UNMET NEEDS

Improper Social Care Assessments for Older People in England

HUMAN RIGHTS WATCH

SAMUEL CENTRE FOR SOCIAL CONNECTEDNESS

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Improper Social Care Assessments for Older People in England

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Summary

> [They] just came in with an agenda of cutting my 15 hours per week to 6.5. They announced it. They told me 'We are not there to give you more, but we are going to cut it.' They had worked out that that was what I needed [before they arrived].
>
> —Mary Redman, 76, December 2017

Older people in England like Mary Redman can face considerable challenges in accessing the social services which they need to live independent, dignified lives, and to which they are entitled. In interviews with Human Rights Watch in 2017 and 2018, older people expressed concerns with how local officials determined their eligibility for social support. Such services include in-home assistance such as preparing meals, dressing, and bathing. In some cases, older people told Human Rights Watch that they were denied crucial services or had services significantly reduced, causing their health and wellbeing to decline.

Some of those interviewed said that assessors appeared not to understand their disabilities and social care needs. In other cases, before beginning an assessment, assessors announced that services would be cut regardless of an individual's actual need.

Under England's Care Act 2014, any individual who meets financial and needs criteria is entitled to government-supported social support, known as social care. These services aim to promote wellbeing and independence, in addition to health and safety, by "supporting people to live as independently as possible, for as long as possible."

Based on interviews with 104 people, this report documents improper assessments for individual older people's social care in England, and the lack of oversight from the national government, which is responsible for implementation of the Care Act. The report focuses on England, as each nation in the United Kingdom has its own social care system. According to the UK Office for National Statistics, the number of people in England aged 65 and over is projected to increase by over 20 percent over the next 10 years.

Older people gather with staff at a health education program in East London. © 2018 Stephanie Hancock for Human Rights Watch

Despite working with the Care and Support Alliance, which represents over 80 of Britain's leading charities campaigning for a properly funded care system, requests to the British Association of Social Workers, and other extensive outreach, Human Rights Watch was not able to interview social workers or assessors for this report.

The large number of complaints filed with the UK's Local Government and Social Care Ombudsman regarding social care assessments suggests serious concerns with assessments and mechanisms to ensure their quality. The Ombudsman's 2018 annual report, released in November 2018, documented a 140 percent increase in social care complaints over the eight-year period since 2010 and indicated that social care assessments are now among "the biggest areas of complaint." The report noted that the number of complaints indicated "problems with whole systems and policies," rather than "one-off mistakes." The Ombudsman accepts complaints about local government councils and all adult social care providers, including home care agencies.

Day-to-day responsibility for providing social care services in England rests primarily with local authorities. Social care assessments often have significant impact on older people's

health, wellbeing, and independence because they are the gateway to services and supports for independent living. Yet no central government agency monitors assessments for social care services. Local authorities make decisions about care without any outside oversight. This puts the onus on individuals who may be going without needed supports to challenge their assessment with the local authority, bring litigation or file a complaint with the ombudsman's office.

While some of those Human Rights Watch interviewed were able to bring an appeal and get the social care to which they are entitled, the process often led to delays in receiving services and many described facing physical, psychological, and financial hardships as a result. The decision to reduce support services became effective even before individuals had the chance to appeal.

Social care is funded by a mix of local taxation (notably council tax) and general central government funding allocated to local authorities. Central government funding to local authorities has been cut in recent years. According to the UK National Audit Office, the body charged with scrutinizing public spending for Parliament, the funding local governments receive from the central government to deliver social care and other services has fallen by almost half between 2010-11 and 2017-18. The funding reductions are part of austerity measures by the central government to cut spending and increase taxes following the global 2008 financial crisis. In a 2017 study by the Care and Support Alliance, which represents over 80 of Britain's leading charities campaigning for a properly funded care system, social workers and others who conduct needs assessments reported they faced pressure from managers and officials responsible for funding decisions to reduce social care costs.

The UK government has obligations under domestic law in the Care Act 2014 and the Human Rights Act, and under international law to ensure the rights to live independently in the community, to health, and to private and family life. The UK government should ensure that older people receive the support they need and are entitled to by regularly monitoring social care assessments to ensure accuracy and fairness, and that services continue during appeals.

Methodology

This report is based on 104 individual in-person and telephone interviews. Human Rights Watch interviewed 27 older people between the ages of 58 and 94 and 20 family carers in England between September 2017 and November 2018, in 11 local government authorities: Tower Hamlets, Cumbria, Bournemouth, North Yorkshire, Hertfordshire, South Derbyshire, Essex, Barking and Dagenham, Salford, Dorset, and Surrey. Wales, Scotland and Northern Ireland have their own social care systems and fall outside the scope of this research. Based on requests for confidentiality, Human Rights Watch has used pseudonyms for some interviewees. Pseudonyms are indicated by a name in quotation marks.

Human Rights Watch also interviewed 51 representatives of nongovernmental organizations, known in the UK as charities, as well as lawyers, service providers, academics, policy experts, staff from the National Health Service, Clinical Commissioning Group staff responsible for planning local health care, and current and former local government staff. We also conducted group interviews arranged by partner organizations in supported housing accommodations and community centers in East London, Bournemouth and Poole.

Despite working with the Care and Support Alliance, which represents over 80 of Britain's leading charities campaigning for a properly funded care system, requests to the British Association of Social Workers, and other extensive outreach, Human Rights Watch was not able to interview social workers or assessors for this report.

We sent letters to the 11 local governments where we conducted research, as well as to the Department of Health and Social Care, and the Ministry of Housing, Communities and Local Government in England, requesting answers to questions related to the findings of this report. Three local authorities, Dorset County Council, North Yorkshire County Council, and the London Borough of Barking & Dagenham responded to our questions. Their responses are in Annex 1. The other local government authorities and the ministries did not respond.

Background on Social Care in England

Local government authorities in England are required by the 2014 Care Act to carry out needs assessments "for any adult with an appearance of need for care and support..."[1] These services aim to promote wellbeing and independence, in addition to health and safety, by "supporting people to live as independently as possible, for as long as possible."[2] Assessments are typically carried out by a social worker employed by a local government authority. Under the Care Act, all local authorities must use the same eligibility standards in social care needs assessments and must fund at least part of an individual's social care support if a person has less than £23,250 (approximately US$29,415) in savings and assets. England has 152 local authorities with adult social care responsibilities.

However, some research has found that not all people may be getting the care to which they are entitled. According to 2018 research published by Age UK, a nongovernmental organization advocating on behalf of older people, 1.4 million older people in England are living with unmet needs for social care.[3] A July 2017 longitudinal survey (repeating surveys of the same variables over time) by Ipsos MORI, a market research company in the UK, found that 73 percent of those qualifying for care under the Care Act do not receive services for at least some of their needs.[4] According to Age UK, unmet need for support for vital daily activities among older people in England has increased by 48 percent since 2010.[5]

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[1] Care Act 2014, Statutory Guidance, https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance (accessed December 19, 2018).

[2] Ibid.

[3] Age UK, "New Analysis Shows Number of Older People with Unmet Care Needs Soars to Record High," July 9, 2018, https://www.ageuk.org.uk/latest-press/articles/2018/july-2018/new-analysis-shows-number-of-older-people-with-unmet-care-needs-soars-to-record-high/ (accessed December 14, 2018).

[4] Ipsos MORI, "Unmet Need for Care Full Report," July 2017, https://www.ipsos.com/sites/default/files/2017-07/unmet-need-for-care-full-report.pdf (accessed November 16, 2018).

[5] Age UK, "The Health and Care of Older People in England 2017," February 2017, p. 29 https://www.ageuk.org.uk/documents/EN-GB/For-professionals/Research/The_Health_and_Care_of_Older_People_in_England_2016.pdf?dtrk=true (accessed June 28, 2018).

Older people who can access programs in their communities told us how much they valued them.
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According to experts at Age UK and The Health Foundation, an independent charity committed to bringing about better health and health care for people in the UK, when assessments do not accurately recognize a person's support needs, or those needs otherwise go unmet, there can be increased pressure on England's overstretched National Health Service to fill the gap.[6] The absence of social care can lead to older people being hospitalized and lengthen stays even after becoming medically fit for discharge.

[6] Age UK, "New Analysis Shows Number of Older People with Unmet Care Needs Soars to Record High," (calculating that delayed discharges from hospital due to social care not being in place costs the NHS £289,140,954 per year); and The Health Foundation, "Social Care Funding Options: How Much Will They Cost?" May 2018 (finding that a failure to fund social care will create "additional costs for other public services, particularly the NHS.").

The Context of Social Care Budgeting

According to some expert reports, the reduction in social care for older people in the UK appears to be linked to financial considerations, including fewer resources available at the local level. For example, the Association of Directors of Adult Social Services, a membership body of the directors of adult social care at the local government level in England, reported in its 2018 budget survey that "75 percent of directors reported that reducing the number of people in receipt of care is important or very important for them to achieve necessary savings." For this survey, directors were asked about levels of confidence in being able to meet specific duties in the coming year. Only 34 percent were fully confident that they would be able to meet their obligations under the Care Act and other regulations.[7]

In 2016, the Chief Executive of the Care Quality Commission (CQC), the independent regulator of all health and social care services in England, warned that adult social care in England was "approaching a tipping point," noting that "increased need" was colliding with "reduced access."[8] In 2017, [CQC] warned that "the entire health and social care system is at full stretch" and that what was needed was "a long-term sustainable solution for the future funding and quality of adult social care."[9] That same year, three prominent think tanks warned that social care would be facing a £2.5 billion funding gap for the year 2019-20.[10]

A day care center employee who has been working at the same London center for more than 11 years described increasing demand for services at his center for people losing social care at home. Adult social day care often provides social care supports, social activities, meals, and some health-related services. "Now, decisions are based on finances, not needs. About five years ago, we started seeing people with higher and higher

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[7] Association of Directors of Adult Social Services, "Budget Survey 2018," p. 16 https://www.adass.org.uk/adass-budget-survey-2018 (accessed June 28, 2018).

[8] The Kings Fund, "The World's Biggest Quango," May 2018, https://www.kingsfund.org.uk/sites/default/files/2018-05/worlds_biggest_quango_ifg_may2017.pdf (accessed June 19, 2018), p. 77, referencing Care Quality Commission, "'Adult Social Care "Approaching Tipping Point,' Warns Quality Regulator," press release, October 13, 2018.

[9] The Kings Fund, "The World's Biggest Quango," p. 87, citing Care Quality Commission, "The State of Health Care and Adult Social Care in England: 2016/17: Summary," 2017.

[10] The Kings Fund, "The World's Biggest Quango," p. 87, citing Nuffield Trust, "The Health Foundation and The King's Fund (2017) The Autumn Budget: Joint statement on health and social care," 2017.

levels of need. We're getting a lot of people [referred] to us, with loads of disabilities … we've always got referrals, but now [demand is so high] we can't even pick up the phone."[11]

[11] Human Rights Watch interview with Joynul Hoque, outreach worker at day care center in London, January 22, 2018.

Problems with Older People's Social Care Assessments

Mary Redman

Mary Redman, 76, lives in a small town near London, has osteoarthritis and depression and had benefitted from social care since she was in her 30s to support her to shop, attend doctors' appointments, and participate in community groups, among other activities. She told Human Rights Watch that during a 2016 assessment, the assessors told her they would cut her services before even assessing her level of need. She said the uncertainty of appealing the assessment decision compelled her assistant to look for other work and contributed to depression, causing her significant hardship. She explained:

> [They] just came in with an agenda of cutting my 15 hours per week to 6.5. They announced it. They told me 'We are not there to give you more, but we are going to cut it.' They had worked out that that was what I needed [before they arrived].[12]

Mary Redman at 35, with her daughter in her father's garden in England, 1976. © 2018 Human Rights Watch, Courtesy of Mary Redman

In addition to this announcement, Redman said her assessment contained stark inaccuracies. Although she has difficulty gripping and has used a walking frame [walker] for many years, the assessment report stated that Redman carried a heavy tray across her kitchen, which she said never happened. Redman successfully challenged the assessment, yet the process took a year and led her personal assistant of 30 years to quit and look for other work:

[12] Human Rights Watch Skype interview with Mary Redman, December 18, 2017.

> It has ended up with me losing one of my most treasured friends, who was my personal assistant. [She] helped around the house. [Osteoarthritis] affects hands. I can't grip, and it's painful, also in my spine and feet. She did light housework. We would go shopping one day a week to stock up. She would go with me to hospital appointments, or other things I needed help accessing … After the start of this review, she was so uncertain as to whether she would have a job at the end of the review that she gave her notice.

Mary Redman at 60, with her dogs in 2001. © 2018 Human Rights Watch, Courtesy of Mary Redman

> It was all a battle to appeal [the assessment]. The effect on me if I don't get out. The effect on me with keeping my house clean. Even the effect on me with keeping myself clean. I suppose you might call it depression …
>
> I tend to get infections in my feet more often [after foot care was cut]. I hadn't realized that it was an infection until I collapsed and took an ambulance to the hospital.[13]

Redman returned home from the hospital and was successful in her appeal.

"Barbara," the director of a social care program in London for more than 20 years, described a similar situation during a 2012 assessment of her mother, who had advanced dementia:

[13] Ibid.

> The social workers [with the local authority] did that assessment. They came in and said [her care] was being reduced. The assessment was supposed to be about my mum's needs, and bespoke. With [the local authority's] cuts, they were one-size-fits-all.[14]

Joy Watson

Joy Watson, 59, who lives outside Manchester, was diagnosed with dementia in 2013. The loss of services following a social care reassessment resulted in serious hardship while Watson appealed. Her appeal did not fully reinstate her services, so she pursued her case in court. She told us through tears about losing funding for her carer and support worker after what she believed to be an incorrect assessment in 2016:

> Right from the onset, I realized that the person doing the assessment didn't know anything about dementia. She was more [occupational therapy] oriented. She was very keen to know whether I could dress myself or walk, but she didn't take into account any of my dementia symptoms. My support worker [at that time] was trying to explain to her the problems I have with dementia. [But] her questions were geared to more typical [physical] things. The worst thing was I lost all my benefits. I had had them [her support worker and her husband as a caregiver] for many years. I had personality disorder and depression. When I got diagnosed with dementia, I was worse! The day after I lost all my benefits, my husband lost his carer's allowance.[15]

Watson appealed with the local government authority, but her original level of services was not restored. She appealed again, to a court, with the assistance of a lawyer specializing in public law and older people's rights:

> We took it to court … For seven months, my life went on hold. I was borrowing from people to pay bills, my son was paying our bills, and I didn't know what our future was. [The court case was expected to take] three months, then six months, seven months …

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[14] Human Rights Watch interview with "Barbara," London, January 18, 2018.

[15] Human Rights Watch telephone interview with Joy Watson, July 19, 2018.

"Farhaz," who has dementia, receives help from his wife who encourages him as he walks across their living room. © 2018 Stephanie Hancock for Human Rights Watch

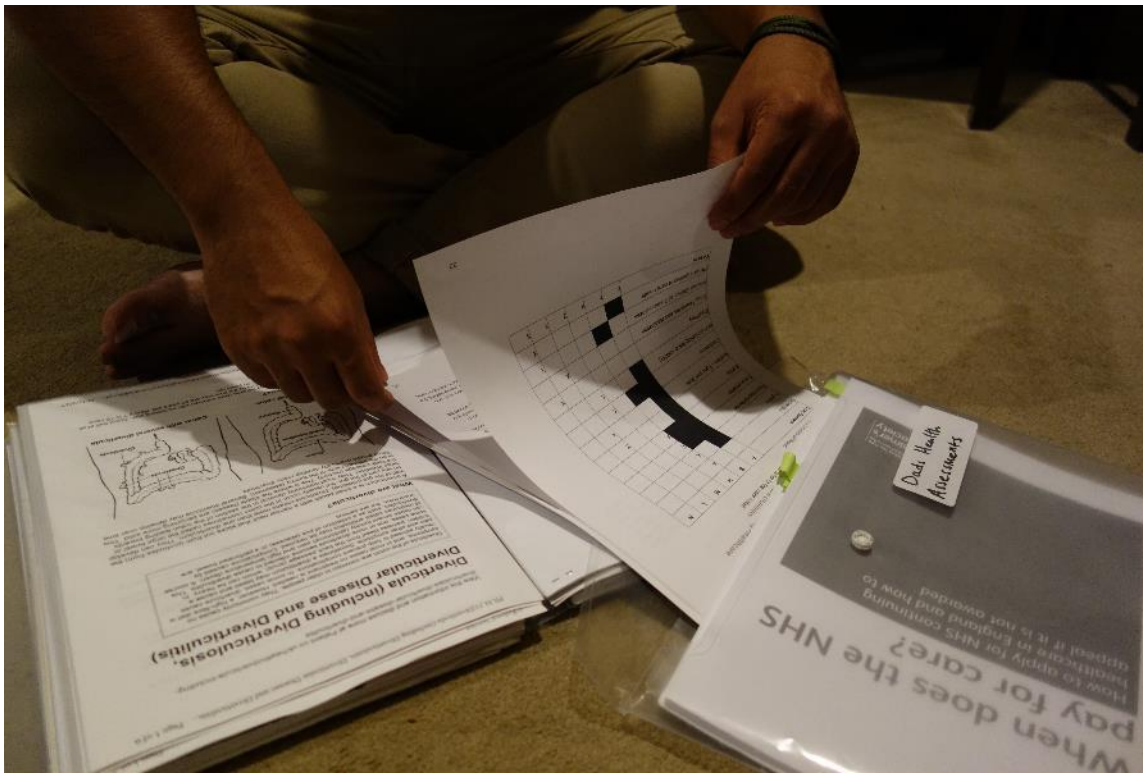
Watson was successful in her legal appeal. Reflecting on her experience, she told us:

> People who make these decisions, the professional people, I don't think they realize what the consequences are for people with dementia. I don't think they understand the effect it has, the uncertainty, the fear of the future.[16]

"Farhaz"

"Mohammed," 27, told Human Rights Watch that his father, "Farhaz," now 80, began receiving social care from his local authority in London when he was diagnosed with vascular dementia 15 years ago. At that time, he had services to help manage his incontinence, keep him active, and provide respite for his family caregivers. Mohammed, who lives with his father and his mother, described their recent struggle to maintain the services his father still receives; daily visits from a care worker for bathing and dressing and visits to a day center a few days per week:

[16] Ibid.



"Mohammed" goes through the paperwork for "Farhaz's" social care assessments. © 2018 Stephanie Hancock for Human Rights Watch

> We got letters from the local authority a few years ago, talking about changes to care packages [through assessments]. Our care worker [for Farhaz] … told us we should ask for the submission from the assessor before it is finalized and submitted because sometimes they delete things [we have said to show levels of need]. I kept a table of the things [my father would] say and do [that showed the degree of his dementia].
>
> My father has hallucinations … We [his family] have to watch him all the time now. He ate half of a tub of barrier cream [diaper cream]. Eighty percent of the time he is very quiet, and 20 percent of the time he is very aggressive. He spends the whole day looking at his hands, folding tissues.
>
> [The assessor] was late, and she fell asleep three times. You know it's a problem when you're being really nice [in spite of these things] because I

> was fearful she would say no [to continuing the service] … I didn't feel [the draft assessment] was representative of what was said.[17]

The assessor concluded the written assessment claiming that Mohammed's father's needs were "non-intense, non-complex, routine and predictable."[18] Acting on the advice of the care worker and information from Age UK, an older person's advocacy group, Mohammed asked for the draft assessment before it was finalized and requested a reassessment by another assessor. His father is fortunate: the reassessment found a higher level of requirements for support, which qualified him for specialized services from the National Health Service (NHS) Continuing Healthcare.[19]

"Peter"

"Peter," 61, had a brain injury following a stroke in 2003, which required six months of hospitalization. Since that time, he has limited mobility, uses a mobility scooter, and experiences severe anxiety. After his hospitalization, he spent years in homeless shelters, and moved into his current accessible home in East London in 2012. An assessment of his support needs originally provided him 1.5 hours of assistance per week to clean his house. During a 2017 reassessment, Peter asked for an additional hour per week, including to change and wash the sheets on his bed. The social worker conducting the assessment told him that he would actually get less and linked it to financial concerns. According to Peter, the social worker said she wouldn't dare ask for that and that an extra hour was more than her job was worth. Peter said the social worker told him his care would be reduced from 1.5 hours to one hour due to the cuts in the funding of social care and said 'we [the local authority] have basically got to cut back on everything.'[20]

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[17] Human Rights Watch interview with "Farhaz," London, March 15, 2018.

[18] Decision Support Tool for Continuing Healthcare, received from "Farhaz" on May 7, 2018, on file with HRW.

[19] The National Health Service is England's free-at-the-point-of-service health services for all, regardless of income. https://www.nhs.uk/using-the-nhs/about-the-nhs/principles-and-values/. Some people with long-term complex health needs qualify for free social care arranged and funded solely by the NHS. This is known as NHS continuing healthcare. https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/nhs-continuing-healthcare/ (accessed December 19, 2018).

[20] Human Rights Watch interview with "Peter," London, January 23, 2018.

Peter wrote a letter to his local government in May 2017, complaining about this cut in his services, but he had not received a response by late January 2018 when he spoke to Human Rights Watch.

"Martha"

"Julie" told Human Rights Watch that her mother, "Martha," 65, was in a bus accident in March 2018 in a town east of London. Following the accident, Martha was incontinent and had so much back pain that she could not walk. Julie said the doctors sent her mother home from the hospital's accident and emergency department that same day. Martha returned to the hospital the next day where a social services staff member conducted a social care assessment. Julie explained:

> She came to my house. She was in excruciating pain, she couldn't walk. She was leaking [urine] on my settee; she was in absolute agony. [The next day,] we went back to the hospital ... Social services did her [social care] assessment. They said she was medically fit to go home, [but that] she just couldn't walk. She lives in a first floor flat, up two flights of stairs. They said, 'She can just stay at yours, you have a downstairs toilet.' Right now, she is sleeping on my settee ...[21]

At the time of the interview in May 2018, Julie had been calling her own local authority and Martha's local authority for additional support for her mother, without progress. She said, "With our social services, with the council, they're telling us, 'No.'"[22]

Jenny Bullen

Jenny Bullen, 67, of West Lancashire, cared for her mother who lived in another town for 10 years. Her mother had dementia and had experienced paranoia and psychoses for all her adult life. She passed away in 2014, at 89. Bullen told us that she struggled to get her mother's local government authority's social services to assess her support needs during the final year of her life.

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[21] Human Rights Watch telephone interview with "Martha," May 2, 2018.
[22] Ibid.

> [Assessors] would come and sit with us for maybe half an hour. They would look at my mum who seemed very calm. She was very socialized. She was having language problems, but she would say, 'Oh yes, oh yes.' She actually couldn't tell her story.[23]

Eventually, the police found Bullen's mother one morning after she had wandered around her town all night. Bullen asked the local authority for supervision at night for her mother. The local authority refused, saying that the only way her mother could have supervision at night would be for her to move into an institution and sell her flat to pay for it, or to pay for 24-hour in-home support herself. This refusal led Bullen's mother to eventually be placed in an institution. Bullen explained:

> The 24-hour care was beyond my mum's means, mine and my sister's means. So, we had to find residential care for her. We just couldn't trust that she knew how to keep herself safe in this flat. With the people who were assessing, it was like, 'Well, this is the pot of money we've got.' I tried to appeal, but mum actually died before that appeal came into fruition [in 2014]. … The local authority came back to me to say that we could have some extra money, because [mum] should have had some extra care [as I had appealed]. It wasn't the money we wanted, it was the care![24]

[23] Human Rights Watch telephone interview with Jenny Bullen, December 13, 2017.
[24] Ibid.

Suspension of Services During Appeals

Currently, individuals can appeal needs assessments to their local authority, to the national Local Government and Social Care Ombudsman, or they can take their case directly to court.

As described above, people with whom Human Rights Watch spoke who did file an appeal regarding their social care assessment lost services very soon after an assessment. This left them without services they depended on, pending the outcome of an appeal. This can result in declines in health and well-being.

Dominic Carter, a Senior Policy Officer with the UK Alzheimer's Society told Human Rights Watch that getting assessments correct is critical, because many face challenges in making appeals. "Lots of people living with dementia are living alone. Making a formal appeal can be too much, and they deteriorate because the [new] package [of care] is not right. Declines can be quick."[25]

The Care Act is silent on the suspensive effect of an appeal. Department of Health guidance from 2006 states that "Decisions need to be made on a case-by-case basis, but there should generally be a presumption in favour of freezing, unless there is a good reason against it (for example, if it puts a service user at risk)."[26]

In responses to Human Rights Watch's inquiries, two local authorities stated that they have the discretion to maintain services pending appeals or issue services pending an appeal but did not make clear the criteria they use for such decisions or how often they do continue to provide services. The Dorset County Council reported that it will continue services "as the as long as the original care plan fulfils the council's statutory duties to meet the person's needs."[27] The North Yorkshire County Council said that managers "have the authority to continue services (if already in receipt) whilst a complaint is awaiting

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[25] Human Rights Watch telephone interview with Dominic Carter, Senior Policy Officer, UK Alzheimer's Society, July 16, 2018.

[26] Department of Health, "Learning From Complaints Social Services Complaints Procedure for Adults," 2006, para. 6.5, http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/assetRoot/04/13/77/86/04137786.pdf (accessed November 18, 2018).

[27] Letter from Michael Ford, Dorset County Council, to Human Rights Watch, October 29, 2019. Available at www.hrw.org.

outcome" and that "a service would be provided pending the outcome, if one was not already in place, and if appropriate, and available within available resources."[28]

The Department of Health and Social Care is currently developing a process for streamlined appeals, to be introduced by April 2020, as provided for in the Care Act.[29] As part of the reforms, the government should consider allowing services to continue to maintain individuals' health and wellbeing during appeals.

[28] Letter from Christine Appleyard, North Yorkshire County Council, to Human Rights Watch, November 15, 2018. Available at www.hrw.org.

[29] House of Commons Library, "Briefing Paper, Social Care: Announcements delaying the introduction of funding reforms (including the cap) (England)," February 23, 2018, https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/compendium/subnationalpopulationprojectionssupplementaryanalysis/2014basedprojections/howthepopulationofenglandisprojectedtoage (accessed November 18, 2018).

Lack of External Oversight of Social Care Assessments

In its 2017-2018 complaints report, released in November 2018, the Local Government and Social Care Ombudsman stated that assessments remain one of the biggest areas of complaint, and noted "a shift from one-off mistakes to problems with whole systems and policies, or procedures being incorrectly applied."[30]

Social care assessments have huge relevance for the wellbeing and rights of those being assessed, yet there is currently a lack of sufficient oversight and monitoring of assessments to ensure consistent accuracy and objectivity. Older people's rights advocates, staff of one local government agency, and staff of the Local Government Association, told Human Rights Watch that they were unaware of any system by which central government audits needs assessments to ensure they are being administered reliably.

The National Audit Office states clearly that:

> The Department of Health & Social Care is responsible for health and adult social care policy in England. Local authorities commission social care and a small minority also provide care services. Local authorities do not have direct accountability to government .... .[31]

Human Rights Watch sent letters to 11 local government authorities requesting information on monitoring of social care needs assessments. The three local governments (Dorset County Council, North Yorkshire County Council, and London Borough of Barking & Dagenham) that responded indicated processes for reviewing social care needs assessments are conducted within each council's own structures, and they were not aware

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[30] Local Government and Social Care Ombudsman, "Social care pressures reflected in Ombudsman's annual review of complaints," November 28, 2018, https://www.lgo.org.uk/information-centre/news/2018/nov/social-care-pressures-reflected-in-ombudsman-s-annual-review-of-complaints (accessed November 30, 2018).

[31] National Audit Office, "Adult Social Care At A Glance," July 2018, p. 6. https://www.nao.org.uk/wp-content/uploads/2018/07/Adult-social-care-at-a-glance.pdf (accessed November 30,2018).

An older man walks down the hall during a drop-in cafe for older people in East London.
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of any systematic independent monitoring or monitoring of assessments by the central government.[32]

At time of writing we have not received responses from other local government authorities. We also contacted the Department of Health and Social Care and the Ministry of Housing, Communities and Local Government in England, requesting information on monitoring of social care needs assessments. We did not receive responses from them at the time of writing.

Local authorities submit reports to England's Department of Health and Social Care on some aspects of their social care provision annually, such as how many people are living in nursing facilities, in residential care, and receiving short-term and long-term social care

[32] Letter from Michael Ford, Dorset County Council, to Human Rights Watch, October 29, 2019; Letter from Christine Appleyard, North Yorkshire County Council, to Human Rights Watch, November 15, 2018; Email from Stephan Leibrecht, London Borough of Barking & Dagenham, to Human Rights Watch, November 19, 2018. Available at www.hrw.org.

at home, in the Adult Social Care Outcomes Framework. The Department of Health and Social Care does not audit this information, nor does it use the information to improve local government authorities' delivery of social care. In its 2018-2019 guidance for local authority reporting, it states: "The Government does not seek to performance manage councils in relation to any of the measures set out in this framework. Instead, the Adult Social Care Outcomes Framework (ASCOF) will inform and support improvement led by the sector itself, underpinned by strengthened transparency and local accountability."[33]

Data reported to the Department of Health and Social Care may not always be accurate. A staff member at a local authority working on social care administration described the pressures she faces in reporting her local authority's statistics on social care provision to the Department of Health and Social Care. During data compilation for an annual report for 2017, her manager asked her to overstate the number of people who had received short-term services had subsequently been deemed "healthy" and did not require a continuation of services:

> … You have to take into account that none of this is audited … What I'm shocked at is that there is no auditing of our [social care] numbers … We've had pressure to change the figures [we report on social care]. Because it's not audited, there's a lot of making things look nicer.[34]

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[33] Department of Health and Social Care, "The Adult Social Care Outcomes Framework 2018/19 Handbook of Definitions," March 2018, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/687208/Final_ASCOF_handbook_of_definitions_2018-19_2.pdf (accessed November 16, 2018).

[34] Human Rights Watch telephone interview with "Elise," January 9, 2018.

International Legal Standards

The Right to Health and to Family and Private Life

The International Covenant on Economic, Social and Cultural Rights (ICESCR), ratified by the United Kingdom but not yet incorporated into domestic law, guarantees the right of everyone to the enjoyment of the highest attainable standard of physical and mental health conducive to living a life in dignity, including for older persons.

Like the ICESCR, the European Convention on Human Rights, ratified by the UK and incorporated into domestic law through the Human Rights Act 1998, guarantee the right to private and family life. European Court of Human Rights jurisprudence has determined that private life covers "a person's physical and psychological integrity," "personal development," and "personal autonomy," and more specifically is "considered relevant to complaints about public funding to facilitate the mobility and quality of life of disabled applicants."[35] The court has also interpreted this right to protect people from the "disruption of home or family life" causing "stress and distress," including when lack of financial support or community-based services would force older persons with disabilities out of their homes.[36]

The United Nations Committee on Economic, Social and Cultural Rights, which monitors implementation of the ICESCR, has called on governments to "implement measures especially for low-income families who wish to keep elderly people at home. This assistance should also be provided for persons living alone or elderly couples wishing to remain at home."[37]

The UK is a party to the Council of Europe's original European Social Charter of 1961, which requires it to respect a range of social and economic rights, including the right of everyone

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[35] European Court of Human Rights, *McDonald v. The United Kingdom*, judgment of 20 August 2014, paras. 46-47.

[36] European Court of Human Rights, *Watts v. The United Kingdom*, decision on the admissibility of application no. 53586/09, para. 97.

[37] UN Committee on Economic, Social and Cultural Rights, General Comment No. 6, The Economic, Social and Cultural Rights of Older Persons (1995), 8 December 1995, art. 10, para. 31.

to health, to social and medical assistance, and the right to benefit from social welfare services.[38]

The UK has not ratified the Council of Europe's Revised European Social Charter, adopted in 1996. Article 23 of that Charter, titled "the right of elderly persons to social protection" obliges parties to undertake or encourage measures to enable older people to remain full members of society for as long as possible, requiring that they should have …" adequate resources enabling them to lead a decent life and play an active part in public, social and cultural life;"[39] and to choose their lifestyle freely and to lead independent lives in their familiar surroundings for as long as they wish and are able, by means of "the health care and the services necessitated by their state[.]"[40]

The Right to Live Independently in the Community

Older people have the right to live independently in the community and to community-based services under the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which the UK ratified in 2009. Support for living independently can include: "access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation." The right to live independently and be included in the community should not depend on the level of support a person needs.[41]

Many older people in need of social care have disabilities, defined by the CRPD as "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."[42]

In its October 2017 review of the UK, the UN Committee on the Rights of Persons with Disabilities expressed concern about changes in "policies and measures that affect the ability to live independently in the community," and that "responsibility for supporting

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[38] Council of Europe, European Social Charter, 18 October 1961, arts. 12, 13, and 14, https://rm.coe.int/168006b642.

[39] Council of Europe, European Social Charter (Revised), 3 March 1996, art. 23, https://rm.coe.int/168007cf93.

[40] Ibid.

[41] Convention on the Rights of Persons with Disabilities (CRPD), adopted 24 January 2007, G.A. res. A/RES/61/106, entered into force 3 May 2008, ratified by the United Kingdom of Great Britain and Northern Ireland on 8 June 2009, preamble.

[42] CRPD, art. 1.

independent living has been transferred to the devolved administrations and local authorities without providing appropriate and earmarked budget allocation."[43]

[43] Concluding Observations on the initial report of the United Kingdom of Great Britain and Northern Ireland to the United Nations Committee on the Rights of Persons With Disabilities, October 3, 2017, para 44, http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhspCUnZhK1jU66fLQJyHIkqMIT3RDaLiqzhH8tVNxhro6S657eVNwuqlzuoxvsQUehREyYEQD%2bldQaLP31QDpRclCKZKktydtAkeqhq77NL01.

Recommendations

To the UK Government

- Ensure that older people have access to the services they need to realize their rights to live independently in their communities with their rights to health and private and family life protected.
- Establish a mechanism to monitor and evaluate social care needs assessments and the staff who conduct them to ensure consistency and equality nationally.
- Ratify the Council of Europe's Revised European Social Charter.

To the UK Parliament

- The Health and Social Care Committee and the Housing, Communities and Local Government Committee of the House of Commons should examine the impact of austerity measures on local authority social care provision under the Care Act 2014.

To the Ministry of Housing, Communities and Local Government

- Review successful appeals against initial social care needs assessments and collect data about the reasons assessments were identified as problematic; data should consider the age, gender, ethnicity, location, and place of residence of those assessed as well as the types of shortcomings in initial assessments; use this information to make corrections and improvements in the system with a goal of ensuring provision of services to which people are entitled and reducing the number of times individuals must appeal in order to secure social care services.
- Direct local authorities to establish and document clearly the specific reasons to justify services being safely reduced or eliminated pending an individual's appeal of an initial social care assessment and in all cases to strongly consider continuation of services pending appeals.

To the Department of Health and Social Care

- Include, in the reform of social care appeals processes planned for 2020, the suspensive effect of appeals.

- Execute a plan for the long-term stability and sustainability of the social care system in England to ensure that the human rights of older people are fully respected.

To Local Governments

- Ensure the accuracy of needs assessments, including when there are not enough resources locally to meet those needs.
- Document clearly the specific reasons to justify services being safely reduced or eliminated pending an individual's appeal of an initial social care assessment and in all cases to strongly consider continuation of services pending appeals.
- Ensure that individuals are fully informed of their rights and available options to appeal social care assessment decisions and provide reasonable accommodations to individuals who may require assistance in the appeals process.

Acknowledgments

This report was researched and written by Bethany Brown, Older Persons' Rights researcher in the Disability Rights Division of Human Rights Watch. Jane Buchanan, deputy director of the Disability Rights Division, Diederik Lohman, director of the Health and Human Rights Division, and Benjamin Ward, deputy director of the Europe and Central Asia Division edited the report. Clive Baldwin, senior legal advisor, provided legal review, and Babatunde Olugboji, deputy program director, provided program review for Human Rights Watch. Cara Schulte, associate, Health and Human Rights Division, provided production assistance and support. Print production was coordinated by Jose Martinez, senior coordinator; and Fitzroy Hepkins, production manager.

Human Rights Watch thanks individuals who shared their personal stories, as well as officials, service providers, and experts who agreed to be interviewed. We also thank all the organizations that supported this work by facilitating interviews, and providing invaluable insight, including Dennis Reed of Silver Voices, Kirsty Woodard of Ageing Without Children, Jane Caldwell and the team of Age UK East London, Sally Copley and the team of the Alzheimer's Society, and Rajbinder Johal and the team of Independent Age.

Human Rights Watch would like to thank the Samuel Centre for Social Connectedness for its partnership throughout this research. Social connectedness is a guiding theme in Human Rights Watch's work for older people's human rights. We would like to thank Eloise O'Carroll, Social Connectedness Fellow at the Samuel Centre for Social Connectedness, for her research assistance. And, we offer our deepest thanks to Kim Samuel for her unwavering belief in the power of social connectedness.

Annex 1: Correspondence with Local Authorities

Cara Schulte

From: Christine Appleyard [redacted]
Sent: Thursday, November 15, 2018 11:24 AM
To: Bethany Brown
Subject: RE: HRA Research on Oversight for Social Care Assessments in England.
Attachments: NYCC.docx

Hi Bethany,

Please see attached response, albeit brief, hope it is useful.

Kind regards

Chris

Chris Appleyard
Head of Practice, Personalisation and Safeguarding
NYCC Health and Adult Services
[redacted]
Thank you.Please note that my working days are Tuesday, Wednesday ,Thursday and Friday's.

From: Bethany Brown [redacted]
Sent: 13 November 2018 22:05
To: Christine Appleyard [redacted]
Cc: Cara Schulte [redacted]
Subject: Re: HRA Research on Oversight for Social Care Assessments in England.

Dear Ms. Appleyard,

Thank you very much for your reply. We would endeavour to include any response from your council in our report, but our printing deadlines are unfortunately unforgiving. If you would be able to send this in the next day or two, we could at least include it online as an addendum.

Regards,
Bethany

From: Christine Appleyard [redacted]
Sent: Wednesday, November 7, 2018 4:57:11 AM
To: Bethany Brown
Cc: Cara Schulte
Subject: HRA Research on Oversight for Social Care Assessments in England.

Dear Bethany,

Thank you for your letter sent to Richard Webb, Corp. Director of Health and Adult Services, North Yorkshire County Council, on 15.10.2018 and emailed to Angela Gray.

I write to advise that we are gathering the information required to respond to your questions and will send this as soon as possible.

Yours Sincerely

Chris Appleyard

Chris Appleyard
Head of Practice, Personalisation and Safeguarding
NYCC Health and Adult Services
[redacted]

Thank you.Please note that my working days are Tuesday, Wednesday ,Thursday and Friday's.

Access your county council services online 24 hours a day, 7 days a week at www.northyorks.gov.uk.

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North Yorkshire County Council.

2

Q1. Does North Yorkshire monitor Social Care needs Assessment for older people? If so could you provide details on that monitoring, including who conducts it, how frequently, and the sources of information for such monitoring, such as the assessments themselves, interviews with assessors, their supervisors, and individuals whose needs have been assessed, medical and other documents relevant to the assessments? Is this information public? If not, is it shared with central government or others?

- Annual adult social care survey – completed by Business Intelligence
- ASCOF return – Completed by Business Intelligent (shared with central government)
- Reablement service users survey – completed by Reablement team
- Annual review of service – completed by assessors (shared with service user)

Q2. Does North Yorkshire County Council collect other evidence about the quality and consistency of social care assessments and there compliance with the care Act? If so, what is the nature of that evidence, is it made public, or shared with central government of other?

- Quality assurance audit tool (case file audits) (internal)
- Supervisions (internal)
- Peer Supervision (internal)
- Action Learning sets (internal)
- As a result of specific projects, national quality audit tools are used.
- Complaints process

Q3. Are you aware of any independent monitoring of assessments for older people in your local authority area? These might include, for example, monitoring conducted by monitoring groups or citizens; charity representatives; lawyers; social workers or others?

- Local Government & Social Care ombudsman
- CQC

4. How does North Yorkshire County monitor training for assessors who conduct social care assessments?

- Supervision and appraisal process
- Electronic record of learning with managerial interface

5. Does North Yorkshire County Council monitor successful appeals or social care needs assessment for older people, and initial decisions and the reason that those initial assessment were re-evaluated? If so, how does it use that information?

- Complaints process informing managerial decisions

6. Does North Yorkshire County Council or any other body have the authority to decide that an individual can access services pending an appeal against an assessment decision to limit, deny or end such service? Does North Yorkshire County Council or any other body monitor the situation including the health and wellbeing, for individuals who have had service limited, reduced, denied or ended and are appealing the needs assessment decision?

- Managers have the authority to continue services (if already in receipt) whilst a complaint is awaiting outcome. However, a service would be provided pending the outcome, if one was not already in place, and if appropriate, and available within available resources.

  - Frontline assessor involved would monitor the wellbeing.

Cara Schulte

From:	Michael J Ford [redacted]
Sent:	Monday, October 29, 2018 10:39 AM
To:	Bethany Brown
Cc:	Cara Schulte; Liza Knight
Subject:	Human Rights Watch Research on Oversight for Social Care Assessments in England
Attachments:	Dorset County Council Final.docx; MJF HRW letter 29-10-18.pdf
Follow Up Flag:	Flag for follow up
Flag Status:	Completed

Dear Ms Brown,

Thank you for your letter of 15 October 2018 to the Chief Executive. I have attached our reply, which is within the timescale you requested.

Your sincerely

Michael Ford
Policy & Project Manager

From: Cara Schulte [redacted]
Sent: 15 October 2018 20:21
To: Chief Executive [redacted]
Cc: Bethany Brown [redacted]
Subject: Human Rights Watch Research on Oversight for Social Care Assessments in England

Dear Ms. Ward,

Attached please find a letter with some questions for you regarding research we are conducting for an upcoming report on social care needs assessments for older people at home in England. As the letter states, we are asking if you would kindly offer any responses by November 5, 2018. A hard copy of this letter has been mailed to your address.

If you have any questions, please be in touch with Bethany Brown, Researcher on Older People's Rights, at [redacted].

Sincerely,

Cara Schulte

Dorset County Council

Unclassified

Adult Services
County Hall
[redacted]

Telephone: [redacted]
We welcome calls via text Relay

Email: [redacted]
Website: www.dorsetforyou.gov.uk

Date: 29 October 2018

Bethany Brown
Researcher
Human Rights Watch
350 Fifth Avenue, 34th Floor
New York, NY 10118-3299

Dear Ms Brown,

Human Rights Watch Research on Oversight for Social Care Assessments in England.

I am writing in response to your letter of 15 October to the Chief Executive about social care needs assessments for older people at home.

It was helpful to read the background information that you provided before the questions. However, I think the concerns you highlight about appeals not being 'suspensive' are specific to cases where a person's care and support plan might change following a review which reflects changes to their needs or circumstances. The duty on the local authority in such cases is to ensure that a review occurs, and if needed, a revision of the plan follows it.

1. The council monitors social care needs assessments through the statutory supervision process and mandated review and authorisation steps (linked to the scheme of delegation) in case management. Each locality team has a quality assurance forum that monitors standards of documentation and assessment. The principal social worker and principal occupational therapist carry out case audits that are council-wide. Where appropriate, we cooperate with other health and care professionals who can inform us of any concerns about the ability of the draft care plan to meet needs. Assessments are individual and person-centred. The information is not public, it is protected by the United Kingdom's data protection regime.

2. The council collects other evidence about quality, consistency and compliance with the Care Act and publishes it in accordance with the Adult Social Care Outcomes Framework (ASCOF). The framework is used both locally and nationally to set priorities, measure progress and strengthen transparency and accountability.

3. I am not aware of any systematic independent monitoring of social care assessments carried out for older people in Dorset. However, we participate in sector-led improvement work, for example by the Local Government Association.

4. The council is part of a nationally recognised teaching partnership aimed at increasing the quality of social work education, and we influence curriculum renewal. Our local teaching partner is Bournemouth University which is accredited by the Health and Care Professions Council. Within the council we organise induction training and identify

Debbie Ward, Chief Executive and Director for Adult and Communities

training needs through formal Performance & Development review steps. Certain training needs are met by internal provision.

5. The Care Act duty to involve the person applies in all settings. Local authorities in England are required to take steps to agree the final care and support plan with the person and to provide an independent advocate if this is needed. Where a person does not agree the plan, we may ask another worker, who may be independent of the council, to carry out an assessment. If the disagreement is not resolved there is a complaints procedure that meets the requirements of the Local Authority Social Services and National Health Service Complaints (England) Regulations 2009. The 'learning' from compliments and complaints is used in service redesign and in training.

   The lack of a formalised appeal structure within care and support in England was highlighted when the Care Bill progressed through Parliament. The government acted to include powers within the Care Act to introduce an appeals system. The Department of Health intends to develop detailed proposals for the system and to set these out in regulations. The regulations are expected to specify whether decisions made by local authorities on care planning and personal budgets will be eligible for appeal. The appeals system will come into force in April 2020.

6. In most cases the council has discretion to allow a person to continue to access services pending an appeal such as you describe, as long as the original care plan fulfils the council's statutory duties to meet the person's needs. The wellbeing principle from the Care Act applies in all cases where we are carrying out a care and support function, or making a decision, in relation to a person. Wellbeing is a broad concept that encompasses, but is not limited to, physical and mental health. We recognise that similar circumstances may affect individuals differently, so we endeavour to achieve fairness through personalisation rather than through uniformity.

I hope this response has been helpful.

Yours sincerely

Michael Ford
Policy and Project Manager.

Cara Schulte

From: Cara Schulte
Sent: Monday, November 19, 2018 12:38 PM
To: Bethany Brown
Subject: Fwd: Human Rights Watch Research on Oversight for Social Care Assessments in England, response from Barking and Dagenham

Hi Bethany,

FYI. Let me know if you need anything on my end.

Thanks,
Cara

Get Outlook for iOS

From: Liebrecht Stephan [redacted]
Sent: Monday, November 19, 2018 12:27 PM
To: Cara Schulte
Subject: Human Rights Watch Research on Oversight for Social Care Assessments in England, response from Barking and Dagenham

Dear Cara Schulte,

We apologise for the slight delay in returning this to you.
Below are the answers to your questions.
Please contact me directly if you require further information.

1. Does the London Borough of Barking & Dagenham monitor social care needs assessments for older people? If so, could you provide details on that monitoring, including who conducts it, how frequently, and the sources of information for such monitoring, such as the assessments themselves, interviews with assessors, their supervisors, and individuals whose needs have been assessed, medical and other documents relevant to the assessments? Is this information public? If not, is it shared with central government or others?

- All assessments are approved at Team Manager level. This includes a quality check. Approval of an assessment usually includes an approval of the funding. We are using the FACE Overview Assessment tool which includes a resource allocation tool. The assessment is completed directly on our data base system Liquid Logic which enables a full audit trail of the process, from the home visit to the assessment and support plan.

2. Does the London Borough of Barking & Dagenham collect other evidence about the quality and consistency of social care assessments and their compliance with the Care Act? If so, what is the nature of that evidence, is it made public, or shared with central government or others?

- We are undertaking case file audits which include an audit of the assessments. They are spot checks. The findings are used to improve quality and are not shared publicly.

3. Are you aware of any independent monitoring of assessments for older people in your local authority area? These might include, for example, monitoring conducted by monitoring groups of citizens; charity representatives; lawyers; social workers or others.

- There are no formal processes but we are always open to criticism, for example from our Health partners who are sharing case work with us as part of our Integrated Care System.

4. How does the London Borough of Barking & Dagenham monitor training for assessors who conduct social care assessments?

- We are offering new Social Workers training on how to use the FACE overview tool.

5. Does the London Borough of Barking & Dagenham monitor successful appeals of social care needs assessments for older people, and initial decisions and the reasons that those initial assessments were reevaluated? If so, how does it use that information?

- We are using the Complaints process which is overseen by a separate dedicated team. The number of Complaints regarding the outcome of social care assessments is very low.

6. Does the London Borough of Barking & Dagenham or any other body have the authority to decide that an individual can access services pending an appeal against an assessment decision to limit, reduce, deny or end such services? Does the London Borough of Barking & Dagenham or any other body monitor the situation, including the health and wellbeing, for individuals who have had services limited, reduced, denied or ended and are appealing the needs assessment decision?

- No (not applicable as no appeals process)

Yours sincerely

Stephan Liebrecht | Operational Director: Adult's Care and Support
Phone: [redacted] | Mobile: [redacted] | [redacted]

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2

UNMET NEEDS

Improper Social Care Assessments for Older People in England

Under England's Care Act of 2014, any individual who meets meet financial and needs criteria is entitled to government-supported services and support, known as social care. In interviews with Human Rights Watch in 2017 and 2018 in 12 cities across England, older people, their families and groups who work with them expressed concerns with how local authorities determined eligibility for social care. In some cases, older people said that they were denied crucial services or had services significantly reduced, causing their health and wellbeing to decline. Social care services include in-home assistance such as preparing meals, dressing, and bathing.

Focusing on England, *Unmet Needs: Improper Social Care Assessments for Older People in England* identifies a lack of oversight, from the United Kingdom government, for local authority social care needs assessments. While some of those Human Rights Watch interviewed were able to bring an appeal against their assessment and get the social care to which they are entitled, the process often led to delays in receiving services. Many older people described facing physical, psychological, and financial hardships as a result.

The UK government has obligations under domestic law in the Care Act and the Human Rights Act, and under international law to ensure the rights to live independently in the community, to health, and to private and family life. The report calls on the UK government to ensure that older people in England receive the support they need and are entitled to by regularly monitoring social care assessments for accuracy and fairness, and guaranteeing services continue during appeals.

Older woman leaving a community center with programs for older people in East London.

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