Supplementary methods

Contents:

PRISMA-ScR checklist
Search strategy
Scoping of wider SC literature (community)

PRISMA-ScR checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	Title page (p1)
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	4-6
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	7, 8
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	6
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	8-9

Information sources	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	8
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Supplementary material
Selection of sources of evidence	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	8-9
Data charting process	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	9
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	9
Critical appraisal of individual sources of evidence	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	Not applicable
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	9-10
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	10, PRISMA flow diagram
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	18-19
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	n/a
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	18-19, Tables 1 & 2, Supplementary material
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	11-20

DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	20-21
Limitations	20	Discuss the limitations of the scoping review process.	21
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	22
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	22

Search strategy – initially run on 1st June 2023; updated search run 18th July 2024 (restricting from 2023 to present)

a) Ovid (Social Policy and Practice; Embase; Medline(R) databases):

1. (low* social care or low* level social care or moderate social care or moderate level social care).mp.
2. ((moderate need or moderate needs) and social care).mp.
3. ((Non-eligible or "not eligible") and social care).mp.
4. ((Non-eligible or "not eligible") and Care Act).mp.
5. (Low* level support and social care).mp.
6. (Low* level care package and social care).mp.
7. (Sub-threshold and social care).mp.
8. (Sub-threshold and Care Act).mp.
9. ("advice and support" and social care).mp.
10. ("advice and support" and Care Act).mp.
11. ("information and advice" and social care).mp.
12. ("information and advice" and Care Act).mp.
13. (Support from the voluntary sector and social care).mp.
14. (Support from the voluntary sector and Care Act).mp.
15. (Support from the Third sector and social care).mp.
16. (Support from the Third sector and Care Act).mp.
17. (prevention services and social care).mp.
18. (prevention services and Care Act).mp.
19. (preventative services and social care).mp.
20. (preventative services and Care Act).mp.
21. (Signposting and social care).mp.
22. (Signposting and Care Act).mp.
23. (Maintain* independence and social care).mp.
24. (Maintain* independence and Care Act).mp.
25. (Promot* independence and social care).mp.
26. (Promot* independence and Care Act).mp.
27. (Promotion of independence and social care).mp.
28. (Promotion of independence and Care Act).mp.

29. (informal support and social care).mp.
30. (informal support and Care Act).mp.
31. (enablement and social care).mp.
32. (enablement and Care Act).mp.
33. Unmet social care need*.mp.
34. (Unmet need* and social care).mp.
35. ("self neglect" and "social care").mp.
36. "social support".mp.
37. "support needs".mp.
38. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37
39. (ADLs or Activities of daily living or Family Relationships or Personal Relationships or Feeding or Eating or Nutrition or Recreational Services or Recreational Facilities or Personal Care or Personal hygiene or Shower* or Bath* or Caring Responsibilities or Continen* or Incontin* or Toilet Needs or Carer For or Dressing or get* dressed or education* or employment or work or train* or volunteer*).mp.
40. 38 or 39
41. (prison* or offend* or inmate*).mp.
42. (England or Wales or Scotland or Northern Ireland or UK or United Kingdom or Great Britain).mp.
43. 40 and 41 and 42
44. limit 43 to (english language and yr="2013 -Current")

b) Criminal Justice Abstracts (CJA) database:

(“Low* social care” OR “Low* level social care” OR “moderate social care” OR “moderate level social care” OR “Non-eligible social care needs” OR (“Moderate need*” AND “social care”) OR (“Non-eligible” AND “social care”) OR (“Not eligible” AND “social care”) OR (“Non-eligible” AND “Care Act”) OR (“Not eligible” AND “Care Act”) OR (“Low* level support” AND “social care”) OR (“Low* level care package” AND “social care”) OR (“Sub-threshold” AND “social care”) OR (“Sub-threshold” AND “Care Act”) OR (“Advice and support” AND “social care”) OR (“Advice and support” AND “Care Act”) OR (“Information and advice” AND “social care”) OR (“Information and advice” AND “Care Act”) OR (“Support from the voluntary sector” AND “social care”) OR (“Support from the voluntary sector” AND “Care Act”) OR (“Support from the Third sector” AND “social care”) OR (“Support from the Third sector” AND “Care Act”) OR (“prevention services” AND “social care”) OR (“prevention services” AND “Care Act”) OR (“preventative services” AND “social care”) OR (“preventative services” AND “Care Act”) OR (Signposting AND “social care”) OR (Signposting AND “Care Act”) OR (“Maintain* independence” AND “social care”) OR (“Maintain* independence” AND “Care Act”) OR (“Promot* independence” AND “social care”) OR (“Promot* independence” AND “Care Act”) OR (“Promotion of independence” AND “social care”) OR (“Promotion of independence” AND “Care Act”) OR (“informal support” AND “social care”) or (“informal support” AND “Care Act”) OR (enablement AND “social care”) OR (enablement AND “Care Act”) OR “Unmet social care need*” OR (“Unmet

need*” AND “social care”) OR ("self neglect" and "social care") OR "social support" OR "support needs" OR ADLs OR "Activities of daily living" OR "Family Relationships" OR "Personal Relationships" OR Feeding OR Eating OR Nutrition OR "Recreational Services" OR "Recreational Facilities" OR "Personal Care" OR "Personal hygiene" OR Shower* OR Bath* OR "Caring Responsibilities" OR Continen* OR Incontin* OR "Toilet Needs" OR "Carer For" OR Dressing OR "get* dressed" OR education* OR employment OR work OR train* OR volunteer*) AND (prison* or offend* or inmate*) AND (England or Wales or UK or United Kingdom or Great Britain)

Google searches for social care in the community setting (to help inform search strategy)

Date	Term searched for	Relevant sources	Potential terms to consider
07/03/23	"non-eligible social care"	Adult social care charges under the spotlight (Northamptonshire County Council, 2010)[1]	Personal assistance, transport services, social activities, ExtraCare, meals on wheel services, disabled adults, vulnerable people
07/03/23	"non-eligible social care"	Services for Adults with Autism & Staff Training (Croydon Council, 2015)[2]	Advice and support, adult social clubs, drop-in services, family support services
07/03/23	"non-eligible social care"	Exploring the relationship between access to social care and healthcare utilisation by older adults (Spiers 2019)[3]	Unmet need, maintaining independence, promoting independence, activities of daily living, routine daily tasks, shopping for groceries, preparing meals, cooking meals, meaningful participation, signposting, sources of support, social participation "… social care may prevent health deterioration by supporting older adults to carry out routine daily tasks. These sorts of activities, such as washing, dressing, shopping for groceries and cooking meals, facilitate physical activity and social participation, which are critical for the maintenance of mental, cognitive and physical health." "Receipt of social care that supports and maximises independence with activities of daily living will prevent deterioration in health and thus use of healthcare"
07/03/23	"non-eligible social care"	Adult Social Care Services Market Position Statement 2013-2014 (Wokingham Borough Council)[4]	Community based prevention services, prevention service for non-eligible social care needs
07/03/23	"non-eligible social care"	Strategic Planning and Commissioning. Day Services Commissioning Strategy (Essex County Council, 2013)[5]	Low level care package, natural support networks, community resilience Definition of low-level social care needs: "having difficulty in performing domestic care tasks or have difficulty with bathing, showering or washing but not with other personal care tasks."
09/03/23	"unmet need" and "social care"	King's Fund and Nuffield Trust[6]	Difficulties getting out of bed; "Signposted away", "redirected"

	(2013 onwards)		Also useful for background info, e.g., in the UK… "More than a million people who have difficulties with the basic activities of daily living, such as getting out of bed, washing and dressing, now receive no formal or informal help at all." Talks about difficulties in defining, let alone measuring, unmet need. Check their reference Vlachantoni et al 2011
20/03/23	"unmet need" and "social care" (2013 onwards)	London School of Economics[7]	Definition: Refers to Health Survey for England 2018: "Unmet need is defined as needing help but not receiving any help in relation to at least one Activity of Daily Living in the last month"
20/03/23	"unmet need" and "social care" (2013 onwards)	Dunatchik et al 2019[8]	Unpaid care The authors note that there is no universally agreed definition of unmet social care need for adults, and that "the definition of unmet needs itself and its causes are complex". They include a section on ways of defining unmet social care needs which focus on ADLs and IADLs. Note that a limitation of this is that it is "very task-focused and may underplay the importance of other aspects of life such as social contact and maintaining a sense of purpose, which are outcomes under the Care Act 2014". "we used an activities-based approach to conceptualise unmet adult social care needs, developing a definition based on the ADL, IADL and mobility care needs of ELSA respondents and the help or aids received for those needs. The reason for this choice is that it allows the inclusion of people who do not have their needs met but may not identify as having unmet needs. Furthermore, by using a standard list of activities and asking about difficulty we could include people who might not even consider they have a need for care." Also undertook qualitative interviews with older people and found that they "considered need for social contact and purpose to be as important as meeting needs with ADLs and IADLs." However, for this project they developed their definition as:

			Has difficulties with at least one ADL or two or more IADL or mobility activities (excluding difficulties with stairs4); AND Does not receive care (paid or unpaid) or have an adaptation for at least one of their ADL difficulties or at least two of their non-ADL difficulties. <u>Specific aspects around mobility</u>: Climbing several flights stairs without resting Climbing one flight stairs without resting Walking 100 yards <u>Specific aspects around ADLs</u>: Dressing, including putting on shoes and socks Bathing or showering Getting in and out of bed Walking across a room Using the toilet, including getting up or down Eating, such as cutting up food <u>Specific aspects around IADLs</u>: Doing work around the house or garden Shopping for groceries Managing money, such as paying bills and keeping track of expenses Taking medications <u>Home adaptations</u>: Bath or shower seat Alarm that can call for help Toilet equipment or commode Stair lift Bed lever or bed rail Hoist Changes to kitchen

			<u>Aids used</u>: Cane or walking stick Zimmer frame or walker Manual wheelchair Buggy or scooter Electric wheelchair Elbow crutches Note that "relatively younger people may be more reluctant to access services which are perceived as being designed for older people." Discussion includes a section on the pros and cons around the fact they did not use self-defined care needs.
20/03/23	"unmet need" and "social care" (2013 onwards)	NIHR SSCR[9]	Difficulties of daily living
20/03/23	"unmet need" and "social care" (2013 onwards)	Community Care website[10] (dated 2019)	Care and support needs; non-eligible needs "The most frequent reason for needs being unmet was as a result of delays, most commonly in assessment/reassessment or putting in place elements of the care and support plan." Note that there is no statutory definition of the term unmet need and that in fact "there is no reference at all to individual unmet need in the Care Act 2014 and the accompanying care and support statutory guidance." "The legislation recognises that individuals will have care and support needs that are not eligible, which local authorities will mostly not meet, and these are described as 'non-eligible needs'." "There is a duty to explain the decision not to meet needs and provide information and advice to individuals to assist them in preventing, reducing and delaying needs that have been determined as non-eligible, and this must be done in writing. But

			there is no obligation to determine or record whether non-eligible needs are met or unmet." "The British Association of Social Workers (BASW) has also called for a review of the application of the Care Act, "which should include an evaluation of how potential eligible needs are being reduced, how the criteria operates as a threshold, and how non-eligible needs are being addressed." But at present the major source of information about unmet need is through complaints to the ombudsman, meaning case studies derived from these complaints will continue to be one of the major sources of learning in the training events that I facilitate."
20/03/23	"unmet need" and "social care" (2013 onwards)	Human Rights Watch 2019[11]	Lack of oversight: "no central government agency monitors assessments for social care services. Local authorities make decisions about care without any outside oversight." Includes some examples of problems with assessments if we want to go into more detail even if just for the Background section.
20/03/23	"unmet need" and "social care" (2013 onwards)	Forrester-Jones & Hammond 2020[12]	"'Need' and 'unmet' need remain conceptually complex, with functional-based approaches to measure it remaining the default. More qualitative accounts of what unmet need means for the everyday lives of people with disabilities are missing."
20/03/23	"unmet need" and "social care" (2013 onwards)	Gousia & Towers 2020[13]	'Unmet social care needs' Definition: "The definition of unmet social care needs has been a long-standing debate in the literature." "The operationalization of unmet social care needs in this study was shaped by three main considerations: (i) the literature on unmet social care needs in England, (ii) the data in hand and (iii) the policy background. To ensure policy relevance, our definition of social care needs was chosen to reflect, as closely as possible, that used by local authorities (LAs) under the Care Act 2014 when assessing whether someone has needs eligible for LA support in England."
20/03/23	"unmet need" and "social care" (2013 onwards)	Vlachantoni 2019[14]	'Unmet need for ADLs'

20/03/23	"unmet need" and "social care" (2013 onwards)	Age UK[15]	'Struggle to wash/get in the bath'; 'difficulty going to the toilet'; 'find it hard to get out of bed on their own'; 'find it hard to eat on their own'; 'find it hard to get dressed on their own'; 'find it difficult to walk across a room on their own' 'unable to cope at home'
20/03/23	"unmet need" and "social care" (2013 onwards)	Spiers et al 2022[16]	'support to maintain independence' "Populations are considered to have an 'unmet need' when they could benefit from, but do not get, the necessary support" "The operationalisation of unmet need for support is not standardised. First, there are different ways to identify populations with a need for support: need can be perceived (i.e. people report they need help) or assumed (i.e. people report difficulties staying independent). Second, there are varying ways that a need is considered unmet (Table 1)." Absolute: From a population with a need for care, identify those who receive no help Relative: From a population with a need for care, identify those who state they need more help/judge existing help to be insufficient Combined relative and absolute: From a population with a need for care, identify those who receive no help AND those who need more help/judge existing help to be insufficient. Direct question: A direct question about whether a person perceives themselves to have an unmet need. Unmet need could therefore be absolute or relative, but question may not ascertain whether needs are judged to be unmet because of no help (absolute) or insufficient help (relative).
20/03/23	"unmet need" and "social care" (2013 onwards)	Healthwatch 2021 'Social care: What is in the new plan?'	"Our research shows that people don't always understand what social care is, who provides services, how care is paid for, their rights, or who they should turn to for help. Awareness of social care is also low, and the public wants access to trusted, independent local sources of information on social care."

			Note the Government White Paper (https://www.gov.uk/government/publications/people-at-the-heart-of-care-adult-social-care-reform-white-paper) which includes a communications campaign to improve advice/information re social care. "The Government's plan notes a lack of data and evidence about whose needs are not being met or only partially met. The paper also references issues with how different people and organisations define what counts as 'unmet need.' Our view There needs to be a plan to improve the quality of data in the social care sector to understand better unmet needs and the obstacles to getting care people face. We have also kicked off a project to shine a light on the experiences of people living with unmet social care needs. We plan to share the findings with the Government so that policymakers can find solutions to make sure everyone can access the support they need."
20/03/23	"unmet need" and "social care" (2013 onwards)	SCIE (Social Care Institute for Excellence)[18]	A useful resource talking about 'prevention in social care'
20/03/23	"unmet need" and "social care" (2013 onwards)	Care Quality Commission[19]	'Unmet and under-met needs' Refers to importance of "the risk of a tsunami of unmet need across all sectors, with increasing numbers of people unable to access care. We said that funding must be used to enable new ways of working that recognise the inter-connectedness of all health and care services – not just to prop up existing approaches."
20/03/23	"unmet need" and "social care" (2013 onwards)	Nuffield Trust[20]	<u>ADLs</u> Getting up and down stairs Having a bath or shower Dressing or undressing

			Getting in and out of bed Getting around indoors Taking medicine Using the toilet Eating, including cutting up food Washing face and hands <u>IADLs</u> Shopping for food Doing routine housework or laundry Getting out of the house Doing paperwork or paying bills Useful for Background. Refers to 'what is social care'.

1 https://www.homecare.co.uk/news/article.cfm/id/1549382/adult-social-care-charges-under-the-spotlight

2 https://democracy.croydon.gov.uk/Data/Adult%20Social%20Services%20Review%20Panel/20150701/Agenda/ass20150701_08_01_report0406.pdf?cmte=ASS&meet=18&href=/akscroydon/images/att5643.doc

3 https://theses.ncl.ac.uk/jspui/bitstream/10443/4776/1/Spiers%20GF%202019.pdf

4 https://ipc.brookes.ac.uk/files/market-position-statements/wbc_market_position_statement_2013-14.pdf

5 https://cmis.essex.gov.uk/essexcmis5/Document.ashx?czJKcaeAi5tUFL1DTL2UE4zNRBcoShgo=GFFOpkkH6JtwP5qg2BNwbpo1t4FDXYLqK5pelyZzOfUHxhrOQB1D6A%3D%3D&rUzwRPf%2BZ3zd4E7Ikn8Lyw%3D%3D=pwRE6AGJFLDNlh225F5QMaQWCtPHwdhUfCZ%2FLUQzgA2uL5jNRG4jdQ%3D%3D&mCTIbCubSFfXsDGW9IXnlg%3D%3D=hFflUdN3100%3D&kCx1AnS9%2FpWZQ40DXFvdEw%3D%3D=hFflUdN3100%3D&uJovDxwdjMPoYv%2BAJvYtyA%3D%3D=ctNJFf55vVA%3D&FgPlIEJYlotS%2BYGoBi5olA%3D%3D=NHdURQburHA%3D&d9Qjj0ag1Pd993jsyOJqFvmyB7X0CSQK=ctNJFf55vVA%3D&WGewmoAfeNR9xqBux0r1Q8Za60lavYmz=ctNJFf55vVA%3D&WGewmoAfeNQ16B2MHuCpMRKZMwaG1PaO=ctNJFf55vVA%3D

6 https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/Social_care_older_people_Kings_Fund_Sep_2016.pdf

7 https://blogs.lse.ac.uk/socialpolicy/2021/03/29/re-thinking-unmet-need-in-adult-social-care/

8 https://journal.ilpnetwork.org/articles/10.31389/jltc.33

9 https://www.sscr.nihr.ac.uk/unmet-social-care-need/

10 https://www.communitycare.co.uk/2019/04/18/unmet-need-rife-complaints/

11 https://www.hrw.org/report/2019/01/09/unmet-needs/improper-social-care-assessments-older-people-england

12 https://researchportal.bath.ac.uk/en/publications/adult-social-care-and-unmet-needs

13 https://onlinelibrary.wiley.com/doi/full/10.1002/pon.5656

14 https://www.cambridge.org/core/journals/ageing-and-society/article/unmet-need-for-social-care-among-older-people/5FE8A6898D87DE5A0DBF9C3C0D022D60

15 https://www.ageuk.org.uk/latest-news/archive/12m-older-people-dont-get-the-social-care-they-need/

16 https://academic.oup.com/ageing/article/51/10/afac228/6776175

17 https://www.healthwatch.co.uk/response/2021-12-03/social-care-what-new-plan

18 https://www.scie.org.uk/prevention/social-care

19 https://www.cqc.org.uk/sites/default/files/2022-10/20221024_stateofcare2122_print.pdf

20 https://www.nuffieldtrust.org.uk/files/2018-10/qualitywatch-social-care-older-people.pdf