

ARTICLE

# Understanding unmet aged care need and care inequalities among older Australians

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## Abstract

In Australia, numerous reviews and inquiries have documented concerns about inadequate access to, and the quality of, aged care. Despite those concerns, research is yet to appraise fully how care needs are assessed, prioritised, and met or left unmet. This paper asks two interrelated questions: (1) How should we conceptualise and measure unmet care need and care inequalities among older people? (2) What are the policy parameters for assessing needs, prioritising access to support and monitoring quality in aged care in Australia? Key insights from academic literature are used to critically review Australian policy documents describing rights, assessments, prioritisation, quality standards and performance indicators for the aged care sector. Using the concepts of care inequalities and care poverty, the paper develops a framework for understanding and measuring needs and unmet needs in aged care, and for encompassing fundamental and valued aspects of life for older people, their carers and their care network. The paper argues that the concept of care poverty opens the space to discuss what level of unmet need and inequality in access to aged care in any society may be considered *intolerable*.

**Keywords:** unmet need; care inequalities; care poverty; aged care; Australia

## Introduction

Numerous inquiries and reviews in Australia have documented concerns about unmet need in both residential aged care and community aged care (Royal Commission into Aged Care Quality and Safety (RCACQS), 2019a). Despite the evidence and recommendations of these reviews, unmet need, in terms of poor quality services and a lack of services, remains a pressing issue in the aged care sector. Two key inquiries into the quality and standards of care in residential care in Australia – *The Oakden Report* (Groves *et al.*, 2017) and the *Review of National Aged Care Quality Regulation Processes* (Carnell and Paterson, 2017) – highlighted significant failings. These reviews preceded the creation of a new Aged Care Quality and Safety Commission (ACQSC) and the establishment of RCACQS in 2018. The RCACQS interim report on the sector concluded that they had:

heard compelling evidence that the system designed to care for older Australians is woefully inadequate. Many people receiving aged care services have their basic human rights denied. Their dignity is not respected and their identity is ignored. It most certainly is not a full life. It is a shocking tale of neglect. (RCACQS, 2019b: 12)

The lack of data to assess the quality of care of the aged care system is noted in the assessment of the RCACQS Counsel Assisting's Final Submissions:

Identifying the precise extent of substandard care in Australia's aged care system is a difficult task due to deficiencies in the data available to measure the quality of care. This should not be the case. It should be a straightforward task to assess the quality of care provided in our aged care system. That it is difficult says much about the maturity of the sector and the lack of curiosity of the government that funds and regulates it. (RCACQS, 2020: 13)

These data gaps have led the RCACQS to commission surveys to provide insights into potential indicators for quality of care, quality of life outcomes, and concerns and complaints procedures for older people in residential care and receiving community care (Batchelor *et al.*, 2020a, 2020b; Caughey *et al.*, 2020). While the recent surveys identify unmet needs in care delivery and outcomes for care recipients 'inside the system', a comprehensive picture of unmet need in society also requires understanding the situation of older people who remain outside the system and experience problems in gaining access to services. Among known access issues is that around 100,000 older Australians are on a waiting list for a Home Care Package (HCP) at the level of their assessed needs (Department of Health, 2019a).<sup>1</sup> Recognising this shortfall, in 2017, the Australian Government set up a National Prioritisation System to guide the allocation of available aged care places. However, comprehensive measures of unmet need for aged care and the demand for aged care services do not yet exist in Australia. According to Tune (2017: 49), who undertook the *Legislated Review of Aged Care*, 'robust measures of demand and unmet demand in aged care are a significant way off'.

Nationally representative household survey data in the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC) can provide some insights into self-reported unmet need in the broader community. In 2018, one in three (34.1%) of the 1.3 million Australians aged 65 years and over living in households, and who reported having a need for assistance, had unmet needs for activities of daily living (ADLs) ('self-care, mobility and communication') and/or instrumental activities of daily living (IADLs) (such as 'home help, home maintenance, meal preparation') (ABS, 2019). The proportion reporting that their needs were partly unmet had increased since 2015 (ABS, 2019). The most common unmet needs were for 'property maintenance, household chores, and cognitive or emotional tasks' (ABS, 2019). Such data, while informative, rely on respondents recognising and expressing that they have a need for assistance and that they also have an unmet need for care and support. Policy documents outlining the performance indicators for the Australian aged care sector note that for many

other dimensions of unmet need, data do not yet exist (Steering Committee for the Review of Government Service Provision (SCRGSP) 2019).

Despite the concerns about processes and outcomes in the aged care sector, research is yet to examine how the policy parameters and processes by which aged care needs are assessed, prioritised and accorded a service response may generate unmet needs in Australia. Internationally, researchers have examined whether increasingly marketised and individualised aged care systems can meet needs. Recent studies in the United Kingdom and Finland have explored the concept of need, the extent and types of older people's unmet needs, and factors associated with experiencing unmet needs (Vlachantoni *et al.*, 2011; Harrison *et al.*, 2014; Brimblecombe *et al.*, 2017; Ipsos MORI, 2017; Kröger *et al.*, 2018, 2019; Vlachantoni, 2019). Other studies in Europe, the United States of America and Australia have investigated the consequences of unmet aged care need (LaPlante *et al.*, 2004; Freedman and Spillman, 2014; He *et al.*, 2015; Low *et al.*, 2015; Visvanathan *et al.*, 2019). Research in Finland has also drawn attention to social policy concerns, highlighting inequalities in the receipt and distribution of adequate care among individuals and households, and thresholds of inadequate care that can be considered a form of 'care poverty' (Kröger, 2010; Kröger *et al.*, 2018, 2019).

This paper builds from these international studies to examine the Australian aged care context by asking two interrelated questions:

- (1) How should we conceptualise and measure unmet care need and care inequalities among older people?
- (2) What are the policy parameters for assessing care needs, prioritising access to support and monitoring quality in aged care in Australia?

The paper first examines approaches to understanding unmet care needs, drawing on the literature about needs and unmet needs, noting ways in which unmet needs may be generated. It then extracts key insights and questions from this literature to analyse and to review how need and unmet need is characterised in the documents of the contemporary Australian policy framework and in *My Aged Care*.<sup>2</sup> The analysis examines legislative, policy and service parameters that underpin definitions, assessments and prioritisation of need, quality standards in services and performance indicators for the sector. The analysis provides insights into which needs are regarded as socially and politically legitimate and to be allocated resources through taxpayer-subsidised services; the analysis also identifies the systemic processes that generate unmet needs. The paper then outlines a framework for conceptualising and measuring unmet care needs in Australia that can, arguably, more comprehensively assess and measure whether and how aged care systems generate unmet needs, care poverty and care inequalities.

### Understanding aged care needs and unmet need

Understanding unmet aged care need requires examining how needs, and specifically aged care needs, are conceptualised, recognised and assessed. The vast literature on the concept of human needs and social policy responses to meeting needs contains a number of important distinctions that can provide useful insights to address this issue (see *e.g.* Dean, 2010; Lister, 2010). Needs may be distinguished from a

category of claims regarded as wants (Lister, 2010). One way the literature distinguishes needs from wants is by identifying the harm that will result as a consequence of the need not being met (Lister, 2010). Alternatively, Ignatieff suggests that this distinction can be grounded in broader social agreements about the nature of need and resource allocation, such that the responsibility to identify and meet the 'needs of strangers' invokes

questions about human obligations. To ask what our needs are is to ask not just which of our desires are strongest and most urgent, but which of our desires give us an entitlement to the resources of others. This natural pairing of the idea of need with the idea of duty and obligation is what distinguishes need from desire. (Ignatieff, 1985: 27)

Therefore, identifying *which* needs associated with ageing can justify public expenditure to be met through a care-giving response requires both an assessment of potential harm to individuals and broader social and policy agreement about the value of meeting specific types of needs.

The literature emphasises that the needs and unmet needs of concern to social policy can be defined and prioritised in different ways. Bradshaw's (1972) taxonomy of 'social need' clarifies the sometimes competing processes that define and prioritise need. He outlines four types of social need:

- (1) 'Normative needs' refer to needs defined by standards set by 'the expert or professional, administrator, or social scientist', among whom there may be competing 'expert' perspectives and whose views may change as a consequence of 'developments in knowledge, and changing values of society' (Bradshaw, 1972: 72–73).
- (2) 'Felt need' locates the assessment of need in the person themselves, which, Bradshaw notes, can be constrained or overinflated by an individual's understanding of available support, willingness to recognise a 'loss of independence' and help-seeking tendencies (Bradshaw, 1972: 73).
- (3) 'Expressed need or demand is felt need turned into action' (Bradshaw, 1972: 73), which he suggests can underestimate real need, as some people may not demand a service even if they have a need, and further, notes that unmet need in this case is often measured by 'waiting-lists' (Bradshaw, 1972: 73).
- (4) 'Comparative need' compares rates of services provided to different population groups and defines unmet need as existing where there are lower rates of service provision for some groups. As Bradshaw notes: '[t]his is an attempt to standardise provision but provision may still not correspond with need' (Bradshaw, 1972: 73).

Bradshaw thus emphasises the complexity of defining need and that policy makers face challenges in defining what is a 'real need' or a need that society should organise to meet. Bradshaw's taxonomy categorises processes for assessing needs for services, making distinctions between who articulates the needs, the competing claims about the standards against which need is assessed, and the potentially different criteria or characteristics upon which equity across groups is assessed. He contends that by

distinguishing between these different types of need it is possible to 'clarify and make explicit' the processes that have been used to define and prioritise needs (Bradshaw, 1972: 81).

Fraser (1987, 1989) also emphasises processes through which needs are interpreted, underscoring the political and discursive dimensions when needs move from the private or family sphere to become contested 'needs claims' within the public or 'social' realm (Fraser, 1987, 1989). For Fraser (1989: 294), the political processes of recognising needs occurs in three 'moments' of struggle: (a) 'validat[ing] the need as a matter of legitimate political concern...'; (b) interpreting and defining the need and how to - meet the need; and (c) '[satisfying the] need ... to secure or withhold provision'. These moments represent three points in the social policy sequence in which need can be interpreted and indicate also that unmet need can be generated through a rejection of a claim.

In these processes of needs claiming, Fraser (1987, 1989) describes three types of needs discourses: 'expert', 'oppositional movement' (from the subjects with needs) and 'reprivatisation', which seek to relocate responsibility for the need within the private realm. Like Bradshaw, then, Fraser (1987, 1989) notes the contests over the *content* of needs claims between 'experts' (normative need) and the subjects of needs claims (oppositional or expressed need), and also highlights the politicised content articulated by those seeking to reprivatise needs. Her approach also explicitly outlines different discursive mechanisms through which needs claims can be articulated, that is, *how* needs may be expressed. Thus, she contends that needs may be articulated through 'needs-talk, rights-talk, [or] interests-talk' and may be expressed in the language of different discourses such as 'therapeutic ... administrative ... religious ... feminist ... or socialist' (Fraser, 1989: 294–295). Importantly, Fraser (1989: 295) raises questions about how competing needs claims may be resolved: 'By appeals to scientific experts, by brokered compromises, by voting according to majority rule, by privileging the interpretations of those whose needs are in question?' Another key element is how those with needs are positioned as subjects, whether as citizens bearing rights, consumers in a market or clients of the state (Fraser, 1987, 1989; *see also* Dean, 2010).

The complex political and discursive processes involved in defining needs lead Fraser to raise two points: 'One is the question whether and how it is possible to distinguish better from worse interpretations of people's needs. The other is the question of the relationship between needs claims and rights' (Fraser, 1989: 311). In answering the first question, Fraser (1989:312) argues for (a) 'procedural considerations' in processes for interpreting needs to ensure that they 'approximate ideals of democracy, equality and fairness', and (b) 'consequentialist considerations' that consider distribution of outcomes and whether some interpretations of needs generate disadvantages for some groups. On the second question, Fraser argues 'in favor of the translatability of justified needs claims into social rights' (1989: 312). The value of Fraser's analytical framework for this analysis is to bring attention to the competing interests and discursive processes that seek to define aged care needs as a legitimate social and public concern, how such needs should be defined and met, and whether the outcomes are fair.

The outcomes of administrative, political and discursive processes used to define need described by Bradshaw and Fraser generate the policy and service parameters

for addressing need through resource allocation, prioritisation and service provision. These parameters include policy frameworks and guidelines, eligibility criteria, and discretion available to assessors and service providers that are, as Liddiard describes, all ‘rationing devices’ (Liddiard, 2007: 121, in Vlachantoni *et al.*, 2011: 63 and Vlachantoni, 2019: 658). Bergmark *et al.* (2000) point to two philosophical principles that may underpin different perspectives on appropriate resource allocations and competing priorities for services to meet need: efficiency (which they note may be challenging to identify) and distributive justice. They note that principles of distributive justice may be perceived in three ways: through the principles of ‘need, ... merit ... [or] contribution or just possession’ (Bergmark *et al.*, 2000: 316). The first prioritises disadvantage, the second rewards ‘achievement or morally desired behaviour’ while the third allocates resources based on contributions (fees and insurance) (Bergmark *et al.*, 2000: 316). Their discussion underscores the different values and principles that frame decisions about which needs should be recognised and prioritised (*see also* Bradshaw, 1972). It is thus important to understand if, and how, ideas or principles of efficiency and justice are used to prioritise need and allocate resources in an aged care system.

### Conceptualising unmet need

Conceptualising and measuring unmet need is more complex than need because it encompasses both recognising and assessing need and then identifying a lack of assistance or support (Vlachantoni, 2019). From the service provision perspective, Vlachantoni *et al.* (2011: 65) conceptualise unmet need as ‘determined by the interaction between a person’s type and level of need and the type and level of support they receive, and affected by their demographic, socio-economic and health status characteristics’. The model by Vlachantoni *et al.* (2011: 65) describes different types of groups with unmet need including those with:

- ‘a low level of need who receive no support’;
- ‘a moderate level of need who fall just below the formal [or outside] assessment criteria’; or
- ‘high needs who receive formal support but who are unsatisfied by it’.

The unmet needs outcomes of such groups occur due to a range of mechanisms within the policy and service processes. Table 1 draws on the preceding points raised by Bradshaw and Fraser to outline the mechanisms and processes that generate unmet need. Table 1 also identifies existing Australian measures and policy parameters that describe need and or unmet need, some of which will be discussed in more detail further below. Using Bradshaw’s taxonomy, a *lack* of assistance or support, or unmet need, can arise due to the lack of felt, expressed or normative need, or the absence of informal support and service provision (which may be comparative need if the lack is for a specific group).

Unmet need may occur if an older person does not translate a felt need into expressed need due to a lack of recognition of own need or due to broader social discourses that regard some needs as not socially legitimate enough to be met by public provision. As the need of the older person is not expressed, unmet felt

**Table 1.** Mechanisms generating unmet needs

Type of need (Bradshaw, 1972)	How unmet need occurs/mechanisms	Measures of unmet needs	Australian policy parameters/measures/data
<i>Felt needs</i> of older person	Felt need is not translated into expressed need due to: person not recognising own need or effect of broader discourses in policy, services, media and advocacy about what it is socially acceptable to claim as an aged care need.	Difficult to measure because need is not articulated by person.	No existing measures.
<i>Expressed needs</i> of older person	Expressed need of individual not recognised as a need requiring a response by services and public policy or by family or friend informal carers.	Identification of self-reported unmet needs for formal and informal care and support as articulated by older person (and/or carers).	<ol style="list-style-type: none"> <li>1. SDAC data on self-reported unmet need for formal and informal services.</li> <li>2. Consumer Experience Reports.</li> <li>3. Complaints to the ACQSC.</li> </ol>
<i>Expert/normative needs</i> – recognised in formal needs assessments by experts, administrators or researchers	<p>Needs not assessed in formal aged care assessments.</p> <p>Experts’ perceptions of need differ from individual’s perceptions.</p> <p>Needs of sub-groups are not assessed in a culturally safe or appropriate way.</p> <p>Lack of access to assessments due to referral and system navigation issues.</p>	Formal needs assessment differs to older person’s (and or carers’) quality of life assessments and perspectives on needs. Access to assessment of needs.	Aged Care Assessment Tool.
<i>Expert and comparative needs</i> – addressed through service provision	Needs recognised in a needs assessment but not met through service provision due to either: <ul style="list-style-type: none"> <li>Lack of service provision due to targeting, rationing, cost, cultural inappropriateness, access</li> </ul>	Lack of services. Poor quality of services. Poor quality of life outcomes as a result of services.	Regulatory framework: <ol style="list-style-type: none"> <li>1. Prioritisation processes, waiting lists, costs/affordability.</li> <li>2. Aged Care Quality Standards, Consumer Experience Reports, Charter of Aged Care Rights, National Aged Care Mandatory</li> </ol>

(Continued)

Table 1. (Continued.)

Type of need (Bradshaw, 1972)	How unmet need occurs/mechanisms	Measures of unmet needs	Australian policy parameters/measures/data
	<p>inequalities due to geographical location or lack of services for sub-groups.</p> <ol style="list-style-type: none"> <li>Poor quality services due to inadequate management, staffing, resources, infrastructure, and lack of culturally safe care for Aboriginal and Torres Strait Islander peoples, and lack of appropriate care for culturally and linguistically diverse groups, and other sub-groups.</li> </ol>		Quality Indicator Program, Quality of Care Principles, Aged Care Diversity Framework.
<i>Expert/normative needs</i> – recognised through aged care policy	<ol style="list-style-type: none"> <li>Limited range of needs recognised and identified by policy.</li> <li>Inadequate resource allocation by policy makers to meet identified needs.</li> <li>Needs not recognised as requiring a collective response in policy and ‘reprivatised’ to be met by family.</li> </ol>	Performance indicators for policies and programmes. Funding allocations to meet needs.	<ol style="list-style-type: none"> <li>Performance Indicator Framework for Aged Care Services objectives, outputs and outcomes.</li> <li>Residential care: Aged Care Funding Instrument, Australian National Aged Care Classification.</li> <li>Home care: budget allocations for packages.</li> </ol>

Notes: SDAC: Survey of Disability Ageing and Carers. ACQSC: Aged Care Quality and Safety Commission.



needs are difficult to identify and measure; to date no such measures exist in Australia. The impact of social discourses about acceptable aged care needs claims also highlights the issue of social desirability bias in assessments of self-reported unmet need.

Unmet needs for formal and informal support may also occur as a result of the expressed needs of older people not being recognised by policy (for formal services) or by family and friends (for informal support). Data about expressed needs in Australia exist in the self-reported SDAC data for unmet need for assistance for ADLs and IADLs from formal and informal sources. The SDAC data on unmet need for formal services is one measure used in the Australian Government's Performance Indicator Framework (PIF). Unmet need can also arise through expressed needs in relation to *inadequate* or poor quality service provision, such as expressed dissatisfaction in the Consumer Experience Reports collected by the ACQSC or in expressed complaints.

The assessment processes for service eligibility can generate unmet needs based on the expert or normative standards used, and the domains of needs identified, which may differ from the individual's perception of their own needs, particularly for some population sub-groups. In Australia, the recognised domains and standards for needs are defined in the Aged Care Assessment Tool. Unmet need may also be generated through lack of access to the assessment processes that may be the result of referral or system navigation issues.

Unmet need can arise through lack of access to services due to prioritisation criteria and targeting or *inadequate* or poor quality service provision that could be defined in relation to standards or quality indicators (normative need), or comparisons of services received across population sub-groups (comparative need) (Bradshaw, 1972; Diwan and Moriarty, 1995). The Australian regulatory and policy framework defines the criteria for priority access to services and the range of quality standards for government-subsidised services. Thus, these policy documents outline the types of needs recognised by experts and the normative standards or thresholds for meeting need and recognising the needs of diverse groups.<sup>3</sup>

Within the framework proposed by Fraser (1987, 1989), unmet need could also occur as a result of the *erasure* of oppositional movement or expressed need by competing claims from 'expert' discourses about needs. The erasure of need could occur through reprivatisation discourses and practices, whereby some groups may have the political power or authority to remove certain needs from the domain of social policy concern and thus limit the availability of government-provided services or funding. The overarching PIF maps the policy discourses about objectives, outputs and outcomes for the Australian aged care sector and the politically legitimated needs in the Australian context. Unmet need may be generated through the processes defining the level of resources available to satisfy identified needs. Instruments and policies allocate resources to satisfy needs for older people in residential care using definitions in the Aged Care Funding Instrument and the new Australian National Aged Care Classification. For older people seeking home care, needs are satisfied on the basis of the funding policies that determine resources allocated to, and prioritisation processes for, HCPs.<sup>4</sup>

## Aged care policy and service parameters in Australia

**Table 1** outlined mechanisms that could generate unmet need and relevant Australian policy parameters and measures. These policy parameters include the broader legal and regulatory framework, assessment processes, processes of prioritisation and access to services, and quality indicators in service provision that describe the absence of or inadequate provision of care. This section first briefly outlines the context and legal framework for aged care in Australia. It then uses key questions identified in the literature on needs to analyse policy guidelines and standards that underpin the policy processes through which older Australians' aged care needs are met or left unmet (**Table 2**).

### Australian aged care context and legal framework

In Australia, like many countries, most aged care is provided by unpaid carers, including family members and friends (RCACQS, 2019c: 24), with some care purchased in the private sector, and a significant amount provided through government-subsidised and -regulated home-based and residential care services. In 2017–2018, the Australian Government-subsidised sector provided aged care to over 1.3 million people, around two-thirds of whom received basic home-based services through the Commonwealth Home Support Programme (CHSP) and around 117,000 received HCPs (Department of Health, 2018a: 9). Over 240,000 people received residential care services in 2017–2018 (Department of Health, 2018a: 9).

Legislative frameworks define the rights that individuals have to receive services and support to meet aged care needs. The RCACQS (2019a) outlined two key relevant Acts in Australia:

- the *Aged Care Act 1997 (Cth)*, which addresses processes to approve providers for residential care, HCP and flexible care; and
- the *Aged Care Quality and Safety Commission Act 2018 (Cth)*, which covers accreditation or quality review and complaints (for government-subsidised programmes).

The research by the RCACQS also notes that these Acts interact with regulations relating to the Australian Competition and Consumer Commission, the Australian Health Practitioner Regulation Agency, and health and safety regulators in each state and territory (RCACQS, 2019a).

This legislative framework outlines the Australian Government's role in regulating government-subsidised services to meet needs. For example, the *Aged Care Act 1997* indicates that: 'Aged care providers are required to "maintain an adequate number of appropriately skilled staff to ensure that the care needs of care recipients are met" (paragraph 54-1(1)(b) of the Act)' (Grove, 2019: 169). However, as noted by Grove (2019), the Act does not articulate in detail what specific skills or staff ratios are required to meet such needs.

At present, rights to having aged care needs met in Australia are limited to: accessing information; obtaining needs assessments for eligibility for government-subsidised services; seeking access to services; receiving quality care; and raising

**Table 2.** Review of needs in policy documents

	Assessment	Prioritisation (Assessments and National Prioritisation System (HCP))	Service provision
Who identifies needs?	RAS/ACAT assessors. Older person, representative, carer.	Experts: through referrals, assessors	Experts: ACQSC quality assessors, providers. Older person/consumer, family, carers and advocates for feedback and complaints.
What domains of needs are identified?	Older person: social connections, social and community participation, unpaid support, physical and mental health, medical, home and personal safety, risk of vulnerability, goals, motivations and preferences, reablement. Carer: sustainability, strain.	Risk to health and safety of older person. Risk of client entering residential care. Lack of carer support and sustainability of caring role.	Clinical care, personal care, support for everyday living, and social, psychological and relational aspects of how care is delivered as outlined in: •Aged Care Quality Standards. •Single Charter of Aged Care Rights. •National Aged Care Mandatory Quality Indicator Program. •Consumer Experience Reports.
Whose needs are identified?	Older person and carer (carer strain). Sustainability of the care relationship.	Older person. Care relationship.	Older person.
Types of needs within Bradshaw's framework	Expert (normative) needs based on standards. Felt/expressed need of older person and carers. Comparative need: special needs groups.	Expert need regarding criteria. Comparative need in relation to others and regarding time on assessment lists/national priority queue.	Expert needs based on standards. Felt/expressed need of consumers and carers in relation to quality of services. Comparative need in relation to specific special needs groups.
How can needs be discussed?	Conversation between assessor and client/and carer about circumstances and needs including both: •Expert medical discourse: validated tools. •Consumer goals and preferences.	Expert medical/therapeutic discourse. Relational discourses about sustainability of informal care relationship.	Reference to standards of care (expert therapeutic discourse); principles of care delivery (consumer rights discourse). Feedback and complaints mechanisms with reference to rights. Consumer Experience Reports: satisfaction with quality of care surveys.
What principles are used to justify needs/	Disadvantage relating to need assessment of older persons.	Disadvantage based on access to informal carers or sustainability of	

(Continued)

**Table 2.** (Continued.)

	Assessment	Prioritisation (Assessments and National Prioritisation System (HCP))	Service provision
resource allocation claims?		caring role rather than complexity or intensity of needs of older person, <i>per se</i> .	Effectiveness/efficiency of government-subsidised aged care system in meeting articulated needs.
How are competing needs claims resolved?	Not identified.	Expert perspectives and administrative procedures.	Regulatory and monitoring processes and complaints mechanisms.

Notes: HCP: Home Care Package. RAS/ACAT: Regional Assessment Services/Aged Care Assessment Teams. ACQSC: Aged Care Quality and Safety Commission.

concerns or complaints about government-subsidised services (Australian Human Rights Commission, 2019: chap. 12). Rights for older people in Australia are thus framed with regard to their role as consumers (and co-contributors to the costs) of government-subsidised aged care services, which are to be obtained through a market, as opposed to a role as citizens with rights to receive services. Some services require financial contributions from users,<sup>5</sup> and while financial hardship provisions for older people with limited means to pay for services to access support exist,<sup>6</sup> there is no legislated right for older people to receive aged care services or have their needs met. Thus, aged care needs are not addressed through ‘rights talk’ (Fraser, 1989), except perhaps in the limited sense of rights to consumer protection. The lack of universal rights to ‘quality, safe, empowering and timely care’ for all older people who need it has been identified by the RCACQS (2020) as a key issue to be addressed in future reform with its call for new legislation embedded in a rights-based approach.

### **Analysing policy parameters**

Table 2 outlines the key questions identified in the literature on needs used to analyse the policy guidelines and standards that underpin the policy processes through which the aged care needs of older Australians are met or left unmet. The questions are:

- (1) Who gets to identify needs? (experts, carers, advocates, those with lived experience?).
- (2) What domains of needs are identified? (*e.g.* functional, social, emotional, informational?).
- (3) Whose needs are identified? (older person, carer, care dyad, care network?).
- (4) What types of needs are identified? (using Bradshaw’s framework – normative, felt, expressed or comparative).
- (5) How can needs be discussed? (by reference to quality standards set by experts, relative provision across groups, rights or interests, discourses and languages use).
- (6) What principles are used to justify needs claims or allocation of resources? (efficiency, justice, other?).
- (7) How are competing needs claims resolved? (when different perspectives about needs exist, whose perspective is most authoritative?).

The final question identified is broader, since it brings attention to the overarching system of aged care and the consequences of unmet need (and will be discussed further below):

- (1) Are the processes of interpreting needs procedurally and consequentially fair?

### **Assessment**

Access to government-subsidised services is through an initial screening interview by phone that initiates a referral to a needs assessment process conducted by the Regional Assessment Services (RAS) for CHSP or the Aged Care Assessment Teams (ACAT) for HCP and residential care (Department of Health, 2018b). The domains of need assessed to develop a support plan encompass:

- Family, community engagement and support.
- Carer, caring responsibilities and sustainability of caring relationships.
- Level of function.
- Physical and personal health.
- Health-care connections and health conditions.
- Cognitive capacity and psycho-social circumstances.
- Home and personal safety.
- Level of complexity and risk of vulnerability.
- Support considerations.
- Goals, motivations and preferences (Department of Health, 2018b: 2).

In assessment processes, the qualified assessors identify a wide range of aged care needs against specified validated tools (Department of Health, 2018c). Such assessments are also an opportunity take into account the felt and expressed needs of older people, particularly in relation to goals and preferences. The focus of the assessment, then, is on the older person. In some cases, carers of older people are asked about difficulties and concerns, the sustainability of the caring role, the supports needed and carer strain tools may be used (only used in around 8% of ACAT assessments).<sup>7</sup> Clarkson *et al.* (2018) have noted that the shift to consumer-directed care has seen a shift in emphasis from needs defined by experts to felt and expressed needs from clients. Whether this shift occurs in actual practice rather than merely rhetoric is a question for further empirical research. This shift may also bring up questions for assessors and providers in distinguishing between ‘needs’ and ‘wants’ within broader views about socially legitimated ‘needs’. In Australia, concerns are noted about ‘the timeliness, quality and consistency of the assessment process’ (Tune, 2017; RCACQS, 2019b: 137). The policy documents do not indicate how different perspectives regarding needs identified by assessors, older people and carers in this process might be resolved.

### **Prioritisation**

The supply of government-subsidised aged care places in Australia is capped and based on ‘a national target provision ratio’. The overall ratio target has increased from the 100 places in 1985 to ‘125 aged care places per 1,000 people aged 70 years and over, including 78 residential care places, 45 home care places and 2 restorative care places, to be achieved by 2021–22’ (Tune, 2017: 50). Since 2017, it has become more evident that the demand for aged care support has exceeded supply for some services, requiring prioritising processes in service allocations (Department of Health, 2018c).

Prioritising occurs in referrals to assessments through RAS and ACAT. A high priority rating for RAS assessments is based on risk relating to client’s health and safety, while the criteria for high priority for ACAT assessments is that:

the person’s safety is at risk (e.g. high risk of falls or abuse), or there is a high likelihood that the person will be hospitalised or required to leave their current residence because they are unable to care for themselves, or their carer is unavailable. (Department of Health, 2018c: 19)

Wait times for assessments vary and then, after assessments, there may be further waiting for CHPS and HCP. While the RCACQS (2019b: 148) indicated that there are no data on wait times for CHSP, they also report that many ‘people may experience a wait when searching for a provider – “provider waiting” – and then potentially have to wait for the provider to become available to deliver the service – “service waiting”’. After assessment, the allocation of HCPs is through the National Prioritisation System. While ‘time waiting for package (commencing from the date of Delegate approval)’ is one criterion, the other criteria for high priority when allocating packages are similar to processes of assessment, relating to personal safety or older person’s risk of entry to residential care and the availability of a carer or sustainability of the care relationship (Department of Health, 2018d: 2).

Prioritising for HCPs thus emphasises comparative need, based on the relative length of time on a waiting list, and the specific expert-defined needs (risk to safety and entry to residential care) ranked and defined by assessors, rather than other needs identified by the older people or their carers. Arguably, such an approach defines priority based on the principle of most disadvantage, where one key criterion of disadvantage is the potential lack of support from a carer, rather than the intensity or complexities of older person’s needs *per se*. The ‘mean waiting time’ between assessment and receipt of the highest level (Level 4) of HCP in 2017–2018 was 22 months (RCACQS, 2019b: 154–155). While waiting for HCP, people may receive a lower-level package, with a waiting time of 3–6 months minimum (Department of Health, 2019a: 13) or have approval to access support through CHSP (Department of Health, 2019a). An alternative option while waiting for government-subsidised support is to engage aged care services through the private market, an option available only to older people with sufficient private means or where family means may be utilised.

Prioritising processes for assessment and service allocation also focus on limited needs for the older person and the sustainability of the provision of care by the carer rather than the carers’ needs in their own right; nor are carers always included in service assessment and planning (Carers NSW, 2020). A separate new system of support for carers was introduced in Australia in 2020<sup>8</sup> to which carers should be referred from the RAS or ACAT assessment. However, it is unclear at this stage how these two systems will interact and whether the level of funding to support carers will be adequate. In prioritising processes, competing perspectives on needs claims are resolved by expert perspectives and administrative procedures.

### **Service provision**

In government-subsidised aged care services, processes of recognising and identifying the domains of needs of older people are articulated in the documents and activities of the ACQSC and the Department of Health. Such documents include the Quality of Care Principles 2014 (*Aged Care Act 1997(Ch)*), the Aged Care Quality Standards (ACQSC, 2019a), the National Aged Care Mandatory Quality Indicator Program (Department of Health, 2019b) and the Single Charter of Aged Care Rights (ACQSC, 2019b). Unmet needs are identified by expert assessors against such standards and through feedback and complaints from older people and their carers/advocates through mechanisms of the ACQSC.

All organisations providing aged care services funded by the government are assessed in terms of compliance with and performance against the new Aged Care Quality Standards. The new standards were introduced in July 2019 after criticisms about the old Accreditation Standards for focusing on compliance with processes to be met at a minimum level rather than quality of care and quality of life outcomes for aged care consumers (Carnell and Paterson, 2017). As a result, the focus of needs identified in such standards has shifted from what might be seen as structure and process indicators to outcome indicators relating to the experience of care and quality of life (Donabedian, 1988; *see also* discussion in Braithwaite *et al.*, 2007). As well as articulating quality standards for care to address needs in the domains of personal care, clinical care and support for daily living, the new standards highlight dimensions of social, psychological and relational need in articulating *how* care should be provided (ACQSC, 2019a). The standards indicate that care must be provided in such a way that respects the dignity and choice of older people and engages them in an ongoing partnership about assessment and planning of care (ACQSC, 2019a). Other standards relate to organisational processes: that consumers feel they are in a safe and comfortable environment, are supported to provide feedback and make complaints, and have an adequately trained workforce and appropriate governance mechanisms (ACQSC, 2019a). These domains of need include, but go beyond, expert-defined standards relating to clinical, personal and practical care. They also emphasise the felt experience of older people and the requirement to engage with older people's preferences and concerns, underscoring the social, psychological and relational elements of meeting aged care needs (for discussion of the perspectives of care workers, *see also* Meagher *et al.*, 2019).

These broader domains of need are also reflected in the Single Charter of Aged Care Rights (ACQSC, 2019b), an example of explicitly shifting from 'needs talk' to 'rights talks' in service quality documents, albeit framed within a consumer rights perspective. These rights and quality standards provide a framework of expectation about what constitutes adequate or good care. Complaints made against such standards to the ACSQSC can be supported by advocacy organisations and quality in residential care is monitored through unannounced reaccreditation audits by assessors from the ACQSC (Department of Health, 2019c).

Information about quality to enhance consumer choice in the market for aged care is provided through two main mechanisms: the National Aged Care Mandatory Quality Indicator Program (NACMQIP) and Consumer Experience Reports (CER). Under the NACMQIP, residential care homes must report against three specific measures – pressure injuries, use of physical restraint and unplanned weight loss – the data from which will be publicly reported (Department of Health, 2019b). In CER, a sample of residents provides responses to questions covering numerous care needs (ACQSC, 2019c). CER have been implemented in home care services quality reviews from 2019 (ACQSC, 2019d). Framed within a discourse of providing information for consumer choice, such measures across the different domains may also provide more insight into the degree to which services are able to satisfy the needs of older people from their own perspectives. However, to date the RCACQS (2019b: 131) has noted that finding out information about service quality was a 'time-consuming and difficult process, and still does not



necessarily yield information that allows a person to differentiate between barely adequate and high quality services'. The RCACQS Counsel Assisting's Final Submissions have recommended that CER be expanded to enable 'greater weight to be attached to the consumer experience' in accreditation and compliance monitoring as well as for consumer information (RCACQS, 2020: 444–445).

Quality regulations in aged care service provision thus comprise a mix of expert, comparative and expressed definitions of need and unmet need, and the responsibility for assessing quality falls to all stakeholders, including older people and their carers. Although all the mechanisms discussed above may improve safeguards for people receiving services, they rely in part on the capacity and efficacy of consumers, carers and advocates in voicing concerns about inadequate care and having their expressed needs heard and complaints dealt with appropriately. Furthermore, the quality mechanisms do not apply to people receiving services that are not government subsidised. Principles underpinning quality processes relate to appropriate and effective use of government subsidies for funded services combining elements of efficiency and justice discourses.

### **Performance of the aged care sector**

The aged care services PIF and associated measures (SCRGSP, 2019) also provide insights into how need and unmet need is defined in the aged care system and the Australian Government's own criteria for success. The stated overarching aims of 'the aged care system' are 'to promote the wellbeing and independence of older people (and their carers), by enabling them to stay in their own homes or by assisting them in residential care' (SCRGSP, 2019: 14.10). The PIF provides information about concepts used and available data to measure 'equity, effectiveness and efficiency' in terms of 'outputs' (services delivered) and the 'outcomes' of the services (SCRGSP, 2019: 14.10).

Table 3 reports the concepts, definitions and measures for the outputs of the system for equity and effectiveness (as efficiency relates only to system costs). The output measure for the concept of equity is 'access', which is a comparative need measure of 'use by different groups' that includes the special need groups defined in legislation. It is noted that caution should be used in applying and interpreting this indicator due to different levels of need in some groups and cultural variability in unpaid support and use of services (SCRGSP, 2019: 14.13), thus highlighting complexity when assessing comparative need.

The concept of effectiveness is measured through indicators for access, appropriateness and quality. The indicators defined for access are waiting times, unmet need and affordability. Currently, data are not available for either waiting times or affordability. The PIF identifies data for the two measures of explicitly defined unmet need: (a) a measure of expressed need by older people in national survey data (SDAC) and (b) an expert-defined need relating to unmet need for appropriate residential care. The PIF defines the indicator of appropriateness in terms of 'addressing clients' needs' (SCRGSP, 2019: 14.18). While no data are available for this indicator, the PIF proposes that this output be measured by three components: input into planning, match of needs and inclusion for diverse groups. It is not clear whether these indicators will be assessed by experts or by older people. Four output

**Table 3.** Performance Indicator Framework: outputs

Concept	Definition	Measures
Equity – access	‘Use by different groups’	‘the proportion of service clients who are from a special needs group, compared with the proportion of the aged care target population who are from that special needs group’ (SCRGSP, 2019: 14.13).
Effectiveness – access	Waiting times	Entering care within 3 months of assessment (if ready to enter care) (SCRGSP, 2019: 14.15).
	Unmet needs	<ul style="list-style-type: none"> <li>‘Unmet need in the community’ [is] measure[d] by the proportion of older people (aged 65 years or over) who were living in households and reported being in need of assistance, that also reported that their need was not fully met’ (ABS SDAC data).</li> <li>‘Hospital patient days used by aged care type patients’ (SCRGSP, 2019: 14.16).</li> </ul>
	Affordability	‘the out-of-pocket costs for aged care services (after subsidies) as a proportion of disposable income’ (SCRGSP, 2019: 14.18)
Effectiveness – appropriateness	Addressing clients’ needs	<ul style="list-style-type: none"> <li>‘care recipients or their representatives had input into the planning of their care’</li> <li>‘the supports identified in the care planning process to address an individual’s needs were provided (match of needs)’</li> <li>‘individual interests, customs, beliefs and cultural and ethnic backgrounds were valued and fostered’ (SCRGSP, 2019: 14.18).</li> </ul>
Effectiveness – quality	Compliance with service standards	<ul style="list-style-type: none"> <li>‘For residential aged care, the measure is the proportion of re-accredited facilities given three-year accreditation.’</li> <li>‘For home care and support, the measure is the proportion of reviews that met all expected outcomes under each of the three Home Care Common Standards’ (SCRGSP, 2019: 14.19).</li> </ul>
	Adverse events	<ul style="list-style-type: none"> <li>‘Adverse events in residential aged care: may report on the NACMQIP indicators.’</li> <li>‘Hospital leave days from residential aged care for preventable causes.’ (SCRGSP, 2019: 14.20-21).</li> </ul>
	‘Client and carer satisfaction’	<ul style="list-style-type: none"> <li>‘The proportion of people aged 65 years or over living in households, who are satisfied with the range and quality of organised and formal service options available.’</li> <li>‘The proportion of primary carers living in households (caring for people aged 65 years or over), who are satisfied with the range and quality of formal service options available to help them in their caring role.’, (SCRGSP, 2019: 14.21)</li> </ul>
	Complaints received	<ul style="list-style-type: none"> <li>‘The number of in-scope complaints received for residential aged care services per 1000 residential aged care residents (permanent and respite). Complaints within scope relate to Australian Government funded providers of residential care, Home Care, CHSP or flexible aged care services’ (SCRGSP, 2019: 14.23).</li> </ul>

Notes: ABS SDAC: Australian Bureau of Statistics Survey of Disability Ageing and Carers. NACMQIP: National Aged Care Mandatory Quality Indicator Program. CHSP: Commonwealth Home Support Programme.

Source: Based on SCRGSP (2019).

measures assess ‘quality’: ‘compliance with service standards’ for residential and in-home care; number of adverse events (which may report on the NACMQIP indicators); ‘client and carer satisfaction’ with range and quality of services (identified in the SDAC for older people and primary carers); and the number of complaints received relating to recipients of government-subsidised aged care services (SCRGSP, 2019: 14.20–14.23). Data are currently available for all the quality measures except for the number of adverse events (SCRGSP, 2019: 14.20–14.23). While the PIF only explicitly defines one output indicator as unmet need, nearly all the output indicators are, in effect, indicators of unmet need, whether by reference to lack of services for different groups (comparative need) or by lack of access, appropriateness and quality in the effectiveness domain (felt/expressed and expert/normative need).

The PIF also provides insights into the concepts and measures that define the measurable broad *outcomes* for the aged care sector (Table 4). The four outcomes indicators identified in the PIF are:

- ‘Social participation in the community’. Measures for this indicator are based on SDAC data on participation in social and community activities.
- ‘Enabling people with care needs to live in the community’, for which no data are available.
- ‘Maintenance of individual function’, which defines measures for a sub-population based on a validated tool.
- ‘Wellbeing and independence in residential care’ (quality of life), for which no data are available (SCRGSP, 2019: 14.25–14.28).

These conceptualisations of outcomes for the Australian aged care system are important for two reasons. First, they provide a statement that identifies *which* needs of citizens or ‘needs of strangers’ (Ignatieff, 1985) are recognised in policy discourse as being worthy of a social, collective care-giving response. Second, in articulating these needs, the PIF goes beyond measuring functional indicators such as ADLs and IADLs, and also draws on expert, older person and carer perspectives about whether needs are being met. However, at present data are limited and only available for social participation in the community for older people and maintenance of individual function. While stated key objectives of the aged care system are the wellbeing and independence of the carer, there are no outcomes measures for carers for these dimensions. The current indicators referring to carers within the PIF relate only to two outputs and one outcome:

- Appropriateness: whether the carer (as a representative of the older person) had ‘input into the planning of their care’.
- Quality: SDAC data on whether primary carers of older people were satisfied with the range and quality of formal services received to ‘help them in their caring role’.
- Quality of life (outcome): ‘the degree to which an individual resident’s wellbeing meets their personal expectations and those of their carers’ (Based on SCRGSP, 2019: 14.18–14.28).

**Table 4.** Performance Indicator Framework: outcomes

Concept	Measures
Social participation in the community	<p>'The estimated proportions of older people (aged 65 years or over) who:</p> <ul style="list-style-type: none"> <li>participated in social or community activities away from home in the last three months</li> <li>had face-to-face contact with family or friends not living in the same household in the last week</li> <li>did not leave home or did not leave home as often as they would like' (SCRGSP, 2019: 14.19–25).</li> </ul>
Enabling people with care needs to live in the community	'Proportion of older people with care needs who are living in the community' (SCRGSP, 2019: 14.27). No data available.
Maintenance of individual function	The clients' level of physical function data from the Transition Care Program (TCP) entry to exit 'measured as the difference in average Modified Barthel Index (MBI) score on TCP entry and exit' (SCRGSP, 2019: 14.27).
Wellbeing and independence in residential care	'Proportion of older people in residential aged care assessed as having a high quality of life. Quality of life is the degree to which an individual resident's wellbeing meets their personal expectations and those of their carers' (SCRGSP, 2019: 14.28). No data available.

Source: Based on SCRGP (2019).

Key issues for assessing unmet need in the Australia aged care system at present are the lack of quality data that can assess all these indicators in the PIF and also whether these indicators are able to provide a comprehensive assessment of unmet needs generated by the aged care service system.

### **Policy settings for interpreting need**

To identify whether the policy processes for interpreting needs are procedurally and consequentially fair in the sense described by Fraser (1989) would require a broad review of policy development, decision-making and the distribution of outcomes, which is beyond the scope of this paper. The current RCACQS and numerous historical inquiries have facilitated processes by which the views and voices of many stakeholders in the aged care sector can be heard, and which may meet some requirements for procedural fairness for voice, but not necessarily decision-making power. Despite the extensive documentation of concerns, the numerous inquiries and reviews have not resulted in comprehensive changes nor identified concepts or measures that can document fully both need and unmet need. Thus, the question about whether the outcomes of the existing mechanisms for interpreting needs in Australia are consequentially fair is not possible to answer with publicly available data.

Policy debates provide insight into challenges that remain in the Australian aged care system. A key issue underpinning unmet need in the form of lack of services, identified by the Productivity Commission (2011) and Tune (2017), is whether the limits on the numbers of government-subsidised places could be removed – 'uncapping supply' (Tune, 2017). Tune has argued that:

Uncapping supply is a substantial policy shift and requires at least four conditions to be met:

1. Government needs an accurate understanding of the underlying demand that the system will be designed to meet.
2. Consumers must make equitable and sufficient contributions to the costs of their care, without those contributions being so high that they create a barrier to accessing care.
3. There must be a robust system for assessing eligibility and ongoing care needs for government-funded aged care services.
4. Government policy must ensure the equitable supply of care across different population groups, and in settings where there is limited choice or competition, such as remote locations. (Tune, 2017: 35)

These four points all raise important questions for any analysis of unmet need in Australia:

- Whether the extent of ‘demand’ can be measured and what needs will be included in the conceptualisation of demand?
- Whether requirements for consumer contributions and co-payments will generate greater unmet need through lack of affordability and inequalities in costs?
- What types of needs will be recognised through assessment processes and the extent to which they will be met through a government-subsidised support system?
- Whether inequalities between different groups will increase or decrease?

On the first issue, Tune argues that no data sources can provide a ‘robust measure of demand’ (Tune, 2017: 7) for formal aged care services, as the notion of demand relies on the complex interaction of extent and type of needs, preferences for types of services, access to informal care and willingness and capacity to pay for services (Tune, 2017: 41–42; Productivity Commission 2011). Tune outlines the somelimitations of existing Australian data. First, nationally representative data sources (SDAC) do not yet measure need that would qualify as a need ‘eligible to be met through subsidised aged care services’ (Tune, 2017: 42). Second, data on, and processes for, eligibility approvals and use can ‘both overstate and understate the true level of demand’ due to approval for multiple services, which may address current and future needs, and that older people may be discouraged from seeking assessments, given waiting lists and referral processes (Tune, 2017: 43). Third, data on ‘elapsed time’ between approvals for services and entry to services may be an indicator of ‘care not being available’ but may also be an indicator that an older person chooses not to take up the care that is available for a range of reasons (Tune, 2017: 47). Finally, data on eligibility and approvals through ACAT do not include data for the CHSP through which many people access support (Tune, 2017: 48).

Tune expresses doubt about the capacity of market-based systems to facilitate equity in care:

Uncapping supply in a market-based system can result in most services being targeted to consumers whose care is cheapest and easiest to provide, or who can

pay the most out of their own pocket. A capped system that determines who receives care and where may not be able to meet all needs, but can deliberately provide access for those whose care is expensive or complex. (Tune, 2017: 36)

The Australian Government policy parameters thus articulate the aims of the aged care system, the types of needs that will be recognised, processes for assessing needs and eligibility, quality standards and performance indicators of equity, effectiveness and efficiency, as well as remaining challenges. The policy and review documents also provide insights as to how aged care needs claims in Australia are resolved at present. In the rationing of services through the ‘capped supply’ system, expert needs views of assessors and administrators determine priorities. Thus, using Fraser’s sequence of moments of struggle for interpreting need, one can conclude that while aged care needs may be recognised as a legitimate social policy concern, and extensive processes exist for defining a wide range of needs, the documented failings of the marketised service system in provision and the lack of regulatory oversight lead to a lack of services and inadequate care.

The politically defined limit on the number of services in Australia, currently generating high levels of unmet need in Australia (as evidenced in the waiting lists for home care), and the lack of regulatory oversight about quality of care concerns, arguably, have in effect served as ‘reprivatisation practices’, shifting responsibility for costs, quality and providing care back to the individual and family.<sup>9</sup>

### **Framework for assessing unmet needs: mapping care poverty and care inequalities in Australia**

Policy and service processes thus recognise some types of needs and are implicated in generating unmet need. However, at present the extent to which aged care needs are unmet in Australia, from the perspective of all aged care stakeholders, including older people and their carers, is not known and requires an alternative overarching framework. International research has used different approaches to investigating unmet aged care need in terms of the types of needs, who defines the needs and the thresholds that define unmet needs.

Measures of unmet need can focus on the type of activity for which the person requires assistance or the type of service needed. For example, Kröger *et al.* (2019) identify unmet need in relation to both formal and informal support for ADLs and IADLs, while Brimblecombe *et al.* (2017: 438) examine needs for different types of services, such as ‘home care, personal assistant, cleaner, day care, lunch club, meals on wheels, supported employment’. Thresholds of unmet need have included a distinction between ‘relative’ unmet need (a person reporting that they have unmet need for some activities) and ‘absolute’ definitions, restricted to those for whom all needs are unmet or who do not receive any support (Vlachantoni *et al.*, 2011; Kröger *et al.*, 2018, 2019; Vlachantoni, 2019). Although studies have identified services for the person receiving care may also provide support for the carer (*e.g.* Brimblecombe *et al.*, 2017), most studies on unmet need have focused on the older person’s needs and unmet needs, and not on the needs or unmet needs of their informal carer in their own right, or the care dyad or a care network (including formal care workers).

In many cases the existing research provides information on need and unmet need based on the self-reported perceptions of the older person (Vlachantoni *et al.*, 2011; Kröger *et al.*, 2019). In some cases, the analysis includes and compares the similarities and differences in perceptions and priorities regarding needs and unmet needs between professional perspectives or the perspectives of the unpaid carers and the person being cared for (Brimblecombe *et al.*, 2017; Clarkson *et al.*, 2018). The latter studies underscore the challenges of gaining agreement on the extent of need and unmet need.

The consequences of unmet need occur at both the individual and social level. The literature identifies the impact of unmet need for individual older people, ranging from extreme consequences, in the form of mortality (He *et al.*, 2015), through to harms encompassing 'discomfort, weight loss, dehydration, falls, burns, and dissatisfaction with the help received' (LaPlante *et al.*, 2004: S98). The literature further highlights restrictions on self-care, mobility and household activities, such as: 'having to stay in bed, ... going without eating, going without showering/bathing/washing up, accidentally wetting or soiling their clothes ... and making a mistake in taking their medications' (Freedman and Spillman, 2014: S45). Australian studies have also considered the consequences of waiting times for home care support, identified as increased risks of mortality and admission to residential care (Visvanathan *et al.*, 2019) and relative carer burden (Low *et al.*, 2015).

However, to date the social causes and consequences of unmet aged care needs and the social policy implications have not been fully addressed. These issues are usefully encapsulated and measured in the concepts of 'care poverty' and 'care inequalities' outlined by Kröger *et al.* (2019). Initially developed in relation to child care, Kröger's concept of 'care poverty' identified situations where children were 'fully lacking care or the conditions of their care were unacceptable' (Kröger, 2010: 397). In the later formulation applied to care of older people, 'care poverty' is defined as 'the deprivation of the adequate coverage of care needs resulting from an interplay between individual and societal factors' (Kröger *et al.*, 2019: 486). The concept of Kröger *et al.* (2019: 487) encompasses the lack of 'sufficient assistance from informal or formal sources' leading to unmet need. This concept, thus, brings the focus of analysis of inadequate care to the micro-level; however, importantly, the authors situate individual unmet needs within the social context:

Care poverty takes a bottom-up approach to the lack of care, starting from the everyday lives of older people, but, at the same time, it interprets the problems of individuals in the context of societal structures, in particular, of welfare state policies. (Kröger *et al.*, 2019: 487–488)

The concept of 'poverty' is often used to describe an *inadequacy* that is *intolerable* or a fundamental deficit with regard to human needs (see e.g. Veit Wilson, 1994, 1998). The academic literature also emphasises that the idea of 'poverty' encompasses both a lack of some essential and valuable aspect of human life and the imperative for society to respond to address that lack (See discussion in Hill, 2005). Thus, using the terminology of Sen (1993), the concept of Kröger *et al.* of 'care poverty' defines the 'evaluative space' for this poverty assessment as the extent

to which needs for care are adequately met, by either informal or formal sources, regarding good aged care as an essential component of human life.

Kröger *et al.* (2018: 13) further describe care poverty as representing ‘a deprivation of a basic need, a violation of human rights and a failure for social policy’, linking the social arrangements for the provision of aged care to human rights or welfare rights. These authors also highlight the dimensions of inequality in access to care that are constructed through welfare state policies (Kröger *et al.*, 2019: 487–488). Thus, the concept of ‘care inequality’ can be used to develop axes to rank advantage and disadvantage in relation to the meeting of aged care needs among individuals within a society. Such an approach can identify those more at risk of care poverty.

In Australia, the lack of government-subsidised services and adequate quality regulation in a marketised system may create situations of ‘care poverty’ in relation to formal services that are only remedied through unpaid care or privately purchased care in the unregulated market. The consequent inequalities in care will then not only be defined by the unequitable distribution in meeting aged care needs of older people through formal services but also in further dimensions or axes of inequality including the unequal distribution of:

- access to support from informal carers;
- time and monetary costs that older people and their carers are required to expend to meet aged care needs (including inequalities in service literacy and efficacy in navigating the aged care system);
- quality of care services received, due to uneven regulation and lack of regulatory coverage of the private markets for care; and
- consequences of unmet need, such as the impact on the health and wellbeing of both the older person and their carer/care networks given unmet need, and additional stressors involved in seeking to obtain services.

In this policy context, the lens of care poverty and care inequalities provides important insights for assessing and measuring the degree to which aged care needs are met. This lens allows a broader conceptualisation of the axes of care inequalities, highlighting the ways in which the system structures advantage and disadvantage in access to aged care.

The framework below outlines the key issues that policy makers and researchers should define in an assessment of care poverty and care inequality in relation to aged care.

First, they should establish the relevant ‘evaluative space’ for care inequalities and care poverty. The domains or the categories of needs to be assessed include:

- (1) Functional needs, as in the existing literature: ADLs and IADLs.
- (2) Specific types of services for older people, either reported by the older person, the carer or a service provider.
- (3) Social, emotional and other relational needs that align with the objectives of aged care systems of ‘wellbeing and independence’, social participation and quality of life.
- (4) Human rights conceptions of dignity, respect and choice (articulated in the quality standards and user rights).



- (5) Appropriate dementia care and palliative care.
- (6) Specific needs of diverse groups, including culturally safe and appropriate definitions of, and responses to, needs.

Analyses must outline dimensions of inequality encompassing individual, social and institutional factors that generate differential access to, and experience of, care across all the domains of needs. Such inequality dimensions should identify access to, and quality of, aged care, time and monetary costs of co-ordinating and obtaining care, and the consequences of unmet need for care, such as health impacts for the older person and the carer. The challenge for this broader definition of an evaluative space for unmet need is finding appropriate measures and data in all domains of needs and across all the inequality dimensions.

Second, researchers need to define the appropriate unit of analysis. The policies reviewed in this paper focus on wellbeing and independence for the carer, as well as the older person, highlighting the importance of developing a broader unit of analysis than the individual older person only, and a multi-layered approach for the examination of care inequality and care poverty that identifies the needs and unmet needs of:

- (1) The older person, distinguishing between unmet needs for formal services and informal support.
- (2) The carer/s.
- (3) The relationship/s in the care dyad or care network (including paid care workers).

Third, researchers need to determine the criteria for ranking advantage and disadvantage in met/unmet care needs along the different axes of care inequality and relative weight allocated to each domain. The approach to defining need will also need to determine whether the unmet need will be subjectively (felt/expressed) or objectively (normatively) defined and by whom, or whether through some combination.

Fourth, researchers should clarify the threshold/s that will define 'care poverty': are the thresholds absolute (complete unmet need) or relative (some unmet need, inadequately met needs or poor quality care), and how will the threshold be measured across different domains?

Fifth, any analysis should map the systemic mechanisms that may increase or decrease care inequalities and care poverty. Those mechanisms include: policy settings (funding, eligibility criteria, means testing, prioritising criteria, service literacy and advocacy), service provider practices and discretion, and resource allocation across geographical location.

Finally, researchers and policy makers should draw on existing literature to analyse factors associated with, and groups more vulnerable to, care poverty and disadvantage, as assessed by care inequalities.

## Conclusion

Building on insights and questions raised in the international literature examining need, unmet need, care poverty and care inequality, this paper has developed an

analytical framework and examined how current policy processes and parameters in Australia understand, assess and measure aged care needs. The policy analysis describes mechanisms that generate unmet needs, which needs are identified, and by whom and how they can be articulated, and thus points to key limitations in existing approaches in needs assessments, prioritising and quality regulation in service provision. Two crucial dimensions are (a) the lack of rights to receive services and (b) the lack of key concepts and data to assess broad dimensions of aged care needs for older people, carers and care networks in Australia. Further research is required to understand the intermediate-level processes through which needs are interpreted in policy and service delivery, such as service provider discretion, and how the existing policy parameters are generating inequalities in the distribution of unmet needs.

The concepts of care poverty and care inequality are important tools for conceptualising unmet needs for aged care and underpin key issues to be defined in a framework to measure unmet need and inequality in access to care for older people. Such concepts can highlight the processes in which aged care needs are socially and politically defined and legitimated, and the mechanisms through which such needs are recognised, prioritised, and met or left unmet. The concepts also provide a framework for understanding needs in aged care that go beyond functional activities to consider other fundamental and valued aspects of life for older people who require care and support, and their carers. Importantly, the concept of care poverty opens the space to discuss what level and type of unmet need and inequality in access to good quality aged care in any society may be considered *intolerable*.

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## Notes

1 As Meagher *et al.* (2019) note: only 35 per cent of older people approved for HCP have received a package at the level at which their needs were assessed.

2 My Aged Care is the Australian Government's system that provides information, assessment and access to government-funded aged care services (see <https://www.health.gov.au/initiatives-and-programs/my-aged-care/about-my-aged-care>).

3 The Aged Care Diversity Framework provides a policy framework for government, advocates, service providers and older people within which the different needs of older people with diverse life experiences can be recognised (see <https://www.health.gov.au/sites/default/files/documents/2019/12/aged-care-diversity-framework.pdf>). Analysis of the ways in which the policy constructs needs and unmet needs for diverse groups is very important but beyond the scope of the current paper.

- 4 The ways in which the funding and resource allocation instruments generate unmet aged care need in Australia is very complex and a full discussion of this topic is also beyond the scope of this paper. For useful reviews in the context of the RCACQS and changes to the Aged Care Funding Instrument, see *Financing Aged Care* (<https://agedcare.royalcommission.gov.au/publications/consultation-paper-2-financing-aged-care>) and Eagar *et al.* (2019).
- 5 Aged care consumers are expected to pay part of the costs of services if they have the means (SCRGSP, 2019: 14.2). For services in the home, there is an annual and lifetime cap (Australian Government Department of Health, 2019a).
- 6 Statement of Glenys Ann Beauchamp, Department of Health to Royal Commission on Aged Care Quality and Safety, (4 February 2019. Document: WIT.0022.0001.0001 p. 17). <https://agedcare.royalcommission.gov.au/media/27304>
- 7 Statement of Fiona Kathryn Buffinton to Royal Commission on Aged Care Quality and Safety (22 July 2019, Document WIT.0299.0001.0001: p. 10) <https://agedcare.royalcommission.gov.au/system/files/2020-06/WIT.0299.0001.0001.pdf> .
- 8 The Integrated Carer Support Service commenced in 2020.
- 9 To the best of my knowledge, longitudinal data to document the extent and distribution of reprivatization, including private expenditure on care and allied health services in the market, and time spent in advocacy and monitoring quality of care over time, do not yet exist. The PIF notes that there are no data on out-of-pocket costs (an indicator of affordability) (SCRGSP, 2019).

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