, transparency, and usefulness of data on unmet need (Cuthbert and Cuthbert, 2005; Forrester-Jones and Hammond, 2020; Audit Scotland, 2022; Cairns, 2022). Scotland needs a clearer contemporary definition of unmet need in social care, and this is developed further below.

Next, we further explore the picture in Scotland regarding social care and unmet need, distinctions between practice and policy, what challenges are experienced on the ground, and why locality matters.

### *(ii) Social care in Scotland and the importance of local context*

Certain challenges in social care are broadly common across the UK, such as years of significant underfunding, rising demand and costs for care and support, a precarious and narrow provider market, increasing pressures on unpaid carers, changing demographics, an undervalued workforce, and increasing workforce shortages (Northern Ireland Social Care Council, 2017; Local Government Association, 2021; Wales Centre for Public Policy, 2021; Audit Scotland, 2022; Social Care Institute of Excellence, 2022). These common challenges reflect the general the position of social care within each devolved nation in the UK. Nevertheless, the ways these challenges are faced by governments vary across devolved nations.

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<sup>24</sup> <https://fraserofallander.org/demand-and-expenditure-for-adult-social-care-in-scotland/>, accessed 17 Jan 2023.



The Scottish Parliament has devolved legislative powers regarding health and social care. The vision of Scotland's social care reform is founded on a narrative to improve outcomes for people and communities. Implementation has included a wide range of interventions across social care settings, social groups, and local contexts (Hendry et al., 2021). Normally the local authority in which a person is ordinarily resident is financially responsible for the community care services for that person. According to The Public Bodies (Joint Working) (Scotland) Act 2014, local authorities in collaboration with NHS Scotland should provide services in such a way that the needs of service-users *in different parts of the area* in which the service is being provided are taken into consideration (Care Information Scotland, 2020, our emphasis). Services should also be *“planned and led locally in a way which is engaged with the community (including, in particular service-users, those who look after service-users, and those who are involved in providing health or social care)”* (ibid. para. 5)<sup>25</sup>.

In relation to unmet needs, local context matters for four reasons. First, because individual circumstances and socio-economic demographics have an impact on the construction of people's needs and expression of unmet needs. Second, because *“the national framework recognises that local authorities should set local eligibility criteria for access to personal and nursing care services”* (Scottish Government, 2022c: 4), and these eligibility criteria will differ across local authorities. Third, because each local authority faces different demographic, workforce, and financial challenges, and distinctive social inequalities, all of which will affect delivery of social care. Fourth, because each local authority should be engaging with local communities about how to provide services, accounting for varying needs in *“different parts of the area”*. Recording and addressing unmet social care needs should, following IRASC (Scottish Government, 2021a: 72), become incorporated into Scotland's social care commissioning strategies, taking account of local inequalities. There are a wide range of inequalities to account for when considering unmet needs, as described in the next section.

### C. Social inequalities, care poverty, the 'disability lens' and lived experience of unmet needs

#### *(i) Social inequalities, disability, care poverty, and unmet need*

Scotland's Census for 2021<sup>26</sup> showed that 19.6% of people said their day-to-day activities were limited by a long-term health problem or disability (mainly physical disability or deafness)<sup>27</sup>. People with long-term health conditions were more likely to live in social rented housing than people with no condition. When comparing the two largest cities of Edinburgh and Glasgow, data show that people in Glasgow have reported higher levels of bad and very bad health, higher rates of people with a long-term health problem or disability, and higher levels of providing unpaid care (including higher percentage of young carers). Glasgow also has higher rates of unemployment (also due to disability or long-term sickness)<sup>28</sup>. *“Scotland's Wellbeing: national outcomes for disabled people”* (Scottish Government, 2019a) further

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<sup>25</sup> See also <https://www.gov.scot/publications/ministerial-strategic-group-health-community-care-review-progress-integration-health-social-care-final-report/>

<sup>26</sup> <https://www.scotlandscensus.gov.uk/census-results/at-a-glance/health/>

<sup>27</sup> The terms in this section are used as referenced in the Census report and are kept as they are in original text.

<sup>28</sup> <https://www.scotlandscensus.gov.uk/search-the-census#/explore/snapshot>

demonstrates the link between disability and poverty. Families with a disabled member are also more likely to live in relative poverty, disabled people are more likely to experience food insecurity, and living costs tend to be higher for disabled people (Brunner and Glasgow DPO Network, 2022: 18-19). There is a clear association between socio-economic factors, poverty, and incidence of health conditions and impairments. These impact on peoples' needs and unmet needs for social care (Scottish Government 2022b: 9) not only at an individual level but at local, regional and national levels within Scotland. IRASC (Scottish Government, 2021a) proposed a National Care Service for Scotland to encompass social care services, with a prime argument for a nationally so-ordinated service being to achieve consistency and address inequalities (Scottish Government, 2022d).

Because research on unmet need has been primarily focused on individualised, 'activities-based' needs of older people, less attention has been paid to wider social inequalities and their link to unmet need (Kröger, 2022). Kröger's (2022) concept of "care poverty" makes this connection and opens up the scope of unmet need by highlighting that unmet need is not only the result of personal circumstances but of wider social inequalities (2022: 27):

The concept of care poverty ... looks at the lack of care from both individual and societal perspectives, understands informal and formal care as resources, and analyses their unequal distribution. Inadequate coverage of care needs is understood as a result of the interplay between individual and structural issues. Identifying those population groups left without adequate care thus becomes critical ... In care poverty, care is not simply one more specific item that people cannot afford. Instead, it is seen as a vital, non-material resource necessary for well-being in the same way as economic resources in poverty research.

Kröger distinguishes between three domains of care poverty: personal (broadly corresponding to ADL), practical (broadly corresponding to IADL), and socio-emotional. Kroger defines socio-emotional needs as: "*social, emotional, and psychosocial needs, or needs for belonging, intimacy, social interaction, and social support ...*" (2022, p.44) and argues that whilst these are inadequately captured by ADL/IADL they are fundamental to quality of life (2022, p.42). Each domain can be measured in either absolute (fully unmet) or relative (insufficiently met) terms (2022, p.50-51). So (2022, p.26):

... *care poverty* means the deprivation of adequate coverage of care needs resulting from interplay between individual and societal factors ... where people in need of care do not receive sufficient assistance from either informal or formal sources... Needs for care result from individual characteristics and life courses, but at the same time, these needs also result from societal structures. For example, there are distinctive health inequalities across different social groups.

In Scotland, IRASC notes that in its consultations, "*Equality – and inequality – were raised with us again and again.*" (Scottish Government, 2021a, p.14) and that the report recommendations have regard to: "*structural inequalities and pre-existing inadequacies in*

*the current social care support system*” (Scottish Government, 2021a, p.30) Addressing inequality is implicit in the definition of independent living in IRASC, a definition adopted over many years by the Scottish Government, COSLA, the NHS and the disabled people’s independent living movement (Scottish Government, 2021a, p.9), and which aligns with Scotland’s National Performance Framework outcomes:

Independent living means people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community ... It means having rights to practical assistance and support to participate in society and live a full life.

Kröger’s (2022) approach to addressing inequalities in unmet needs can be traced in the connection Kröger (2009) also draws between care research and disability studies research.

### *(ii) The disability lens*

Understanding of unmet need can be conceptually improved by adding a disability studies lens. First, because disability studies, alongside the disability rights movement, is founded on the social model of disability and Independent Living principles. The social model of disability underpins Scottish Government’s approach to disability policy<sup>29</sup> and independent living principles underpin IRASC (Scottish Government, 2021a).<sup>30</sup> Second, scholars within disability studies have consistently analysed the impact on disabled people of social inequalities such as poverty, disabling societal attitudes and structural barriers, integrating this with the lived experience of disabled people (see Beresford, 1996; Barton and Oliver, 1997; Grech 2009; Eide and Ingstad, 2011; Barnes, 2019). Lived experience is foundational to operationalising the IRASC recommendations (Scottish Government, 2021a). The lived experiences of disabled people demonstrate that disabled people have the same complex personal and social lives, needs and aspirations as every other citizen, changing through the lifecycle – yet all too often disabled peoples’ needs and aspirations go unmet, including by social care (Shakespeare, 2014; Witcher and participants, 2014). This undermines equal opportunities, wellbeing and quality of life, as for older people (Kroger, 2022: 42), and therefore needs to be recorded as an unmet need if not met.

Through the disability lens, unmet need ceases to be only a personal requirement and must also be understood as an expression of inequality for certain social groups, reinforcing the work of Vlachantoni (2011) and Kröger (2022), and consistent with mainstream analytical

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<sup>29</sup> E.g., ‘A Fairer Scotland for Disabled People set out the Scottish Government’s approach to policy for disabled people. It is based unequivocally on the social model of disability as opposed to the medical model. The medical model focuses on the impairment, rather than on society’s inability to meet the needs, rights, and aspirations of disabled people. The social model is rooted firmly in the United Nation on the Convention of the Rights of Disabled People (UNCRPD) and is also aligned to the aims of the independent living movement; which is that disabled people can live the life they choose, participating equally alongside other citizens in their families, communities, workplaces and wider society, with the support they need.’ (Scottish Government, 2021b: 5)

<sup>30</sup> ‘Independent living means people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. It does not mean living by yourself, or fending for yourself. It means having rights to practical assistance and support to participate in society and live a full life.’ (Scottish Government, 2021a: 9)

approaches used across social policy. As IRASC also argues, there is a need to account for unmet need arising because people live in different circumstances, and social care should mean *“supporting people to achieve their outcomes, to have a good life and reach their potential, including taking part in civic life as they themselves determine”* (Scottish Government, 2021a, Recc. 39). This perspective necessitates public authorities tackling social, economic and environmental barriers that currently reproduce and amplify disabled peoples’ (unmet) needs through the lifecourse.

A disability lens ensures that we do not overlook the impact of cultural hierarchies, power nexi and medicalised approaches to social care that can also treat disabled people as *“counterfeit citizens”* (Hughes, 2015). For too long the medicalised model of disability dominated policy and service provision affecting disabled people (Oliver, 2004) and decisions, judgments and assessments are not entirely free of this history. This needs to be remembered to avoid stigmatising histories influencing value judgements about individuals’ unmet needs, and so to modernise how unmet needs should be understood, prioritised and addressed, integrating contemporary social model of disability and independent living principles.

Also from disability studies, psycho-emotional needs and internalised oppression (Thomas, 1999; Reeve, 2014) of people receiving social care are relevant to experiencing and reporting unmet need. These can affect whether people accurately express their social care needs, leading to under-reporting and risk of inaction by local authorities, particularly for those in greatest need (Vlachantoni, 2011). Local authorities need systems that remove barriers to asking for social care support for those in highest need. One resource to improve the accuracy of individual understanding and reporting of unmet needs is the role of Disabled People’s Organisations (DPO) – organisations led by and for disabled people. These build collective capacity among disabled people, including raising awareness of social care services and policies including Self-Directed Support, human rights, and independent living principles (e.g. Witcher and participants, 2014; Glasgow Disability Alliance, 2019).

Disability studies evidence plus social inequalities evidence suggests that if unmet social care needs are accurately recorded, we should expect those unmet needs to be higher in areas that have higher social, economic and environmental barriers for disabled people to be able to *“have a good life and reach their potential”* (Scottish Government, 2021a, Recommendation 39). Accurately recording those unmet needs should lead to actions by the state to reduce the causes of those social gradients and to put in place the personalised social care that individuals need beyond that barrier removal.

The disability lens reminds us that disabled peoples’ lives and needs are social (as for everyone), and choices in how unmet needs are recorded requires awareness of social inequalities. Recording unmet needs must be a statistical means to a progressive end, addressing those inequalities and integrating social model of disability and independent living principles to enable social care to be *“supporting people to achieve their outcomes, to have a good life and reach their potential, including taking part in civic life as they themselves*

*determine*” (Scottish Government, 2021a, Recc. 39). However, disabled people are not a monolithic category and the lived experiences of disabled adults in relation to unmet need requires further elaboration.

### *(iii) People’s lived experiences and unmet need - the disability perspective*

The disability lens offers another insight when exploring unmet need; that social groups are diverse. Levels of unmet need can vary between people from the same social group. Disabled people can also belong to more than one social group, which may also affect the level of their unmet need. Understanding the complex realities of people requiring social care further informs why capturing unmet needs demands a more nuanced framework than ADL/IADL. This section explores the intersectional identities and impairment variations among disabled adults.

As we have seen, research on unmet need has mainly focused on older people and has been concerned with activities of daily living; yet older people are not a block category. Older people with mental health conditions, learning disabilities and other impairments tend to have higher unmet needs (see McNulty et al., 2003; Strydom et al., 2005; Cummings and Cassie, 2008; Rowe et al., 2013). Some older people care for another family member which may increase their level of (unmet) need as both an older person and a carer (Taggart et al., 2012). Being non-white also impacts on unmet need. For example, Boneham et al. (1997) researching older people from ethnic minorities in Liverpool, identified low levels of service use despite considerable unmet need, evidence of neglect, nearly half of the participants having a physical disability, and language barriers. Participants lacked knowledge of services or perceived services as culturally inappropriate. This accords with the wider picture of BAME communities having higher unmet need for social care (Scottish Government, 2022b).

The dominant focus on the unmet needs of older people overlooks the many disabled people that need social care through the lifecourse. Research has identified unmet needs for younger disabled adults, especially regarding transition services, notably lack of choice and control, mental health support, unmet education, training and employment needs, lack of information regarding benefits and housing, and transition services being time-limited (Hudson, 2006; Bhaumik et al., 2011, Allcock, 2018). Further studies have found unmet needs in relation to young disabled people’s social life and interpersonal relationships (Stalker, 2002). Whilst studies on younger disabled people have primarily focused on people with learning disabilities, similar issues are likely to be also faced by young people with other impairments, including mental health support needs (Broad et al., 2017). Sexuality, especially sex and relationships education for young disabled people is another unmet need (Shah, 2017). Research involving people with autism and learning disabilities indicates that parents can become solely responsible for their sex education, leading to parents trying to support their sons’ emerging socio-sexual needs, whilst managing sometimes challenging sexual behaviours (Pryde and Jahoda, 2018).

Unmet needs for disabled women also demand specific consideration. Shah et al., (2016) indicate that disabled women are vulnerable to violence over the course of their lives,

including physical and sexual violence, emotional abuse, or economic coercion, by their carer or partner (sometimes the same person). They then face barriers to access appropriate support services. Sexual health, reproductive rights, parenting support and wider health provision does not meet the needs of disabled women - a clear lack of application of human rights legislation and integrated policies (Glasgow Disability Alliance, 2022; Wiseman and Ferrie, 2020).

Other intersectional groups also have potentially high unmet needs. This may be because they face additional barriers, such as disabled people with mental distress (Glasgow Disability Alliance and Gribben, 2022), disabled migrants (Burns, 2017), homeless people with mental health issues (Harris et al., 2006), or people with alcohol related brain injury (Aziz, 2014). For people with early onset dementia, research suggests that they experience high levels of unmet need in domains such as daytime activities, company, intimate relationships, and information, leading to an increase in neuropsychiatric symptoms. (Bakker et al., 2014).

Unmet needs can also be created by assumptions that people's impairments and personal and social needs are static. Support needs can change very fast, including for people with progressive conditions such as motor neurone disease (MND) or chronic illness such as Multiple sclerosis (MS). Evidence on MND has shown unmet social care needs associated with aiding mobility, future proofing of homes, trust, and consistency in care (Ferrie et al., 2013). In chronic and progressive illness, the boundaries between healthcare and social care needs can blur, further problematising how we should think about unmet need. Moreover, evidence shows that health and social care services can disbelieve people living with chronic illness and chronic pain and fail to acknowledge the trauma that often accompanies living with a poorly understood, contested or under-diagnosed health condition (Chronic Illness Inclusion, 2021, para. 1).

The above lived experiences show that disabled people's lives and needs can be complex and intersectional. Many disabled adults have social care needs across the course of their lives, changing over time according to impairment changes, and personal and social circumstances, sometimes rapidly. To accurately identify unmet need in social care and its extent, the evidence suggests that it is imperative to take a wider social perspective on needs and unmet needs than the ADL/IADL approach can achieve.

#### D. Rethinking (unmet) need

##### *(i) Expanding our understanding of need*

To this point we have demonstrated that, at a policy level, perceptions of need are very narrow, and the conceptualisation of unmet need is vague, undefined, or simply absent in key official documents. We have shown that in adult social care, service provision is primarily associated with assistance with ADL/IADL. This activities-based approach is task-oriented and individualised and can miss people's psycho-emotional needs and the impact of wider social inequalities, ultimately diminishing the lives of disabled adults through the lifecourse. By using a disability lens, rooted in the values of the social model of disability and the

principles of independent living (footnotes 29 and 30, above), we showed that a measure of unmet needs must reflect the diversity, inequalities, intersections and fullness of disabled peoples' lives, maintaining a focus on quality of life.

The focus on 'activities of daily living' misunderstands what need is. We have seen how considering socio-economic factors and demographics, both at an individual level (see Vlachantoni 2011, 2019) and a social level (see Kröger, 2022) can offer a fuller analysis of unmet need in social care amongst older adults. In social policy, Burchardt (2021) argues that the definition of unmet need used in social care is "*way too narrow*", referring in effect to a lack of commodities and services, so misrecognising independent living and the contemporary mission of enabling disabled adults to "*have a good life and reach their potential*" (Scottish Government, 2021a, Recommendation 39). This echoes a wider concern about the marketisation of the social care sector in liberal states and the risks of care provision increasingly being interpreted as a commodity purchased by consumers (Brennan et al., 2012; Henderson et al., 2017; Idriss et al., 2021). Tronto (2010) has written about the dangers of thinking of care as a commodity and as purchased services, rather than as a process, arguing that the commodification of need denies people the right to make independent judgments about their needs. Further, people in need of care can downplay their need for support due to affordability concerns or lack of knowledge about possibilities, leading to a paradox in which under-reporting of needs may result in higher unmet needs. Narrow interpretations of need by service providers and social care professionals do not reduce the lived experience of unmet need – they just don't measure it.

As an alternative, Burchardt refers to Dean's (2020) work on "*Understanding human need*". Dean surveys various perceptions of need, including bottom-up approaches to the definition of need and how it is met, as well as the issues that shape the discourse on need, making two insightful points, which Burchardt (2021) also foregrounds. First, that people do not have the need to be 'independent' but to be inter-dependent and social (aligned with the social model of disability and independent living principles). Second, that purposeful human activity and autonomy are central for peoples' need for a meaningful life. Burchardt (2021) traces these back to the disability rights movement, concluding that "*a focus on 'activities of daily living' – can openers and grab rails – is insufficient*", further demonstrating how the "disability lens" offers both a fuller and a more accurate means of conceptualising unmet need in social care.

#### *(ii) Need and care*

The role of carers also forms part of the discussion of unmet need. The availability of informal care affects the level of unmet needs of disabled people (Vlachantoni, 2019). Informal carers cover unmet need for non-existent services in the community, for example human company and emotional support (Carers Trust, 2021). Informal carers are also not a monolithic category. Young carers' input is often overlooked by professionals, affects their social life, and impacts on their levels of sadness or depression (Thomas et al., 2003). Many informal carers are forced to give up work because of their caring responsibilities and most are not aware of their rights under the Carers (Scotland) Act 2016 (Audit Scotland, 2022), the majority

of them being women (Scottish Government, 2022a). Women are also the majority of the formal social care workforce and are overworked, underpaid, and undervalued (Beresford, 2008), reinforced by social care being described as 'low-skilled work' by the UK Government (Hughes, 2021). How Scotland quantifies 'unmet need' also needs to account for the extent to which informal care provision is categorised as adult social care needs being 'met' versus informal care acting as an unsuitable, unsatisfactory or merely cost-saving substitute for gaps in professional, formal care that should be being provided to enable disabled adults to *"have a good life and reach their potential, including taking part in civic life as they themselves determine"* (Scottish Government, 2021a, Recc. 39).

Working toward a feminist theory of caring, Fisher and Tronto (1990) differentiate between four phases of care: caring *about* (paying attention to the need for caring); caring *for* (taking responsibility to meet the need identified); caregiving (meeting the caring need); and care receiving (response to caregiving, including whether the need is met). Tronto (1998: p.17) notes that *"... care is fraught with conflict. Indeed, conflict seems inherent in care. There are more needs for care than can ever be met. Determining which needs are important inevitably involves slighting other needs."* This conflict cuts across all levels; personal, institutional, and political. This is why recording peoples met and unmet needs matters: capturing this conflict opens up the opportunity in Scotland to address it. But if we do not expand our understanding of what need and care in terms of enabling disabled adults to achieve independent living through the lifecourse, we will never be able to accurately record the range of needs that are necessary to meet in order to universally achieve Recommendation 39 of IRASC (Scottish Government, 2021a): *"supporting people to achieve their outcomes, to have a good life and reach their potential, including taking part in civic life as they themselves determine."*

### *(iii) Care and power relations*

Disability scholars and activists have been very outspoken about those who build a career on other people's needs, to the point of becoming *"professional disability parasite(s)"* in Davis' resonant phrase (1993, p.199). From social care support staff to health professionals, power is exercised over to those who require health and social care support. Tronto (1998, p.17) agrees: that *"care involves power relations."* For Tronto (1998), care requires a complicated process of judgment as people need to make moral, political, technical, and psychological judgments when they provide care. Focusing on older people's care, Tronto (1998) highlights that at times the caregiver has abilities, knowledge, or resources that the care receiver lacks. This imbalance results in the caring relationship becoming a power struggle. Cameron et al. (2020) also highlight the *"softer"* ways that power may be exercised by professional carers over disabled people such as a) 'othering' disabled people as being a separate group in society; b) subordination, by expectation to accept professionals' decisions passively; c) boundary maintenance, by legitimising professionals' authority (e.g. through codes of conduct) and disregarding the person's lived experience and expertise; and d) conditioning emotional subjectivity, i.e. accepting feelings that reinforce one's subordination as being somehow 'normal'. However, these should not be seen simply as attitudes of individual professionals but as reflections of the wider disabling structures of society (Cameron et al.,



2020: 76). It is clear how this power imbalance compromises accurate expression of care needs by disabled people, and so risks under-recording.

Without downplaying disabling practices within health and social care, we can also bring into play what Keyes et al. (2015, p.236) describe as “*empowerment through care*”. Their understanding of empowerment “*emphasises the need for support from services that redresses imbalances between service providers and people accessing services, breaking down barriers to inclusion and promoting citizenship*” (Keyes et al. 2015, p.245). They found this happening in their work with a Community Health and Social Care Partnership in Scotland where, among other outcomes, it was evident that individual empowerment was enabled through creating processes to support people to make decisions, and to think about their lives and aspirations holistically and relationally, rather than relying on individual self-assessment. This means achieving relational and actual autonomy for disabled people, rather than forms of individualised autonomy. So, to create social care services which are attentive, responsible, competent, and responsive to people’s needs (Tronto, 2020) services need to recognise that people are inter-dependent (Dean, 2020). This is consistent with the notion of independent living and social model of disability, as supported by IRASC and the Scottish Government (footnotes 29 and 30, above). Independent living may be achieved with adequate provision of support, but this presupposes (a) an inter-dependent and social identification of social care needs, and (b) the resultant accurate understanding and recording of needs, which is the only way to (c) enable the fulfilment of actual unmet needs.

#### 4. Conclusion

This critical exploratory review has sought to fill a gap in literature on unmet needs in adult social care. It had a particular focus on disabled adults and the Scottish context. Drawing on data from academic, government, and ‘grey’ literature, we sought to develop how unmet need is conceptualised. We saw that individualised activities-based models of understanding need are out of step with contemporary understandings of independent living. We identified barriers that people face in expressing unmet needs, including power imbalances with care professionals. We saw that disabled people are diverse and have equal needs for independent living as other citizens, but that lived experience for disabled adults is of detrimented opportunities and structural inequalities. Social care has a foundational role in enabling equal lives for disabled people through the lifecourse and across Scotland, aligning with the National Performance Framework outcomes and contemporary notions of independent living (Scottish Government, 2021a, p.9):

Independent living means people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. It does not mean living by yourself, or fending for yourself. It means having rights to practical assistance and support to participate in society and live a full life.

Our analysis confirmed previous findings around the lack of concrete definitions of need and unmet need, the lack of available or convincing data on unmet needs through the lifecourse,

as well as issues in evaluating and recording unmet needs. Social care research on unmet needs has been focused mainly on older people and in relation to the individualised ADL/IADL framework. This misses macro-level inequalities, including within local authority areas, as well as social and inter-dependent elements that support relational autonomy and give meaning and purpose to disabled peoples' lives, so fulfilling independent living principles.

The lack of clear data on unmet needs for disabled adults is to some extent also a strength. It is an opportunity for developing new means of accurate identification and measurement of unmet needs in adult social care in a way that tackles inequality, whilst also reflecting contemporary concepts of independent living, the social model of disability, and disabled peoples' diversity and aspirations through the lifecourse. These accurate measures can then inform the strategic social care commissioning process.

To achieve independent living outcomes for all Scotland's adults that need social care first requires identifying and measuring the unmet care needs of three groups. Those who need social care but receive none; those who receive some social care but need more; and those who need their social care to be amended in order to achieve independent living. **'Unmet needs in adult social care' in Scotland should therefore be defined as: (a) the number of adults in Scotland that need any, more, or amended, social care to enable them to achieve and sustain independent living, and (b) the range of those unsatisfied care and support needs.**

Scotland needs a process to drive the work to accurately identify and aggregate unmet need in social care consistently across the nation. There is a need for detailed and consistent record keeping of unmet needs during needs assessment. Not only in relation to existing services but with a focus on independent living. This more accurate needs assessment and record keeping then requires consistent aggregation and analysis at local authority level to create accurate locality data to identify unmet social care needs and so to better inform priorities for social care-related policy at local level. To fulfil the National Care Service aim to tackle regional and Scotland-wide levels of inequality then requires a further level of aggregation and analysis. To our knowledge, there is no independent, Scotland-wide body (a) to evaluate the quality of needs assessment across local authorities, (b) to support social care services with the transition to accurately and consistently recording and measuring unmet social care needs, or (c) to strategically co-ordinate, analyse, interpret, and respond to unmet needs findings as they emerge across Scotland, tackling inequalities in the process. There is a need for such a body to drive through accurate evaluation of unmet needs in social care in the context of independent living, and it should involve disabled people, Disabled People's Organisations and social care user groups in the process.

In conclusion we would like to refer to two key pieces of writing that have informed this review, and two ideas that underpinned our work. First, we do not consider need and unmet need as value-free concepts. We echo Godfrey and Callaghan's (2000, p.2) views on the "*socially*

*constructed nature of need*” and on the nature of questions such as *“how need is shaped and defined”* and *“whose needs are legitimate?”* as political and not just as theoretical. Therefore, this review has taken this standpoint and advocates for a better understanding of the social and political factors, gradients and inequalities which contribute to the construction of unmet need, whilst maintaining focus on people’s individual circumstances. The second viewpoint that we pay attention to is from IRASC (Scottish Government, 2021a, p.102) that *“assessment should be the product of a full understanding of the individual’s needs, rights and preferences, and that when that assessment is translated into a package of supports any unmet needs should be recorded.”* Fulfilling need and recording any unmet need in adult social care is not about service provision for notional ADL/IADL, but about the independent living outcome of supporting disabled adults to live a fulfilling, inter-dependent, and social life (Dean, 2020) with their rights and preferences at the centre.

This review is a contribution to the wider effort to strengthen the social care system in Scotland through the proposal for a National Care Service. This is intended to *“ensure the quality, fairness and consistency of provision of social care services meets individuals’ needs, regardless of where they live in Scotland”* (Scottish Government, 2022c). A new, co-ordinated Scottish approach to identifying and recording unmet needs in social care for disabled people through the lifecourse will offer the accuracy of data that is the necessary basis for future allocation of social care resources to progressively transform how disabled people are able to live their lives and so play an equal role in Scotland’s communities.

## 5. References

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