Response to the LGA green paper for adult social care and wellbeing

September 2018

About us

Merton Centre for Independent Living are a user-led Deaf and Disabled[1] people's organisation run by Disabled people, for Disabled people, across the full spectrum of disability. We deliver a range of services to Deaf and Disabled people in London Borough of Merton, such as advice and advocacy services, including support for people navigating benefits and adult social care systems and processes.

We would like to thank our members who helped us respond to this consultation via our Craftivism and Chat Group.[2]

The role of local government in helping to improve health and wellbeing in local areas, and decision-making at a local level

Our members told us that Local Government does have a big role to play in improving health and wellbeing in local areas. However, our members were clear that this is a role which has to be shared with local Deaf and Disabled People and local communities. We need to have a shared role in decision-making, in service design and even in service delivery. There should be multiple routes to enable this kind of shared decision-making and it can include direct contact between Councils and residents, as well as through user-led organisations. Organisations like ours have a specific role to play around creating a bridge between the Local Authority and helping local residents navigate sometimes complex systems of interaction.

> The Council should have a big role to play. But their definition of health and wellbeing is totally different to ours. Member

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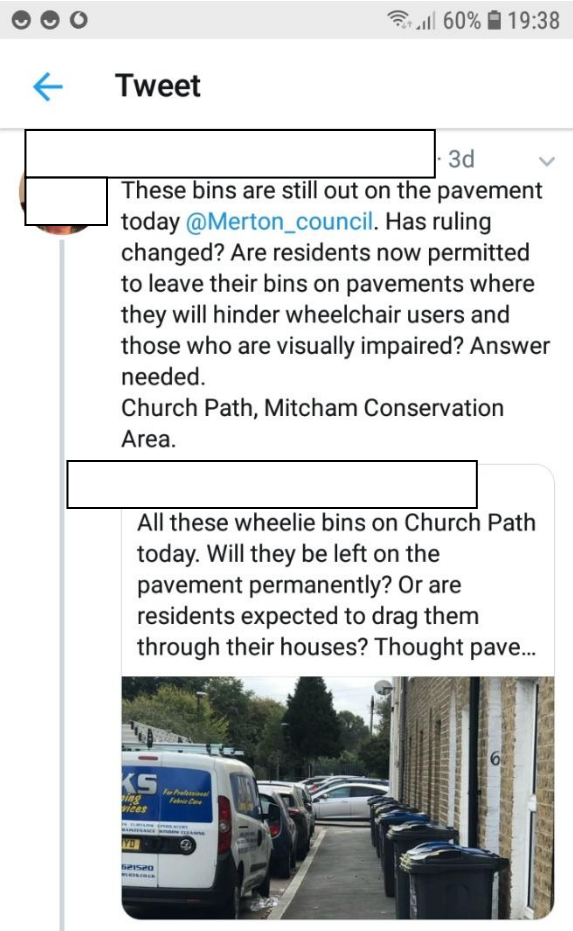
[1] In the interests of brevity, throughout the document we tend to use Disabled People when we mean Deaf and Disabled People

[2] https://www.mertoncil.org.uk/getting-involved/craftivism-and-chat/

Our members felt that the local Council is approaching health and wellbeing from a different angle to what it means to them. From our members' perspective, health and wellbeing is about getting out and about, it is about connecting with people and it is about being independent. For us and our members, independence is about choice and control, to make decisions, and to have options. Our members defined this for us in 2016 at our event, 'Independence: what does it really mean?'

However, the local authority has a different vision of what independence means. For them, it means not using services, or using less of them. It is primarily a financial discussion, rather than something which really interrogates health and wellbeing. Certainly we have seen both locally, and nationally, that the discussion is all about money. We responded to the Long term funding of adult social care inquiry by the Housing, Communities and Local Government Committee. In that we said that Disabled people's lives are not a cost which needs to be managed, limited, or somehow ‘made sustainable’. In actual fact, costs are created by local and central government’s failure to invest in prevention, and failing to invest in making communities suitable for independent living. Some of the practices and approaches of social care delivery create costs.

We also said that if the Government wants to fund social care sustainably for the long term, then they need to reframe the debate to one about investment in Disabled people’s potential and life chances, and provide proper mechanisms to challenge discrimination and disadvantage[3]. We have also seen locally that much of the debate is framed around cost with local councillors referring to social care as a burden. In a recent local article the Leader of the Council is quoted as saying that “funding adult social care is the biggest strain on the council"[4] and earlier this year it the CEO of Merton Council said “social care will be a constant financial burden on the council in the future.”[5]



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These bins are still out on the pavement today @Merton_council. Has ruling changed? Are residents now permitted to leave their bins on pavements where they will hinder wheelchair users and those who are visually impaired? Answer needed.
Church Path, Mitcham Conservation Area.

[redacted]

All these wheelie bins on Church Path today. Will they be left on the pavement permanently? Or are residents expected to drag them through their houses? Thought pave...

This kind of language and way of thinking is disappointing and unhelpful because it narrows the focus and discussion to being all about care needs. However, looking at a wider perspective, everything from wheelie bins to welfare benefits impacts on Disabled people’s ability to live independently.

All these factors lead to a situation

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[3] You can read our full submission to the inquiry here: http://data.parliament.uk/writtenevidence/committeeevidence.svc/evidencedocument/housing-communities-and-local-government-committee/long-term-funding-of-adult-social-care/written/80829.pdf

[4] https://www.wimbledonguardian.co.uk/news/16883799.we-have-to-do-some-cuts-council-needs-to-find-17m-in-next-four-years/

[5] https://www.wimbledonguardian.co.uk/news/16364469.social-care-the-biggest-financial-challenge-facing-merton-council/?ref=twtrec

where Disabled people have worse wellbeing than non-Disabled people, which is demonstrated by the 2017 residents survey[6] which covered people’s feelings of overall life satisfaction, their lives being worthwhile, happiness, and anxiousness. Disabled people were significantly less positive in all four aspects of wellbeing covered by these questions. The 2014 survey also looked at wellbeing and also found that Disabled People had much lower welbeing than non-Disabled people. The two surveys are not comparable as they use different scales. Nevertheless, there is broadly a downward trend in wellbeing for Disabled People. Wellbeing is at the heart of the Care Act with local authorities having a responsibility to promote service users’ wellbeing, so the Council has a clear role to play in achieving parity of wellbeing between Disabled and non-Disabled people.

> Physical and mental health go together. Everything falls apart when the two are disconnected. You need to treat people as people and not separate things up. Member

Clearly for us it is particularly important that decisions are made at a local level - without this there cannot be co-production with service users and communities. However, it is important to ensure that there are national standards and avoid ‘post-code lotteries’. For example, our Council’s approach to some social care issues is different to that of other areas and is characterised by social care users saying they have low choice and control[7], whereas for example in Hammersmith and Fulham, charging for care has been abolished.

The impact of funding challenges

It isn’t entirely evident what efforts have been made to improve social care locally as mechanisms whereby this might be done, such as user forums or monitoring of contracts and service delivery have been reduced.

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[6] https://democracy.merton.gov.uk/documents/s17872/10b.%20Residents%20Survey%20Research%20Report%20April%202017.pdf

[7] https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-adult-social-care-survey

Cuts in services are also having a severe impact on the lives of Disabled people in Merton. We have seen growing evidence of:

- Delays and people being denied access to assessments
- Reductions in hours of support for service users based on lack of resources rather than changes in need, even when this is clear it will have a negative impact on health and wellbeing.
- Increasing numbers of safeguarding concerns, many relating to the results of cuts in services.
- Increased charges for services
- A general failure to comply with the Care Act

The lack of services and support has a clear impact on people's health and wellbeing. In some cases we believe this has lead to the death of service users, and it has certainly lead to people needing to use hospital and acute services more often than they would have. For others it has a day-to-day impact on quality of life, denying people access to independent living and the ability to participate as full citizens. Many of these impacts were predicted in a research undertaken by Healthwatch Merton in 2015[8] which showed that local people felt the quality of existing social care services was reducing and that support to help future needs, 'prevention', was made impossible by reducing services. The report found that Disabled and older people felt cuts were making them more vulnerable, that their wellbeing was being reduced and physical health worsening. Families were being put under immense strain and social connections severed. The ultimate consequence for some was that life was no longer worth living. Respondents to the report referred to the cuts to support as "social cleansing", and accused the Council of "treating people no better than animals."

We have seen Disabled People:

- hospitalised following a reduction in care package
- die following discharge from hospital with no social care in place
- lose at Employment Tribunal because of poor advice about their directly employed personal assistants
- denied support to manage their health and wellbeing needs, who then need to access mental health services,

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[8] https://www.healthwatchmerton.co.uk/sites/default/files/hwm_asc_focus_groups_write_up_report.pdf

- denied the opportunity to contribute to their local community group and so become socially isolated.

While we recognise that funding to local authorities is reducing, there are still local choices to be made about where to allocate funding. It is concerning that there was no consultation prior to budget-setting this year.

The previous year, the local authority undertook a borough-wide consultation on council tax. The consultation was a 4-page full-colour spread which failed to show any images of Disabled people, even though it pictured other Council duties, including rubbish collection. We were particularly concerned by the way in which Merton Council focuses very narrowly on budgets, as opposed to looking at the impact of spending and budget cuts. We have repeatedly pointed out, pound for pound a cut in support for Disabled people has a far greater impact on people's lives, compared to a cut in street sweeping, for example. In fact, the way in which the Council's consultation asked the public to rank services, as if rubbish collection was equivalent to supporting independence for Disabled and older people, was disturbing.[9]

They are comparing disabled people's lives to bin collection. I can't tell you how that makes me feel.
Member

The Council is asking my neighbours to decide whether or not I should live independently and with dignity. They don't have that right! Member

Barriers to implementing the Care Act 2014

As well as the issues above, there seems to be a lack of awareness and understanding of the Act amongst Council staff at all levels. Locally it has been acknowledged that Care Act training is an outstanding training

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[9] Our response to the consultation: https://democracy.merton.gov.uk/documents/s15657/Appendix%203b%20MCIL%20Council%20Tax%20and%20Council%20Spending%20Consultation%20Response%20Nov%202016.pdf

need which we understand is planned for some time next year. Other issues with implementation of the Care Act will be compounded by some of the issues raised in the BASW survey around having an undervalued workforce, high turnover and high use of temporary staff. The study conducted last year[10] found that conditions for practice are pushing many social workers away. A standout finding was that 52% of UK social workers intend to leave the profession within 15 months, due to high, unmanageable caseloads, a lack of professional and peer support and burdensome red-tape and bureaucracy.

Another significant barrier to implementing the Care Act is the limited remedies available to individuals. A complaint to the Ombudsman takes months to resolve and is not a route really intended to resolve immediate issues. For people who might wish to bring a legal claim in the hope that this would resolve any issues more quickly, some people are denied access to justice as they can’t get Legal Aid because of the way expenses are calculated, especially disability related expenses.[11] Even for people able to access Legal Aid, finding a solicitor available to take a case is extremely challenging. For example we have been unable to find legal support for a woman detained in a care home without having had a mental capacity assessment. Even where cases are brought, courts seem reluctant to be drawn into telling local authorities how to spend their money and how needs should be met.

Suggestions for improving the adult social care and support system

Our view was that there need to be safeguards to ensure that resources are used as effectively as possible. Even with the pressures on public finances, there still seems to be waste and unnecessary bureaucracy, even when vital, direct services are being cut. Sometimes, services which prevent issues (and cost) later on, are cut. For example, monitoring of care packages and support for direct payments users was cut locally leading to increased issues in these areas including more safeguarding alerts, breakdown in care packages, and in one case that we know of, an Employment Tribunal.

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[10] UK Social Workers: Working Conditions and Wellbeing http://cdn.basw.co.uk/upload/basw_42443-3.pdf

[11] An inquiry has been launched into this by EHRC https://www.equalityhumanrights.com/en/our-legal-action/inquiries-and-investigations/legal-aid-victims-discrimination-our-inquiry

There need to be measures to support, improve and increase the social care workforce. And, importantly, there needs to be a move towards genuine co-production with service users in all aspects of design and delivery of social care.

We support the recent position statement from the Independent Living Strategy Group[12] chaired by Baroness Jane Campbell which includes calls for:

- an enforceable right to independent living
- a national network of disabled people-led organisations to promote and support the right of disabled people to live independently
- extending the NHS's 'need, not ability to pay' principle to social care and for fully funding the service as part of 'new social contract' between the citizen and the state (as recommended by the 2018 Darzi review of health and social care).

Our members also had a lot to say about this area:

Council departments have to work together. Get rid of the 'them and us' culture in departments, the own separate budgets in each department and every one having their own pot of money. Join up the budget and the money goes to where needs it. Member

Taxes need to be increased. This should not just be about taxes on individuals, corporation tax should also be considered. Member

Stop freebies at top – plough money into health, social care, and police instead. Member

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[12] https://www.inclusionlondon.org.uk/campaigns-and-policy/act-now/independent-living-a-position-statement-from-the-independent-living-strategy-group/

Listen to us. Connect everything. Make everything accessible
Member

Use technology better, make care plans accessible, tie-up with GP records. Member

We had some concerns with some of the funding proposals suggested, for example, we were concerned that means-testing benefits which are currently not means-tested would be both costly and likely to build up problems for the future if the level of means test does not keep pace with the cost of living. Another area of concern was the idea of a further 1 percent on council tax. Unless this is both mandatory and ring-fenced, then it would simply exacerbate the post-lottery phenomenon. For example, in Merton, the social care precept, worth around £2 million in the first year, could have been added to people's Council Tax bills without any impact on people's pockets, because a GLA precept was ending at the same time. However, the local Labour administration went on record to say that they weren't going to be told what to do by George Osborne and initially decided, against fierce opposition, including from the voluntary sector and local residents, not to take up the 2% precept as they had made an election promise not to increase taxes for four years. Because the social care precept was optional for local authorities, rather than mandatory, it was turned into a political football.

Views on bringing wider welfare benefits (such as Attendance Allowance) together with other funding to help meet lower levels of need for adult social care and support?

The experience of reform of benefits in recent years has been negative, with challenges gaining, and retaining benefits. For example, the number of people who were previously on DLA losing out in the change-over to PIP is really significant. We found that in our area, the number of DLA recipients losing out in the transfer to PIP is significantly higher than the national average, which is already high[13]. In Merton alone, 903 Disabled people who previously received DLA have lost their benefit or seen it reduced in the transfer to PIP, over half of people migrated so far. It is expected that at least a further 1,073 Disabled people in Merton are going to lose out in the full roll-out of PIP. In addition, new applicants to PIP are being refused the benefit in more than 50% of cases.

The experience of ILF, which was closed and transferred to local authorities, has also been very poor[14]. The ILF was ground-breaking in giving funds directly to Disabled people to purchase their own support, and it had very low overheads. Earlier this year a service user told us that social workers were describing the ILF as having been the "Rolls Royce of care", in order to depress expectations of what support the Council will offer. We found this so demeaning, and indicative of a culture which sees independent living as a cost rather than an investment in people's wellbeing.

> At my review they said I had to use their cheaper homes for respite. I went to visit them. There was no hoist in the room. I couldn't fit my wheelchair in the loo. I asked if I could shower every day and the manager said there is a queue and I could have a strip wash instead. I call that a "cat's lick". I asked about activities, they said "most people stay in their rooms". I asked about going out, they said "no one goes out". I wouldn't go in there, I wouldn't put a dog in there. Member

> My life has changed, I have to worry from day to day. It certainly impacts on my health. I spend hours indoors where I don't want to be indoors.
> Member

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[13] https://democracy.merton.gov.uk/documents/s21904/Merton%20CIL%20Briefing%20on%20PIP%20Application%20and%20Assessment%20Issues.pdf

[14] https://www.inclusionlondon.org.uk/campaigns-and-policy/facts-and-information/independent-living-social-care-and-health/ilf-one-year-on/

When they stopped the ILF, everything became difficult. Member

We're concerned that any changes to Attendance Allowance would in reality lead to the loss of Attendance Allowance for large numbers of people.

Conclusion

The conversation has to move beyond cost. Disabled people are employers, and employees, we generate innovative solutions and uniquely effective models of support like peer-led solutions or direct payments. The economy of the entire care industry is driven by Disabled people. However, we will only be able to live the lives we want to lead by co-producing services; "nothing about us, without us".

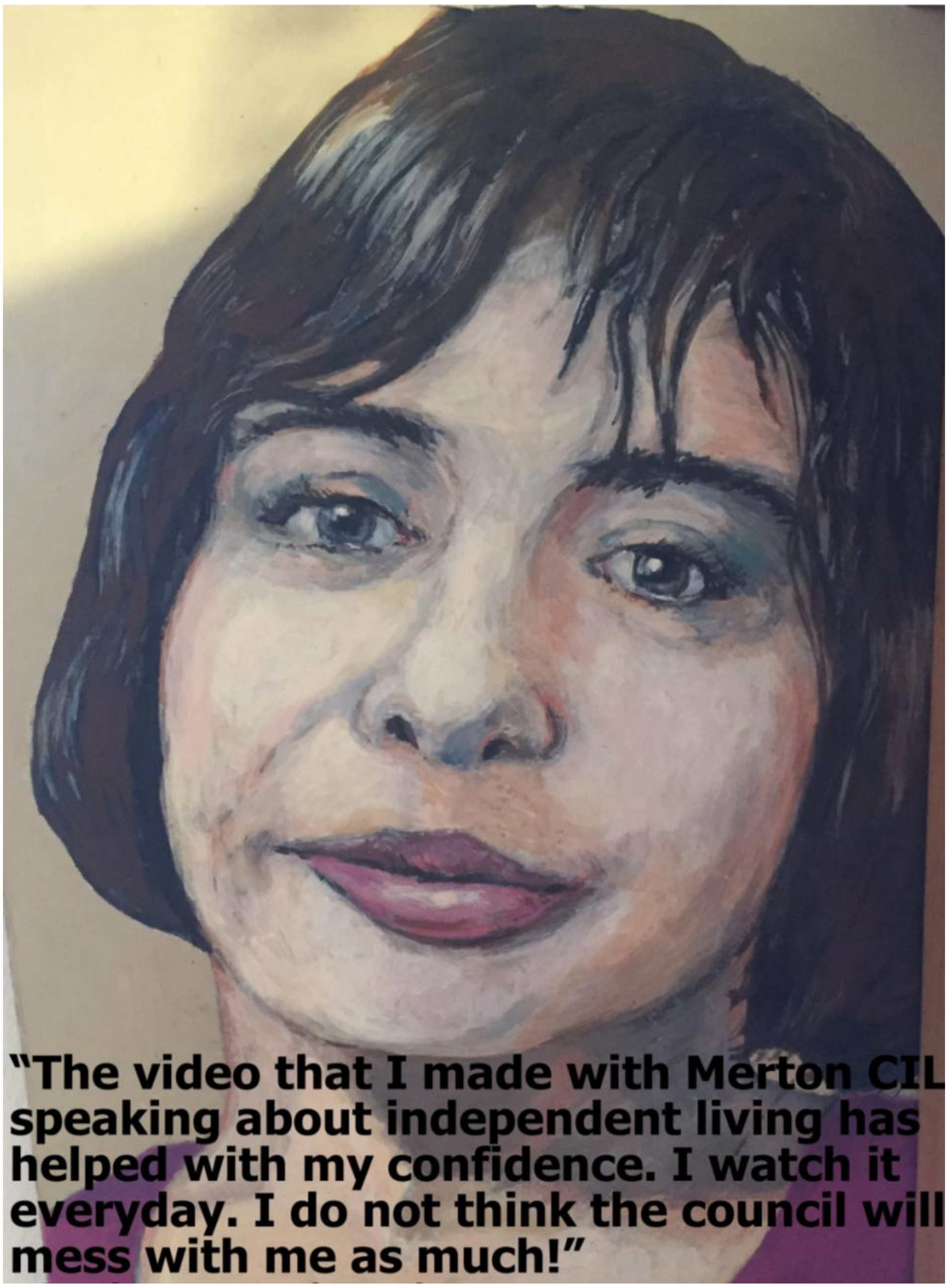
We would like to conclude by sharing the experiences of 3 of our members, in their own words.

Here is what Slim has to say about social care, watch him here: https://www.youtube.com/watch?v=zwuA3BsI8Lo

"I don't want to be institutionalised. I want to live a full and independent life. I think that's my right"

"I want to go out, to be free"

Watch Francoise's story here: https://www.youtube.com/watch?v=Xso0S0N2bRQ



"The video that I made with Merton CIL speaking about independent living has helped with my confidence. I watch it everyday. I do not think the council will mess with me as much!"

Watch Edwina here: https://www.youtube.com/watch?v=i82ZDRquec4

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