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Merton Council

Health and Wellbeing Board - Community sub-group Agenda

Membership

Councillor Rebecca Lanning (Chair)
Rob Clarke
Mark Creelman
Dave Curtis
Abi Fafolu
Dr Vasa Gnanapragam
Phil Howell
Martin Miranda
Councillor Oonagh Moulton
Kalu Obuka
Mohan Sekeram
Councillor Eleanor Stringer
Dr Dagmar Zeuner

Date: Tuesday 25 May 2021

Time: 5.00 pm

Venue: This will be a virtual meeting and therefore not held in a physical location, in accordance with s78 of the Coronavirus Act

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Health and Wellbeing Board - Community sub-group Agenda

25 May 2021

- | | | |
|----|--|----------|
| 1 | Apologies for absence | |
| 2 | Declaration of pecuniary interest | |
| 3 | Minutes of the previous meeting
<i>To agree the minutes of the meeting held on 12th January, 2021.</i> | 1 - 4 |
| 4 | COVID-19 update - (Presentation to be provided at the meeting) | |
| 5 | Presentation and discussion of engagement and insight work
(Presentation to be provided at the meeting) | |
| 5a | BAME Voice | 5 - 66 |
| 5b | Merton Mencap | 67 - 132 |
| 6 | Next steps and LOMP opportunities (Presentation to be provided at the meeting) | |

Note on declarations of interest

Members are advised to declare any Disclosable Pecuniary Interest in any matter to be considered at the meeting. If a pecuniary interest is declared they should withdraw from the meeting room during the whole of the consideration of that matter and must not participate in any vote on that matter. For further advice please speak with the Managing Director, South London Legal Partnership.

Agenda Item 3

HEALTH AND WELLBEING BOARD - COMMUNITY SUB-GROUP
12 JANUARY 2021
(5.00 pm - 6.32 pm)

PRESENT Councillors Councillor Rebecca Lanning (in the Chair),
Councillor Oonagh Moulton, Councillor Eleanor Stringer,
Rob Clarke, Mark Creelman, Abi Fafolu, Dr Vasa Gnanapragam,
Martin Miranda, Kalu Obuka, Dr Mohan Sekeram and
Dr Dagmar Zeuner

IN ATTENDANCE Barry Causer (Public Health Commissioning Manager),
Hetty Crist (Senior Communications Officer, Public Health),
Louise Fleming (Democracy Services Manager),
Clarissa Larsen (Health and Wellbeing Board Partnership
Manager) and Farzana Karamat-Mughal (Democratic Services
Officer)

1 APOLOGIES FOR ABSENCE (Agenda Item 1)

An apology for absence was received on behalf of Dave Curtis (Healthwatch Merton).

2 DECLARATION OF PECUNIARY INTEREST (Agenda Item 2)

There were no declarations of interest.

3 MINUTES OF THE PREVIOUS MEETING (Agenda Item 3)

RESOLVED: that the minutes of the meeting held on 3rd November, 2020 were agreed as a correct record.

4 COVID-19 UPDATE (Agenda Item 4)

The Director of Public Health presented an update on COVID-19 in Merton, outlining the latest data on infection, asymptomatic testing and current restrictions in place.

In the ensuing discussion, members raised a number of questions and comments and the Director of Public Health addressed the following points:

- It was explained that the asymptomatic testing was mainly targeted at front line staff and voluntary sector workers exposed to daily contact with other people.
- It was clarified that ten community pharmacies were currently providing asymptomatic testing, and that other local pharmacies had also expressed an interest and were completing training and risk assessments to ensure testing was delivered safely and effectively.

- Members welcomed the comprehensive data provided. It was requested, if possible, that the age groups between 60 and 80 and over 80s were split in order to track the impact of the vaccination programme.
- The need to address vaccine hesitancy was raised; particularly as the groups that were most impacted by COVID-19 were often those that were most hesitant.

Members were asked to continue to promote the main prevention messages on COVID-19. Members were enthusiastic about the testing programme and were keen to provide any help to work with local pharmacies. Information on the portal and how to book a test at a community pharmacy or Morden Assembly Hall was available via the website www.merton.gov.uk.

5 COVID-19 VACCINATIONS (Agenda Item 5)

The Chair Merton and Wandsworth CCG Borough Committee, the CCG Clinical Director (and local GP) and the Locality Executive Director provided an update on COVID-19 vaccinations. Recognition was given to primary care colleagues for their hard work on the rollout of the vaccination programme.

It was advised that current priorities for vaccination was those over 80, residents and staff of care homes and health and social care staff. There were currently two sites across Merton for vaccinations and those in the priority categories were being contacted and invited to an appointment. It was anticipated that the current priority groups would be vaccinated by mid-February. It was recognised that this was a challenging time frame but that primary care colleagues and others were working very hard to achieve this.

Members were asked to promote the key messages to the community and it was explained that people should not attend a vaccination centre unless they have an appointment.

Communication and engagement work had been undertaken to reach out to communities, including faith leaders, to build trust in the vaccination. It was planned to publicise information on vaccinations in range of different languages, including, braille, to ensure that the most vulnerable communities were reached.

In response to members' questions and comments, the following points were highlighted:

- Government had set a target for the vaccination programme to be rolled out to the priority groups by 15th February, 2021. It was acknowledged that it was important to reach out to care homes to help achieve this target and noted that the AstraZeneca vaccine allowed more flexibility in terms of the offer to care homes.
- Following the Community Steering Hub meeting, concerns had been raised around transport and whether there was provision in place for residents who were housebound and could not get to vaccination sites. It was assured that

where this was the case the vaccine would be brought to those who were housebound.

- Prioritisation of those who receive the vaccine was questioned with the suggestion that teachers might be included. The Director of Public Health explained that prioritisation had been made by JVCI (Joint Committee on Vaccination and Immunisation) on the clear basis of reducing mortality.
- Volunteers had been effectively recruited to help as stewards etc. at vaccination centres and gratitude was extended to the people of Merton for their patience and cooperation in helping the rollout of vaccinations run smoothly.

6 COMMUNITY ENGAGEMENT (Agenda Item 6)

The CCG Communications and Engagement Manager and one of the Merton Young Inspector, outlined the partnership engagement programme and ongoing work with the community, including that specifically with children and young people.

Following the presentation, the opportunity for intergenerational work was raised, with children and young people (who might be bilingual) having potential to provide a 'bridge' to their parents and grandparents in understanding the key messages on COVID-19. It was agreed that this was an important point and that a discussion on vaccine hesitancy and how to tackle it could be a subject for the next Subgroup meeting.

The Subgroup concluded by thanking everyone for their work on engagement, in particular, the Young Inspectors for their work with young people.

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MERTON COVID-19 RESILIENCE PROGRAMME

**An Assessment of the Impact of the Corona Virus
Pandemic on BAME Communities in the London
Borough of Merton**

REPORT

TO

**THE HEALTH AND WELL BEING BOARD
LONDON BOROUGH OF MERTON**

Presented by:

BAME VOICE

5th March 2021

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Part 1

1. INTRODUCTION TO BAME VOICE

The Black, Asian, Minority Ethnic Voice (BAME VOICE) was established in 2016 in response to the need for an independent representative body to look at key local issues and their impact on minority ethnic communities who make up over 35% of Merton's population.

BAME VOICE works strategically to increase the influence, representation and active engagement of all minority ethnic organisations and their communities in Merton in the decisions and policies that affect them. Although the charity operates as an umbrella body in particular, it does not see itself as exclusively representing only BAME organisations in Merton and the surrounding areas but also as a resource body for the Merton community as a whole.

There are 10 community organisations that are members of BAME VOICE. These are:

Name of Organisation/ Association	Main community group represented
1.Eaglobal Empowerment	Bangladeshi, Pakistani, African, Caribbean, Arab
2.Pakistan Welfare Organisation	Pakistani
3.South London Tamil Welfare Group	Tamil
4.Ethnic Minority Centre (EMC)	All BAME groups
5.FUSION Multicultural Group	Filipino, Chinese, Indian, African, Caribbean
6.WIFFA	Caribbean
7.AECHO	African, Caribbean
8. Merton Elders Forum	All Asian groups
9. Jimmy Asher Foundation	All BAME communities
10.Power Centre Church Ministries	All BAME groups

2. BACKGROUND TO THE PROGRAMME

2.1 The Covid-19 pandemic has both revealed and amplified some of the deepest inequalities in society. These inequalities reflect pre-existing inequalities in social, economic and health conditions.

2.2 The virus has hit people from all groups but there is clear evidence that it does not affect all population groups equally. The Public Health England review of disparities in the risk and outcomes of COVID-19 shows that there is an association between belonging to some ethnic groups and the likelihood of testing positive and dying with COVID-19.

2.3 Statistics collected over the past year show that those from BAME (Black, Asian and Minority Ethnic) background making up just 14% of the UK population, have been hit hardest. For example, people of Bangladeshi heritage were dying at twice the rate of white Britons, while other black, Asian and minority ethnic groups had between 10% and 50% higher risk of death.

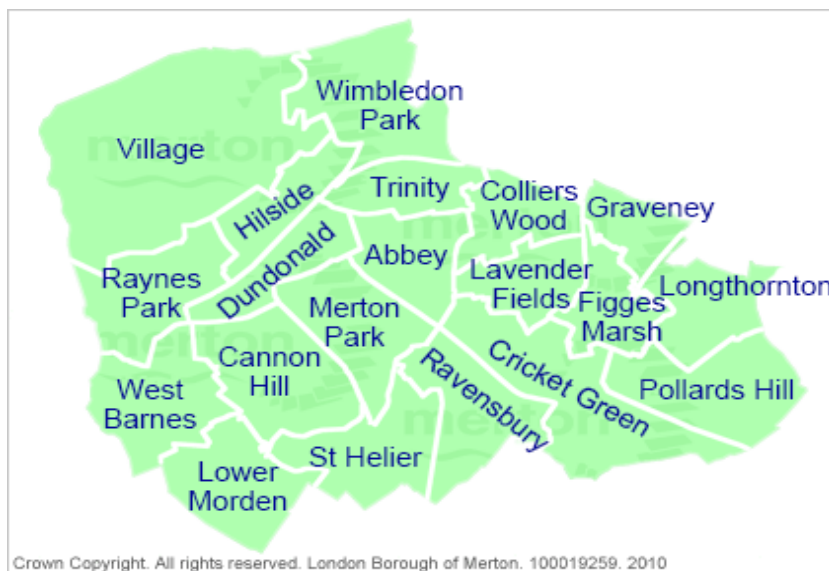
- The risk of COVID-19 related death for males and females of Black ethnicity was 1.9 times more likely than those of White ethnicity.

- Males in the Bangladeshi and Pakistani ethnic groups were 1.8 times more likely to have a COVID-19 related death than White males,
- for females, it was 1.6 times more likely.

ONS, Coronavirus (COVID-19) related deaths by ethnic group, England and Wales: 2 March 2020 to 10 April 2020 (updated 7 May 2020)

<https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronavirusrelateddeathsbyethnicgroupenglandandwales/2march2020to10april2020>

2.4 The London Borough of Merton with 37% of its residents coming from minority ethnic backgrounds, recognised its responsibility to quickly ascertain what impact the virus was having on them, so that mechanisms could be put in place to minimise further risks to their communities, with 60% already living in disadvantaged areas, east of the borough.



Map of the London Borough of Merton showing wards to the East of the borough

2.5 Merton Health and Wellbeing Board (HWB) as part of its aim of understanding the impact of COVID-19 and related issues on health, including mortality and morbidity, and wider impact on the community (including increased isolation and fear or reluctance to seek support from statutory services) in August 2020, commissioned BAME VOICE to:

design and deliver a genuine insight into the lived experience of people across Black, Asian and Minority Ethnic (BAME) communities in the Merton and surrounding area as a result of COVID-19 and related issues.

These insights should focus on:

- the lived experiences of BAME communities generally, not only of the virus's impact on their health
- but, also on the wider existing inequalities particularly east of the Borough where population growth is fastest, and which already has higher levels of deprivation and a more diverse population than in the more affluent parts of the borough.

2.6 The aims of this important work are to:

1. Design and deliver a 'bottom- up" Community Resilience Programme for people of all ages, across Merton's BAME communities.
2. Target the following seven communities as they represent those most affected by COVID-19 - Bangladeshi, Pakistani, East, West, Southern Africa, Caribbean and Sri Lankan/Tamil. The programme, though specifically targeting these 'most affected' communities, does not exclude other Black and Asian communities who are experiencing high numbers of death and hospital admissions caused by COVID-19.
3. Understand the impact that COVID-19 has had and build resilience among the communities in its different forms: physical, mental, financial, environmental and reduce the risks to these communities in terms of infection and health outcomes.
4. Identify any stigma or structural barriers experienced by the communities and help identify practical policy responses or local actions to address specific concerns, including opportunities to support and work with BAME communities on these responses.
5. Be an intervention in its own right, helping support building of trust, signposting to appropriate support programmes and to identify community leaders who could have a wider role in the approach.
6. Provide taster training and support for BAME key workers to tackle workplace bullying, racism and discrimination; to create environments that allow workers to express and address concerns about risk and other issues.
7. Work with key health promotion and disease prevention services and programmes to understand barriers to accessing services, expand the reach of these services and increase the take up of prevention services to assist BAME communities to improve their health and wellbeing thereby improving their resistance to Covid-19 e.g. symptoms, testing, NHST&T, self-isolation and available support e.g. the Community Hub; also healthy weight, flu, physical activity, smoking cessation, mental wellbeing and effective management of chronic conditions including diabetes, hypertension and asthma.

2.7 BAME VOICE committed to deliver *qualitative evidence-based recommendations for policy makers to consider implementing essential resilience and much needed support to these communities to meet vital health, social and economic needs*. BAME VOICE strongly believes that implementation of these recommendations will significantly and favourably impact on the wider Merton borough.

2.7.1 *“BAME VOICE does not propose to reiterate the overwhelming evidence citing systemic racism as the overriding factor in the inequalities which BAME communities come against in every aspect of their lives; this is a well-known and documented fact. What we do feel is a shortcoming in many of these studies, in that, whilst citing the evils of racism and the vulnerability of BAME communities, they often fail to record the resilience, development of new strategies and other coping mechanisms that these communities have had to develop to promote their own wellbeing, and survival.”*

2.7.2

Covid Cases in London Borough of Merton by Specimen Date

Date	New Cases	Cumulative Cases
2021-02-20	1	15525
2021-02-19	23	15524
2021-02-18	33	15501
2021-02-17	27	15468
2021-02-16	32	15441
2021-02-15	29	15409
2021-02-14	34	15380
Total:	179	Previous Seven Days (304)

2.8 The programme was carried out over the period August 2020 to February 2021

- An interim report was delivered in October 2020
- Some 300 BAME community members took part in the programme [see section of this report]
- Key findings and recommendations are highlighted in various parts of this report.

3. EXECUTIVE SUMMARY

3.1 Our discussions and research revealed:

Real anger at not yet experiencing the long identified and promised changes to improving the quality of life of those living east of the borough. Though many acknowledged that much of this could be attributed to central government policies and reduced funding, they felt that some local government decisions had not allowed the changes to move forward.

Hope that real opportunities would be offered to gain back what will have been lost as a result of the corona virus

Hope also that this time, the reality of life for BAME communities, highlighted by the pandemic, will bring about much needed change.

3.2 Whilst acknowledging the existence of racism and condemning it in all its forms, participants in this programme gave their permission for this piece of work to reveal new insights, shake off the dust from existing recommendations and provide decision makers with the tools needed to bring about lasting support to their area. All wanted their anger channelled towards providing a level playing field for all those who live in the borough.

3.3 BAME VOICE INTERIM REPORT 2020:

“There is a lot of strength to build upon, but a number of key factors and key players are missing.” We will provide these in this Report and hope that this time, the cry of the BAME community, heard throughout this pandemic, will be acted on. “We don’t need any more investigations, any more commissions, we know what the issues are: WHAT WE NEED NOW IS ACTION”.

3.4 BAME VOICE passionately believes, however, that “If we are to produce an ethical, true report, we need to recognise that unresolved issues of the past continue to hinder much needed respect and trust on all sides.

- *The Windrush debacle*
- *The Metropolitan Police’s Stop and Search methods*
- *The inequalities within the borough in different areas of life*
- *The continuing high level of serious illnesses among BAME residents*
- *Teenage crime and anti-social behaviour*
- *The local and national Medias’ constant stigmatising of BAME communities and their countries of origin.*

3.5 These cannot be overlooked. 75-80% % of those we spoke to brought up several of these as major issues they felt strongly about. Our findings in these areas will also form part of this work.

3.6 Impact of COVID on the BAME communities in Merton

For many BAME workers, the virus was more of an economic disaster than a health crisis. Government's failure to disclose the seriousness of the virus in its early stages meant that those already living disadvantaged lives had suddenly to prioritise earning a living over safeguarding their health

+ 3.6.1 We found no evidence that deaths and hospital admissions of BAME residents were disproportionate to their numbers within the borough.

+ 3.6.2 The Council's swift action in working with the BAME communities, local businesses, Chamber of Commerce, voluntary organisations, faith and belief groups to provide food and warm clothing outlets, information, advice and support averted any chaos or confusion which could have arisen.

+ 3.6.3 Whilst the communities most affected by the virus were similar to those in other parts of London, numbers were considerably less among the Caribbean and African communities whose numbers were projected to rise quite considerably in 2021.

- 3.6.4 Failure to communicate the seriousness of the virus to BAME communities in appropriate ways e.g. most information sent out were in English, with images people could not identify with, information sent via the internet or on social media, excluding those without the use of these communication tools, meant the communities were unprepared for the enormity of the pandemic when it hit them.

- 3.6.5 What was unanimously agreed by everyone we spoke to, was the universal climate of fear created by the confusion over how to tame this beast which had appeared surreptitiously among them.

- 3.6.6 It would seem, however, that a lesser known or discussed cultural and financial reason could be the driving force behind the high number of infections among some BAME communities. One must not underestimate the cultural pull which providing for those 'back home' has on those who have settled here.

"With any money I earn, I have to think of my family back home. My grandmother who raised me is there. My sisters and brothers are there. They all rely on me. I have to go to work even when I feel ill. No work, no pay. What can I do?"

- 3.6.7 That BAME communities were unaware of the serious nature of the virus brings into question the fact that a significant number of BAME organisations, conduits for important health messages to their communities, had been forced to close due to loss of funding e.g. SLAWO working with domestic violence victims, the Sickle Cell & Thalassaemia Association and ADSAG working with Diabetic sufferers. These particularly vulnerable people did not have the cultural linguistic support they needed during this crisis as the BAME organisation serving them no longer existed.

+ 3.6.8 Concerned with the risk of getting infected, significant numbers of BAME communities, particularly those from the Caribbean, reverted to traditional home remedies e.g., Turmeric, Ginger, Garlic and Vitamin D to strengthen their immune system.

3.7 Some key recommendations

We have included comprehensive recommendations about the way forward in different sections of this report. Whilst recognising that National Government policies and reduced funding have affected local government spending, the following are issues highlighted repeatedly in our interaction with the communities and are, therefore, worth serious reflection by policy and decision- makers:

Health

- 3.7.1 That senior CCG and HWB officials meet on a regular basis with BAME community organisations and communities to examine existing health inequalities East of the borough and the barriers preventing access to services.
- 3.7.2 Locate community health and social services in relatively close proximity to areas identified as where BAME and older people reside. This should help to increase take up of services by these groups.
- 3.7.3 All sections and communities are alerted as soon as a threat is identified, stating the level of the threat and its possible effect on the country/area. Initial information for COVID-19 identified older residents as most vulnerable, creating a false of security among the young.
- 3.7.4 GP surgeries to be placed on high alert to cater for the increased call on their services. Additional funding made immediately for them to provide this extra service. GP's surgeries heavily criticized during this pandemic. Many declared 'not fit for purpose' by more than 50% of the people we spoke to.
- 3.7.5 Pop up health hubs within community spaces to hand out leaflets, provide information and advice. Where infection is an issue, suggest suitably protected staff use amplification equipment to give culturally appropriate health messages and advertise location of help points within the community.
- 3.7.6 Working in partnership with local BAME organisations and communities to fund, develop and implement culturally competent COVID-19 education and prevention campaigns. This is to reinforce benefits of early diagnosis, testing and preparing communities for interventions e.g. contact tracing, antibody testing and vaccination.
- 3.7.7 Cultural Competence (as opposed to Cultural Awareness) courses made mandatory for all medical and social care staff.
- 3.7.8 Introduce regular assertive and confidence building skills workshops for BAME staff from cultures where authority is not normally questioned and poor working conditions are not challenged.

- 3.7.9 Increased psychological support for Council BAME staff e.g. setting up support groups to build up trust, with opportunities for whistleblowing without fear of repercussions. This to be provided in a culturally appropriate manner.**
- 3.7.10 The public to be kept informed about development plans for improvements to East Merton e.g. plans for the former Wilson Hospital to become a community facility, something which offered such hope a few years ago.**
- 3.7.11 Better data collection about ethnicity and religion, including having this recorded on death certificates to accurately monitor the impact on BAME communities.**
- 3.7.12 Increase Social prescribing schemes which have been shown to help reduce barriers in accessing appropriate services, encouraging patients to participate in services and activities which increases their sense of belonging and reduces isolation.**

Education

Whilst recognising that some of these recommended actions are the responsibility of central government, we urge Merton Council to make representations on behalf of its BAME communities in order to eliminate discrimination and bias.

- 3.7.13 Education authorities to ensure that bias is stripped out of the forecasts and decisions for BAME student predicted grades.**
- 3.7.14 The migratory history of BAME communities to Merton to be made available in schools, colleges and libraries with annual events to celebrate the borough's diversity**
- 3.7.15 Put a system in place whereby BAME parents are encouraged to play a more active part in their children's education**
- 3.7.16 Schools to offer culturally appropriate psychological support for BAME children living in difficult home conditions.**
- 3.7.17 Innovative Schemes, working with community organisations which match families who could offer support for each other. This would require the input of professional BAME psychologists and counsellors.**
- 3.7.18. Ban images of starving BAME children on aid donation appeals put up in schools, churches etc which give an unbalanced portrayal of what these countries and their people are really like.**

Employment

- 3.7.19 Council to monitor the redeployment and progression of BAME employees in key roles.**
- 3.7.20 Council to mount Campaigns to bring more businesses and investment to East Merton.**
- 3.7.21 Council to provide Start- up business grants/encourage lowering of rents/leases/Tax relief to BAME and other businesses**
- 3.7.22 As well as investing in communities, Council should also invest in individuals, encouraging BAME Entrepreneurship into East Merton through offering incentives.**
- 3.7.23 Working with the local Chamber of Commerce, Merton Council to encourage established businesses to invest in smaller businesses which may have grown during lockdown**
- 3.7.24 With the Chamber of Commerce, Merton Council to support Annual business activity between East and West of the borough e.g. Business Conferences/ Business Fairs.**

Older and Younger residents

- 3.7.25 Social Services to provide Incentives for young people to become ‘educators’ within their intergenerational homes to older non- English speaking relatives.**
- 3.7.26 Post COVID-19, the establishment of supervised community spaces for older people to socialise, stage, attend events or work together on community projects e.g. community gardening to create a sense of belonging.**
- 3.7.27 The Council/Social Services to support ‘Adopt Grandma/Granddad schemes’ for families, recognising their potential value to the community.**
- 3.7.28 The Council to partner with others in setting up a foundation for sports in East Merton so that young people from these areas can showcase their talents.**
- 3.7.29 Reopen and rejuvenate sports facilities, community centres and Libraries with UK, BAME and other histories/achievements displayed in them.**
- 3.7.30 Children’s services to facilitate a Helpline to support youth people especially those displaying mental health needs; Bereavement and grief-loss of family members and loved ones; Fear of their own death from hearing statistics of large BAME deaths.**

General Recommendations

3.7.31 Action put in place to stop the stigmatising of BAME. Identifying and referring to BAME communities particularly on official documentation as ‘hard to reach’, seldom heard’ ‘disadvantaged’ ‘high risk’ ‘vaccine hesitant ‘does not augur well for good community relations.

3.7.32 That Merton Council spends its reduced central government income more effectively in funding smaller BAME organisations/groups who are more able to bridge the gap between East and West of the borough.

4. METHODOLOGY

4.1 Bottom –Up Approach

BAME VOICE were convinced that if real change is to take place, our research methods had to be determined by those most affected by the issues to be explored- a bottom-up approach. It was vital that the BAME communities themselves led on it, providing qualitative evidence of how they interpreted certain societal conditions, in this case COVID-19, and how government policies were impacting on their real lived experiences.

4.2 Work Collaboratively

What was also vital was the need to work collaboratively with decision makers within the Council, the agencies offering services to communities in the borough, and the wider Merton community.

On this basis, the 6-month programme began in August 2020 and has worked with a representative sample of approximately 300 BAME residents from the Bangladeshi, Pakistani, Tamil, Caribbean and Black African communities [an analysis of this sample is set out in the appendices to this report]. These are the communities identified by Public Health England (PHE) as having been most affected by COVID-19. These participants live mainly in the most deprived wards east of the borough- Abbey, Colliers Wood, Cricket Green, Figges Marsh, Pollards Hill, St Heliers. Other communities such as the Chinese, Indian and Filipino communities were also interviewed. Participants were across all ages, genders, cultures, abilities, religions, sexualities.

4.3 Research using PODS

The methodology used represents an unprecedented approach to community involvement initiatives in Merton. Based on the traditional Afro Caribbean and Asian forms of communication, “one tells another”, groups were formed into PODS to gather the lived experiences relating specifically to COVID-19 and the more general inequalities linked to poor health outcomes.

There were 6 PODs in total with an average of 16 residents in each one. The residents were selected by the facilitator of each pod based on participants meeting the programme's brief e.g. lived in East Merton, came from the seven identified target communities, were front line health and social workers, and had experience of the coronavirus. Each POD was formed from residents within a defined area, meeting outside, or in a large indoor space which initially allowed for social distancing. PODS were mixed e.g. families, friends, neighbours of mixed ethnic origins; youth and older groups, organisations, community leaders/activists, professional front line and other workers in health and social care and other professions.

4.4 Survey/interview Questionnaires

A standard set of questions were designed by the programme development team to determine the impact COVID-19 has had on the five most affected communities, physically, mentally, environmentally. Questions were also asked about specific concerns, measures to prevent a reoccurrence of the negative impact on BAME communities, suggestions for better access to services, other determinants impinging on health and welfare, and possible solutions to the east west inequalities debate.

Standard sets of questions were given to all groups who were encouraged to add their own, as required. The aim of these questions was to establish what challenges the residents face, what help is needed, what barriers prevent access to COVID-19 and other local services.

The project development team also carried out online interviews with BAME health professionals, students, community leaders and service users in the Merton area.

4.5 Training of interviewers

In addition, the delivery team sourced and trained young recruits from these communities to carry out the community interviews. These young recruits will go on to receive further training on how to develop their interviewing skills so they can continue passing on health and other messages to BAME communities in East Merton, signpost people to other sources of information and acting as advocates in breaking down barriers to access.

4.6 Consultation Sessions

- 3 virtual facilitated consultations on Zoom attended by 70 participants
- 2 face to face workshops (safe distance in place) with BAME health professionals, youth leaders, faith leaders, service users, volunteers and students. Topics selected were Assertiveness, Resilience, Leadership as these represent key issues that BAME community members felt needed to be discussed and put on the table
- Key interviews with grass roots leaders, businesses, faith groups, local council leaders to capture case studies

4.7 Other research and data collection methods: Gathering of views and recommendations from non- digital users, door to door (safe distancing), WhatsApp, and telephone interviews.

5 COMMUNITY IMPACT

5.1 COVID-19 appeared at a time when there were already concerns about the high levels of serious illnesses among BAME residents living in East Merton and the implications this might mean for public health. Whether these health determinants were the cause of the major impact the virus has had on BAME communities, is a matter keenly debated by those involved in the health sector. What COVID-19 has undoubtedly highlighted once again are some of the harshest and longstanding inequalities that have remained hidden in our society.

That those most impacted by the virus are from communities with largest numerical population increases, living in areas with the highest infection rates in the borough, will no doubt add to the debate.

In order to understand Black and Asian migration into Merton and its significance to the borough's health outcomes, it is important that this group of people, now given the collective name BAME, are seen not as one homogenous whole but peoples with very different backgrounds and aspirations.

5.2 Migrants from Asia have settled in the UK since the end of the sixteenth century, the most significant wave came following the Second World War with the breakup of the British Empire and the independence of Pakistan, India, Sri Lanka and later Bangladesh. Manual workers, mainly from Pakistan were in the 1950's and 1960's recruited to stem the labour shortage that resulted from World War 2. During the same time, medical staff from the Indian subcontinent were recruited for the newly formed National Health Service (NHS). They were targeted because Britain had established medical schools in the Indian subcontinent which conformed to the British standards of medical training.

Asian migration also took place in the early 1970's following the expulsion of Indian communities (then holders of British passports) from the newly independent Uganda, Kenya and Tanzania. Some of the Asians migrants who settled in Merton were victims of President Idi Amin's purge of foreign influence and control from Uganda in 1972. These had been professional and business people who left behind successful businesses and vast commercial empires but who built up their lives all over again in Britain.

Other Asian migrants, like the Tamils were mainly refugees, fleeing the civil war which engulfed Sri Lanka in 1983. Some, well-educated and literate in English, resulted in the first generation, securing highly professional jobs such as medicine and law after studying at British educational facilities. There were others who came to seek a better life for their families, working in the transport industry or opening up corner shops which have become invaluable to Britain and to Merton's economy.

5.3 The Caribbean story of migration to the UK and to Merton is well documented. The Caribbean contribution to the development of Britain's health, transport, manufacturing industries has been invaluable, yet the struggle for justice for many of those who have worked and lived here continues.

What has become known as the Windrush scandal, in which thousands of workers who have lived in the UK since childhood were denied citizenship has affected many Merton residents and their families.

5.4 The African migratory history is one which spans countless generations, for as Peter Fryer writes in the opening sentence of his Book “Staying Power, “There were Africans in Britain before the English came here”.

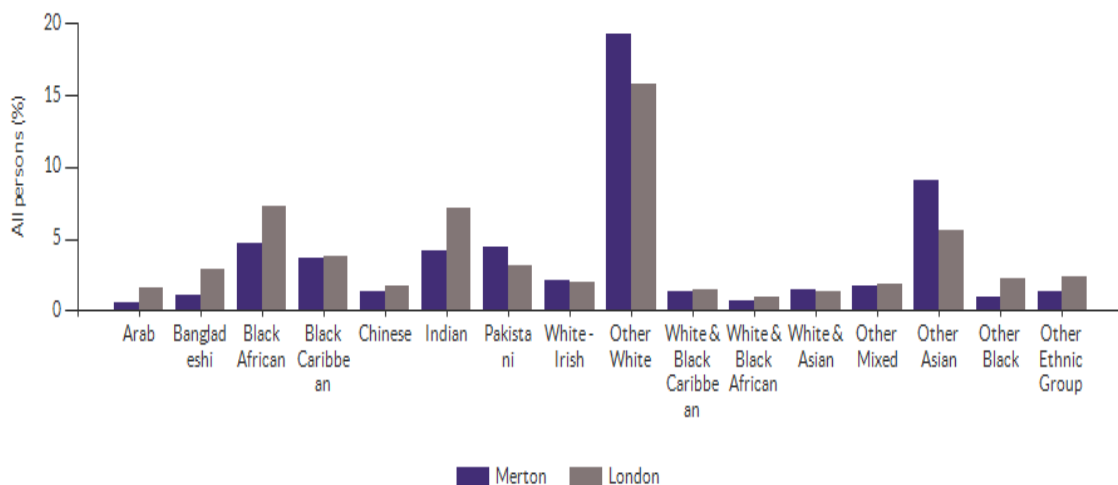
There was very little African settled migration in the UK before the bitter wars of the 1960’s and 1970’s. Most Africans who came to the UK pre and post -World War 2 did so to gain an education (most coming from former colonies) and returning home to build up their newly independent nations.

That many have stayed in recent years to become the fastest growing communities in areas such as Merton, is due largely to the unstable political situation on the African continent.

It would be wrong, therefore, to place all these communities into the same category when seeking an answer to why BAME communities have been so badly affected by the Corona Virus. Not everyone from these communities is at greater risk of becoming hospitalised or of dying.

It was against this backdrop that we began our assessment of the impact the pandemic is having on BAME communities in Merton.

MERTON’S ETHNIC COMPOSITION IN RELATION TO LONDON’S



Date: 2020 Source: GLA

5.5 OUR FINDINGS

5.5.1 The Early stages of COVID-19

The assumption that local authorities with higher proportions of ethnic minority residents are likely to have higher numbers of COVID-19-related deaths has not been validated by Merton borough's statistics nor by our findings over the six months of this research. In general, Merton followed the national trend but there were significant differences in many areas:

- 5.5.1.1 There was no evidence that deaths and hospital admissions of BAME residents were disproportionate to their numbers within the borough.
- 5.5.1.2. The Council's swift action in working with the BAME communities, local businesses, Chamber of Commerce, voluntary organisations, faith and belief groups to provide food and warm clothing outlets, information, advice and support, averted any chaos or confusion which could have arisen.
- 5.5.1.3. Whilst the communities most affected by the virus were similar to those in other parts of London, numbers were considerably less among the Caribbean and African communities whose numbers were projected to rise quite considerably in 2021
- 5.5.1.4. This could be attributed to the fact that many of the Asian casualties were from intergenerational families who told us they had come into contact with the virus at normal family gatherings, whilst single or two to three person occupancy were more common among the Caribbean and African households.
- 5.5.2 What was unanimously agreed by everyone we spoke to, is that very few felt prepared for the enormity of the situation that was emerging. There was a universal climate of fear created by the confusion over how to tame this beast that had appeared surreptitiously among them.
- 5.5.3 That BAME communities were unaware of the serious nature of the virus brings into question the fact that many BAME organisations, conduits for important health messages to their communities, had shut down largely due to inadequate funding. Particularly vulnerable groups in times of crisis, e.g. domestic violence victims, did not have the cultural linguistic support needed as the BAME organisation serving them had ceased to exist.
- 5.5.4 Having learned about the seriousness of the situation, and concerned by the risk of getting infected, large numbers of the BAME communities reverted to traditional home remedies e.g. Turmeric, ginger, garlic and vitamin D to strengthen their immune system. Conspiracy theories were circulated via social media outlets, mainly WhatsApp, as attempts to see their GP became less and less a possibility.

"I wanted my GP to sign a form, was told to leave it at the surgery. Waited two months no response. I asked why I had not heard from them. The GP couldn't be bothered to speak to me so I said I would take the matter up. They treat you differently, the way you speak, the English, It's not our language so they do not bother with you much".

5.5.5 Service users and carers complained about a 'communications break down' during the pandemic

"You feel you are on your own, even those who are supposed to help you seem lost."

"I am a Diabetic patient early sixties. I tried to make an appointment with my GP numerous times. No joy. A few days later a letter came through, asking me to phone for an appointment to take my Flu jab. I also got a call that same day reminding me to call in for a Flu jab. How come I can get a letter and a phone call about a Flu jab and yet not be able to see my doctor about what was really wrong with me?"

"I think this lack of communication makes people not know who to turn to...you are left in a situation where you are going round and round in circles."

5.5.6 The local and national media's relentless reproduction of statistics of deaths or hospital admittance among BAME communities fuelled the anxiety of these communities, as well as the wider community's fear of them as spreaders of the virus.

5.5.7 For many BAME workers, the virus was more of an economic disaster than a health crisis. As many told us, they had to go out to work because they needed the money to survive in spite of them being ill. Government's slowness in disclosing the seriousness of the virus in its early stages meant that those already living disadvantaged lives had suddenly to prioritise earning a living over safeguarding their health.

6. EXPERIENCES OF FRONT-LINE STAFF AND RESIDENTS

6.1 Merton's Medical & Social Care staff from BAME communities

- 6.1.1 Three out of four of the workers we spoke to said they went to work or would consider going to work even when feeling ill or afraid, as no work, no pay.
- 6.1.2 30% felt the stress of dealing with a deadly and unknown sickness had affected their mental health. They needed help to deal with it.

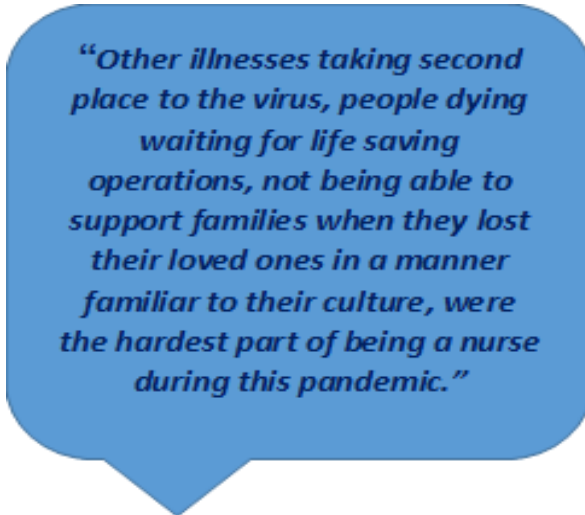
“Concentrating on just surviving sometimes means not caring for myself. I sink into depression, health goes by the wayside”.

- 6.1.3 60% of care home workers not aware of what was happening; their residents got COVID-19.

“Our Management did nothing in the beginning. Later some masks were brought in. You were lucky if you got some, unlucky if you didn't”.

- 6.1.4 Staff isolating put pressure on other staff who had to work overtime in COVID-19 wards or care homes with COVID-19 residents
- 6.1.5 10% key worker stopped going to work, ashamed people would see them as spreading the infection following upsetting remarks heard from the public and the media.
- 6.1.6 20% said they have been subjected to overt forms of oppression, such as disrespectful remarks about their ethnicity or cultural background.
- 6.1.7 20% in hospitals & 30% in care homes felt pressurised into working in COVID-19 wards without the necessary equipment.
- 6.1.8 Others reported covert forms of discrimination such as being ignored during meetings.
- 6.1.9 All felt that risk assessment of all vulnerable front-line workers should have been a priority.

- 6.1.10 “Following reports of COVID-19 bullying and victimisation, our Chief Executive put some plans into action whereby employees were able to report these incidences more freely and action taken immediately to catch the perpetrator.”



6.2 A summary of the lived experiences of some of the BAME residents we spoke to.

6.2.1 60% of residents from BAME communities live in East Merton. We asked them about:

- Their specific concerns about the virus
- How COVID-19 had affected them and their families.
- Their views on and solutions for the inequalities in their area.

6.2.2 Specific Concerns about the pandemic

- Very few local community health facilities are culturally appropriate.
- Level of care being taken for the elderly and vulnerable members of society
- BAME communities not taking the pandemic as seriously as they should, especially younger members.
- Scepticism within certain religious groups
- Misinformation being spread especially to young people
- Children’s education disrupted
- BAME Communities not engaging with messages because of a lack of trust
- Stigma attached to BAME communities purported to be spreaders of the virus
- Not being able to work if I catch the virus
- Fear of hospitals - getting the infection there

- Narrative on BAME communities and COVID-19 misleading, creating mistrust between Government and the communities.
- Reshape of GP practices during pandemic did not meet my needs.
- Passing on the infection to others
- Mental health issues brought on or exacerbated by the lockdowns
- Not trained or capable for the home education of kids
- Media representation of BAME communities and the virus causing alienation of BAME communities
- Being used as scapegoats for any 'experiments' of new tests/ vaccines.

6.3 Impact of COVID-19 on individuals and family.

6.3 .1 Positive Impact

40% said Lockdowns have taught them to appreciate and keep loved ones close, help keep them safe, as the future is not promised to anyone

Significant numbers took online courses, improved themselves academically separate from schoolwork. Zoom not easy, but an opportunity to connect with what the future could be like.

One fifth of young people living in multi- generational households, were able to introduce older family members to the Internet, help them with English, something the older members had not taken up even after many years in the country.

Others had learnt how to cook before going to university, taken driving lessons, got their Licence, appreciated value of saving money, developing spreadsheets to keep track of money spent.

A good number reported they have become more proactive as opposed to reactive pre COVID-19.

6.3.2 Negative Impact

Of the numbers we spoke to, approximately 30% had lost or had jobs suspended having to apply for Universal Credit or being furloughed

“Dad had to apply for universal credit- process took longer than expected, frustration affected his health”

20% had hospital treatment/admissions postponed or cancelled causing stress and family anxiety.

“Mum has a chronic disorder, had to shield. Dad is a key worker. Conflict, does dad go to work or stay home with mum?”

“Husband is self-employed cab driver, business went, we did not know where to go for help”.

6.3.3 Other comments include:

- Physical exercise limitations, gyms closed and outdoor activity curtailed nationally
- “New school rules created mental health issues for my children. My extrovert son was frustrated at having to communicate only with people within his own bubble.”
- “Husband out of work so finances unstable. When I showed symptoms, I had to isolate inside a small room as I did not want to pass on the infection, affected my mental health”.
- “2020 was a struggle. The whole idea of it repeating itself gives me lots of anxiety”
- “How I coped? Had a baby, sense of purpose. Baby, religion and family kept me sane”
- Increase in prices in the nearby local shops put added pressure on finances
- “Did not know where to turn. Did not know what the Council had to offer. I turn to friends and family first. Also, what happens if a problem crops up late Friday evening when Council offices are closed”?

6.4 What was done that was good?

- Financial assistance to employers to help those losing jobs and some of the self employed
- Keeping the public informed at every stage of development of the virus.
- Merton Council Website & CCG’s regular information sharing is excellent
- Hospital workers tested regularly
- The voluntary and community groups coming together offering support to the wider community.
- Setting up ‘Merton Giving’ a collaborative effort for the community by the community.
- Food parcels given out. Better targeting needed though
- British people coming out to support and help each other.
- The Council, CCG & other agencies wanting to learn from the losses suffered by BAME people.

“ It was so good seeing everybody coming together. The Counsellors, Council staff, the MP, the mosques, churches, other faiths, organisations, were all out on the streets giving out food, clothing, advice to those who needed help”.

6.5 What could have been done better?

- The benefits of Vitamin D3 and other supplements to help cope with the virus should have been promoted earlier
- More information and education about how the virus spreads
- More support for the disabled
- More clarity on how and when financial assistance would be given
- Better advertising of facilities available in the borough e.g. support services for married couples experiencing problems and help for domestic violence victims.
- Given consistent and clear instructions so people could adjust and plan better.
- Earlier testing and, more testing sites nearer homes for the vulnerable and elderly.

6.6 Why do you think BAME people were so badly affected by the virus?

6.6.1 For many of the people we spoke to, they initially treated the coronavirus in much the same way as they normally treated the seasonal flu. No indication was given that it would be different or that it would have the catastrophic effect it has had on BAME communities across the UK.

6.6.2 Much has been made about the underlying health conditions of BAME communities, of unsuitable working conditions; of where people live, the type of accommodation they live in, household size, the types of jobs they do and the means of transport they use to get to work. Much has been made of the discrimination they encounter in various areas of their lives.

6.6.3 These facts are true of Merton but to a lesser degree than seen elsewhere.

Our study of the area indicates that the multigenerational living within Asian homes will gradually disappear as older members pass away and the young generation eschew that way of living, moving out when they become economically independent. In recent years, the Caribbean and some African homes with older residents, hold only single or dual occupancy.

6.6.4 It would seem, however, that a lesser known or discussed cultural and financial reason is the driving force behind the high number of infections among some BAME communities. One must not underestimate the cultural pull which providing for those ‘back home’ has on those who have settled here. It resonates in many ways with migrants who brave swelling seas and unsuitable boats, to reach the West, in order to earn enough money to be able to send financial support to those they have left behind in their homelands.

“With any money I earn, I have to think of my family back home. My grandmother who raised me is there. My sisters and brothers are there. I have to go to work even when I feel ill. No work, no pay. They rely on me.

What can I do?”

6.6.5 The information about the seriousness of the virus and failure to communicate them to BAME communities in appropriate ways e.g. in languages which could be read by members of the communities, left them vulnerable. Also, many members of the communities do not have access to the Internet or to social media.

6.6.6 More importantly, local BAME organisations catering for groups with specific needs have shut down e.g. the Somalian women’s groups, the East African domestic violence organisation, the Congolese Youth group, the Sickle Cell charity, all gone. Information, advice and support in these languages and cultures were lost to the borough as these groups moved to other boroughs.

6.6.7 Other cultural factors which may have contributed to BAME casualties are:

- An unwillingness by BAME workers to challenge authority. Feeling less confident to protest against inadequate PPE provisions or poor working conditions led to illness and death.
From a Filipino NHS worker, this explanation: *“There must be something in our culture that prevents us from speaking out or we feel that we just have to follow managers requests, that we cannot say no”.*
- Fake news on social media greatly influenced many BAME people who already had trust issues with health, Council and government officials. This could have prevented them from seeking help when needed.

6.7 Over the years, Health and Social service providers have reported a lack of take up of services by the BAME communities, including recent COVID-19 Testing and Vaccination programmes. Failure to seek medical attention, often when almost too late, is a major concern. What do you think is the reason for this?

6.7.1 A good number of those we spoke to, approximately 30%, said they were happy with the service they received and tried to use local services, turning up for all their appointments. They were surprised that the take up of services was said to be low as there always seemed to be a good number of Black and Asian patients at the hospitals and health clinics they went to.

6.7.2 These are some of the reasons given by others who held different views about the health and social care system:

- “The System doesn’t understand us”
- “Assumptions are made, stereotyping based on a little bit of cultural knowledge without examining our real needs” e.g. Generally known within the Gynaecological field that women from certain parts of West Africa do not indicate they are in pain when giving birth. One woman narrated how she was mocked for screaming and indicating she was in pain. Even though she told them she was not from that part of Africa, they continued to mock her.

This was reflected throughout our sample. Women giving birth reported they felt particularly vulnerable and not understood.

“We are ignored or dismissed”. **“They just don’t listen”.**

- Appreciable numbers felt that too much emphasis was being placed on illnesses affecting older people. They cited Black women, for example who are almost twice as likely to be diagnosed with advanced breast cancer as other women. Black women are five times more likely to die in childbirth. More work needs to be done on other illnesses affecting the BAME communities.
- Gender and language also play a part. A significant number said they felt vulnerable and struggled to articulate and advocate for themselves to their GP or a consultant.
- Trust is absolutely crucial in a doctor-patient relationship. Patients feeling “not heard or understood” may go outside their local area, as did some young residents we spoke to. They were tired of the difficulties of getting an appointment and had fraught relationships with their local medical practice.
- Many felt that if their GP’s failed to listen to them, they in turn, would fail to open up or use the services they recommend, thinking they would be treated the same way when they got there.

6.8 It's been said that the Coronavirus pandemic has brought out the best and the worst in people especially when it comes to ethnicity, culture and religion. Have you encountered any stigma or barriers during the pandemic?

- "I notice a number of people avoid me now when I am out in the streets or in the shops or they kind of move aside when I approach them". Other Asian family and friends say the same happens to them.
- "At the start when the statistics about BAME deaths and infection were all over the media, when I went to work, my colleagues kind of acted in a funny way, as if they wished I wasn't there", as if I was somehow a threat to their health."
- "My Chinese friend and I got chased in Morden. It was when the media said the virus came from China. He got verbally abused as well and he was really shaken up".

"When I am out with my white friends, we tend not to get the same reaction whilst with my black friends we are met with the stereotypical belief that black girls are loud; sometimes we do fit the stereotype but these stigmas affect us, so some girls act it out: "If this is what they think of us then let's behave like that". It's the mindset that other people have. It makes you feel you are not part of society. Even if you are there, you just happen to be there not because you belong there".

6.9 In terms of the existing inequalities East of the borough, thought to be having a negative effect on the health of BAME people living there, how would you address the disparity between East and West of the borough? Below are a sample of the views of mainly young residents who felt COVID-19's exposure of the existing inequalities had highlighted how little their area had to offer them.

The view of a 26 year old Merton resident: *"I think COVID-19 will bring wider inequalities. Let's look at the environment in the west of the borough. Pre COVID-19, I used to drive through there every day. What do you see? Lovely clean parks in Wimbledon, street lights work, clean recreational spaces, well-kept shops and amenities. You can see attempts are made to keep the area clean and lovely and inviting. What do we have that is comparable in the East? Lots of opportunities but nothing is followed through. Too many roadwork, no public amenities, no sense of community, no sense of someone looking out for you. Nowhere to release the tension we encounter each day".*

“People who feel their area is not nice will not be motivated to do anything about it. They develop a certain mind set. They will think; ‘why bother’ as the rubbish pile up on the streets. If the Council/Government won’t bother, if my neighbour won’t bother, why should I bother?” So, they dump their rubbish and the foxes and dogs spread filth all over the streets.”

“I went to school in East Merton, from a Muslim Asian background. No attempt was made to push us forward, particularly the BAME children. You were discouraged from even thinking you could move forward. Sometimes, in our school, it was like the wild, wild west. When you are at a school where no action is taken, the mind set becomes normalised. Then I went to college further into Surrey. Clear difference in expectations between the two areas. There you hit the ground running. I wouldn’t dare throw rubbish in the corridors. We were taught to exist in the real world. It all starts with the school”.

PART 2

In Part 2 we look at practical responses and local actions to be taken to improve Health and wellbeing in East Merton.

7. PRACTICAL RESPONSES TO WHAT HAS BEEN SAID

7.1 Various findings suggest that the poorer socio-economic position of some BAME groups is one of the main factors driving ethnic health inequalities. (PHE, Merton Council Community Plan, Runnymede Trust) Accessibility to and provision of vital services are, therefore, essential for their survival. There are, however, certain issues, mainly historic, which we believe need to be settled before issues of health and wellbeing can be properly addressed.

7.2 There is the important aspect of rebuilding relationships between those who provide services and those who are expected to access them. That relationship needs to be built on mutual respect and a genuine understanding of each other's needs and responsibilities.

7.3 Pejorative descriptions like "Hard to reach", "seldom listened to groups", "disadvantaged communities" "vaccine hesitant", which roll off the tongues of 'headline grabbers' but deeply hurtful to those on the receiving end, are alienating, marginalising and degrading.

7.4 The wider issue of the suitability of the title BAME to describe diverse communities and disparate needs, calls for a national debate and is outside the remit of this piece of work. However, it is important to state that many BAME people feel that the collective category, BAME, does not reflect how people recognise themselves and their self-identity. For instance, 'African' does not capture the ethnic and religious differences of people who originate from the continent (Aspinall, 2011). Similarly, some people of Chinese origin reject 'Asian' as not representative of their identity.

7.5 A second reason why BAME is rejected is because it is positioned as a marker of difference from the majority white population, with the latter treated more favourably. Some believe, therefore, that BAME is seen as a marker of 'race', an old - fashioned concept which suggests that there are genetic differences between people, determined by their skin colour.

7.6 So, there needs to be a clear understanding of who the constituent members are especially when it comes to allocating funding for work with these communities.

7.7 We recommend that:

- **New forms are found of identifying and referring to BAME communities particularly in the media and on official documentation.**
- **The name BAME is reviewed locally here in Merton in advance of any national decision on the matter.**

8. HOW TO REDUCE THESE RISKS?

8.1 There is unequivocal anecdotal and scientific evidence that the conditions under which many BAME communities live put them at increased risk of complications from infectious diseases. The Merton experience of COVID-19 mirror these longstanding inequalities in health, driven by social and economic conditions.

8.2 In response to our findings regarding the Merton handling of the pandemic, we would **recommend** the following:

8.2.1 ALL sections and communities are alerted as soon as a threat is identified, stating the level of the threat and its possible effect on the country/area. Initial information for COVID-19, identified older residents as most vulnerable, creating a false sense of security among the young.

8.2.2 Provision of additional advice and support in appropriate cultural forms; target groups through written **and** verbal translation. e.g. Somali only became a written language in 1976, leaving many older Somalis in Britain unable to read the communications. Ensure advice and messages have been received and understood.

8.2.3 Encourage the setting up and financing of new, forward thinking BAME organisations catering for groups with specific needs and providing Information, advice and support in workable, culturally appropriate ways yet sensitive to and accepting of the culture they now need to embrace.

8.2.4 Building sincere and genuine relationships with leaders of religious institutions e.g. mosques, temples, churches not just in emergency situations or for quick access to their congregation and families, but as regular outlets for health and well- being messages.

8.2.5 Action put in place to stop the stigmatising of BAME communities, making them 'the problem' rather than the circumstances under which they exist and using the strengths within these communities to build local networks of support for improving conditions in their areas.

8.2.6 GP surgeries to be placed on high alert in emergency situations to cater for the increased call on their services. Additional funding made immediately for them to provide this extra service. GP's surgeries heavily criticized during this pandemic.

8.2.7 Pop up health hubs within community spaces to hand out leaflets, provide information and advice. Where infection is an issue, suggest suitably protected staff use amplification equipment to give culturally appropriate health messages and advertise location of help points within the community.

8.2.8 Recognition given of the additional needs of BAME communities by providing available opportunities/outlets for their children while they work e.g. affordable creche/nursery places.

8.2.9 Introduction of regular assertive and confidence building workshops for BAME staff from cultures where authority is not normally questioned, and poor working conditions are not challenged.

8.2.10 Measures are put in place to counter the influence fake news has had on significant numbers of BAME people during this pandemic e.g. use the same media outlets to provide robust challenges to these negative posts.

8.3 What can be done to make BAME people feel they belong in the UK and are a part of the communities in which they live?

8.3.1 It was generally felt that with the older generation giving way to a second and third generation, many of the issues BAME communities now face will cease to exist. The barriers of language, some traditional and cultural practices which have prevented full participation in community health and wellbeing programmes, will no longer be an issue.

8.3.2 However, many felt that the inequalities which exist for BAME communities are current. Staff working in health settings need to be protected from harassment and being put under pressure to work in unsafe conditions. BAME communities may be less willing to trust agencies/government communications due to historical issues and contemporary experiences of stereotyping and discrimination. It is important, however, that this transition is managed well so that past errors are not repeated.

8.3.3 The current COVID-19 pandemic and the hardship it has brought to many, has offered an opportunity to rectify the mistakes of the past and create new opportunities for the future.

An African saying: “Until the lions tell their stories, tales of the hunt will always glorify the hunter”.

This transition needs to be handled with care and sensitivity. It is to tell the story with integrity and truth.

8.4 We recommend the following:

- 8.4.1 The Council recommends to Central Government that Black and Asian history is taught in all schools and institutions of higher learning
- 8.4.2 Unequivocal official support and funding is given to BAME run organisations to promote a narrative which celebrates all cultures and identities, but allows those who have been victims of repression and suppression to tell their stories from their own perspective.
- 8.4.3 Support is given to those organisations who use part-time staff, with the majority of their funding spent on activities for the young people and their communities rather than on administration and management costs.
- 8.4.4 Better data collection about ethnicity and religion, including having this recorded on death certificates to accurately monitor the impact on BAME communities.

- 8.4.5 Learn where people spend their spare time and meet them where they are. Examples might be Saturday schools for black youth to learn about black history, or Hindu temples where entire communities spend big parts of their day, barbershops are community hubs for black males.
- 8.4.6 Encourage the growth of newsletters, as they are often not visible on the surface but go a long way in reaching those not on social media.

8.5 The relationship between certain BAME patients, their GP's and health authorities has come under scrutiny during this pandemic. Trust seems to have been lost in some cases. How can that trust be regained?

8.5.0 We recommend the following:

- 8.5.1 Community meetings held between senior CCG and HWB officials and BAME communities to examine existing health inequalities East of the borough and the barriers preventing access to services.
- 8.5.2 More local community health services situated in close proximity to areas where BAME residents live.
- 8.5.3 Increase social prescribing schemes which have been shown to help reduce barriers in accessing appropriate services, encouraging patients to participate in services and activities which increase a sense of belonging and reduces isolation.
- 8.5.4 Cultural Competence (as opposed to cultural awareness) courses made mandatory for all medical and social care staff.
- 8.5.5 Council communication networks primed to meet people where they are. You go to them, not them come to you.
- 8.5.6 More prevention work carried out in illnesses affecting younger BAME residents e.g. breast/cervical cancer, mental illness.

PART 3

Determinants of Health - Education, Employment

Incorporating the views of young and older members of Merton's BAME communities

&

Recommendations

9. DETERMINANTS OF HEALTH - EDUCATION, EMPLOYMENT

9.1 EDUCATION

9.1.1 Prior to COVID-19, many BAME Merton parents had indicated that the education their children were receiving did not give them the tools they needed to become confident, resilient adults with the same opportunities as others with whom they were travelling. There has been a growth of educational establishments in East Merton over the past few years catering for black children e.g. Accoutre Centre for Learning 2020, Blessed Teaching and Examination Centre. Also, discussions at Black History Month events.

9.1.2 The proliferation of Saturday schools, private tuition classes and now Lockdown tuition, is an attempt by parents to correct that anomaly, but it comes at a price, a price most parents can hardly afford but are willing to make so that their children are given a comprehensive representation of their history and heritage.

9.1.3 Confusion over identity, ethnicity and race have been seen by all as catalysts for some of the radicalisation, anti-social and criminal behaviour by some BAME groups, and the cause of mental health issues among significant numbers of young people.

70% of the young people we spoke to felt confused over their identity. They wanted readily available resources with which they could relate and identify.

“My history was hidden from me at school. There was nothing taught to me that made me proud to be a young black girl growing up in the UK.”

9.1.4 In recognising that education is one of the determinants of health and wellbeing, it is in the interest of the education authorities to ensure that children and young people living in deprived areas have the same opportunities as those in more affluent areas.

9.1.5 The question is often asked, *‘How can it be right that someone’s life chances are so profoundly affected by where they live or how much money they have?’* How can it be right that Black young men make up 40% of the youth prison’s population. Young men the school system failed.

9.1.6 In recent years, there has been a change in the way in which children are graded. Predicted grades at GCSE and A-Level are usually thought to be under-predicted for BAME pupils yet BAME pupils annually out-perform what their teachers and schools predicted their grades would be year on year.

9.1.7 COVID-19 with its changing rules and regulations, has created a climate of uncertainty in all aspects of life but its effect on the educational sector has been catastrophic. Those affected are at their most vulnerable, at a time when they are developing into adults with all the confusion that entails. Added to that is the baggage of disadvantage carried throughout life.

9.1.8 Parents we talked to are concerned that decisions are being planned and taken now so urgent action is needed on this.

9.2 RECOMMENDATIONS

9.2.0 Short term action

Parents we spoke to were aware that Education policy is set nationally by the Department for Education and that their call to action is outside the scope of the Council. They do feel, however, that strong representations should be made to central government expressing their concerns.

- 9.2.1 Education authorities to ensure that bias is stripped out of the forecasts and decisions for BAME student predicted grades.
- 9.2.2 Change the way young people become inspired, not just by going to university. Open up outlets, a safe place where they can go to for advice and development, not just job centres.
- 9.2.3 Teaching of the British colonial past and its influence on the Asian sub-Continent. Africa and the Caribbean to form part of the national curriculum in all schools and taught from a very early age. These histories to be taught from different perspectives allowing for both the colonisers and the colonised points of view to be examined.
- 9.2.4 Books, other written and oral material used in institutions of learning should reflect diversity.
- 9.2.5 Make Cultural Competence courses as well as Unconscious Bias courses mandatory for those in the teaching world working with BAME children and communities.
- 9.2.6 Schools to celebrate/observe all Feast days/ national days/ events like Feast of St David, Diwali, the Eid, Black History Month, the Holocaust and others.
- 9.2.7 Put a system in place whereby BAME parents are encouraged to play a more active part in their children's education.
- 9.2.8 Ban images of starving BAME children on aid donation appeals put up in schools, churches etc which give an unbalanced portrayal of what these countries and their people are really like.

9.3 Medium term action

- 9.3.1 More BAME head teachers and senior teachers appointed to high achieving schools as well as to poor achieving ones. In both cases, they are to be role models in their respective domains.

- 9.3.2 Schools to maintain healthy relationships and work with local cultural and religious organisations/groups to deliver empowering and life enhancing messages to children.
- 9.3.3 Schools to offer culturally appropriate psychological support for BAME children living in difficult home conditions.

9.4 Long term action

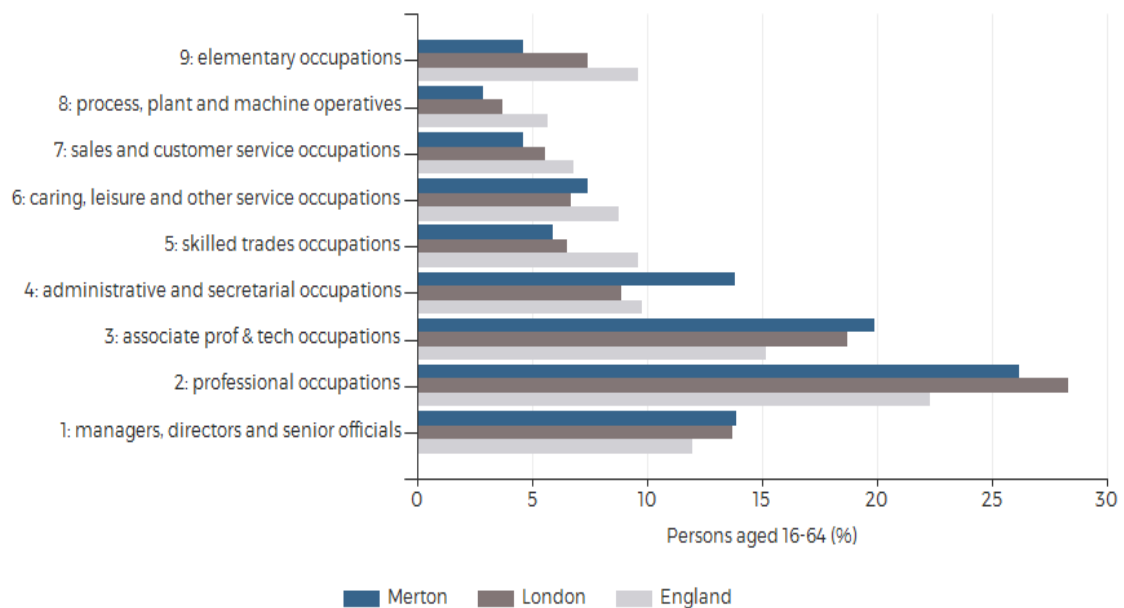
Innovative Schemes, working with community organisations which match families who could offer support for each other. This would require the input of professional BAME psychologists and counsellors.

9.4.1 Innovative Schemes, working with community organisations which match families who could offer support for each other. This would require the input of professional BAME psychologists and counsellors.

Tim is of mixed ethnic heritage. Over the past year, he has started being very angry. When his behaviour became so disruptive and it was no longer possible to have him in class, one of the teachers, a trained psychologist, took him aside and started having some informal sessions with him. When he finally opened up, she found out that his parents had broken up and his mother now had a new boyfriend. Tim had to go out every time the boyfriend visited. Everyone important in that child's life had abandoned him.

9.5 EMPLOYMENT

Occupation, major group of employment in Merton



9.5.1 The employment impact for BAME communities in Merton is mainly due to a lack of vacancies, business and training opportunities locally.

9.5.2 The Sites and Policies Plan employment policies (DM E1-DM E4) seek to encourage employment and business opportunities in town centres, local centres, designated employment sites and scattered employment sites across the borough with adequate access to public transport services.

9.5.3 Whilst there is some evidence that a few businesses did start up in Mitcham pre COVID-19, the heart of Mitcham has remained an unattractive and uninviting centre, dominated by traffic and intermittent road works. Since COVID-19, the area has a deserted feel to it, punctuated only by bursts of shoppers stocking up until the next lockdown.

9.5.4 A recent national survey on the impact of COVID-19 by Runnymede Trust (Haque, Bécares and Treloar, 2020) showed that pre-existing socioeconomic inequalities have not only been amplified by the coronavirus crisis: they have been made worse.

9.5.5 The survey revealed that some ethnic minority groups – such as Bangladeshi and Black African groups – have experienced significant income loss during the coronavirus crisis, and nearly two-thirds of members of ethnic minority groups have struggled with paying bills and paying for essentials during lockdown. Ethnic minority groups have also been less likely to receive any form of sick pay if ill with the coronavirus, even though they have had to self-isolate.

9.5.6 We found this to be largely true of Merton. Those suffering most were the Bangladeshi and Tamil cab drivers who were also among those most ill with the virus.

9.5.7 The African shop and stall holders as well as those managing home care staff suffered serious financial losses. Some did not feel they could recover.

9.5.8 “As an employer of frontline staff there was so much difficulty, the way we work and do things. On the family level uncertainty as children cannot go to school. You cannot plan due to the Corona Virus. The business is hard. People are not spending, no one is coming out, business are not moving as it should be. We thought that they will give better support to BAME businesses but they had a cap of £10,000 limit which when you look at it, cannot do anything for a small business. And you keep paying your rent without receiving any income. The impact is hard and we don't know how we can recover. Shops have closed in Mitcham town centre. Another BAME business also complained of poor sales, reduction of staff and raising costs and worries about how to continue operations. 14 small businesses in the borough complained about the Council's denial of payment of the government discretionary grant and this has had an impact on them and their families worsening their experience during the Corona Virus pandemic.”

9.5.9 We asked the businesses what they would like to see done to help them get back on their feet and what they felt about the disparity between East Merton and West of the Borough.

9.7 RECOMMENDATIONS

9.7.0 Short term action

- 9.7.1 Immediate action would be for the Council to ensure that everyone is aware of the Covid-19 healthcare treatments available in various parts of East Merton.
- 9.7.2 Stopping immigration checks driving people underground, people who might be infected with the virus.
- 9.7.3 Capture and publish ethnicity data showing the effect COVID-19 has had on BAME employment, businesses and communities.
- 9.7.4 Council to mount Campaigns to bring more businesses to East Merton.
- 9.7.5 Council to offer Start- up business grants/Lowering of rents/leases/Tax relief
- 9.7.6 Council to encourage investment into Mitcham.
- 9.7.7 With Chamber of Commerce support Small businesses/Enterprise Training
- 9.7.8 Council to lobby government to increase Statutory Sick Pay. Extend it to those who are not currently eligible because of low pay and zero- hour contracts and to cover those self- isolating.
- 9.7.9 In view of the inequalities, again highlighted by COVID-19, local government employers plan to build a diverse workforce to include BAME employees should be transparent and publicly available
- 9.7.10 Council to support the development of online resources for employers on how to support and protect BAME staff and how to implement guidance and information equitably.
- 9.7.11 Local government employers to provide wellbeing psychological support for their BAME staff.
- 9.7.12 That local government institutions document and publish their ethnicity data with details of who has moved back into full-time or part-time employment, and who is made redundant and who progresses to Universal Credit.

9.8 Medium term action

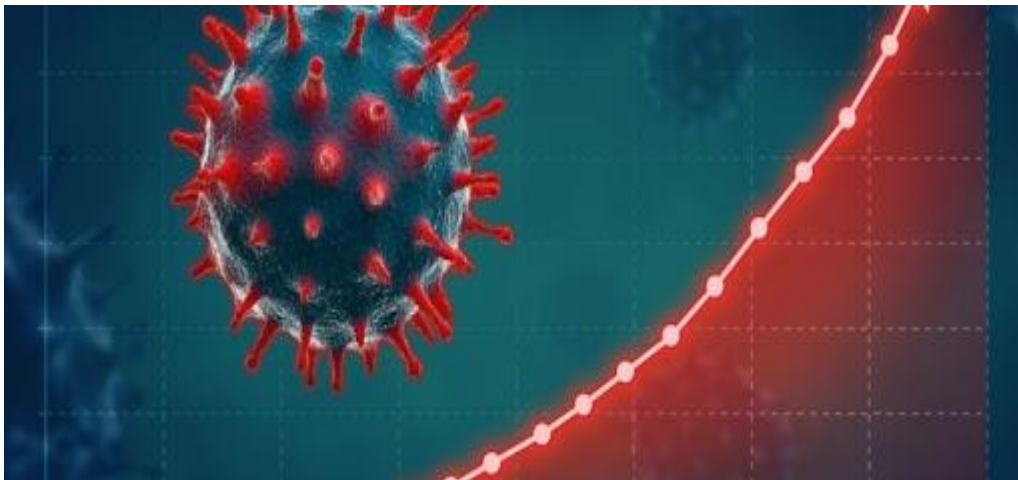
- 9.8.1 As well as investing in communities, there must be a willingness to invest in individuals.
- 9.8.2 Council to encourage Entrepreneurship into East Merton. Support young budding BAME entrepreneurs to set up in East Merton through offering incentives.

- 9.8.3 Chamber of Commerce to encourage established business to invest in smaller business which may have grown during lockdown
- 9.8.4 Measures put in place which ensure that the inequalities between East and West are being minimized

9.9 Long term action

- 9.9.1 Initiate Annual business activity between East and West of the borough (Business Conference/ Business Fair)
- 9.9.2 Encourage the idea of planting new businesses from already successful ones, to give them a boost in establishing themselves
- 9.9.3 That the inequalities in the job market, business field and elsewhere are greatly minimized through equality Impact assessments
- 9.9.4 Monitor the redeployment and progression of BAME employees in key roles.

9.10 OLDER PEOPLE - Their views and their needs



9.10.1 12% of Merton's population are people 65 years and above.

9.10.2 East Merton, where 60% of BAME communities live has some of the highest densities of older people compared to Merton as a whole, particularly in the ward of Graveney but also in Colliers Wood and Figge's Marsh.

Proportion of BAME Residents Aged 65 & Over in Merton, 2004, 2014 and 2020.



9.10.3 Several studies on ageing among BAME communities have shown that in recent years, levels of loneliness and isolation have grown among the over 70's as children, adopting a more Western style of living move away from the traditional intergenerational home. Most affected communities are the Pakistani, Chinese, Caribbean, African and Bangladeshi.

9.10.4 Important for health personnel to work with local leaders when approaching BAME people they wish to help in crisis situations. Although well intentioned, actions can sometimes have the opposite effect of an envisaged outcome.

"It's more the psychological effect the lockdown is having on me and my wife. Some people brought food to the door but we did not need it. We order online. Why did they think we were poor because we are black. I felt ashamed although they meant well.

We would have appreciated a friendly voice at the door assuring us that we would be all right. We were very afraid that we might die without anyone knowing. We have no children."

9.10.5 The pandemic has highlighted the need for services to connect those experiencing isolation with other people from a variety of backgrounds, leading to improved mental health, mobility and independence. These have had to be done by phone, WhatsApp and for those adventurous enough, virtually - a skill which is being learnt by larger numbers of older BAME people as they see the benefits of this new form of communication.

9.10.6 The virtual world has also been of great value to the Afro Caribbean older generation who have relocated to their homelands. Their relocation has created a vacuum in the support structure of the African and Caribbean families which needs to be filled.

9.11 RECOMMENDATIONS

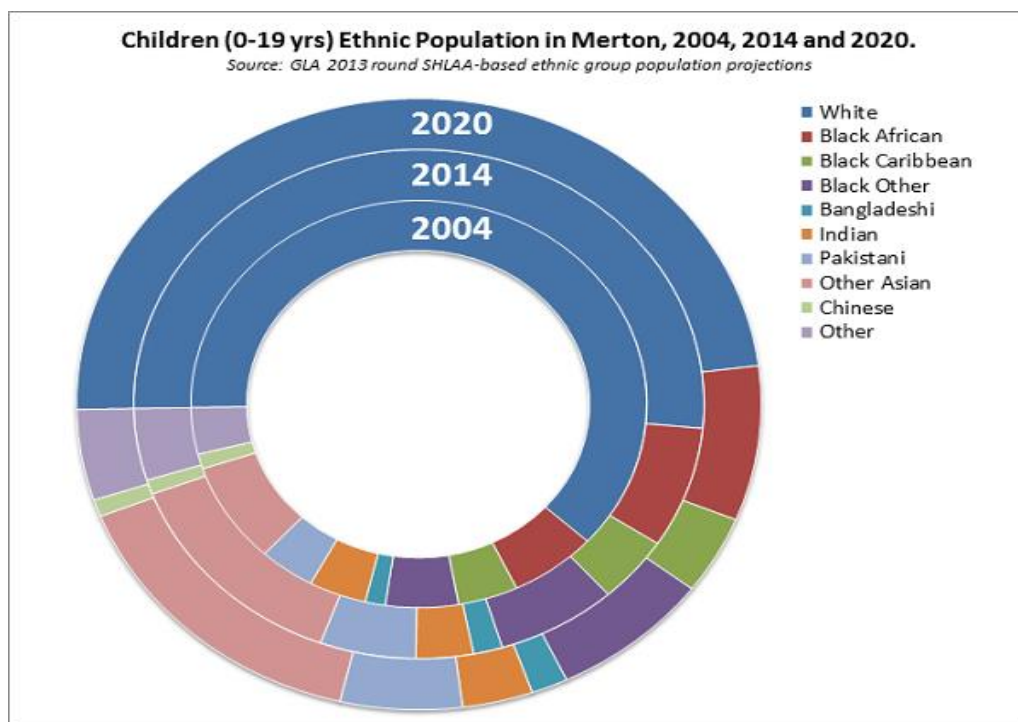
9.11.1 Post COVID-19, the establishment of supervised community spaces for older people to socialise, stage or attend events or work together on community projects, e.g. community gardening to create a sense of belonging

9.11.2 The Council/Social Services to support 'Adopt Grandma/Granddad schemes' for families, recognising their potential value to the community.

9.11.3 Social services to build on this by providing incentives to these young people to continue helping the older generation learn English and become more integrated into their communities.

9.11.4 Provide support that incorporates cultural and traditional practices e.g. carers who go into clients homes are to be trained in the cultural practices of those clients unless not required to do so by them e.g. removing shoes at the door, not calling them by their first name if older.

9.12 YOUNGER PEOPLE



9.12.1 A significant feature of Merton's population in 2021 is the changing age profile of the borough's residents. The number of children and young people aged 0-19 is 25% of the total population and is forecast to increase by 4.4%

- 25% of Merton's population is 0-19 years
- 13% come from low- income families

9.12.2 BAME children in the borough are achieving a good level of development higher than in England. 60% of young people we spoke to from across all BAME communities, were at school, at university or waiting to enter some form of learning or work.

9.12.3 Their main concern was the effect COVID-19 is having on their education and on their social interaction with friends and relations. They felt alienated from their friends with whom they go to school, west of the borough. As there were no leisure facilities in the east to match those in the west, this made it difficult for them to enjoy the same lifestyle as their friends or to feel proud of the area in which they live.

9.12.4 They felt that the lack of social contact outside of school was creating barriers which would not exist had proper relationships been formed through shared interests.

9.12.5 Others spoke of the way COVID-19 had made them aware of the difficulties caused by their parents losing their jobs and being ill with the virus.

9.12.6 Having to survive on handouts from food banks, with more time on their hands during lockdown, opened up a dialogue not experienced before. It brought them closer together and strengthened their resolve to do well.

9.12.7 Having witnessed the negative effect the virus was having on the BAME communities, and the resilience built by members, they felt proud of their heritage, more willing to take ownership of it.

“If learning about the empire had been compulsory, people would have had a greater understanding of modern Britain. “Whether we’re here for 60 years or just got here, there’s a sense that we don’t belong. Things like the Windrush scandal wouldn’t have been so easy to do if people understood what the Windrush was and its significance to the UK”.

“ There are just not enough visible BAME role models in society. Or if they are, they sell out because they want to get into a top job or they feel superior to those they have left behind. They forget where they came from. If only a few of them would look back, things might be different”.

9.12.8 On the question of what could be done to bridge the gap between east and west, a significant number said they no longer trusted Government or the Council to make things better. They felt betrayed that most of their youth clubs had been closed (only two remained but these were in areas known to have anti-social problems) no leisure facilities existed and felt there was nothing they could identify with in East Merton.

9.13 RECOMMENDATIONS

- 9.13.1 The Council should partner with others in setting up a foundation for sports so that young people can showcase their talents.
- 9.13.2 The migratory history of BAME communities to Merton to be made available in schools, colleges and libraries with annual events to celebrate the borough's diversity
- 9.13.3 Reopen and rejuvenate sports facilities, community centres and Libraries with UK, BAME and other histories/achievements displayed in them
- 9.13.4 Social services to provide Incentives for young people to become 'educators' within their intergenerational homes for older non English- speaking relatives
- 9.13.5 Children's services to facilitate a Helpline to support youth people especially those displaying mental health needs. Bereavement and grief-loss of family members and loved ones. Fear of their own death from hearing statistics of large BAME deaths.
- 9.13.6 Schools to form community support groups for young people to access information and advice.
- 9.13.7 Meanwhile, local Government to create services online and make videos to reduce loneliness and isolation.

PART 4

MERTON'S BAME COMMUNITIES - BUILDING RESILIENCE

10. MERTON'S BAME COMMUNITIES - BUILDING RESILIENCE

10.1 There is no doubt that people from BAME backgrounds are dealing with multiple inequalities, which leave them particularly exposed to serious disease and virus's like COVID-19

10.2 The Covid-19 pandemic has not just revealed some of the inequalities existing within Merton's wards east of the borough, it has also exposed a failure to protect and keep afloat, BAME organisations which knew and understood the needs of their communities. Some of these organisations are among the missing key players we spoke about in our Interim Report.

10.3 Working with many voluntary and community organisations pan London, we know that these organisations often find themselves at the sharp end of the many challenges which society faces. The absence of these organisations at a time when their communities are the most impacted by COVID-19 gives rise to a number of key questions:

- 10.4 How long should it take for migrant communities to become fully integrated in the UK?
- 10.5 How do they build resilience when the building blocks are removed from under them, and in situations like coronavirus, there is the combination of greater exposure and greater vulnerability leading to increased risk?

10.6 Built into BAME VOICE's work, were strategies to help build up resilience within the BAME communities in anticipation of a second wave of COVID-19 and other threats which could potentially claim the lives and livelihoods of an already disadvantaged community.

10.7 The second wave of COVID arrived and BAME communities were once again said to be worst hit by the virus with further deaths and admissions into hospitals. For communities said to have been so badly hit, we found that there is still a lot of strength to build on. But there was a lot of hurt and anger at the many years of promises made which had not been kept resulting in such serious outcomes exposed by COVID-19.

10.8 These are communities who have found strategies to cope but now need the official muscle, action, understanding and support to secure a better quality of life, an equal playing field so that they can become a valued part of their respective wider communities, with a sense of having arrived and belonging.

10.9 Belonging carries with it a set of responsibilities. The BAME communities have to look inwards to take control of the valuable assets lost over the years; the divisions within itself, the breakdown of the family unit, the anti – social, gun and knife crime by some of its members, failure to defend and promote their rich cultural heritage, inability to challenge in meaningful ways the discrimination and prejudice they encounter.

10.10 We recorded the thoughts and views of parents, children and the communities:

“Many of our kids are confused. There is the issue of nationality and ethnicity. You are one thing when you do well and another when things go wrong.”

“What needs to be done to help our kids gain their identity? It has to start with education surely”.

“Black history will give them the belief that they can be better. History can be fundamental”.

“Bring the village back - role of aunties, uncles reinstated, we need to form communities of support, learn from each other and move on “.

“Parents, be parents, it’s your job, not the state’s. Take back control of your children’s lives. Listen to your kids and support them”.

“Feed your kids well, teach them well, have a secure home for them”.

“The Kids from all ethnicities are asking questions. They will bring about the change”

This introspection and action need to work side by side with any proposals made to put right the wrongs of the past. Trust has to be built again.

RECOMMENDATIONS

- 10.11 Working with local agencies, community and faith organisations, we propose the following actions by the Council, for a trial period of two years:
- 10.11.1 Start- up grants for small organisations/groups to be run by part time staff and volunteers speaking the language of that particular community, as well as fluent English.
- 10.11.2 Parenting, English, Health & Wellbeing, environmental, law & order courses run for parents and open to all members of the BAME communities.
- 10.11.3 Heritage courses run for young people by BAME heritage organisations.
- 10.11.4 A designated officer from Social Services to become the liaison with each BAME organisation, preferably with a good knowledge of the community with which they will be working.
- 10.11.5 All Social services, health, educational and other Council staff members working with BAME communities to attend Cultural Competency, Unconscious Bias training courses run by BAME trainers/facilitators.
- 10.11.6 Each community organisation to hold an annual event celebrating their heritage inviting the wider community to attend and participate in the activities.

PART 5

THE WAY FORWARD

CONCLUSION

11. THE WAY FORWARD

11.1 Throughout this pandemic, the reporting and presentation of statistics to the public have further disadvantaged BAME communities. Statistics, some later proven to be incorrect, have helped to reinforce prejudices and in some cases placed members of BAME communities' lives in danger. Cab and delivery drivers, healthcare workers, have reported increased insults and attacks as media and other sources identified them as belonging to the source and spreaders of the virus.

11.2 The targeting of whole communities, already struggling with age old prejudices and discrimination, needs urgent review by government and local authorities.

11.3 Also needing an urgent, better and more transparent review is the collection of ethnicity data in order to understand the full impact of COVID-19 on BAME communities. This should include recording ethnicity when health and care staff and patients are tested for the virus or at death of all victims. These statistics to be made readily accessible to organisations working with these communities.

11.4 Merton has in recent years, provided its residents with increased numbers of community-based health facilities to cater for the various needs of the community. Very few of these facilities are situated east of the borough where 60% of BAME communities live.

Locating community health and social services in relatively close proximity to areas identified as where BAME and older people reside, should help to increase take up by this age group.

11.5 Urgent need, therefore, to allocate appropriate investment in community medical facilities. Plans for the former Wilson Hospital to become a community facility located in east Merton for east Merton residents have stalled with very little information about its progress released to the public. The public should be kept informed about the Wilson, which offered such hope a few years ago.

11.6 Increase Resilience workshops, mainly with Merton Council's BAME health and social service staff. Many we spoke to revealed deeply held views on the way the lack of opportunities and progress at work is having on their mental health and wellbeing.

11.7 An outcome from the discussions was the setting up of Support groups /Networks to help those adversely affected by their work situations. Suggest a safe space to be provided for staff to meet and air their feelings, reporting back to the Council's hierarchy.

11.8 The focus of most COVID-19 strategies and campaigns has been on stabilising a situation which was threatening lives, threatening to overwhelm the NHS and threatening to destroy the economy. A prevention strategy was not fully in place but interestingly, the BAME communities, in the confusion of the first few months, found traditional, cultural ways of staving off the virus. The value of Vitamin D, one of the remedies the communities used and reported helpful is now being researched by scientists to ascertain any link with COVID-19 relief.

11.9 Recommend that Vitamin D3 screening for BAME communities and those people diagnosed with low levels be given supplies on the NHS.

11.10 There is now the urgent need for COVID-19 prevention campaigns to send out key messages, in culturally sensitive ways, relaying the seriousness of the virus, its early detection, testing and treatment.

Mobile amplification units using relevant language speakers to give out COVID-19 information/advice at prominent sites within the borough e.g. shopping areas, train & bus stations, places of worship, working with their leaders.

11.11 Working in partnership with local BAME organisations and faith and community groups, the campaigns would encourage communities to eschew some conspiracy theories prevalent within BAME communities and trust the interventions being offered.

11.12 The campaigns should also work with the communities to review traditional habits which are not conducive to life in the UK. e.g. high calorific meals (easily burned off in the heat of the tropics) the use of unmeasured traditional herbs as cures for certain illnesses; certain narcotic inducing plants thought to aid stress and depression.

11.13 It is important, however, that the messages are not forced down peoples' throats.; that failure to receive immediate reaction to requests are not taken as non-compliance, but people taking time to study and understand what is being offered.

11.14 Cultural competency workshops for all who work with BAME communities, that includes all heads of department, head teachers, teachers, medical, health and social care workers.

11.15 More Bereavement and end of life support. BAME communities currently lack access and appropriate advice in relation to end of life care.

12. CONCLUSION

12.1 Our programme's brief was to explore the impact COVID-19 has had on Merton's BAME communities, and to help the five communities most affected by the virus build resilience in anticipation of a second wave of the virus and other threats which could potentially claim the lives and livelihoods of already disadvantaged communities.

12.2 Our six months interaction with these communities confirmed that the virus had had a disastrous effect on the five identified communities. Deaths had occurred, jobs were lost, businesses closed, and children had to work out a new way of learning.

12.3 Whilst this was true for everyone, the underlying conditions under which many BAME communities live has caused shock, anger and frustration at the effect the virus has had on them. It has, nonetheless, given hope that this time, seeing the enormity of the fallout from this virus, something will be done to correct the inaction of the past.

12.4 What we found in the months we spent with 300 residents from these five communities, were people who, though angry and frightened on many occasions, mostly reacted with dignity, working with us to produce strategies we could present to the Health and Wellbeing Board.

12.5 The COVID-19 crises, has exposed the cracks in our society, but it has also offered an opportunity to address the issues which have bedevilled this borough over many years. The hope expressed at the start of the programme was still there as we ended our time with them.

12.6 Like other crisis, COVID-19 has shown us that our society is less divided than it sometimes appears. It may be true that though we are all in this together, though not all in it equally, we are as a community weathering the storm, and hopefully, with the new scientific and other discoveries, we will be able to build a better borough for our diverse and growing communities.

In recognition of the faith that has sustained many Merton residents and the invaluable part the faith communities have played during this crisis, we recommend that a joint' Service of Unity 'be held as soon as it is safe to do so.

PART 6

APPENDICES

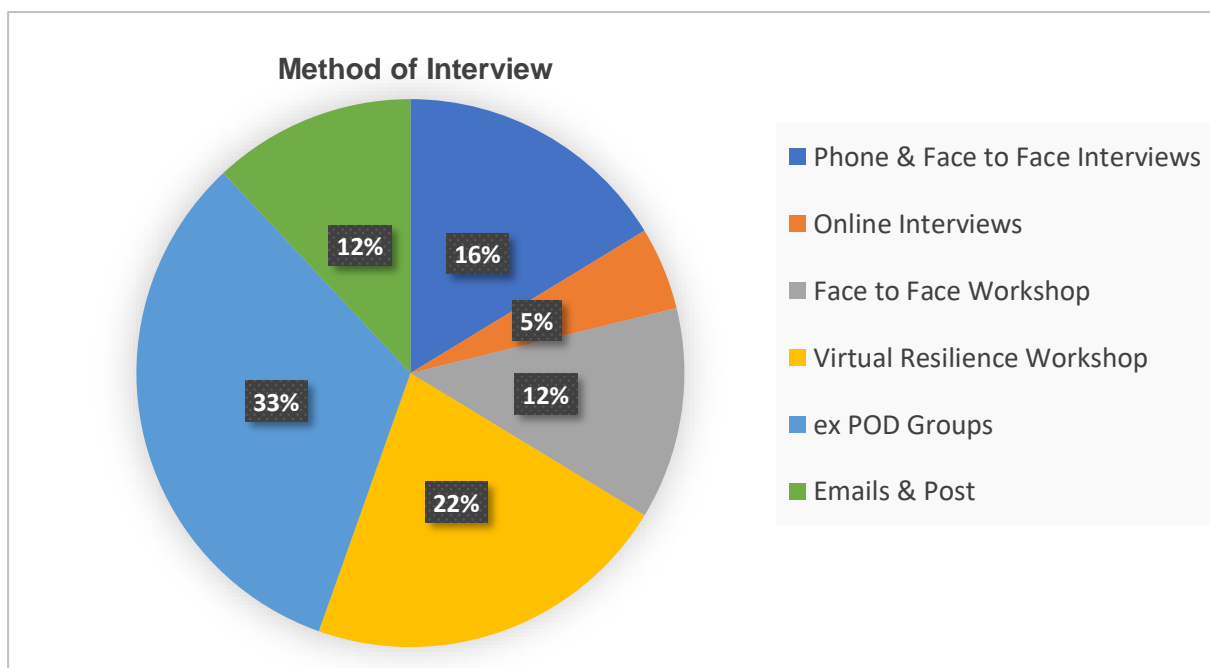
13. APPENDICES

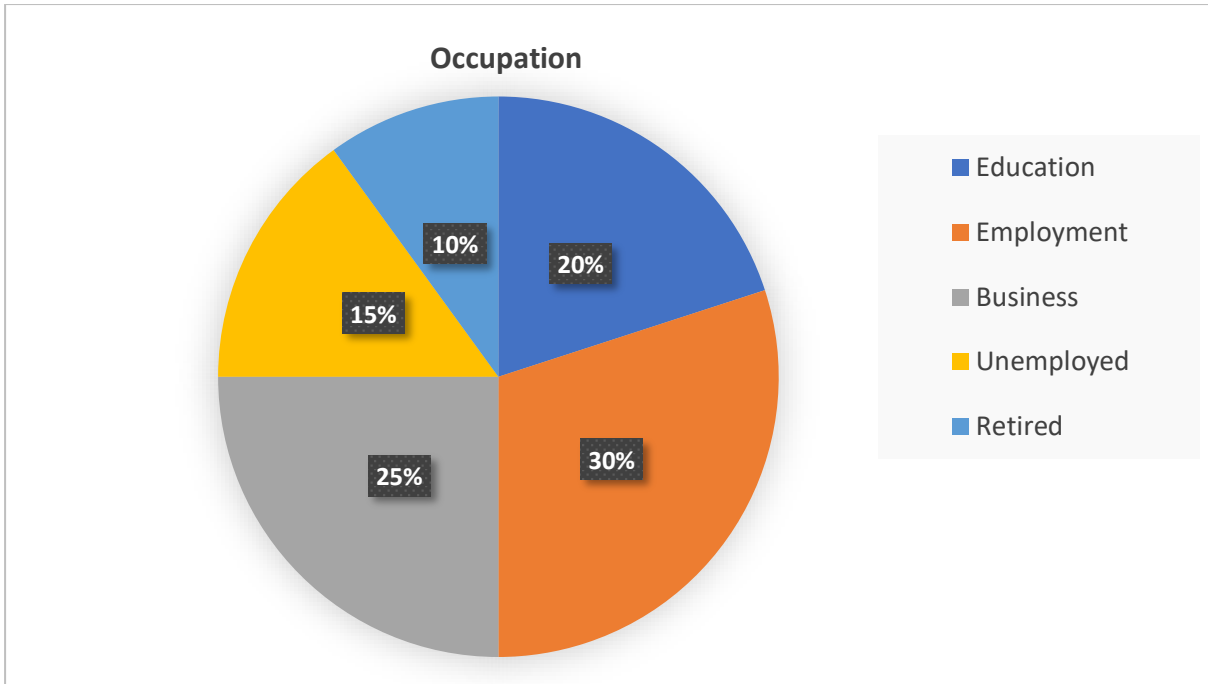
Appendix A: The people we spoke to

Interviews between August 2020 and October 2020

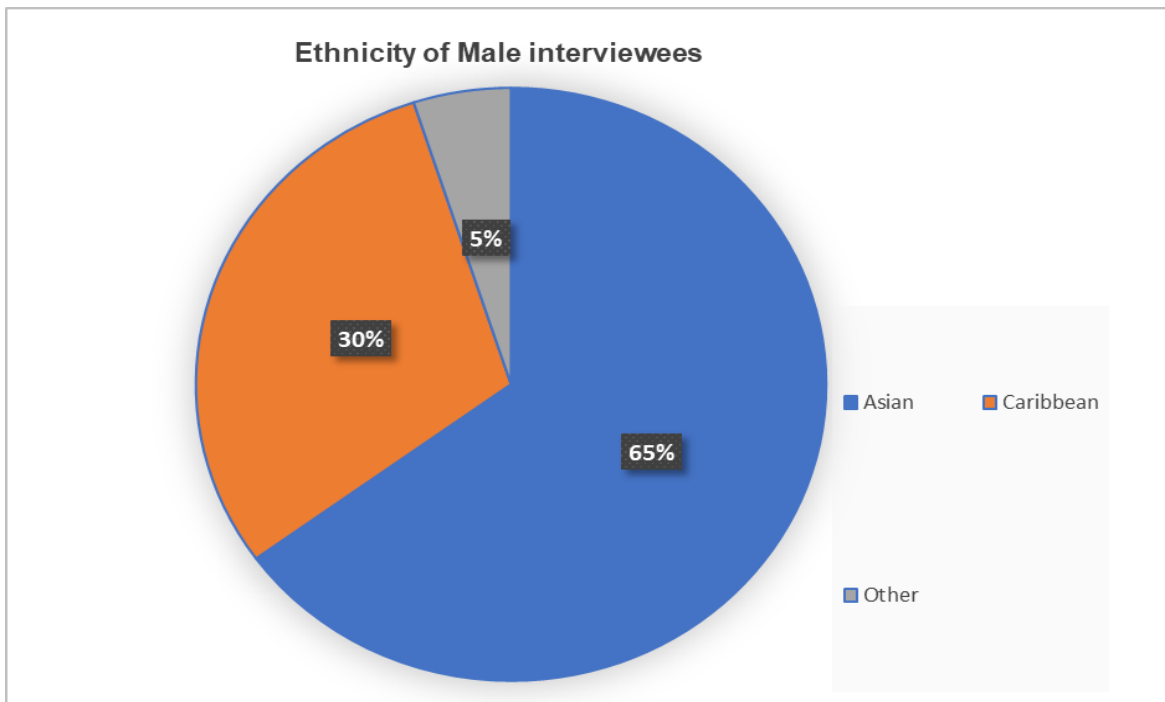
Areas covered - Figges Marsh, Cricket Green, Abbey, Colliers Wood, Lavender, Morden, Graveney, Pollards Hill, Morden

Total number of Interviewees 184

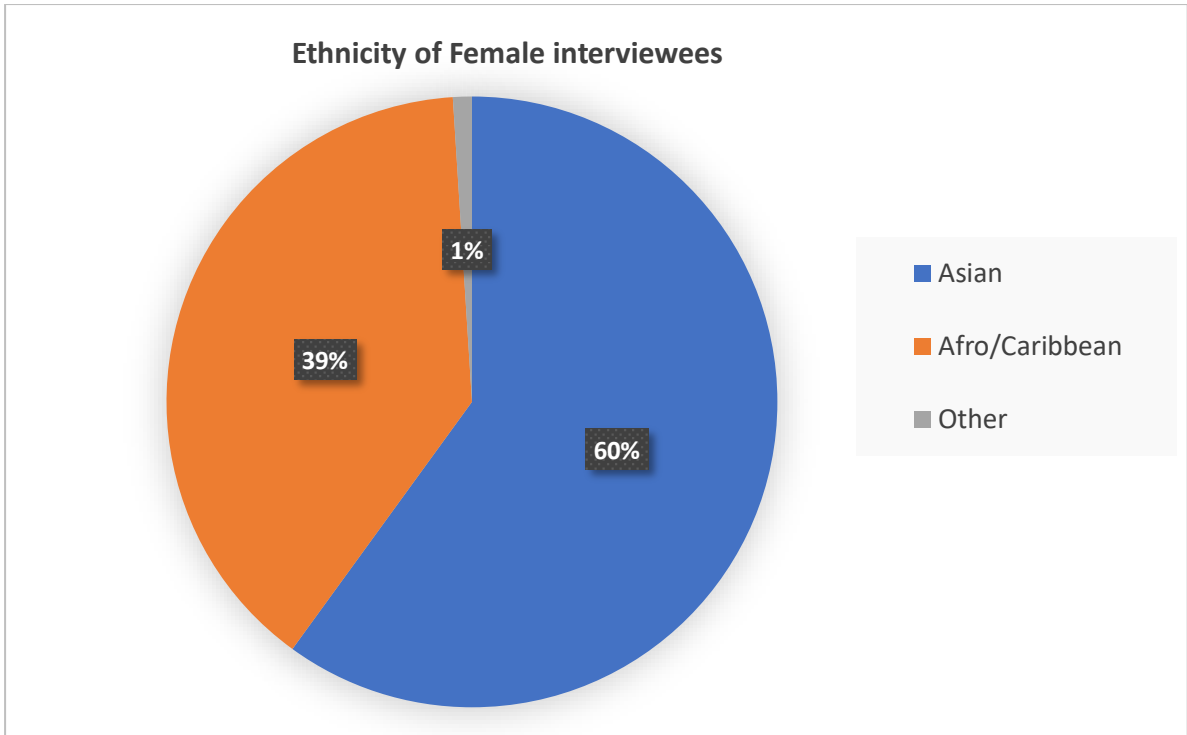




56 Males were interviewed between the ages of 9 – 65



128 Females were interviewed between the ages of 11-55

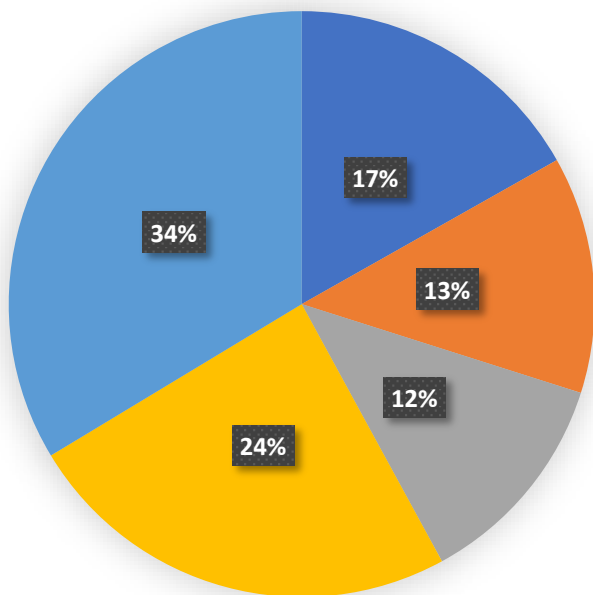


Interviews between November 2020 and February 2021

Areas covered - Figges Marsh, Cricket Green, Abbey, Colliers Wood, Lavender, Morden, Graveney, Pollards Hill, Wimbledon, Raynes Park

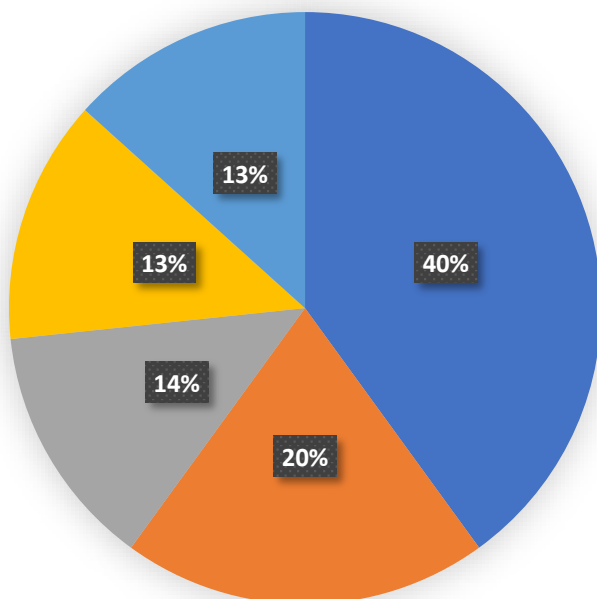
Total number of interviewees 107

Method of Interview



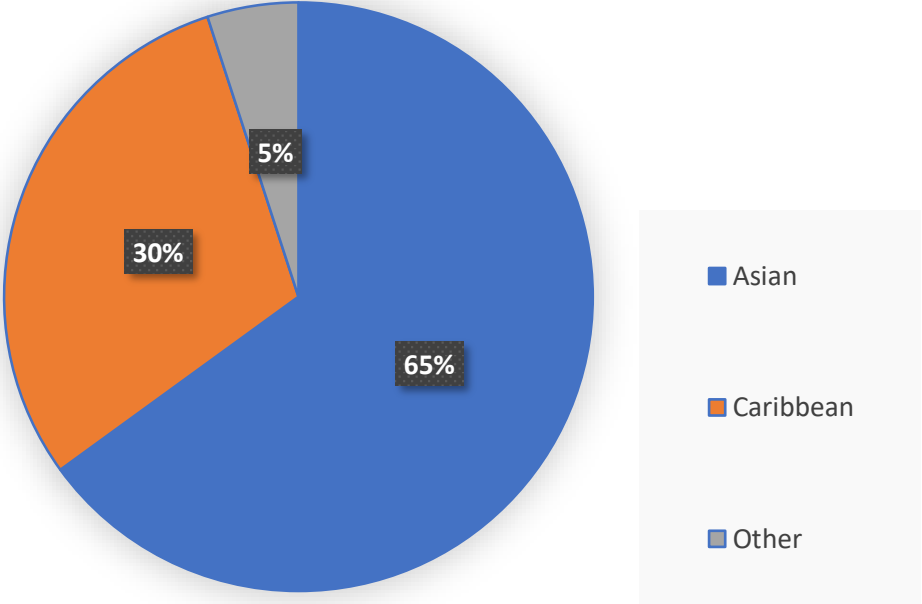
- Face to Face
- Phone Interview
- Online Interviews
- Virtual Resilience Workshop
- ex pod Group

Occupation

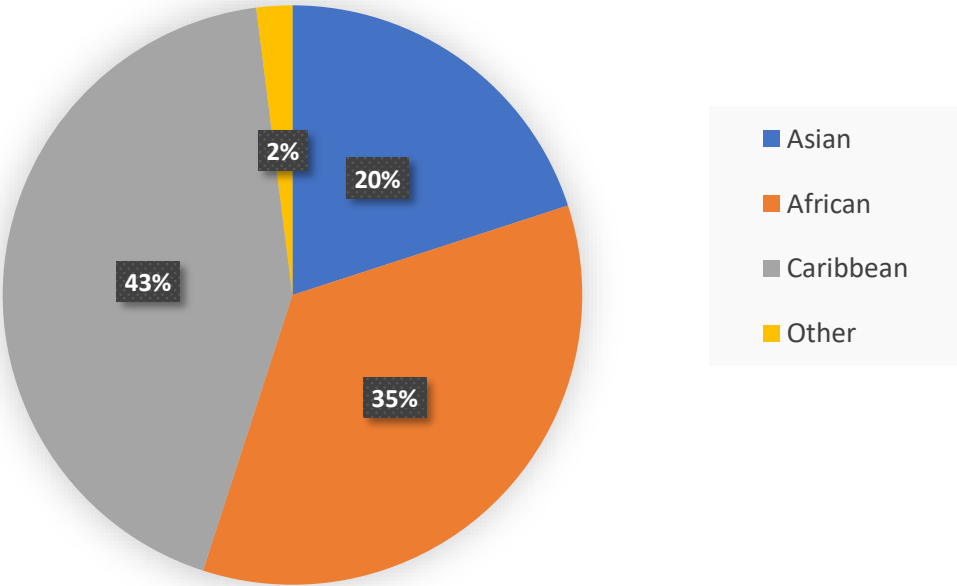


- Education
- Employment
- Business
- Unemployed
- Retired

Ethnicity of Male interviewees



Ethnicity of Female Interviewees



CASE STUDY - CETTA

Female, mid- forties, working as a nursing assistant in a care home. Came down with the virus after several of her patients had been diagnosed with the illness.

What were the conditions like in the home?

“We were not aware of what was happening until one of the patients fell ill and was diagnosed with the virus. He came back to the home. Then others started having it and they died. Our management did nothing in the beginning and then it spread to the middle floor and then to the ground floor. Some masks were brought in then, but you were lucky if you got some, unlucky if you didn’t.

I was still going on, covering for other people as well. Later on I couldn’t cope and I fell ill. Everything started happening with me, my taste buds went. Called 111 and they said I had the virus. But the first paramedics said I had flu. Advised I take Paracetamol. A few days later, I collapsed and the second lot of Paramedics took me to hospital where I stayed for several weeks. On my return after recovery, found things had improved very much to my surprise.

Why were you surprised?

Because my management was not supportive of us as staff in the beginning, we did not have enough protective gear and we were not given adequate information to start with.

What can be done to improve conditions at Care Homes like yours?

Workers given support to speak out about conditions under which they work. Support system in place to help the workforce and for them to help each other.

What would you like to see happen now?

Greater accountability by those who manage staff, more briefings when situations go wrong, more support from government and oversight of homes like ours. Better training for paramedics to differentiate between the symptoms they encounter in their patients.

How are you doing now?

Grateful for the support from family and friends. Hope churches are fully open soon. We are the body of Christ. United we stand, divided we fall.

Appendix C: Acknowledgements:

London Borough of Merton – Health and Wellbeing Board

Public Health England (Merton)

The JCC

AAA Consultancy Services

Eaglobal Empowerment Network

Haliq Inspirational

Ancestral Hands

Positive Network

Merton Councillors: Edith Macauley MBE
Linda Kirby
Agatha Akyigyina OBE
Caroline Cooper-Marbiah
Laxmi Attawar
Eleanor Stringer

Alhaji Haroun Gassama

The Revd. Alison Judge – Merton Priory Team Ministry

Programme Team:

Coordinator Saratha Arunasalam

Volunteers Raghavi Rajan
Ellen Davies
Suki Balendran

Youth Interviewers Mohamed Z Batha
Prasath Jeyakumar
Patrick Olajide

BAME VOICE Officers: Dr P Arumugaraasah
Pastor Edward Abu Maliki
Mr Chellian Lonhedran
Mr Abayeh Savage
Mr Shivaranjith Sivapragasam

Programme Director: The Revd. Mrs Hannah Neale

Report AECHO /AAA Consultancy Services

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Merton Public Health Engagement Report

March 2021

DRAFT

Merton Public Health Engagement Report – March 2021

INTRODUCTION

Purpose

The purpose of the phase 1 was to:

- provide an opportunity for residents with a learning disability and/or autism (LD/ASD) and their carers to **discuss their COVID-19 related concerns** and worries, to receive key public health messages and be signposted to local support services
- understand the **impact of Covid-19** on residents with LD/ASD and their carers
- identify **practical policy responses** or local actions to address specific concerns
- be an **intervention in its own right**, helping to support building of trust
- work with **partners** across Merton to increase engagement with and improve the reach of communications to residents with LD/ASD and their carers on key COVID-19 related issues
- understand **barriers to accessing services**, and ways to expand the reach of these services and increase take up, including GP annual health checks

Phase 2 will be decided based on the findings in phase 1. It will be a practical intervention to support the health and wellbeing of parents and carers of people with LD/ASD, and the people they care for during the remainder of the Covid period.

Merton Mencap

Merton Mencap supports people with a learning disability and/autism who live in and around Merton, and their family carers.

We run 25 projects including holiday playschemes for children with severe and complex needs, travel training, youth clubs for teenagers and young people, a working Café staffed by adults with LD, an LD Carers Support service, practical advice for parents of autistic children, and 2 arms-length parent forums who organise workshops on a range of topics such as mental capacity, assertiveness, and positive behaviour support.

This project was run and managed by an independent consultant who has long-standing professional links and connections with Merton Mencap, the London Borough of Merton, Merton CCG, and parent carers across the borough, and who has carried out a number of similar projects previously for the London Borough of Merton.

EXECUTIVE SUMMARY AND RECOMMENDATIONS

Findings

- What matters most to carers of adults with learning disabilities and/or autism (hereafter referred to as LD/ASD) are:
 - **activities and respite services provided for their cared for person**
 - **isolation, loneliness, and mental health issues**
 - **planning for the future and emergency planning**
 - **access to health services**

the burden of caring has increased during Covid for 75% of carers
- What matters most to people with LD/ASD currently are:
 - **outings and activities**
 - **friends**
- **Resilience:** there is no doubt that many people with LD/ASD have shown great resilience and coped well during Covid, thanks to the efforts of their carers and staff from the statutory and voluntary sectors, but there may be a cost in terms of the health and wellbeing of carers
- Resilience has been easier for those who have **digital access**, one of the main ways people have kept in touch and remained active
- **There has been a significant reduction in independence** in the community for adults with LD/ASD due to Covid
- Adults with LD/ASD have appreciated quieter, less rushed routines and being part of a **more caring community**
- **Young people and adults with LD/ASD who feel anxious or angry** appear to be the most at risk. Indicators of poor mental health indicators include drinking more alcohol, staying in their room on their computer, refusing to communicate, self-harm, threat of suicide, and starting to take drugs. A number mentioned that their medication for anxiety or sleep has been increased
- Parents and carers say the support they need, apart from activities for their cared for person or child, is **financial advice**, help to **plan for the future**, **befriending/contact services**, and **good vaccine information**
- Many people with LD/ASD have **benefited from learning new online skills** and some enjoy virtual activities and virtual learning. St George's LD nurses have told us that some patients with LD/ASD prefer virtual health consultations
- **Education:** some children with disabilities/SEN have found it hard to learn at home and some parents lack the skills needed to teach their disabled/SEN child. Parents are worried about their children falling further behind their peers academically. However, many Merton schools have been providing **good support**
- **School pupils with a disabled brother or sister** may have fallen behind their peers and may need academic and pastoral support when they return to school

- Two thirds of respondents with LD/ASD said they normally attend an **annual health check**. Some parents/carers told us that they were not happy with virtual or phone health checks during Covid
- We found some evidence of **vaccine hesitancy** (mainly needle phobia and concerns about safety and side-effects), but NHS staff have dealt with this well and worked closely with parents to put reasonable adjustments in place

Digital exclusion

- The impact of digital exclusion/poverty and the digital divide has become more apparent during Covid
- Online access has a role to play in each of the main issues for carers mentioned above
- In 2014, BT estimated that the value to an individual of getting online was £1,064 per annum for a basic user due to better connection with friends / family, feeling part of a community, financial savings, and opportunities for employment and leisure; they did not include possible e-health or e-learning benefits
- Our data confirms that Merton carers are above the national average for digital poverty; 33% are basic or non-users compared with only the national average of 22%, and likely to be the most digitally excluded group of residents
- Public services and the NHS are increasingly moving critical services online, and other services will continue to move increasingly online post-Covid; this is likely to exacerbate the existing digital divide
- Some carers will never engage digitally, therefore non-digital alternatives are still required for communicating important health and care information
- Parents of children with SEN/disabilities are not digitally excluded which is positive news for the future
- 90% of adults with LD/ASD who responded have a SMART device and use the internet (with or without support), but some adults with LD/ASD are not offered this choice due to their carers' lack of digital skills, divergent interests, and/or financial constraints; digital exclusion 'by proxy'
- Carers lack motivation to become competent digitally and may require a greater understanding of the benefits, a personal 'hook', as well as financial support and ongoing technical help
- There are a number of complex issues affecting digital inclusion for carers including online safety, practical or decision-making considerations, and low digital confidence
- There appears to be poor awareness of the range and accessibility of assistive technology, and how this could benefit people
- Some children or young people with severe disabilities, who use the internet for learning, do not appear to use it for peer to peer engagement which may mean losing social networks once they move out of education
- Not all professionals are technically skilled and confident as digital advisors for carers or cared for people

Recommendations

- Adults and young people with LD/ASD may need **additional training and support** to recover their previous independence skills
- **Mental health information** needs to highlight support services which have **specialist training/expertise** and **easy access routes** for people with LD/ASD (communication / social communication difficulties, challenging / obsessional / defiant behaviours or anxieties related to LD/ASD, catatonia or selective mutism, hyperactivity, or poor focus)
- Although adults and children with LD/ASD are missing their **outings and activities**, some **online services** could continue in order to build on positive experiences during Covid, but these would need to be part of a digital inclusion strategy to ensure **equal access** to such services
- Carers will benefit from additional help and information about **financial support, planning for the future and for emergencies**, and services providing **social contact**
- Until day, leisure and respite services fully resume, services need to focus on **reducing social isolation** for adults and young people with LD/ASD (services such as Merton Mencap's Companion Service)
- Pupils with a **disabled brother or sister** should be identified, whether or not they are a young carer, so schools can offer additional help if needed
- To tackle the complex barriers to digital inclusion for carers and cared for adults with LD/ASD, we recommend a **local digital inclusion strategy** which recognises this care group as a priority and is based on a sound understand of their needs
- **A one-size-fits-all** digital solution is not appropriate nor likely to be successful, therefore we recommend a person-centred approach to digital interventions

To achieve this, we recommend **specialist training** for front-line professionals, or the development of team of **digital enablers** to provide ongoing help, recognise the divergent interests of carers and cared for people, and ensure that **assistive technologies** are put in place appropriately

- It should be recognised that **some carers will not become internet users** and this choice must be respected, therefore critical information will still need to be made available in other ways, such as via letter, phone, through providers and parent forums
- To help people to see the benefits of digital inclusion, we suggest development of **an awareness programme including a short film** which shows carers and adults with LD/ASD using the internet successfully in a variety of ways. This could be both a tool for front-line staff and for public spaces such as GP surgeries

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Background

Analysis method

Merton Mencap received responses from **159 residents** comprising:

- 37 people with LD/ASD ages 14 - 71
- 66 carers of adults with LD/ASD ages 37 – 81
- 56 parents of children or young people ages 14 – 17 who have LD/ASD

Note: there was a small overlap (7 people) across those cared for by our carer respondents and adult respondents with LD/ASD. As carer's perspectives may differ from their cared for person's views, we did not remove these duplicates.

Analysis is both **qualitative** and **quantitative**. Even with a good numerical response, additional focus groups and detailed conversations are necessary because:

- respondents are self-selecting
- data is not numerous enough to be reliable when segmented (split into multiple subgroups)
- some situations would probably have arisen with or without a Covid crisis
- people's lives are complex, there may be multiple socio-economic and/or historical factors involved, therefore it is not appropriate to assume cause and effect or derive blanket solutions from numerical data alone

To 'reality check' our results and to further develop our links with partners, we spoke to 14 professionals from Perseid School, Merton College, LD Nurses at St George's Hospital, Supported Living/Residential homes, Day Centres, Merton Mencap's LD Carers Support Advisor, Merton CIL, Healthwatch, and Merton's LD Team.

To make sure we covered every possible angle and did not reinvent the wheel, we reviewed relevant published reports, a summary is in below in Section E.

Contact Methods

Initially, we piloted and checked our communications with the Adults First Steering Group who spent time improving the questions and letters, making sure they were easily accessible and understandable for carers.

We then contacted residents via letter, email, phone, and via providers such as day centres and schools, some of whom sent letters out or ran a focus group.

We offered **all methods** of engagement including walks, online surveys, paper forms, phone calls, Zoom focus groups, or email exchanges. We offered to speak via intermediaries such as translators, neighbours, and family members.

We created a **range of accessible materials** suitable for people with LD/ASD and those without digital access. We offered support for people with limited literacy skills and those who do not respond well to direct questioning.

We also used Merton Mencap's **own services** such as *Hub Connected* and our *Café* to run focus groups including 2 virtual sessions facilitated by staff from Merton Health and Care Together.

There are around 3,900 Merton residents with a learning disability according to Merton's JSNA, around 550 of whom are known to the Adult Social Care LD Team. *[Please note that we were not able to email or write directly to carers or clients of Merton's LD Team in Adult Social Care during the engagement work.]*

Merton Mencap's own mailing list reaches around **326 family carers of people** with LD/ASD, many of whom are not known to statutory services, as well as around **568 parents of children or young people** with a learning disability and/or autism spectrum disorder.

Complementary work

Over the same period, we conducted a **parallel project** on carers' digital exclusion for 'Mind the Gap', an initiative by NHS England. We were commissioned via the SW London Health and Care Partnership and worked closely with Clare Thomas. Our work on this topic has been incorporated in the digital results in Section B.

SECTION A IMPACT OF COVID

A.1 Results: people with a learning disability and/or autism (LD/ASD)

This section shows data gathered from **37 people with LD/ASD** who provided their **own responses** with support as necessary from a professional, key worker, carer or focus group facilitator/provider.

1. Respondents' Profile Data

Gender	
Male	78%
Female	22%

Age range of respondents	
70s	1
60s	1
50s	8
40s	6
30s	9
20s	5
18	3
14 - 17	3

Who respondents live with	
With a family carer	30
Independently	3
Supported Living or Care Home	4

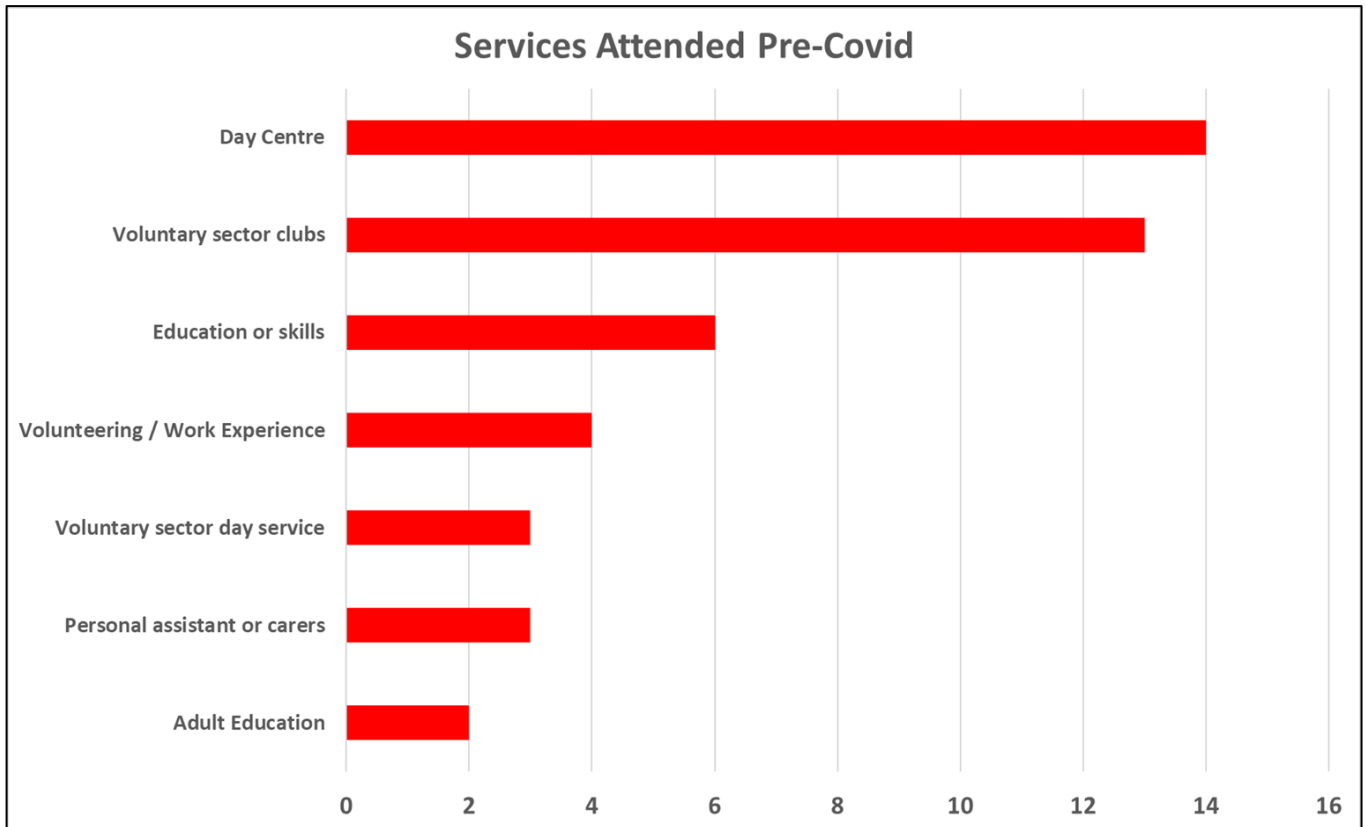
Most respondents were male.

7 respondents (18%) live in supported living, a care home, or independently. The remainder live with a family carer.

We reached respondents who from all areas of the borough, with an equal number living in SW19, CR4, SM4, SW20 and a small number in other areas such as KT3, SW16 and SW17.

2. Services attended pre-Covid

Pre-Covid, respondents attended a wide range of day and leisure services for people with LD/ASD in Merton.



We did not ask respondents which services remained available during Covid. However, we are aware that **none of the above ran normally**, even during non-lockdown periods.

Day centres were open for selected clients who live with family carers.

Voluntary sector day services/clubs offered virtual services, occasional virtual sessions, reduced hours, or a 'keep in touch' phone service, depending on the provider.

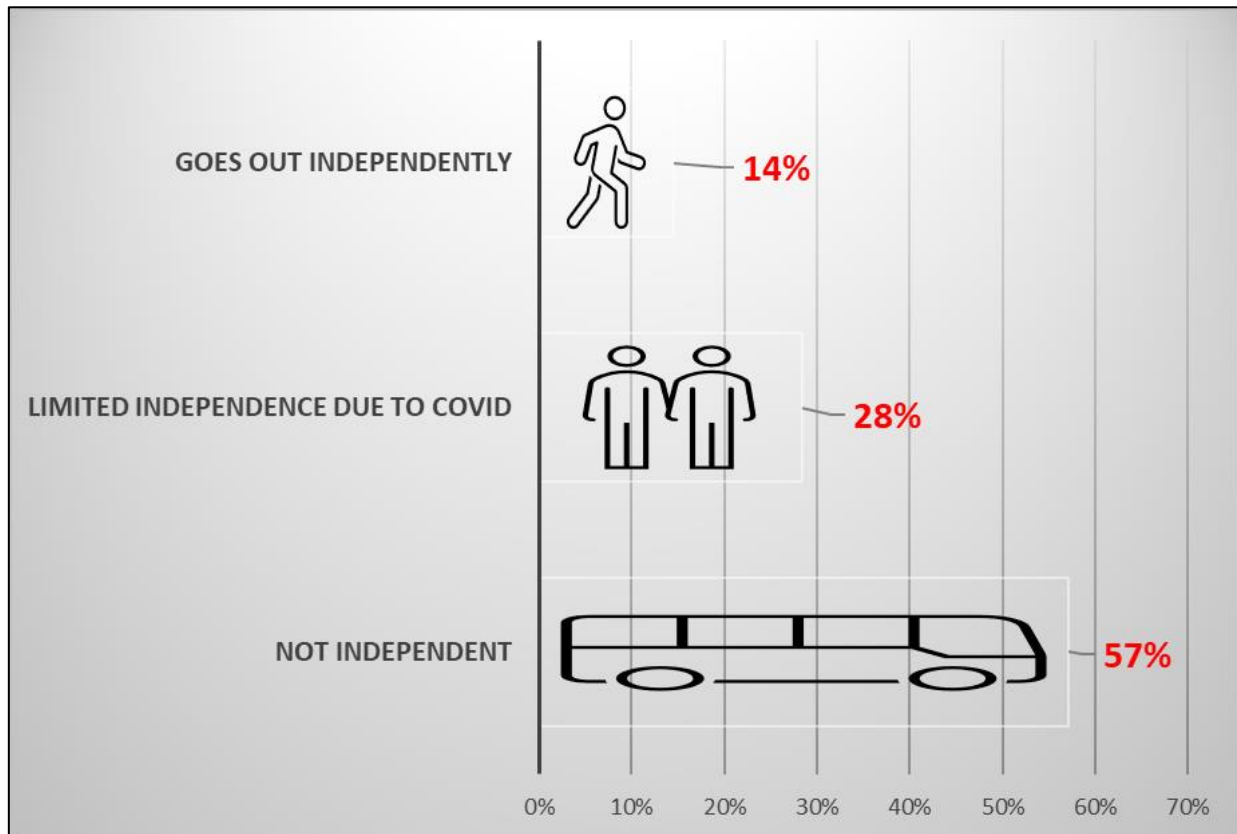
Work experience and volunteering generally closed. Colleges and education provided virtual lessons or offered attendance on reduced hours and days.

Personal assistants / care services reduced initially and particularly if the client or staff member was shielding or had concerns about Covid risk. Many of these in-home services gradually resumed after lockdown 1.

3. Independence skills

The majority of respondents were not independent in the community prior to Covid.

Of those who were partially or fully independent, **2/3 are no longer able to go out alone**. This data matches the responses received from carers about their cared for person's independence.



Reasons for reduced independence include lack of ability to implement safety rules, travel training on hold during lockdowns, self-isolation, reluctance to leave the house due to Covid, fear of travelling e.g., too many people without masks.

Reduction in independence for adults with LD/ASD is a significant issue. **Skills will not be instantly or easily reversible in all cases.**

A number of people will require substantial emotional support and re-training in order to regain 'unused' independence skills and reassure them about safety. People with LD/ASD require opportunities for regular or daily practice in order for basic skills to be retained.

Loss in independence occurred in the home as well as the community. Some adults moved from a flat or supported living to live with their families and did not need to use their cleaning or cooking skills, and others became more emotionally dependent on family carers requiring explanations, reassurance, or additional support for challenging behaviours or mental health needs.

4. Main challenges

Most respondents miss **outings, activities, and friends**.

Although numerically not the largest, those who **feel lonely or angry** are perhaps most at risk. One stated that *'there is nothing to live for'*, others said, *'what's the point in this life?'* and *'the world is upside down'*.

The same applies to children with SEN/disabilities (Section A.3), with many comments relating to self-harm, anger, or withdrawal, and parents asking for children to have access to counselling, therapies or behaviour support.

What do you find hardest at the moment?	Number
Missing outings or going out for meals	28
Missing friends	22
Missing clubs or leisure activities	17
Unhealthy or lacking exercise	16
Feeling lonely, sad, or angry	14
Missing day activities	14
Not being able to go on public transport	11
Wearing masks	10
Social distancing	9
Access to doctor or dentist	9
Having to do things online	7
Spending too long indoors or in room	7
Worrying about being ill	6
Not seeing a personal assistant or carer	6
Confusion about Covid	6
Missing family contact	5
Sleep issues	4

One adult with LD/ASD described being withdrawn and lonely because he has not been able to exercise outdoors. He has Downs Syndrome and is shielded in his supported living home where there is little access to open spaces nearby.

The vaccination programme and new Government guidance will help a number of the shielded cases, but our results bear out the concerns raised by National Mencap last November *"Adding adults who have Down's syndrome to the shielding list could lead to even higher levels of loneliness for people in this group. The risk of catching COVID-19 must be balanced with people's well-being."* See 'Support Provided' in Section D below.

5. Support needs

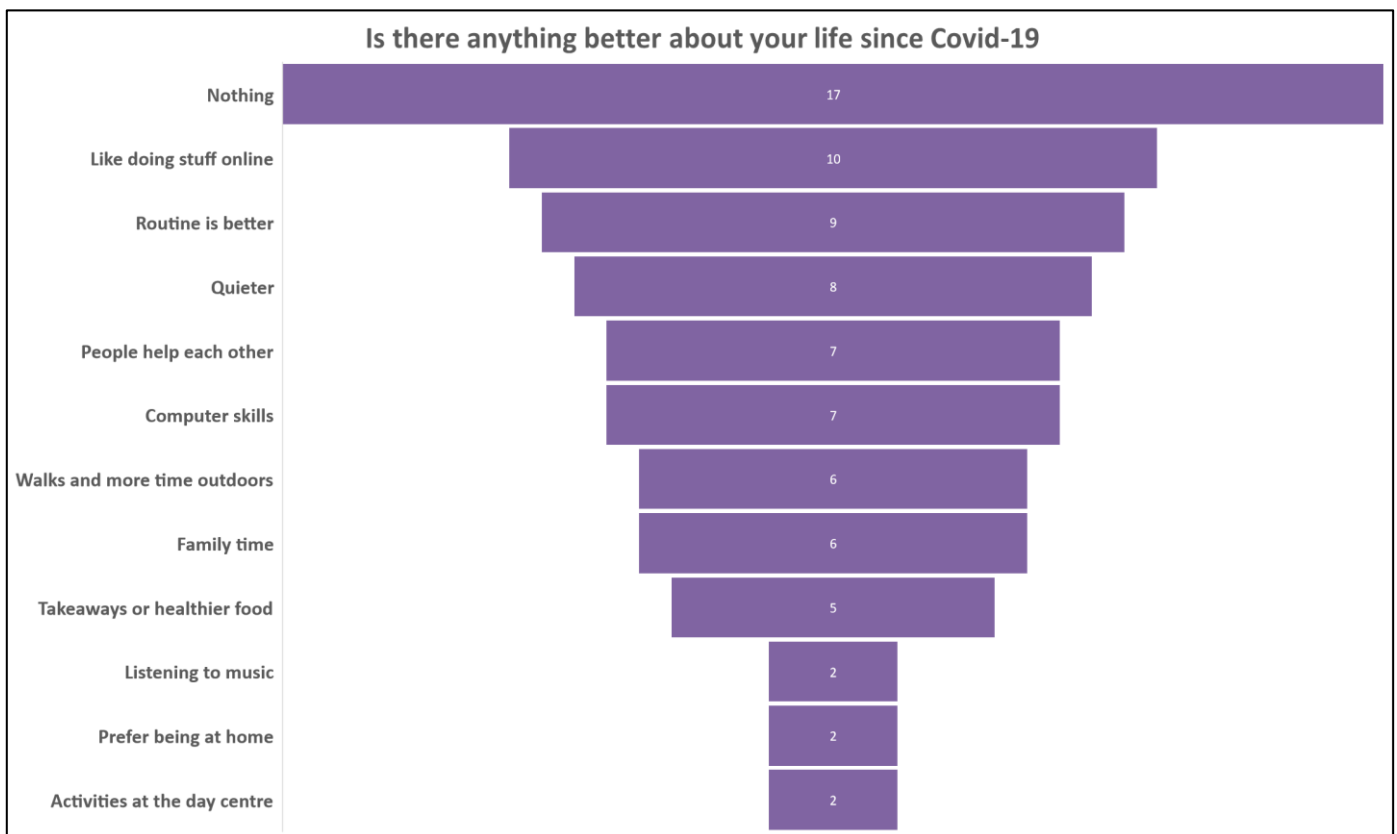
19 respondents said they feel they need extra support, but only 5 were able to give us further details. 2 asked for technology (a laptop or help using the internet), 1 asked for help to make decisions, 1 asked for mental health support, and another said any support would be good.

6. Positives

Nearly half of respondents said that **nothing is better** than before Covid.

17 respondents said that they either enjoy **doing more online** or they have learned new **computer skills** during the Covid period.

Many respondents enjoy quiet time, a calmer less rushed routine, walks, and being part of a kinder, more connected community.



It is clear that most people with LD/ASD look forward to the time when they can **go on outings, resume activities, and see friends.**

However, examples of positive technology use during Covid are:

- A young person at Perseid Upper School has taught himself how to create his own animated games using Roblox
- A young adult who does not enjoy accessing virtual services, has used his time to create 80+ electronic music tracks and uploaded them onto YouTube
- A number of Merton Mencap service users are now able to use Zoom independently, having previously needed help to go online
- Some service users who previously avoided face-to-face services, now attend structured Zoom sessions, perhaps feeling more 'in control' or more 'anonymous' online

Some online services could **continue post Covid** to build on these positives and indeed new and creative ways to use technology could be developed, but not as a cheap substitute for other forms of support, rather to achieve **health and wellbeing outcomes** that are best delivered in this way.

At the same time, a strategy for tackling the issue of **digital poverty/exclusion** in Merton is necessary to ensure that access to such **services fully inclusive**.

7. 'How do you feel about the way Covid has changed your life?'

An almost **equal number of respondents said they are happy, sad, and not sure (a little worried)**. This is a relatively positive outcome considering their extensive loss of access to activities and engagement.

This is thanks to the efforts of family carers, and also statutory and voluntary sector staff in Merton.

8. 'Did you have an annual health check with your GP before Covid?'

25 respondents said yes and 12 said no.

Of those who said yes, 7 said they were not sure if this was still possible during Covid.

Feedback from parents was that annual health checks are not ideal when conducted by phone or online, partly because many adults with LD/ASD do not like this form of contact.

Note: we strongly recommend that the **risk of early mortality** for adults with LD/ASD is **not** included on health forms addressed to the cared for person.

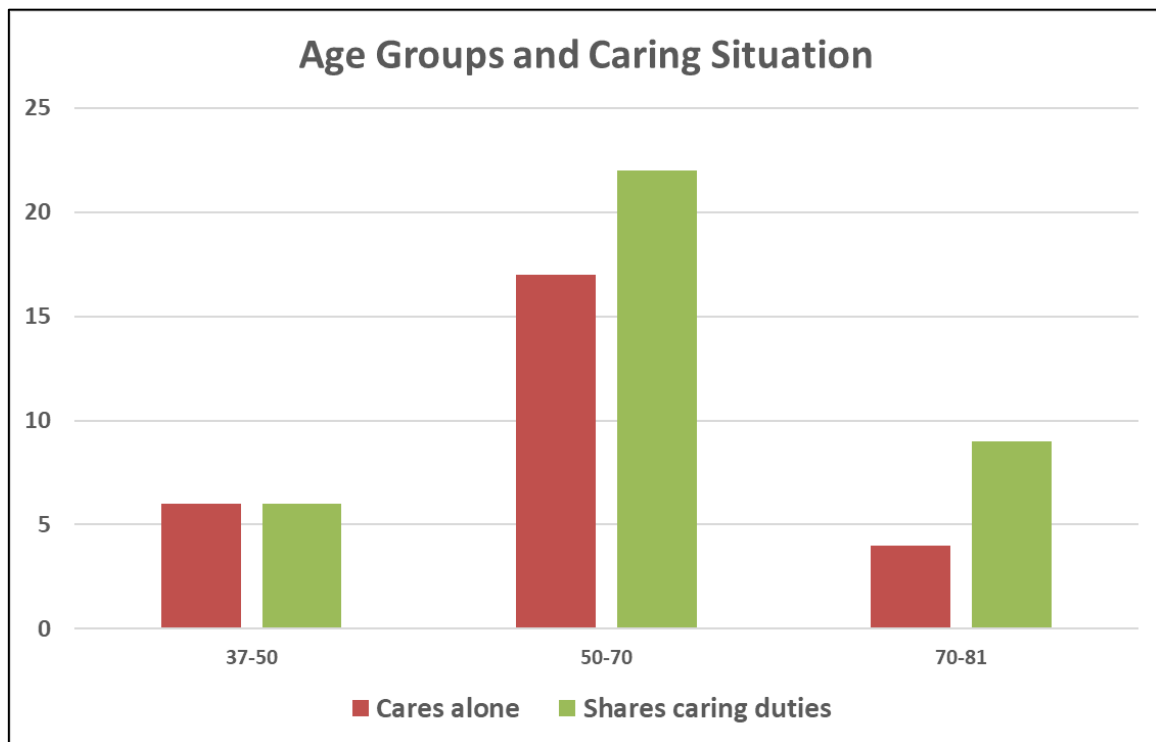
Limited access to healthcare and its' potential impact is a topic discussed in the carers section A.2 below.

A.2 Results: carers of adults with a learning disability and/or autism

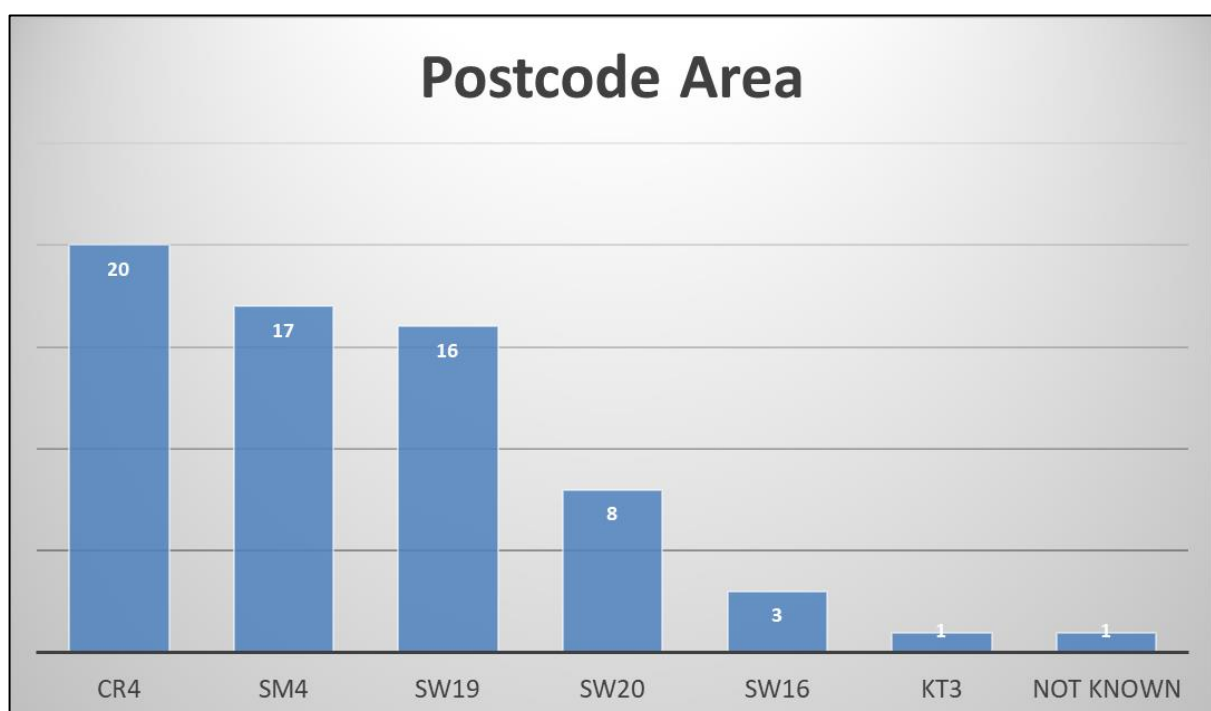
This section is based on the **66 responses** received by carers of adults.

1. Profile of respondents

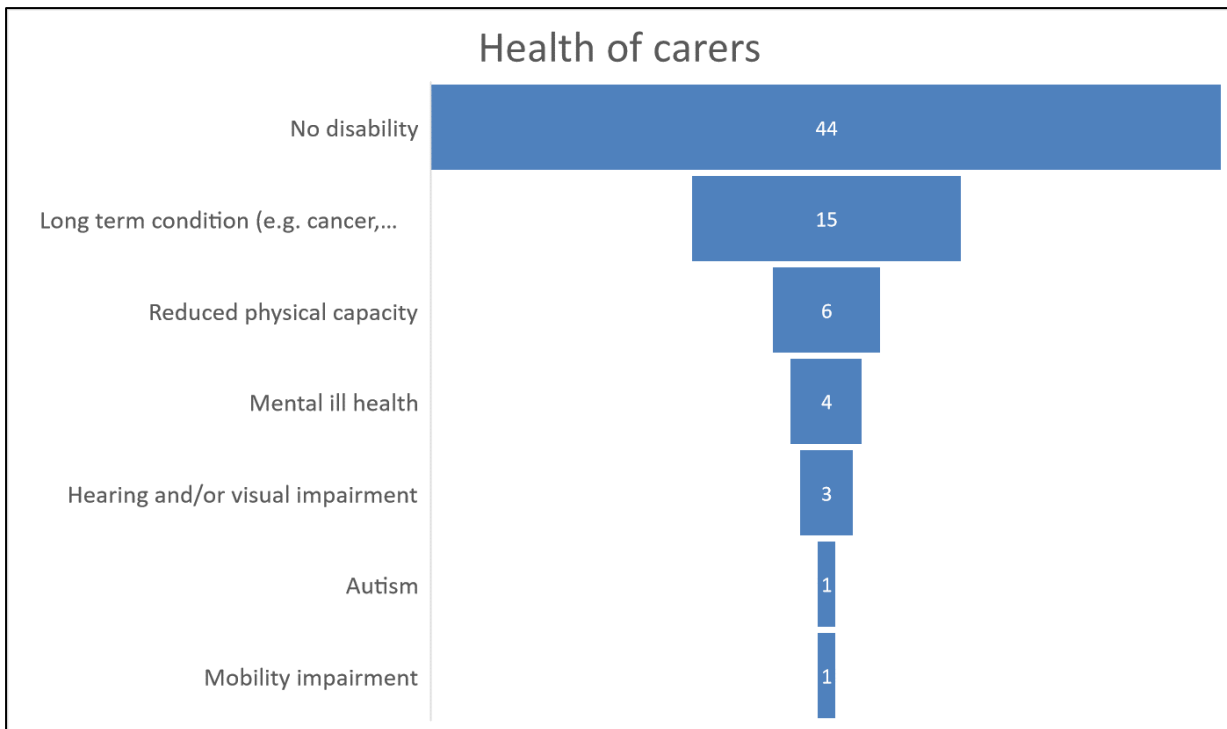
People **caring alone** formed nearly half of our respondents (42%). Even where there are others in a household, primary caring duties tend to fall on one person (normally the person who is not in full time work)



Respondents represent all areas of the borough

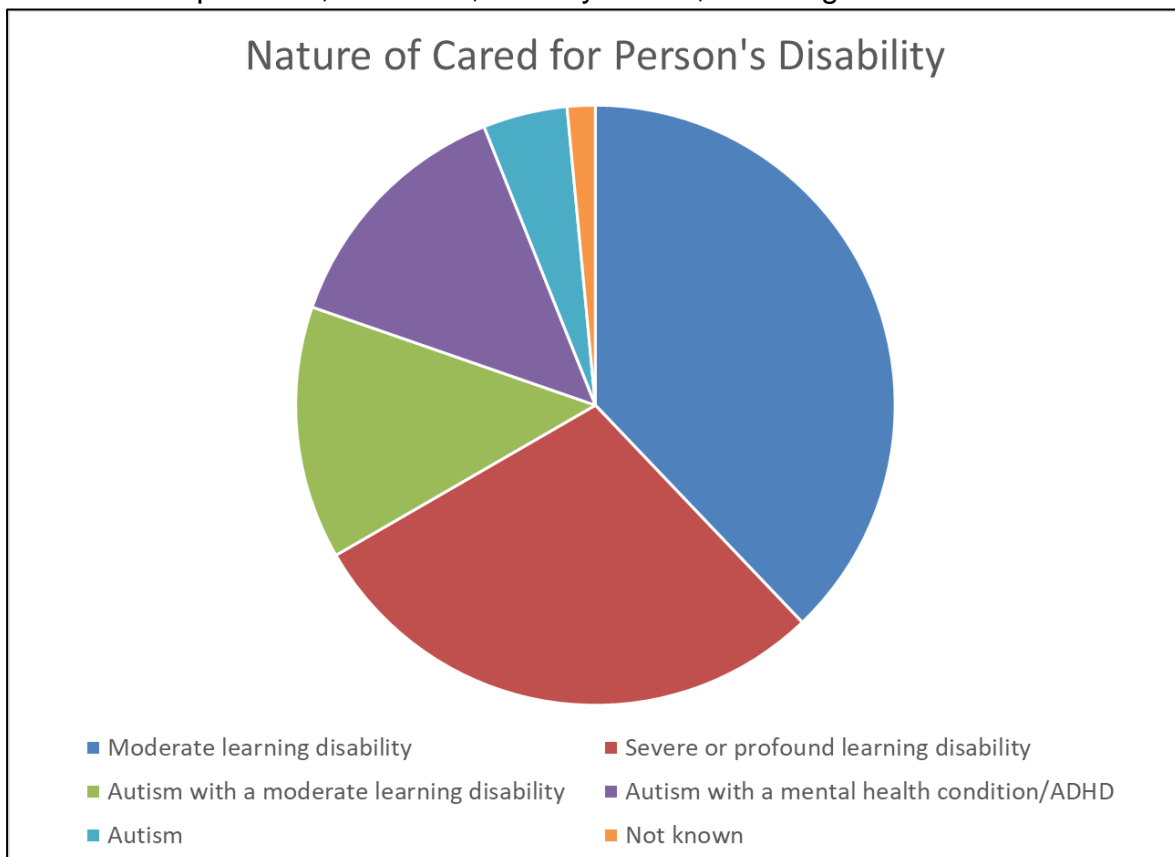


One third of carers have **health issue or impairment**, some likely to be age-related.



Type of disability: 80% of respondents care for people with a learning disability, and 20% for people with autism or autism with an additional diagnosed mental health condition.

Around 1/3 of cared for adults have additional conditions such as epilepsy, a hearing or visual impairment, dementia, mobility issues, or a long-term health condition.



Gender: 90% of respondents were female, more than carers as a whole across the UK (60% of those caring for 50 hours+ per week are women and 75% of those receiving carers allowance are women).

Ethnicity: the ethnic background of respondents was in line with Merton’s resident population.

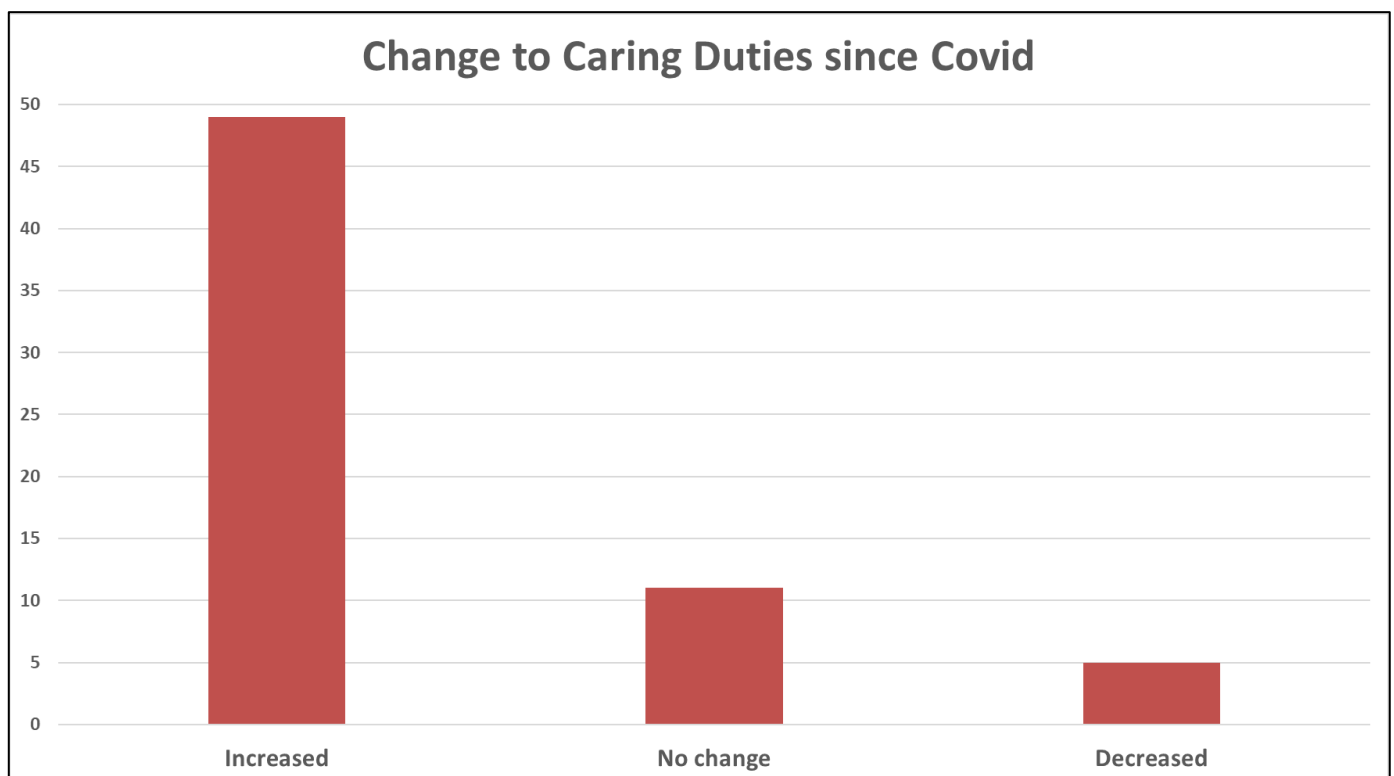
Gender of respondents	Number
Female	60
Male	4
Prefer not to answer	2

Ethnic group	% respondents
Black, Asian or Minority Ethnicity	39%
White	52%
Prefer not to say	9%

2. Change to caring duties

Before Covid, nearly half of respondents cared for 20-49 hours per week. 75% say caring responsibilities have **increased as a result of Covid**

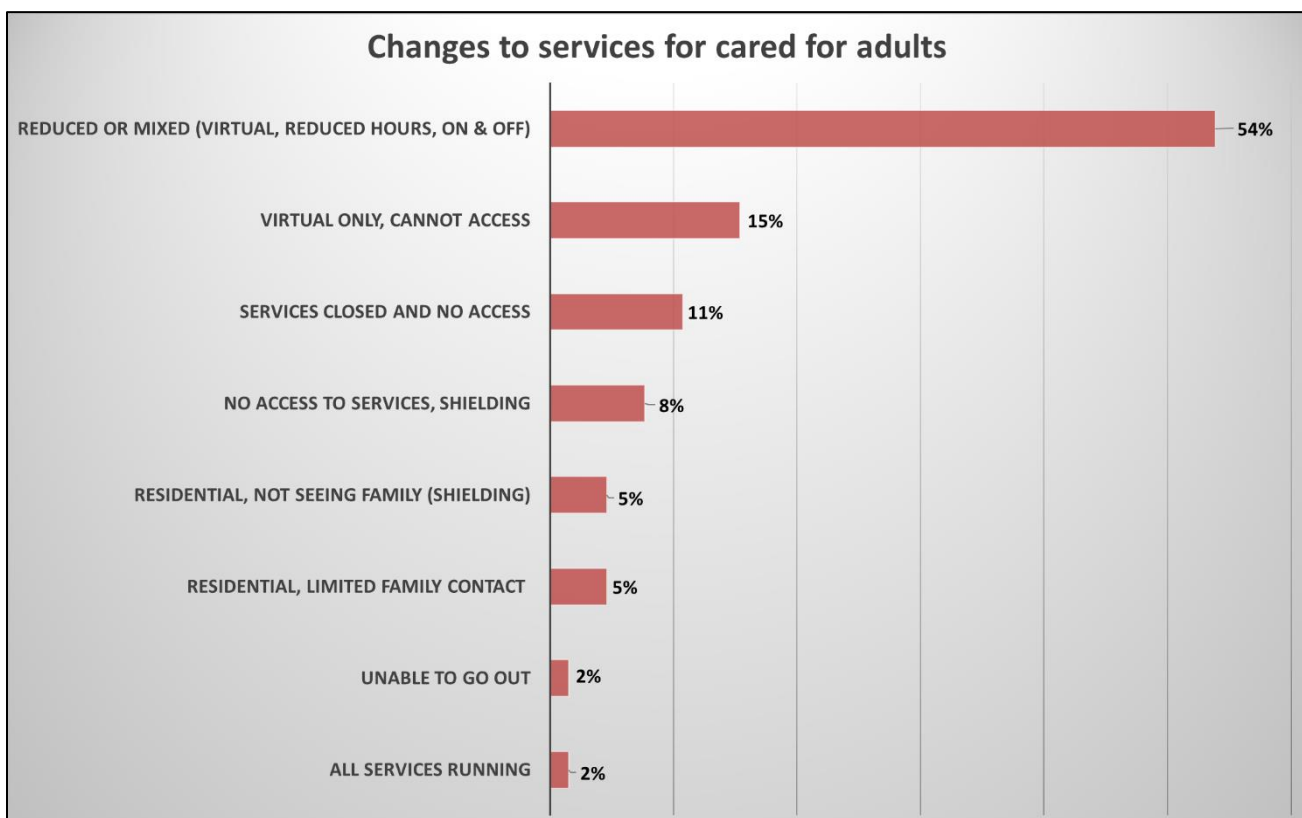
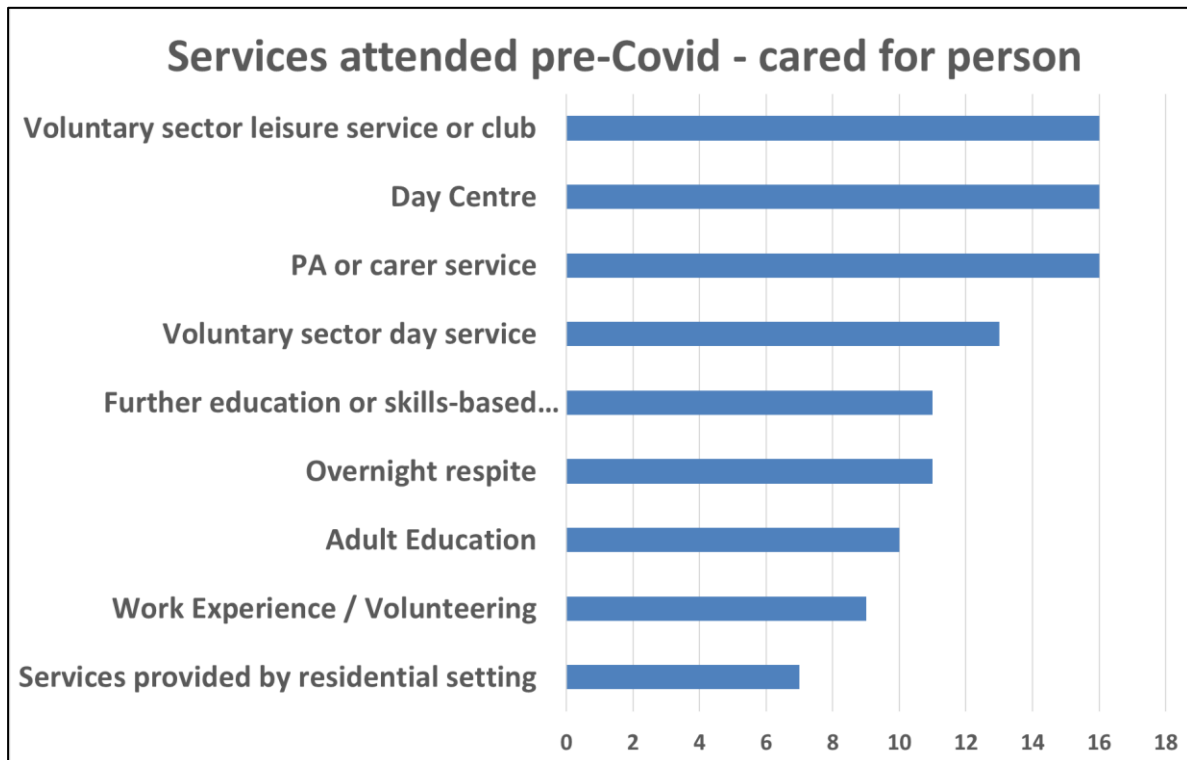
Caring duties before Covid	Number
1-19 hours	14
20-49 hours	29
50+ hours	19
No caring duties	3



3. Access to services

Services attended by cared for people before Covid broadly reflects the range of services available in the borough for adults with LD/ASD.

Only **2% of services attended pre-Covid are running as normal** (these are education settings for 18 – 25 year olds).

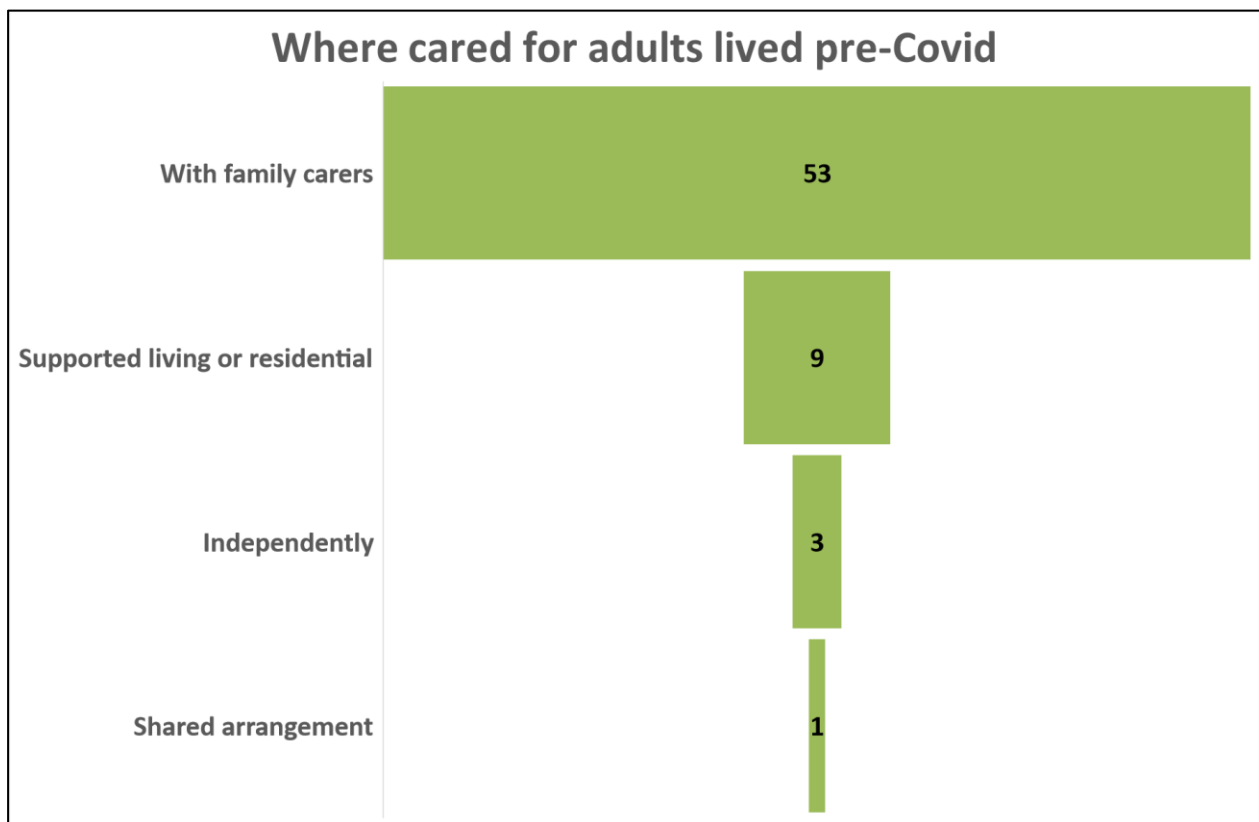


4. Independence

This increase in caring duties due to Covid is not simply due to reduced access to support and respite services. The needs and level of dependency of cared for adults with LD/ASD have also increased.

An indicator of this is the change to independence in the community described in section A above which exactly matches the data provided by carers for their own cared for adults.

However, changes to living arrangements have also impacted impact on caring duties. For example, 2 carers reported that their cared for person moved back with them, another is moving due to a bereavement, and one is looking after an elderly person who otherwise would be in a care home.



However, some adults with LD/ASD have had less access to family, particularly those who are shielding in a residential setting. A number of carers have not seen their cared for person for many months. One person said, *'services literally stopped once Downs were in the CEV group – I feel let down'*.

Carers also report an increase in overall dependency in the home, due to:

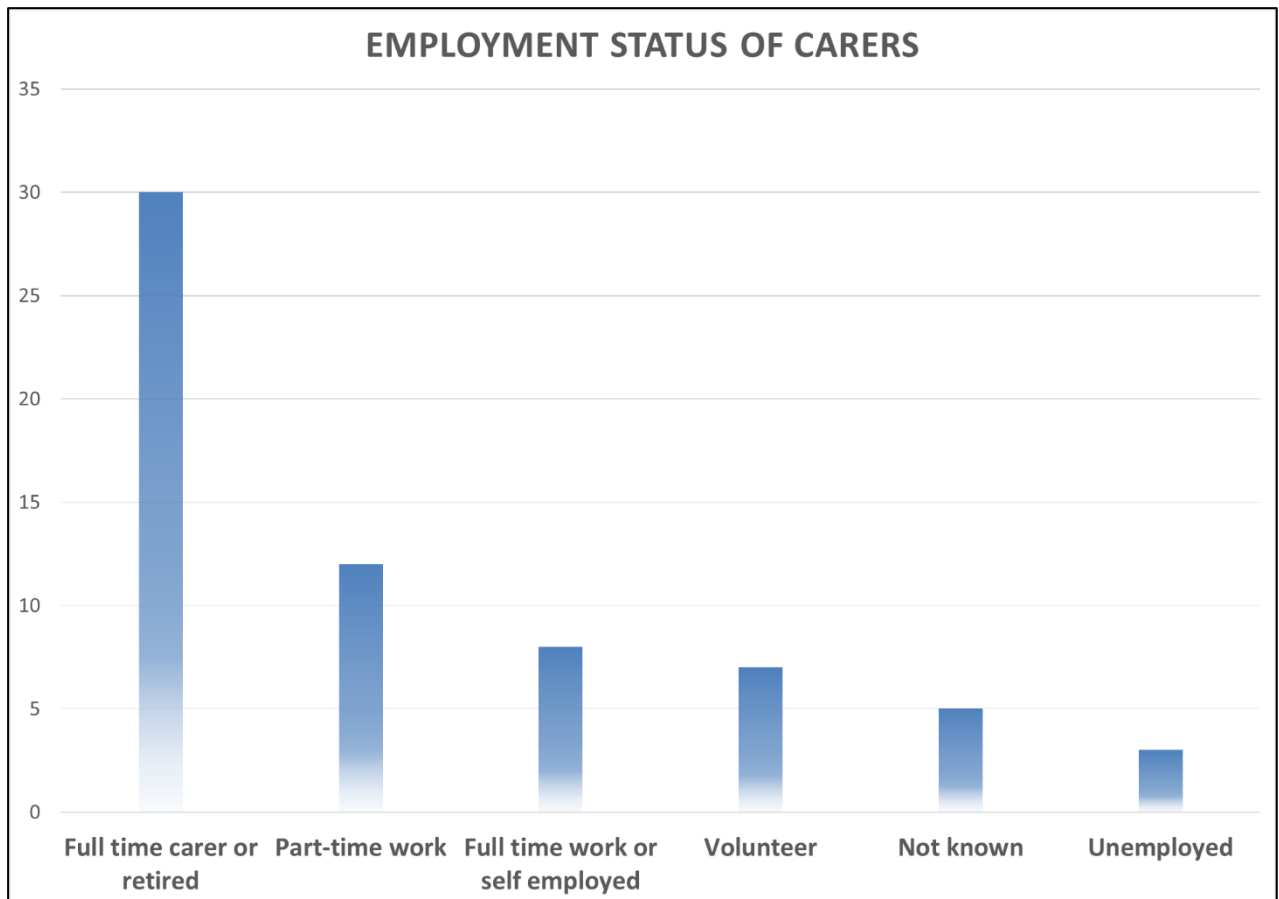
- A need for more emotional support (fear of Covid, confusion about change in routine, lack of sleep, obsessive or challenging behaviours increasing)
- A reduction in independent living skills such as cooking, cleaning, and self-care; being with family generates a greater overall dependency

As with independent travel, increased dependency may not be quick or easy to reverse after Covid and, for some, skills and safety awareness may need re-teaching.

5. Employment

In the UK, women are more likely to give up work to care and they are more likely to care for multiple family members such as an elderly relative or partner as well as a person with LD/ASD (Carers UK).

90% of our respondents were women with significant caring responsibilities. **Less than half were previously employed** or able to volunteer.



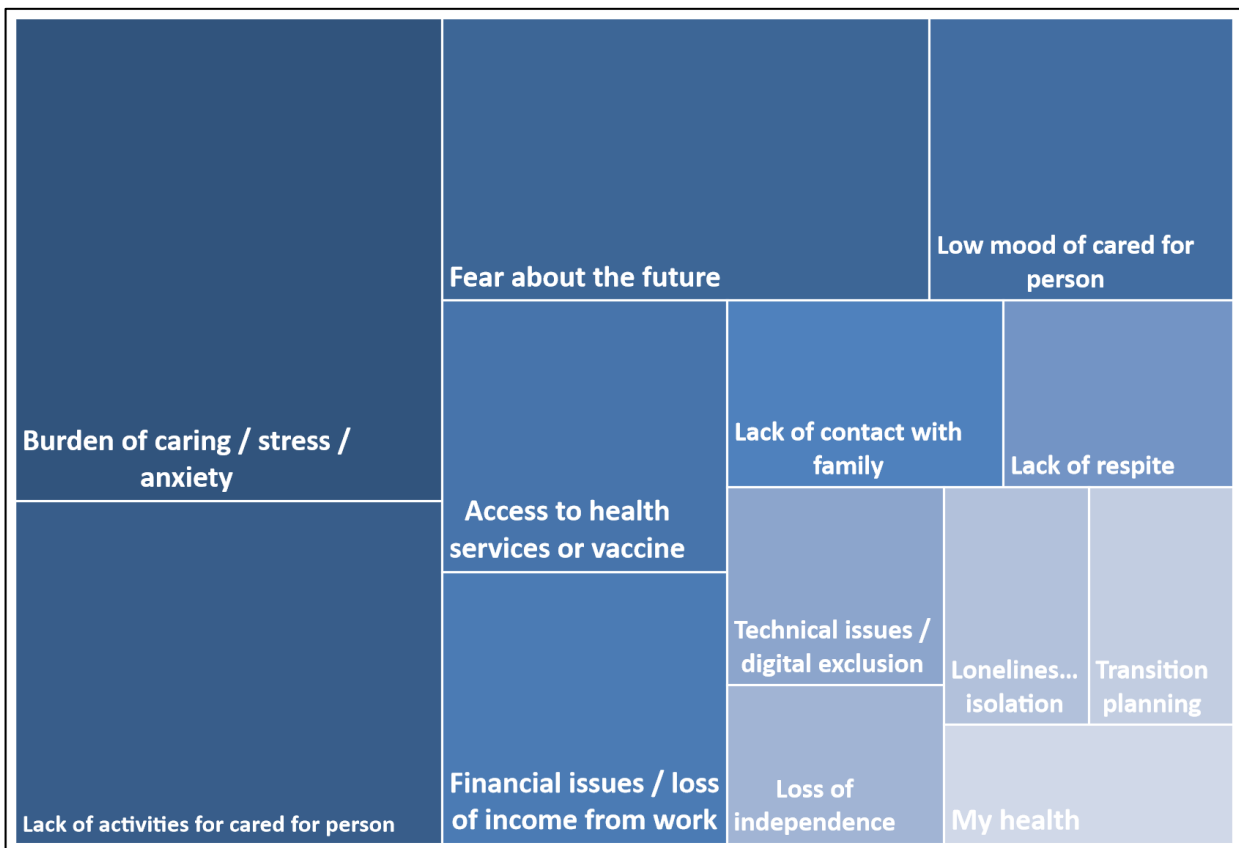
Of those who previously worked or volunteered, almost **1/3 have lost their role, been furloughed, or given up work to care** as a result of Covid. Covid is having an impact on carers' finances as well as increasing caring duties.

We recommend that carers are **supported to return to work** after the Covid period.

6. Main challenges for carers of adults with LD/ASD

Overwhelmingly, the major concern for carers is **burden of caring**, lack of activities for their cared for person, and lack of respite.

This is followed by fear about the future, poor access to health services, financial concerns, and the low mood of their cared for person.



We are also able to report the following challenges which give **cause for concern** despite being lower numerically than those above:

- Aggression, abusive behaviour, self-harm, or threats of suicide by cared for person (**7 families, 10%**)
- Daily struggles described as ‘*on the edge*’, ‘*daily struggle*’, ‘*nearly drained*’ or ‘*crying daily*’ or ‘*extreme loneliness*’ (**11 carers, 17%**)

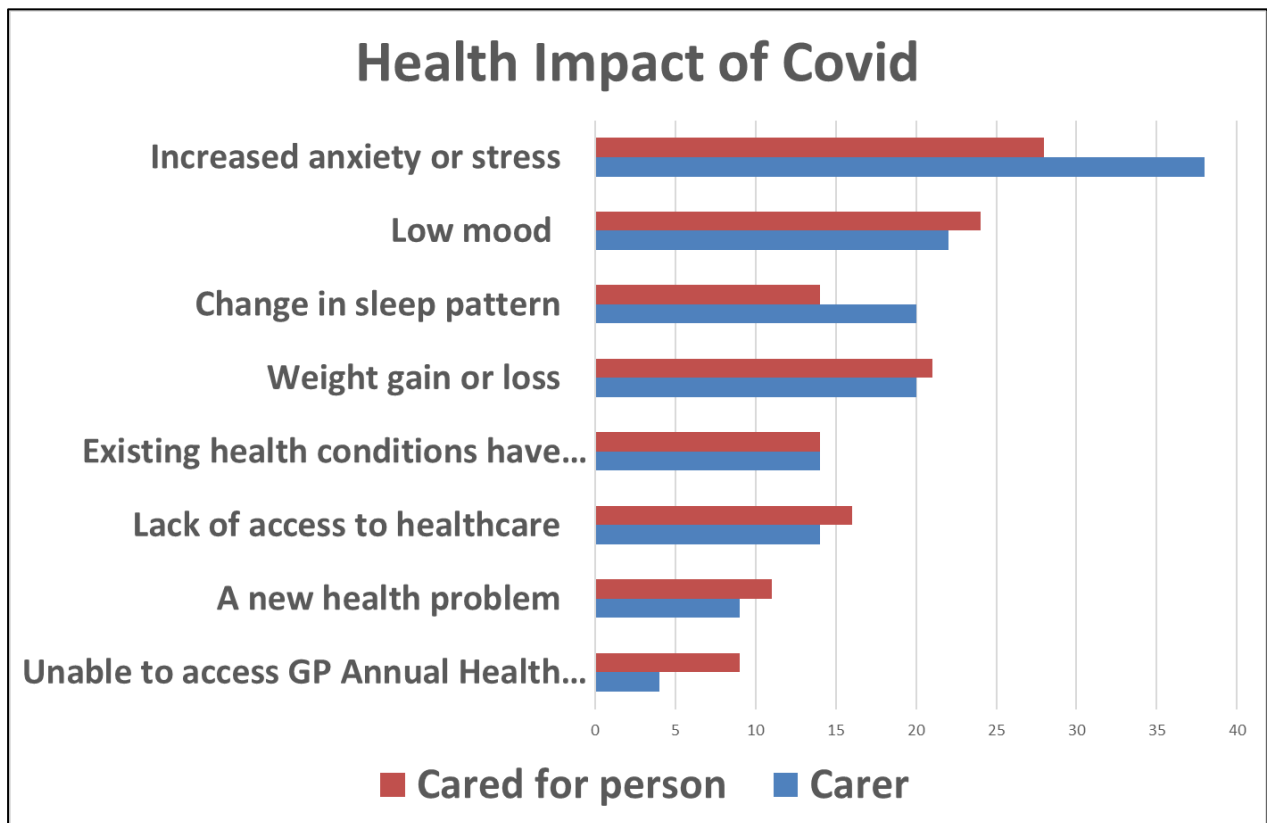
These concerns do not map directly to the types of support carers say they need now – see point 11 below.

7. Health

Whilst careful not to over-emphasise the impact on carers compared with the general population (e.g., weight gain, poor sleep is affecting many), we note that **almost half of respondents reported a significant increase in anxiety and stress**, or low mood.

Carers told us that this is **related to their increased level of caring**.

It should also be noted that carers’ lives during Covid are impacted by fear of their cared for person contracting Covid, not just because of the medical risk, but also because people with LD/ASD are extremely fearful and vulnerable without access to support e.g., in a Covid hospital ward.



Other health experiences were:

- Cared for person having falls / person with epilepsy isolating alone in their room
- GP refused to register cared for person who had moved back home
- GP health check over the phone was not successful (3 carers) or form sent to cared for person mentioning risk of earlier death
- Back issues due to moving and handling of cared for person home (4 carers)
- Alcohol consumption (of cared for person)
- Incorrect medication prescribed
- New blood clotting disorder
- Long waits to access GP / no answer from GP / hospital checks cancelled

8. Vaccinations

9 parents or carers were uncertain about having the vaccine and **14 carers** thought their **cared for person** may not be able to have it. The main reason for cared for people was needle phobia. The main reasons for parents and carers were that the vaccine is unsafe, has not been fully tested in BAME communities, or religious reasons. These are smallish numbers but nevertheless warranted action – see Support Provided, section D below.

9. Support received

The good news is that a wide range of support services have been available to carers. We have a sense that people who received good quality support were grateful and even pleasantly surprised at times.

Some comments we received about supported living, day centre, and NHS staff were glowing, such as *'life savers'*, *'they were just like a real family'*, and *'we couldn't have asked for more'*.

There were **very few carers** who have not received any support at all.

Merton Mencap	Carer, Support Worker, Keyworker, supported living staff	Phone calls	Family	Friends			
	Voluntary sector services and clubs (Guild, PHAB, Baked Bean, Keen 2 Go)	NHS / CCG / Vaccine Staff	Learning and education staff	LD Team Nurses & Psychologists	Day centre / Respite staff		
Social care / direct payments team	Parent Forums	Carers Support Merton	CAMHS / Springfield / Uplift & other mental health services	Benefits service	Age UK		
			Local community	College	Meal delivery	Police	Learning disability nurses St Georges Phar...

10. Ease of access to information

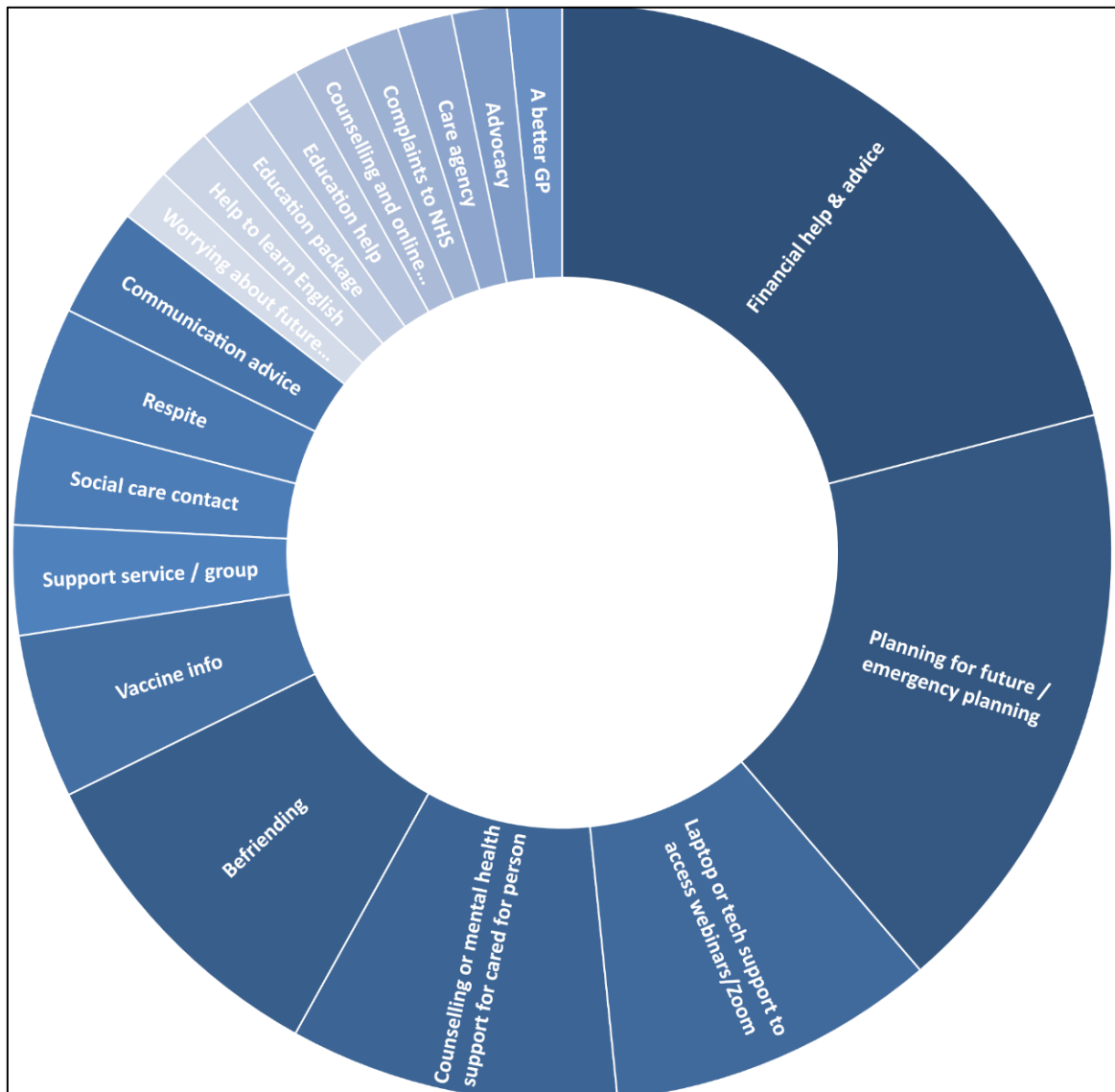
Carers told us that the easiest information to find and understand was from the NHS and local health services, whereas the hardest to understand was Government information.

9. Positives

39 carers (66%) said there are no positives of Covid. 5 said they learned new digital skills and 4 mentioned Zoom sessions for their cared for person.

Their responses are consistent; it is clear that the increased burden of caring dominates and overshadows everything else.

11. Support needed now



Much of the support requested by carers is available via:

- Merton Mencap’s LD Support Advisor (emergency planning, financial advice/small grants, signposting to befriending and counselling services)
- Adults First parent forum (planning for the future, wellbeing seminars)
- Carers Support Merton (digital support project)
- Age UK which offers a befriending service

Merton Mencap also offered support for other items in this list in recent weeks as part of phase 1 of this project – see Support Provided, section D below.

A.3 Results: parents of children or young people with a learning disability and/or autism

1. Profile of respondents

80% of respondents were female, 9% male and 11% preferred not to say. A female-dominated response as for carers of adults.

Respondents live in all parts of the borough with an even spread between postcode areas. Ethnicity was also comparable to carers of adults, with 61% from a white background.

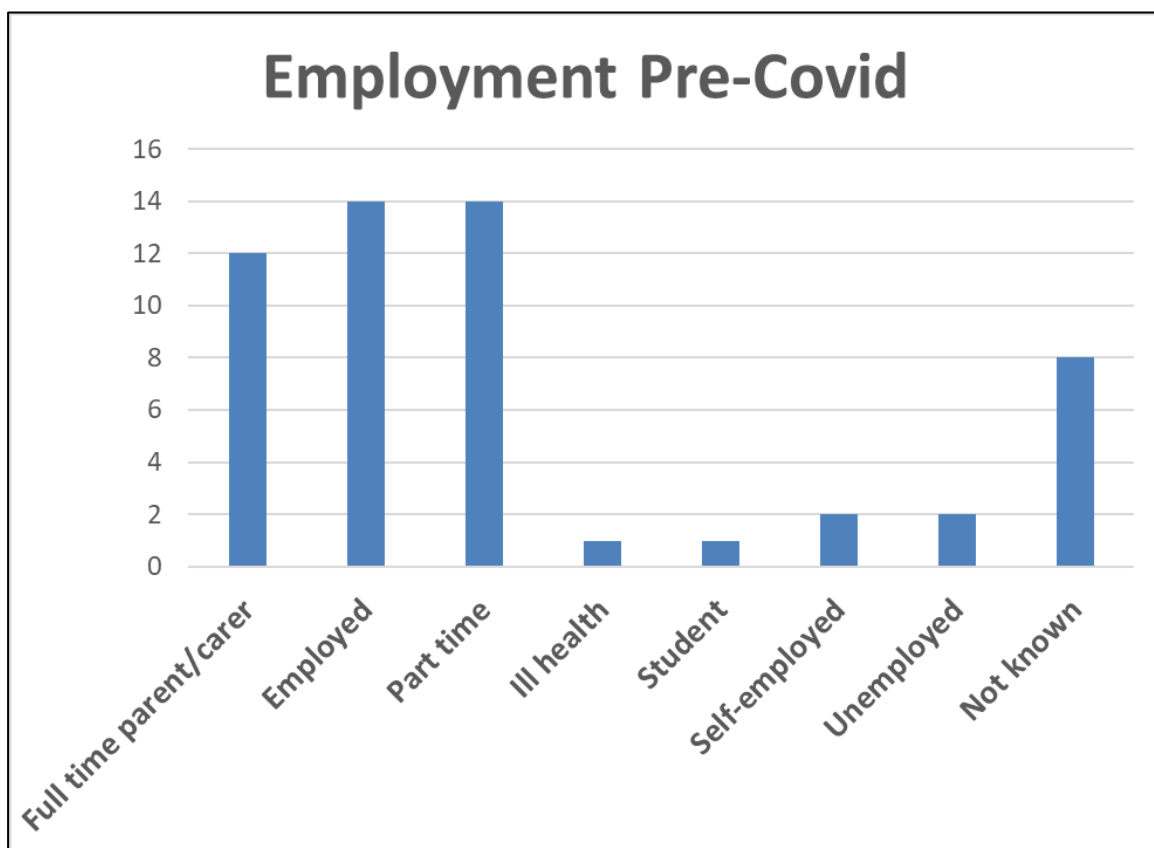
Unlike carers of adults, 70% of our respondents were part of a household where parenting duties are shared, only 9% were single parents (11% did not answer).

50% of respondents' children were secondary school age, 30% primary school age, 10% 6th form age, and 10% unknown.

50% of respondents' children attend special schools, and 50% attend a mainstream school or other setting.

2. Employment

Unlike carers of adults, **the majority of respondents were employed full or part time**. Of these, 8 (15%) have been made redundant or reduced working hours to care or home-school their children. 2 are working more because they are NHS front-line staff.



3. Type of disability or additional needs

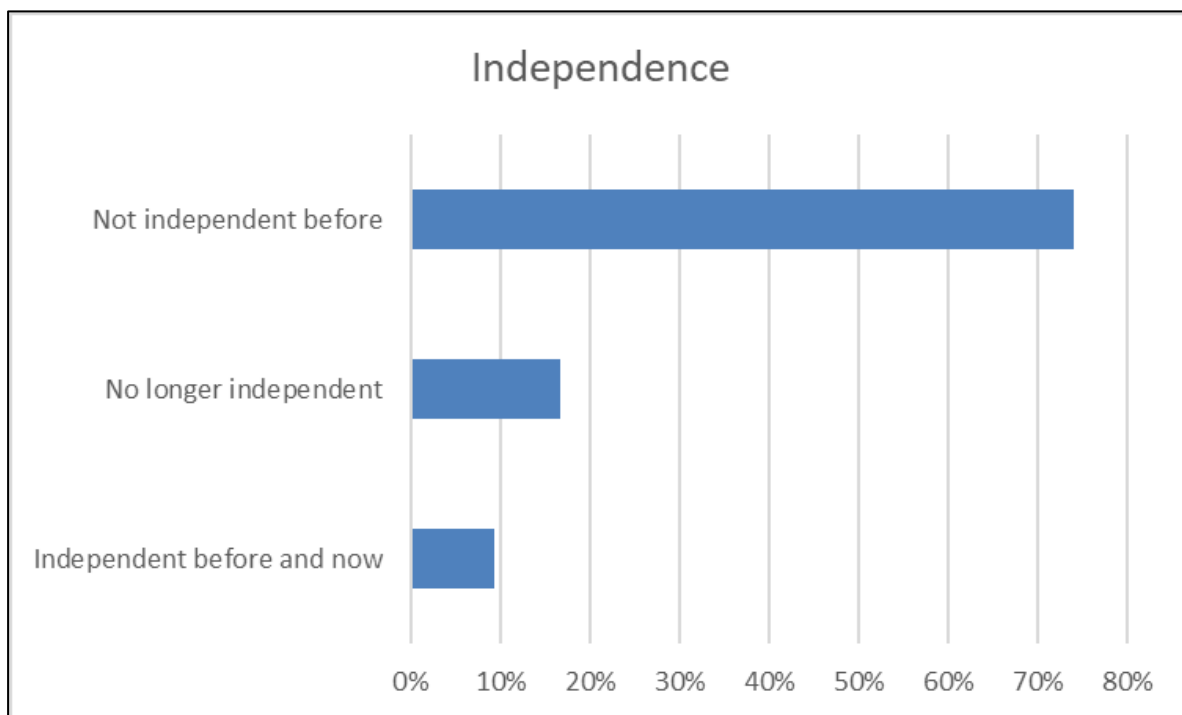
26% of respondents have children on the autistic spectrum and 33% have children on the autistic spectrum with an additional diagnosis of ADHD or another mental health condition. The remaining 24% have a moderate, severe, or profound learning disability or chose not to disclose the information.

This significant bias towards parents of children with ASD and/or ADHD does not reflect our communication channels (Kids First, Perseid School, and parents of children known to Short Breaks who primarily attend Cricket Green and Perseid Schools).

It may be that Covid has had a disproportionate impact on families of children with hyperactivity issues, sensory, or mental health issues; those who rely on regular physical activities to remain calm, focussed, able to manage their anxiety and self-regulate their emotions and behaviour. Some children with ASD have been severely affected by Covid fear, refusing to leave their room without a mask, developing obsessive hand-washing habits, or becoming withdrawn or shutdown.

5 respondents have multiple children with special educational needs or disabilities.

4. Independence



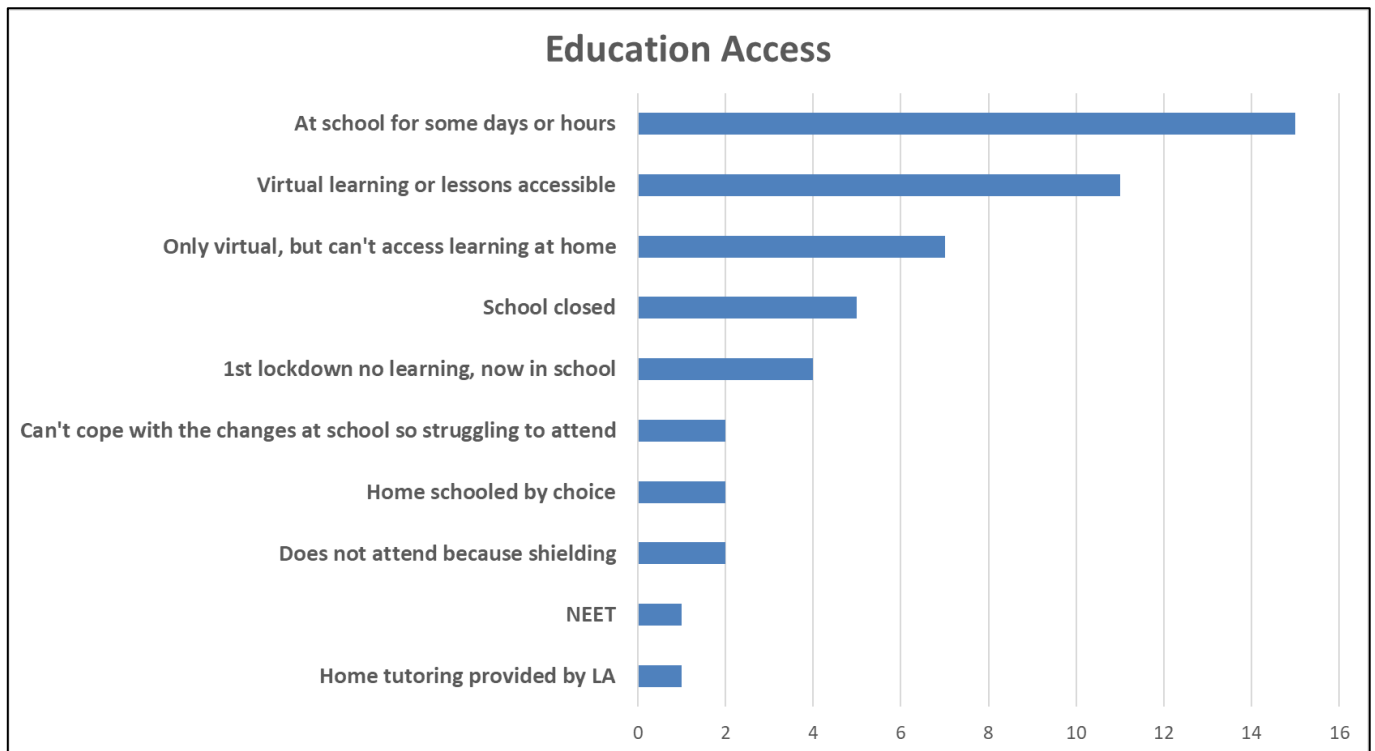
Children would be less likely to be independent travellers due to age. However, there is a similar pattern to adults with LD/ASD, namely, of those who were semi-independent before, 2/3 are no longer independent.

5. Education

The situation has now changed as children are back at school.

Attendance has been patchy during Covid with none of our respondents saying that their child has consistently accessed school.

(Rules and implementation of Government guidance regarding access to school during lockdown 1 was heavily criticised, but this was a national rather than a local problem and was corrected for lockdown 2).



7 parents stated that their child cannot access home learning at all.

11 parents consider learning one of the major challenges of Covid and are concerned that their child has fallen further behind their peers or has accessed little real learning during Covid.

Again, this is a national as well as a local challenge.

6. Main challenges for parents

Apart from parental concerns about learning and access to education support which are highlighted in yellow in the table below, parents' main concern is their child's emotions and anxieties, or challenging behaviours.

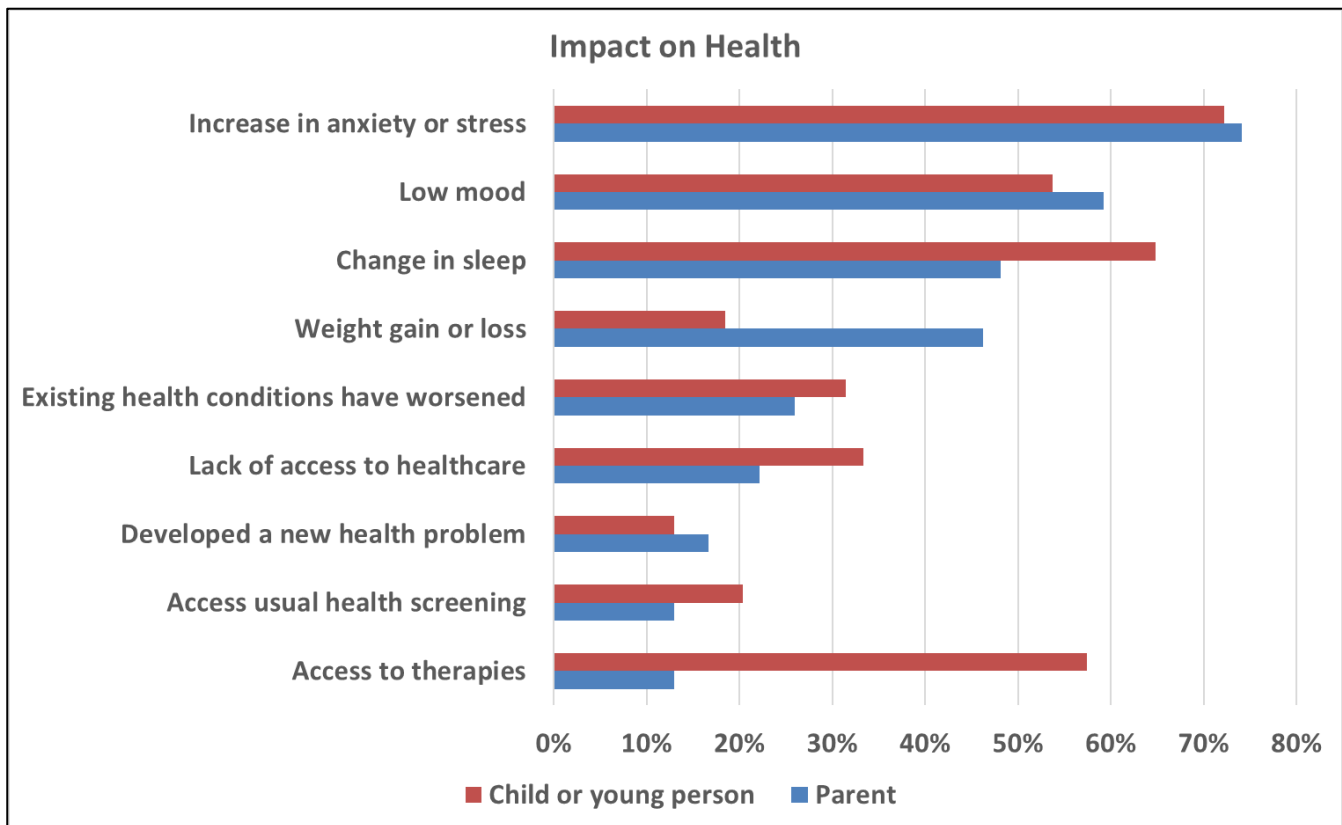
Although some are summarised and grouped, we have also left many individual concerns in the list below to show both the variety and critical nature of the issues.

Challenges	Number of respondents
Child's emotions/anxiety or mental health (2 alerts re. self-harm)	15
Lack of support from services/schools and therapies	13
Anxiety or exhaustion (breaking point)	13
Child's worsening challenging behaviours	12
Anxiety about returning to normal / child's lost skills	11
Parent's isolation - not going out, feeling trapped	9
Change of routine difficult for child	8
Lack of respite	6
Finance or job worries	6
Child's social isolation	5
Education disruption / falling behind	5
Home schooling	4
Keeping child entertained or engaged in learning	4
Child's fitness	3
Too much screen time	3
Child not sleeping	3
Access to health services	2
Child unable to access virtual learning	2
IT challenges	2
Impact on siblings	2
Uncertainty	2
Shielding while health & care staff support family / risk presented by children who can be challenging being confined together	2
Had to engage social services for help	1
Had to report child as missing person	1
Child become involved in drugs	1
Emergency planning	1

A small number of parents and carers of young people/adults with **autism and a severe Covid-related fear** have expressed concern their person has withdrawn into a completely virtual world, normally in their bedroom. Parents are concerned about lack of safety, lack of physical exercise, loss of social skills, and worried that face-to-face social skills may not return.

7. Impact on health

Reflecting the cohort of respondents (children with ASD or ASD and mental health issues) a significant concern is the child's anxiety, low mood, or access to therapies.



The individual examples below bring these figures to life and show why parents' own levels of anxiety and stress tend to be high.

- More medication prescribed by CAMHS due to raised anxiety / increased sleep medication
- Aggression increased
- Child has serious Covid fear / OCD due to Covid fear / Anger about Covid
- Debilitating anxiety and panic attacks
- Can't get tablets or a repeat prescription / can't go to the dentist
- Meltdowns because of changes to routine
- Won't take ADHD medication and now hard to keep him indoors
- Epilepsy much worse
- Child won't leave house due to Covid fear, and now has rashes
- Teenage daughter started to self-harm
- Loss of all my support networks and child is suffering
- Support network gone and I feel isolated
- Stress and depression causing hair loss, back pain and unable to sleep

8. Support received

Although we have heard of a few examples of poor practice, we received **positive comments about support provided to families by Merton schools and colleges.**

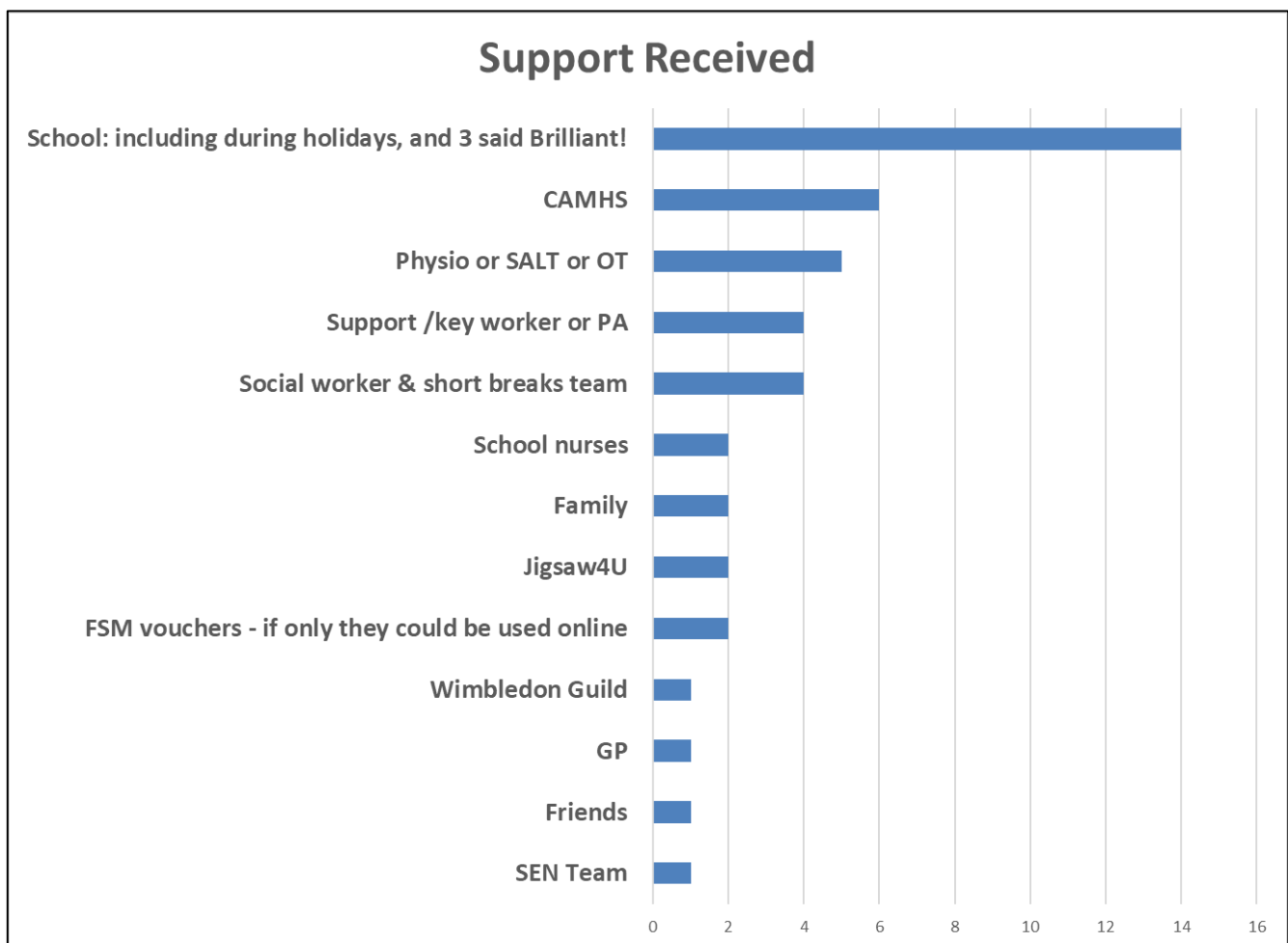
There is no doubt that, without such help and care from education settings, the situation in Merton could have been significantly worse for families.

Example:

Perseid school offered use of their playing field for families who live in flats so they could come out and exercise together in a safe space. They also provided technical IT support, when needed, and helped parents to learn how to teach and support their disabled child.

Merton College's Aurora Centre (for students with severe learning disabilities) recently started to offer drop-in support sessions for parents.

Many schools checked in with children and young people at least weekly.



For those already known to **CAMHS**, parents had nothing but praise, but there were concerns from those whose child is **not eligible**. Services which offer therapies by phone, online counselling, or via apps can be excellent for some young people but are not necessarily specialist enough for young people with disabilities/SEN.

[Merton Mencap and Kids First also received praise, but we don't need to be added to the busy chart]

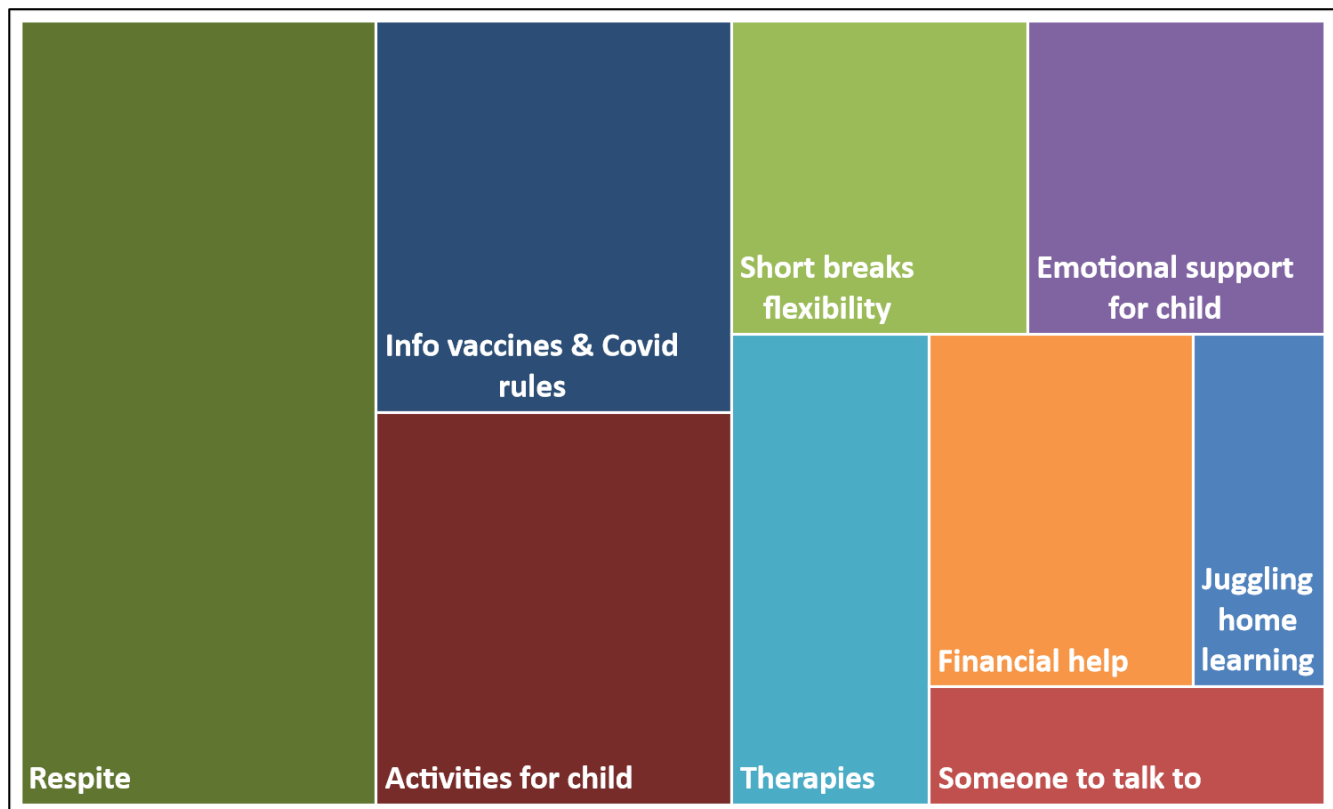
9. Support needed now

Respite and activities for the child or young person are the main things parents need, similar to the needs of carers of adults.

Financial advice and support, and loneliness are also issue for parents.

Information about vaccines and Covid rules was provided by Merton Mencap as a result of this feedback (see Support Provided, Section D below).

Many parents talked to us about the difficulty of juggling their teaching time and splitting attention between their children, **many feeling they were neglecting their neurotypical child**. We are concerned that siblings of disabled children may have fallen behind their peers educationally during Covid. Organisations such as UCL’s Institute of Education and the charity Sibs have published information about this (see Reports, Section E below).



We received a few comments about Short Breaks, some grateful for services which continued to run or for the flexibility offered, but others asking for more flexibility in the they can use a direct payment.

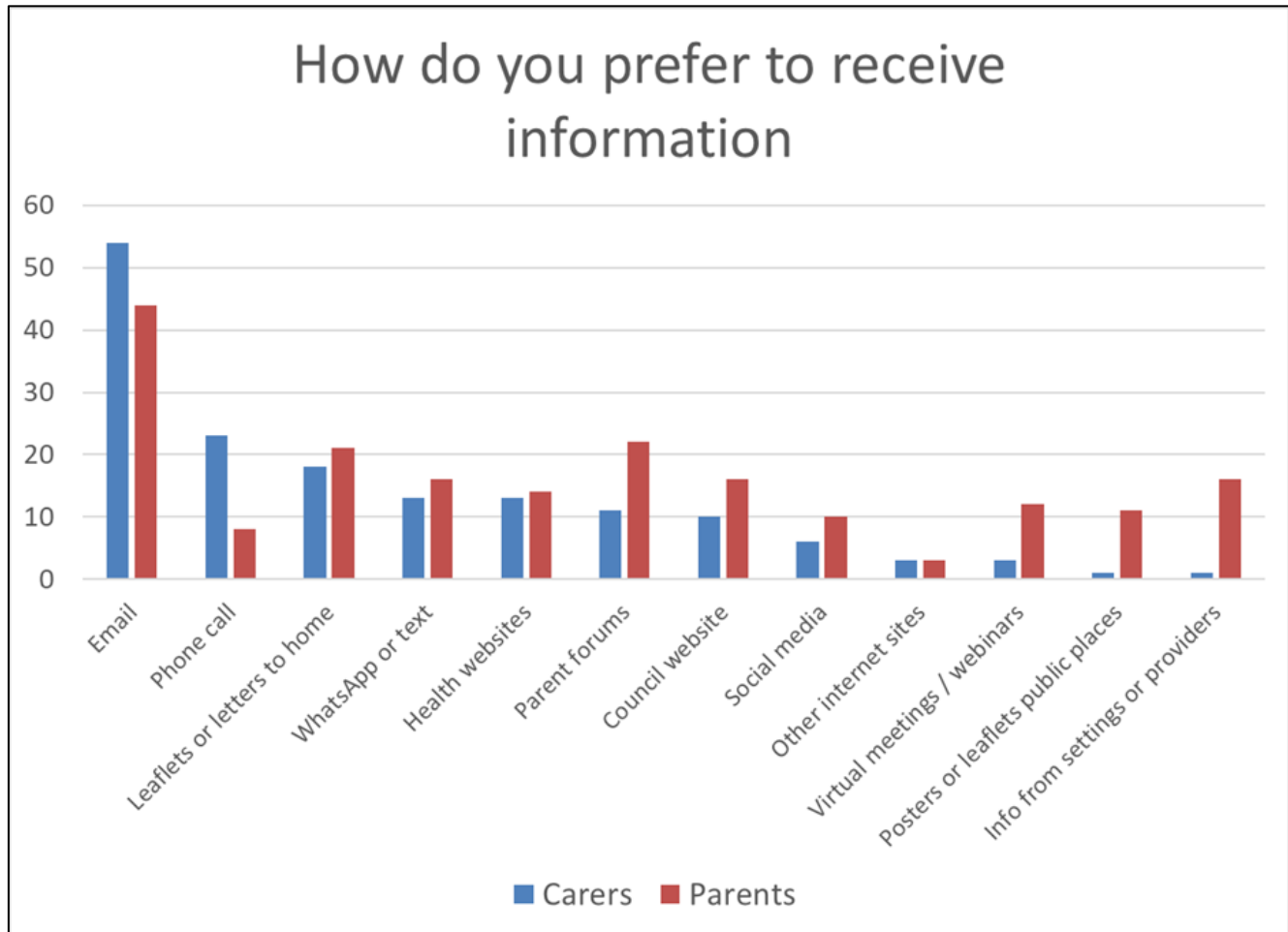
10. Access to public information

The same pattern emerged as for carers of adults. NHS information is most easy to find and understand, followed by local health information. Local Authority and Government information was the least accessible.

11. How to receive important health and service information

Parents and carers prefer email if they are online, otherwise letters, phone calls or information via parent forums. Parents also value information from schools.

Multiple communication channels are required.



SECTION B DIGITAL INCLUSION

1. Background and research

According to the latest UK Consumer Digital Index (2020) 16% of the UK population are unable to use the internet by themselves, around 7% are offline completely, and 22% have basic or no skills (digitally poor). Of those with poor skills, more than a third say nothing would persuade them to go online.

Those most likely to be offline or have poor digital access are in the following groups: over 70s and to a lesser extent the over 50s, people with an impairment, people with an annual household income of less than £17,400, women, and benefits claimants.

According to carers UK, 72% of claimants of carers allowance are women (Carers UK) and 60% of carers caring for over 50 hours per week are women.

Carers are likely to be in 4 out of 5 of these digitally vulnerable groups which we suspect puts them at the highest risk of digital poverty or exclusion.

Cared for adults are in the 5th category (those with impairments) and also tend to be benefits claimants. This also an aging group with more disabled adults now expected to live beyond their 50s and 60s.

Digital skills can be a lifeline for people, especially at this moment in time because of Covid. The Consumer Digital Index 2020 states that the lifestyle and well-being benefits of digital engagement are:

- 87% - helps them to connect better with friends and family
- 84% - helps them to organise their life
- 55% - helps them to feel more part of a community
- 44% - helps them to manage physical and mental well-being

Carers UK say that **8 out of 10 carers have felt lonely or socially isolated** as a result of their caring role and this rises to nearly 86% of carers providing 50 hours or more a week.

The Carnegie Trust reports that motivation is one of the major barriers to digital engagement, people need a personal 'hook' to become internet users, and people prefer to be supported by family members or friends.

2. Our aims

We were aiming to test whether these findings apply to Merton carers and cared for people, and if there are specific barriers to digital participation amongst our population or specific solutions which can be put in place locally.

We were also interested in the digital life of cared for adults with LD/ASD and relationship between this and the digital skills of their carers.

Finally, we wanted to know if parents have a similar or different level of digital inclusion to carers and cared for adults.

3. Digital access

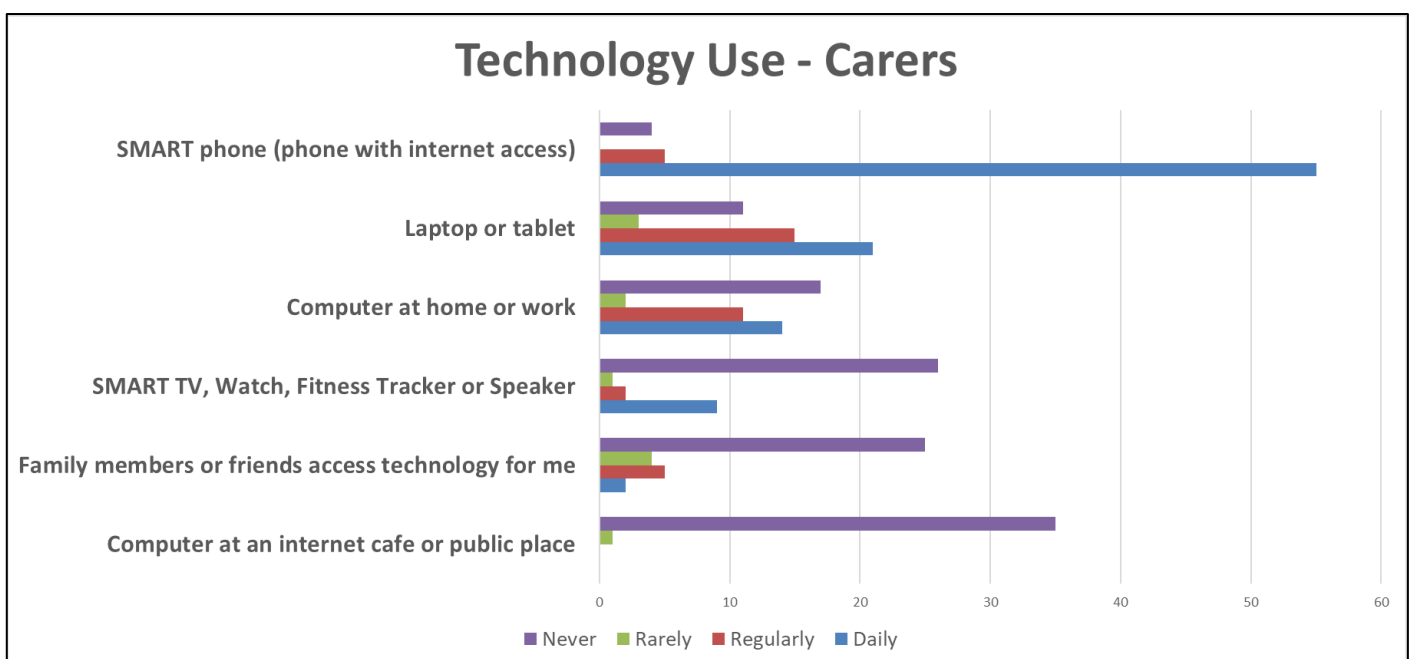
The group with the lowest overall functional internet usage is **carers of adults with LD/ASD of whom 36%** have basic or no digital skills, significantly higher than the national average of 22%. **2/3** of those with basic skills or non-users **do not feel they are missing out** (the figure national figure for people in the same situation is 1/3).

90% of respondents with LD/Autism are internet users, many of whom receive support from family members or staff. This support includes turning the equipment on, selecting websites or apps, or being supervised for internet safety reasons.

The most digitally accomplished group are parents of children or young people. Those whose children have a learning disability are equally as digitally skilled as those whose children on the autism spectrum or have other conditions.

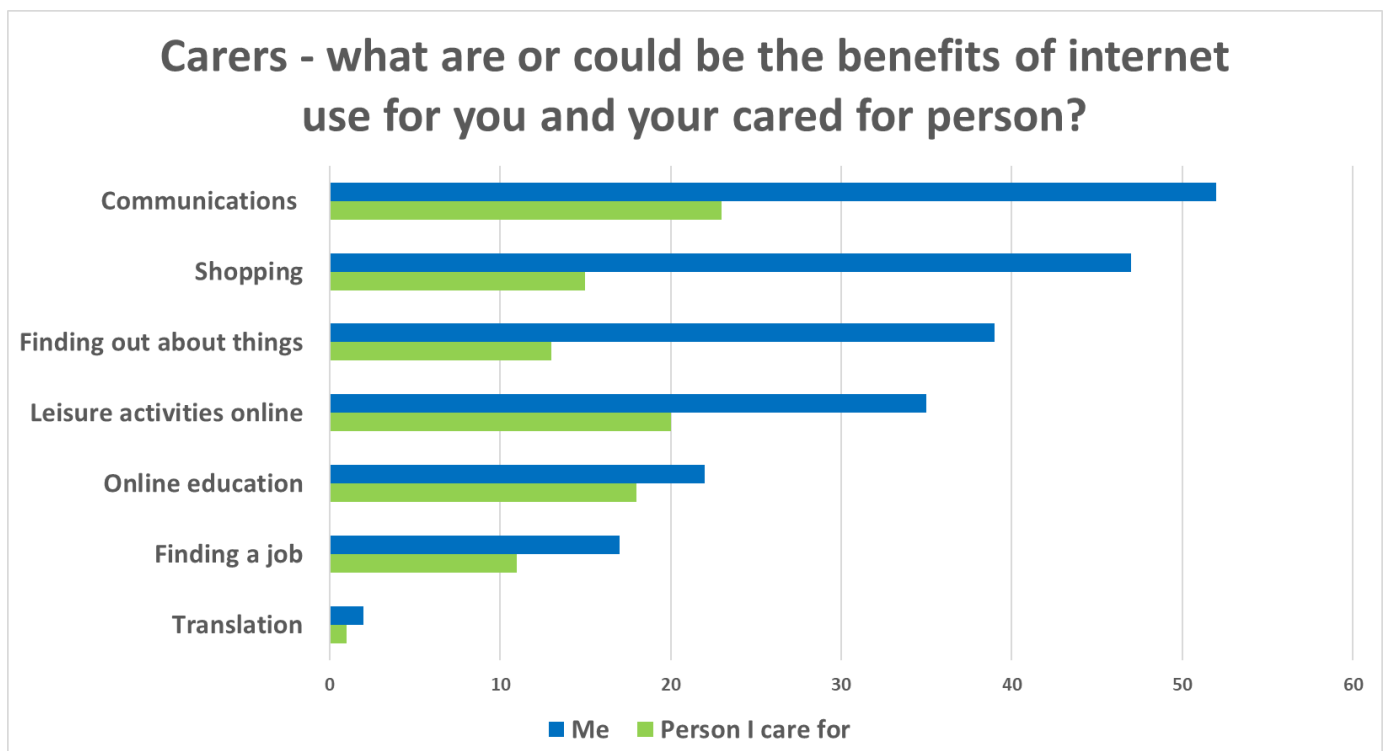
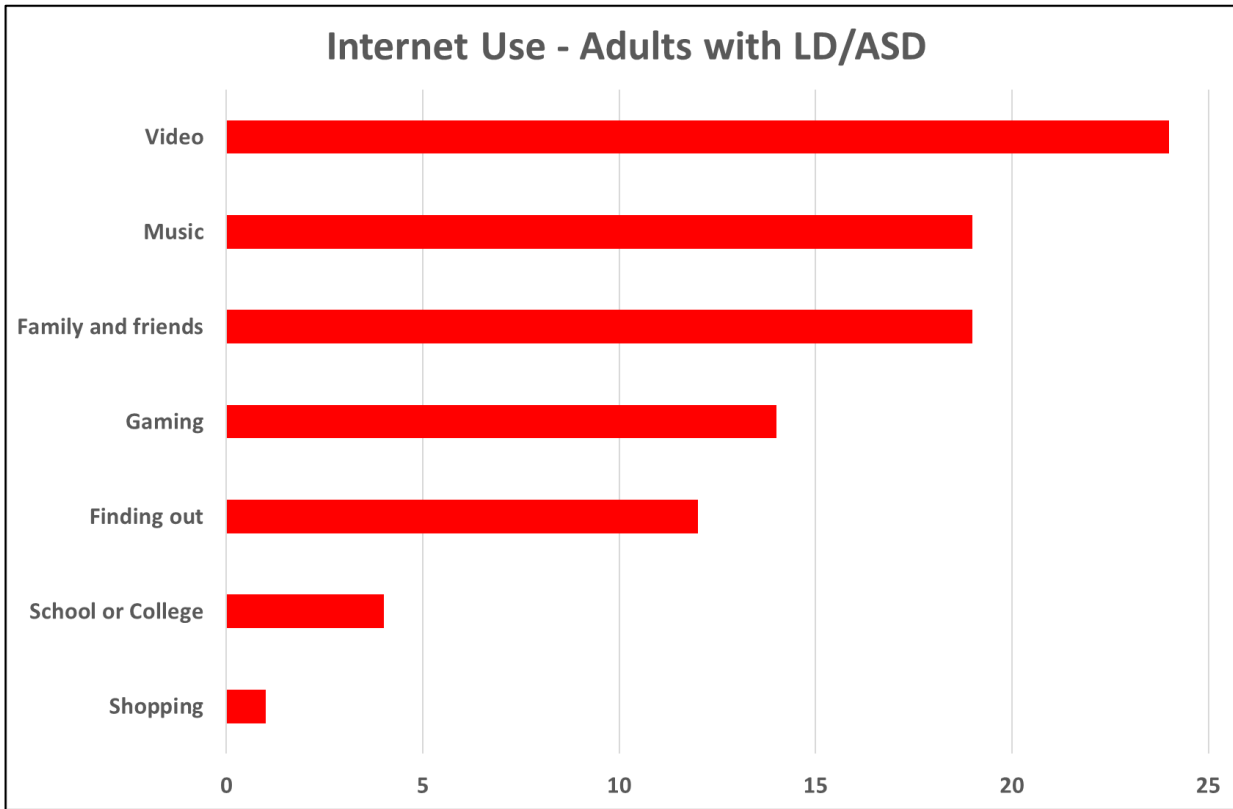
	Functional & independent internet users	Accesses internet with support	% of non or basic users who wish to use it more	Non-users who have no interest in becoming users
People with LD/ASD	53%	37%	Not known	Not known
Carers of Adults	47%	17%	33%	3%
Parents of children and young people	91%	0%	9%	0%

By far the most common equipment used by both carers and adults with LD/ASD is a SMART phone, followed by a tablet or laptop. Very few use a SMART watch, TV, or tracker (unlike parents, who use most of the tech available).



4. Purpose of internet use

Having found that carers are digitally excluded or digitally poor (36% having basic or no skills compared with 22% of the population), we compared the internet usage of carers and their expectations for the person they care for with the responses which were directly from people with LD/ASD.



Carers are likely to be excluding their cared for person from digital access, but for a number of reasons:

- **Skills:** many do not have the necessary skills to teach the person they care for to access the internet, set up the functions they want, or ensure safe usage
- **Divergent interests:** carers' own use is predominantly 'purposeful', getting the shopping, emailing people, accessing support services, or looking things up. Although adults with LD/ASD are more likely to enjoy using the internet video, gaming, music, social groups and virtual activities, carers do not reflect this in their responses on behalf of the person they care for. Some carers are simply not aware of these alternative uses, having not accessed them personally
- **Finance:** to provide access to online entertainment or indeed learning access, it is likely to require more than a SMART phone which is the way most carers access their email and browse internet sites. It costs money to join Netflix or to buy a machine which supports streaming and downloading
- **Funding an internet service:** many carers rely on their cared for person's benefit income or manage their cared for person's benefits (even when they live in supported living or a care home). In supported living, each resident purchases their own internet contract and some carers do prioritise internet service over and above essential items, feeling perhaps that this is a luxury rather than a basic need, or for capability reasons (see below). This was mentioned to us by both carers and professionals
- **Assumptions about capability:** many carers find technology daunting so it not surprising that they doubt their cared for person's ability to use the internet. They assume that it requires literacy, motor skills, technical understanding, and problem-solving skills (perhaps true for their own 'purposeful' internet activities)
- **Poor awareness about assistive technology:** much assistive technology is now built into standard computers or platforms like Google, others are available via apps or free downloads. Assistive hardware can be sourced cheaply or borrowed, such as large, tactile keyboards. Awareness of technology is generally poor, despite being helpful for both aging carers and their cared for persons

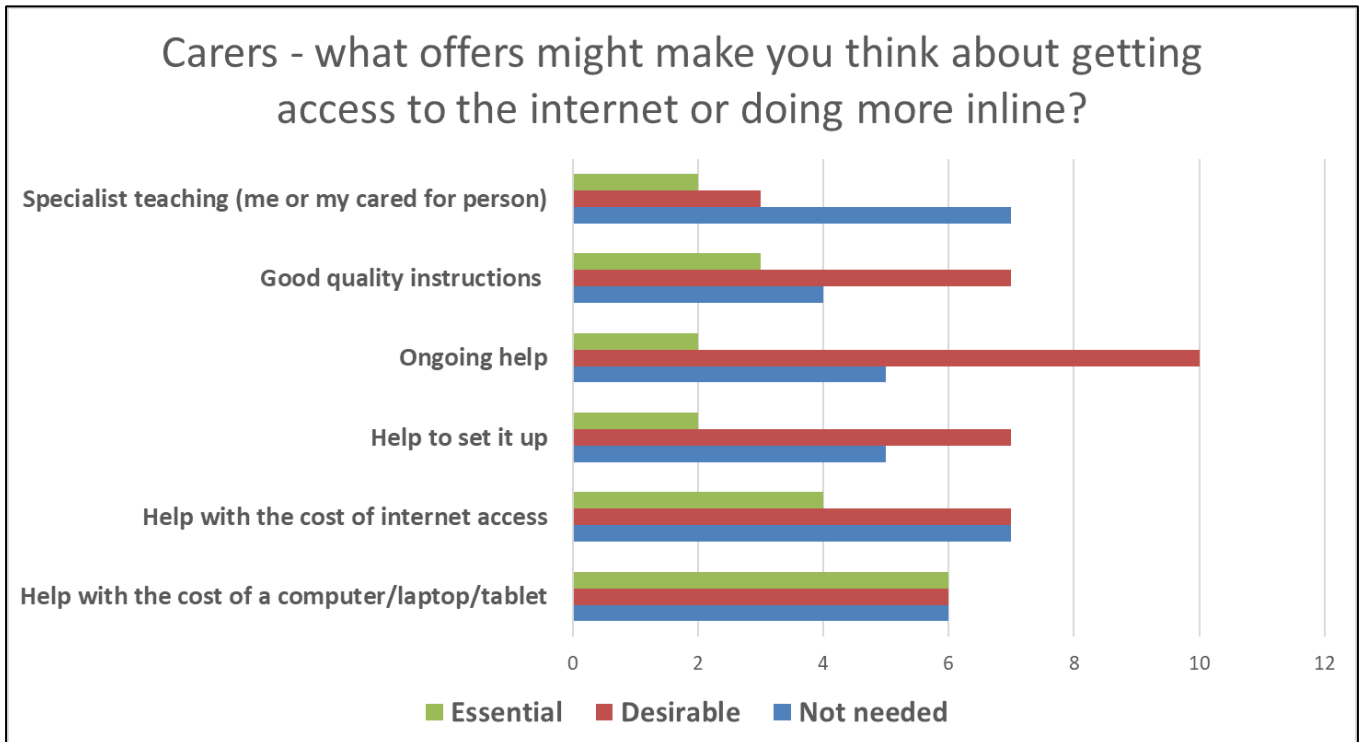
One carer stated, '*she just doesn't have the mental capacity*', another said '*he doesn't need it, as long as he has his TV, he is happy*', and one carer said, '*we have only just weaned him off videos*'.

On the other hand, carers whose cared for person has daily access to the internet tell us that this an essential part of their lives.

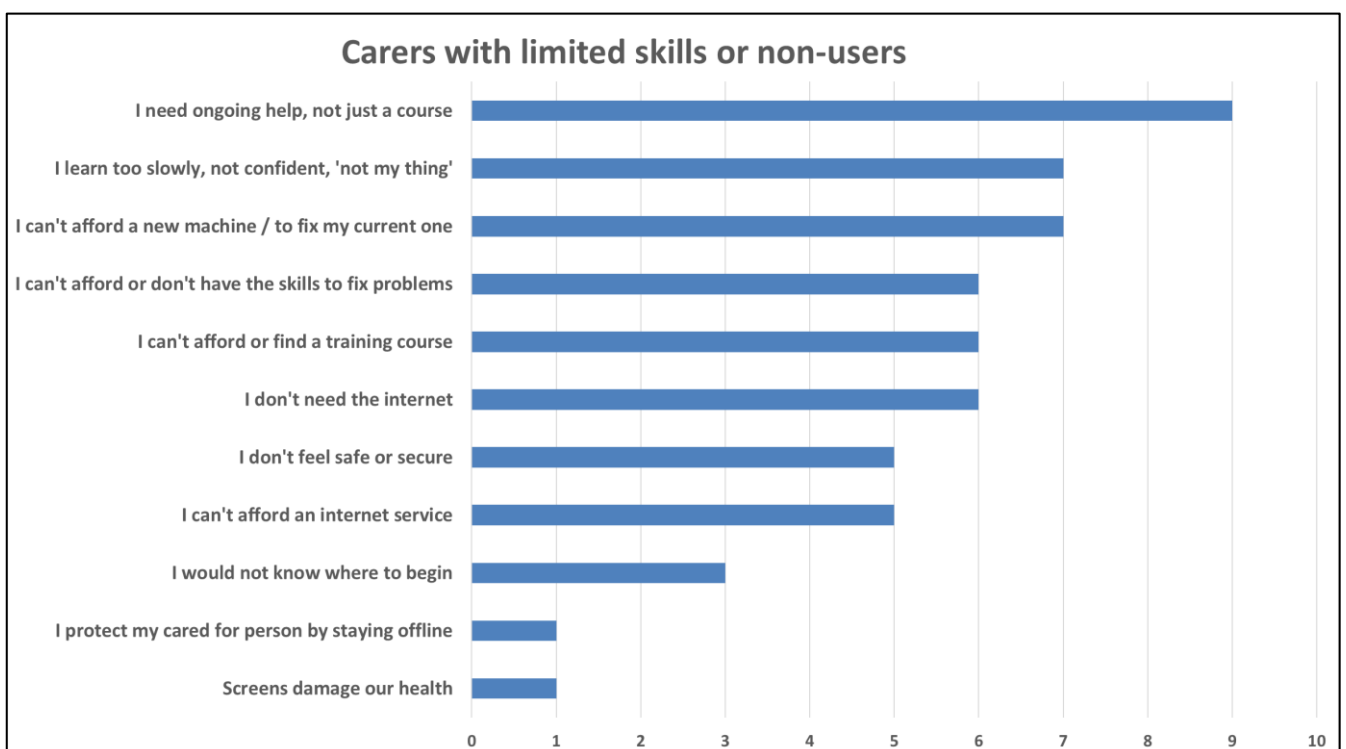
Gaps in internet usage: even people who use the internet extensively, may need support to extend their usage in ways that could be important for them in the future. For example, in special schools, children are all digital to some degree and enjoy gaming and YouTube. Although they access online learning and meet with teachers and therapists online, many **do not appear to use the internet for keeping in touch with peers.**

5. Solutions for non-users or basic users

Whilst **help with costs** is essential for many, the most desirable was **ongoing help** (hand-holding), help with set-up, and good quality instructions. Lack of need for specialist training may reflect carers assumptions about capability of their cared for person, or may suggest reluctance to seek external help or a formal course.



When we asked those with poor digital skills or non-users for their agreement or disagreement with a set of statements, the need for ongoing help was reinforced, and other barriers were also highlighted.



33% of carers who are basic or non-users, stated they would need ongoing help, but many went on to say that there are additional barriers such as online safety, training, being too old and so on. Overall confidence amongst this group appears to be low.

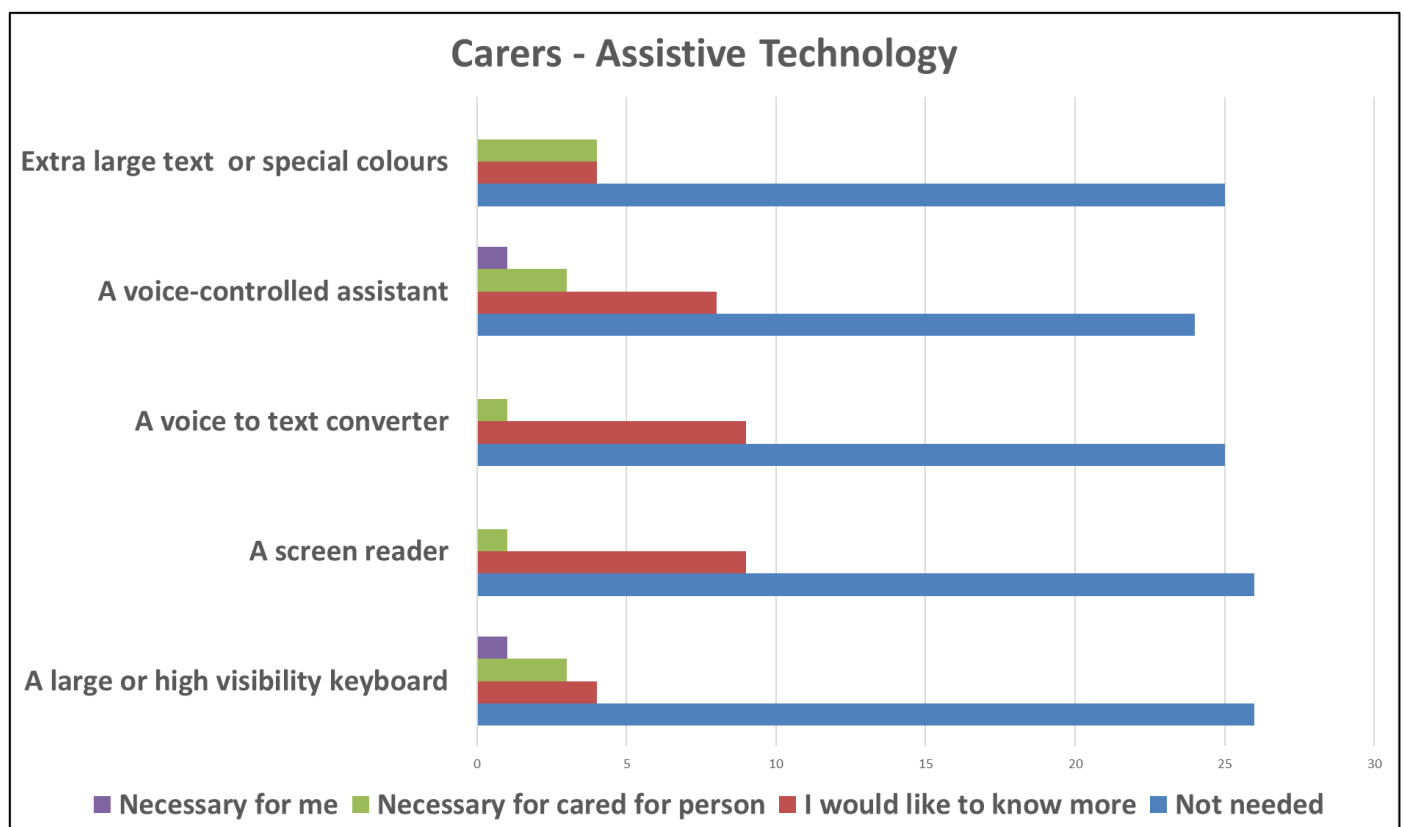
We note that Merton libraries offer hands-on support to help people with digital skills, therefore it may be possible to expand/adapt or publicise this service more to for carers once they reopen.

6. Assistive technology or specialist training

We asked all carers if they or their cared for person need or currently use assistance to use the internet.

There was some appetite for knowing more and few acknowledged that these are or would be necessary for their cared for person, but virtually no carer believes they might benefit from this themselves. Even the easiest options to understand, such as large text or a high vis keyboard, were not selected.

We suspect that this is due to **lack of awareness**, or fear of higher costs or complexity.



7. Previous technical help (carers who are basic or non-users)

Sadly, only 1 carer has been on a course, which they said was 'OK', and 1 carer received free equipment which was also 'OK'.

9 carers said they have received 'good' or 'OK' technical support from family and friends.

3 carers said their cared for person received support, 1 of which was 'poor' and 2 'OK'.

In line with findings by the Carnegie Trust, carers appear to value support from family or friends over other types of technical help.

8. Professionals

Professionals tell us that they do not feel fully equipped to advise clients or carers about digital options, help to set them up, access assistive technology.

Supported living/care home staff often help residents to use Zoom and to access simple games on their tablet, and these efforts make a real difference to people's lives. However, some people do not have an internet service, and those who live independently or with a family carer may not have access to any appropriate support.

Not all digital users are automatically experts at supporting others.

9. Additional points

- Merton Mencap's own data support these findings (67 of our 774 parent forum members do not have an email address and 34 family carers of our service users do not have an email address).
- The barriers to digital use for carers include:
 - **Motivation:** belief that they cannot change, unable to see benefits '*I am OK, we have managed up to now*', '*I don't need to be like other people*', '*it is not a priority, I don't have time*', '*I am worn out*'
 - **Understanding:** belief that high levels of skill are needed, feeling that it would be hard to access support, or that translation is a barrier (a few carers mentioned translation as a barrier to accessing the internet despite automatic translation capabilities on Google, and free apps which translate live conversations)
 - **Lack of exposure / awareness:** limited opportunities to see what can be achieved (with or without assistive technology), or see others using the internet successfully
 - **Practical considerations:** choosing equipment, setting it up, contracting an internet provider (we also note old machines can be counterproductive)

- **Confidence and emotional issues:** fear of failure and safety concerns *‘it may be a dead end’, ‘it looks too hard’, ‘I can’t do it’, ‘I will forget instructions’, ‘I will be scammed’, ‘I will be visible to others’*
- **Financial priorities:** can’t afford machine and/or can’t afford provider, it is not a financial priority compared with daily living (45 respondents care full time and 33 care alone, many of whom will be reliant on benefits)
- Carers may need extra **financial help** to become more digitally included
- All support provided to carers and cared for adults with LD/ASD needs to include essential **guidance about safety** and healthy approaches to internet usage
- Many of the issues suffered by carers during Covid are **worse for those who are digitally poor**, such as social isolation, access to mental health/counselling services, access to activities such as online fitness clubs, finding a job, and reducing the cost of living (purchasing goods, insurance, services, and tickets online is generally cheaper). Specific interventions for carers are also easier to manage online, such as benefits, emergency hospital passports, and virtual health consultations
- Post-Covid, many Government and NHS services will continue the move to online access effectively **widening the digital divide**. Our **care group risks losing their voice and visibility**. Digital exclusion has already impinged the progress of children with SEN/disabilities in terms of education, information, and participation during Covid and this is likely to continue
- When planning interventions, a careful **cost benefit analysis** should be done based on likely number of successes, a clear definition of what success means, and should consider the carers who will remain unwilling to use the internet
- The **return on social investment** of a local digital strategy could be significant as digital inclusion will impact on the independence and wellbeing of whole families (this could be done by measuring pre and post-intervention use of statutory services, for example)

SECTION C PROFESSIONAL VIEWS

1. In conversation with a range of professionals about the challenges families face, most talked about the issue of **digital exclusion** which further supports our findings above. This is at the forefront of people's mind because Covid has exacerbated the digital divide – the gap in opportunities and benefits between those who are digital and those who are not.
2. A number of professionals confirmed our own observation that **adults with ASD** have different technical challenges to those with LD. Whilst some withdraw completely into a digital life, others find it hard to engage digitally because of personality issues, resistance to change, or fear of failure or social visibility. There is potential amongst this group for online exploitation or of experiencing trauma after seeing emotionally disturbing content online.
3. A professional discussion took place around the possibility of a **digital strategy** for Merton bringing together all partners, including Carers Support Merton, who currently have funding to support carers to engage digitally.
4. Conversations also highlighted the issue of **digital skills amongst front-line professionals**, many of whom have good but sometimes narrow digital awareness therefore would not be able to help adults with LD/ASD to use assistive technology or find accessible apps or functions. They suggested specialist, high quality training or creation of a team of digital enablers.
5. One professional talked about how to help carers and adults with LD/ASD to become more aware of digital possibilities and suggested an **awareness programme or a short film** showing people with LD/ASD and carers successfully using the internet in a variety of ways on a variety of equipment. Professionals could show this during home visits, and it could be shown in public spaces.
6. Professionals are having to rely more on **carers to communicate and to make decisions on behalf of adults with LD/ASD**. Normally, people would be in the same room and use gesture, body language and visuals to communicate directly, but this is harder in a virtual situation. Some clients cannot engage at all online even with their carer's support.
7. The second most talked about topic was **social isolation and loneliness**, the need for both carers and adults with LD/ASD to have regular contact or a befriending service. Some clients benefit from phone calls whereas others need more substantial and regular social contact.
8. A topic arose around **transition** for children and young people due to leave education or move to the next phase of education, or indeed move to supported living. Of course, it has not been possible to arrange visits, but we are aware that many providers have done their best to do virtual tours. Hopefully, this issue will be resolved as lockdown eases.

9. One professional confirmed the need for **targeted and accessible information** around Covid rules and vaccine priority/access.
10. Covid has highlighted an issue we already knew existed - some **parents do not have the skills to play, learn or engage with their disabled child**. They can learn when someone works with the child in front of them. Many households do not have basic toys or resources that you might expect in a home with children. Parental learning is something which schools may find difficult to continue post Covid. We remain concerned that some disabled children, who experience life primarily through their special education setting, could be both digitally and socially excluded once they leave education.
11. Whilst some carers have told us that virtual health appointments did not go well, particularly health screenings online, we also hear that some prefer **virtual appointments** as there is less interruption to a person's routine and less risk of infection. It also means the family to not have to travel or pay for parking. This is an area which has potential post-Covid as long as those who cannot engage digitally do not receive poorer care as a result.
12. Hospitals have done a lot of work on engaging **patients who are digitally excluded**, most now offer free Wi-Fi and a free messaging service for families to have messages delivered to their loved ones on the ward.
13. Another professional confirmed the need for careful and patient management of digital training – avoiding **'throwing people in at the deep end'**.

SECTION D SUPPORT PROVIDED

by Merton Mencap as part of phase 1 of engagement

The engagement work was an intervention in its own right, and each conversation we had involved support, advice, and information as well as information-gathering. Other support provided included:

Merton Mencap Learning Disability Carers Advisor (Yvonne Dawes)

Carers can self-refer to this service, to receive:

- A Covid assessment involving 1:1 conversations and support (Yvonne has carried out over 38 assessments and review since Covid began)
- Carers discretionary grants of £100 each
- Financial advice and referrals to benefits advice services and food banks
- Emergency planning such as help to complete a hospital passport and create a list of key emergency phone numbers
- Referrals to activity providers for the cared for person, both Merton Mencap and other community providers, or our Merton Mencap facilitator who works with adults with LD/ASD
- Referrals to befriending services, such as Age UK

Merton Mencap ZOOM activities

- To date, we have run 140 online sessions for adults with LD/ASD such as dance, fitness, and social groups, including guest speakers and seasonal activities and our Café has also run on a virtual basis
- Many of our clubs for young people have also run as well as holiday play schemes and Saturday activities on behalf of Short Breaks

Parent Forums

Kids First and Adults First continued to run and

- Ran information sessions on vaccines, planning for the future, assertiveness & wellbeing sessions, and a staying safe online workshop
- Issued our usual newsletter with tips and key information
- Sent out our factsheets weekly information e.g., about home schooling resources, advertising the Carers Support Merton digital inclusion project for carers

MAPS (Merton Autism Parent Service)

- The service ran via phone and WhatsApp helping parents of children with a diagnosis of autism, or suspected diagnosis

Tailored fact sheets

In response to the feedback we received during the engagement exercise, we issued short information sheets for parents and carers on:

- Covid rules and particularly the exceptions for people with disabilities and their carers, plus how to remain safe (encouraging mask-wearing and safe outside exercise to support mental health)
- Lockdown guidance for people shielding (e.g., allowed out for exercise multiple times per day, if necessary, and can be accompanied by up to 2 carers from their support bubble whilst outdoors)
- Advice on vaccinations for people with needle phobia and practical support such as provision of practice needles
- Advice on accessible mental health support services
- A sheet about the Merton vaccination programme and reasonable adjustments that the NHS can put in place
- Phone & email advice on a 1:1 basis e.g., communicating the reasons for change of routine to an anxious adult with a learning disability, how to access support groups

Pilot: Companion Service

To support people who are isolated and do not have digital access or cannot access Zoom sessions, we started weekly walks in the community for adults. This was well-received but were only able to offer a limited service during phase 1.

SECTION E USEFUL RESEARCH AND REPORTS

Carers UK: Caring Behind Closed Doors October 2020

This report covers all carers, not just those with a learning disability.

81% of carers reported that they were providing more care since the start of the outbreak because the needs of the person they care for have increased due to a reduction in physical activity or local services are reduced or closed.

58% of carers are feeling more stressed and, half saying it had an impact on their health and wellbeing, as well as their ability to take a break.

57% of carers are worried about what happens in case of emergency, as they do not have a contingency plan in place.

74% reported feeling exhausted and worn out as a result of caring during the COVID-19 pandemic.

28% are struggling financially and more than one in ten respondents revealed they were/had been in debt as a result of caring.

33% of carers started using new technology and digital services during the COVID-19 pandemic. But there is a growing digital divide with 10% of carers reporting that their ability to use digital technology was limited because they struggled to afford things like equipment, Wi-Fi, or data.

SCIE UK: Understanding the impact of COVID-19 responses on citizens

Carers' organisations that were well embedded in the community were able to quickly link carers to practical and emotional support. Peer support and mutual support have been vital for carers to feel less isolated. Some have received regular phone calls and practical help such as PPE or food. Some carers, in taking on extra tasks for the person they care for, have become paid employees via direct payments.

SCIE: COVID-19 guide for care staff supporting adults with learning disabilities/autistic adults, March 2021

These guides cover, helping people to understand, relationships, EHC plans, staying well, healthcare, advance planning, Care Act, safeguarding, death & bereavement,

There are good links to resources such as the Beyond Words Books and Mencap resources to help create structure and keep people busy.

It contains some excellent advice about emphasising normality, encouraging, and establishing daily routines which include exercise, social contact, and good sleep routines. The guide emphasises consistency of support and also the fact that we can go back to normal when the risk has passed, perhaps keeping a list of all the things

the person wants to do once restrictions are lifted, so the person can see these have not been forgotten.

Additional advice includes providing calming activities such as listening to music, gardening, or baking and planning a daily walk or run.

Merton Mencap used this guide as the basis of our factsheets and to source advice we provide to Merton carers.

NICE Guidelines: Care and support of people growing older with learning disabilities, April 2018

Recommendations for local commissioners regarding access to appropriate age and learning disability-related healthcare, developing links between local services for those with LD/ASD and elderly persons' services, using technology to provide appropriate support and care for elderly people.

Carnegie Trust: Learning from lockdown, 12 steps to eliminate digital exclusion, October 2020

The reports state that cost, skills, and lack of interest remain major barriers to internet access. The key to tackling digital exclusion is starting with the person, not the technology, and understanding what they are interested in and how the internet might be of value and benefit to them.

The report sets out a roadmap for tackling digital exclusion and explains some of the key reasons as well as key strategies to deal with this.

These reports put national and local government bodies in the front line with regard to tackling digital exclusion.

Lloyds Bank: UK Consumer Digital Index, 2020

This is an annual statistical report about digital activity in the UK. It tells us each year about access, usage and identifies clearly who is most at risk of digital poverty.

This tells us also about attitudes to the internet, its impact on saving money and finance, role in social exclusion, and also the 8 digital foundation skills which form the basis of successful use of a computer.

We used this report as the basis for designing our survey questions on digital exclusion.

UCL Institute of Education Article: The wellbeing of disabled children's siblings severely impacted by lockdown, June 2020

This report recognises that siblings of disabled children are vulnerable to isolation, and not all are recognised as young carers.

Covid has exposed siblings to increased violence and risk and many will need additional pastoral support and/or academic support when they return to education.

Many siblings will have experienced psychological difficulties due to lack of respite, isolation and dealing with behaviours which challenge from their brothers and sisters.

Carers UK: The world shrinks: Carer loneliness 2017

This report is about loneliness. The research reveals that lonelier care experiences affected younger carers under 24 years old (89%), carers of disabled children (93%), people who care for 50 hours or more per week (86%) or 'sandwich carers' who look after loved ones alongside parenting responsibilities (86%), all of which are more likely to be women.

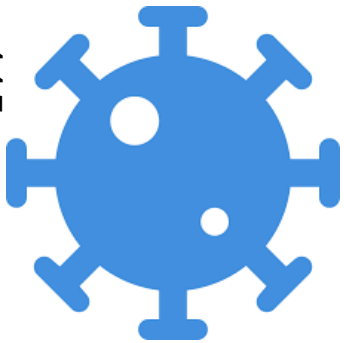
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Engagement Work for Public Health Merton



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Covid



Carers



Parents



**Adults with a learning
disability and/or autism**

The numbers

37

People who have a learning disability and/or autism (people who are cared for)

Ages 14 - 71



10

Professionals or organisations including

- Social care
- Healthwatch
- St George's LD nurses
- Perseid School
- Merton College



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66

Carers of adults

Ages 37 - 81



4

Merton Mencap

Staff Members and their clients



54

Parents of children

Children's ages 3 - 17



8+

Reports



How?

Letters, emails, online surveys, phone, zoom groups, paper forms, providers ran sessions for us



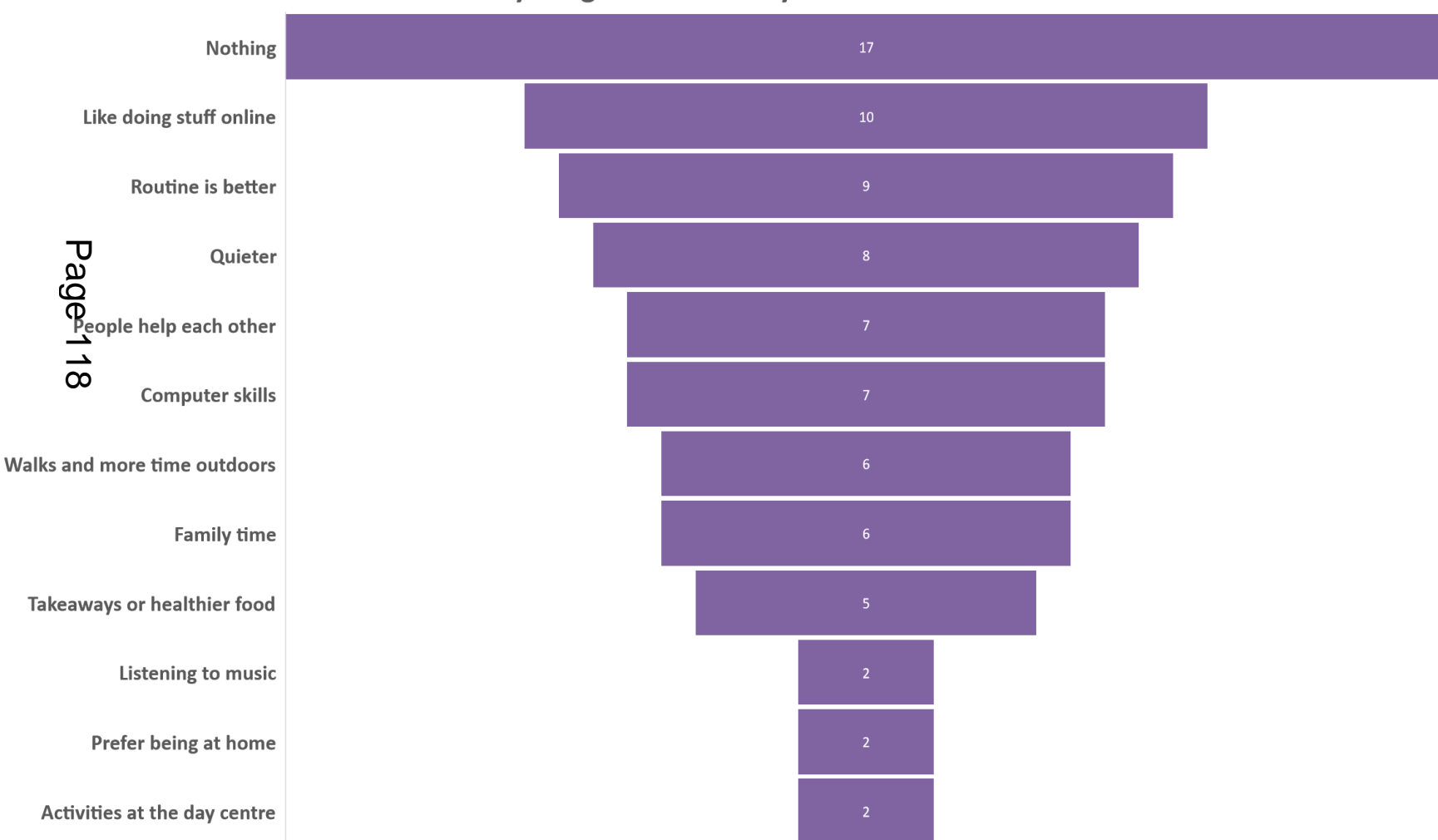
People with LD/ASD miss outings, friends and activities

What do you find hardest at the moment?	Number
Missing outings or going out for meals	28
Missing friends	22
Missing clubs or leisure activities	17
Unhealthy or lacking exercise	16
Feeling lonely, sad, or angry	14
Missing day activities	14
Not being able to go on public transport	11
Wearing masks	10
Social distancing	9
Access to doctor or dentist	9
Having to do things online	7
Spending too long indoors or in room	7
Worrying about being ill	6
Not seeing a personal assistant or carer	6
Confusion about Covid	6
Missing family contact	5
Sleep issues	4



Should anything be retained post-Covid?

Is there anything better about your life since Covid-19



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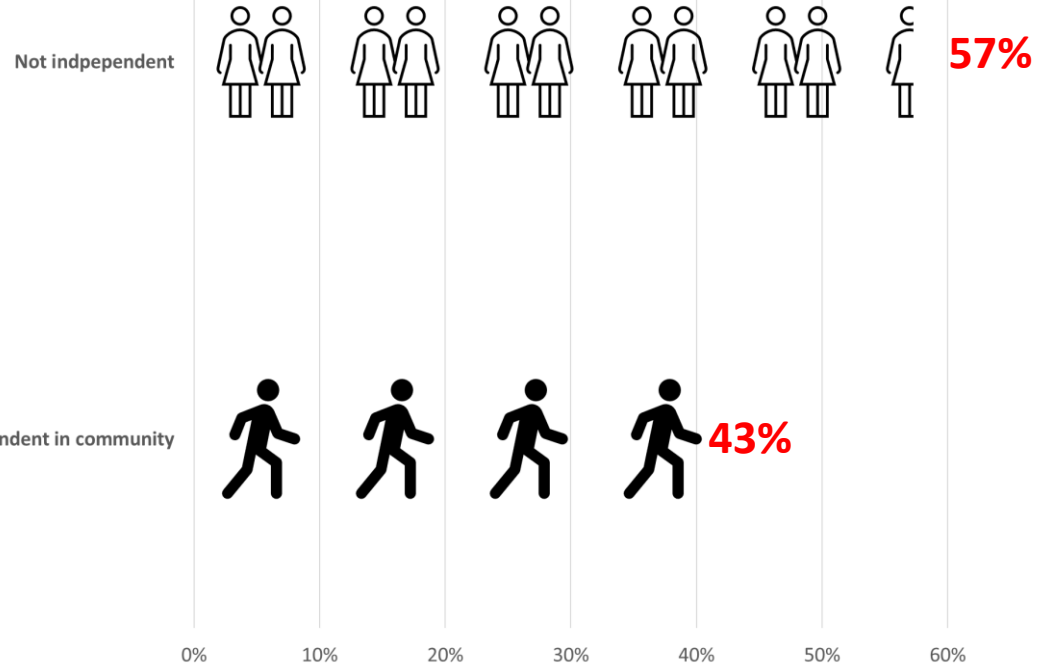
- Nearly half say nothing has been positive
- Being online or computer activities are enjoyed by some people
- For some, virtual health appointments are easier

Online activities could be continued or developed, but not if it increases the digital divide?

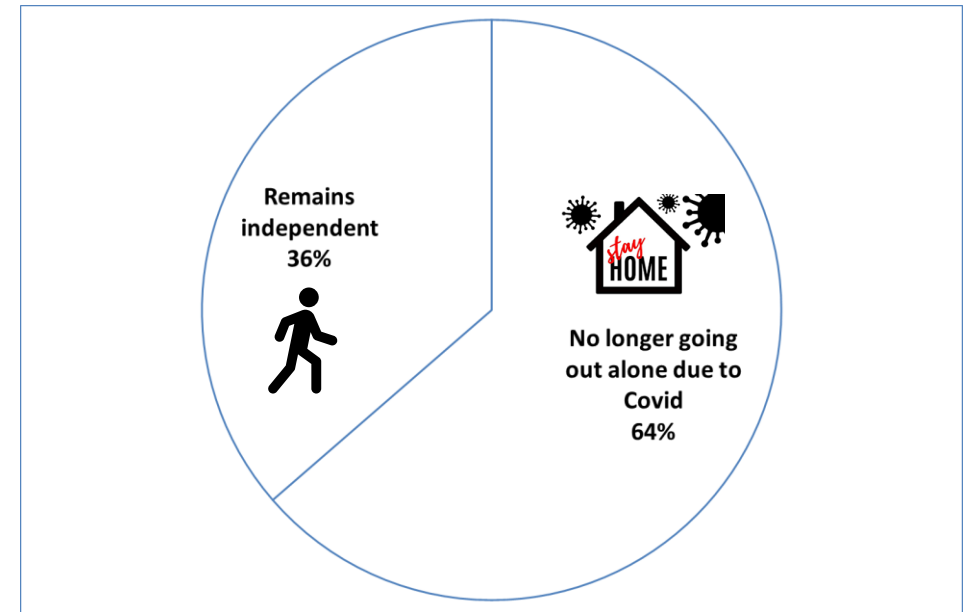
Nearly 1 in 3 no longer go out alone because of Covid



Before Covid



2 out of 3 can no longer go out alone



- Not safe, lack of ability to implement rules
- Travel training stopped
- Self-isolation
- Fear of travelling eg too many people without masks
- Doesn't go out at all



Impact of Covid on services

For those cared for by carers who responded

Over 1/2 access some services

- Virtual
- Running reduced hours or days
- Open except during lockdown
- Open for people who aren't shielding



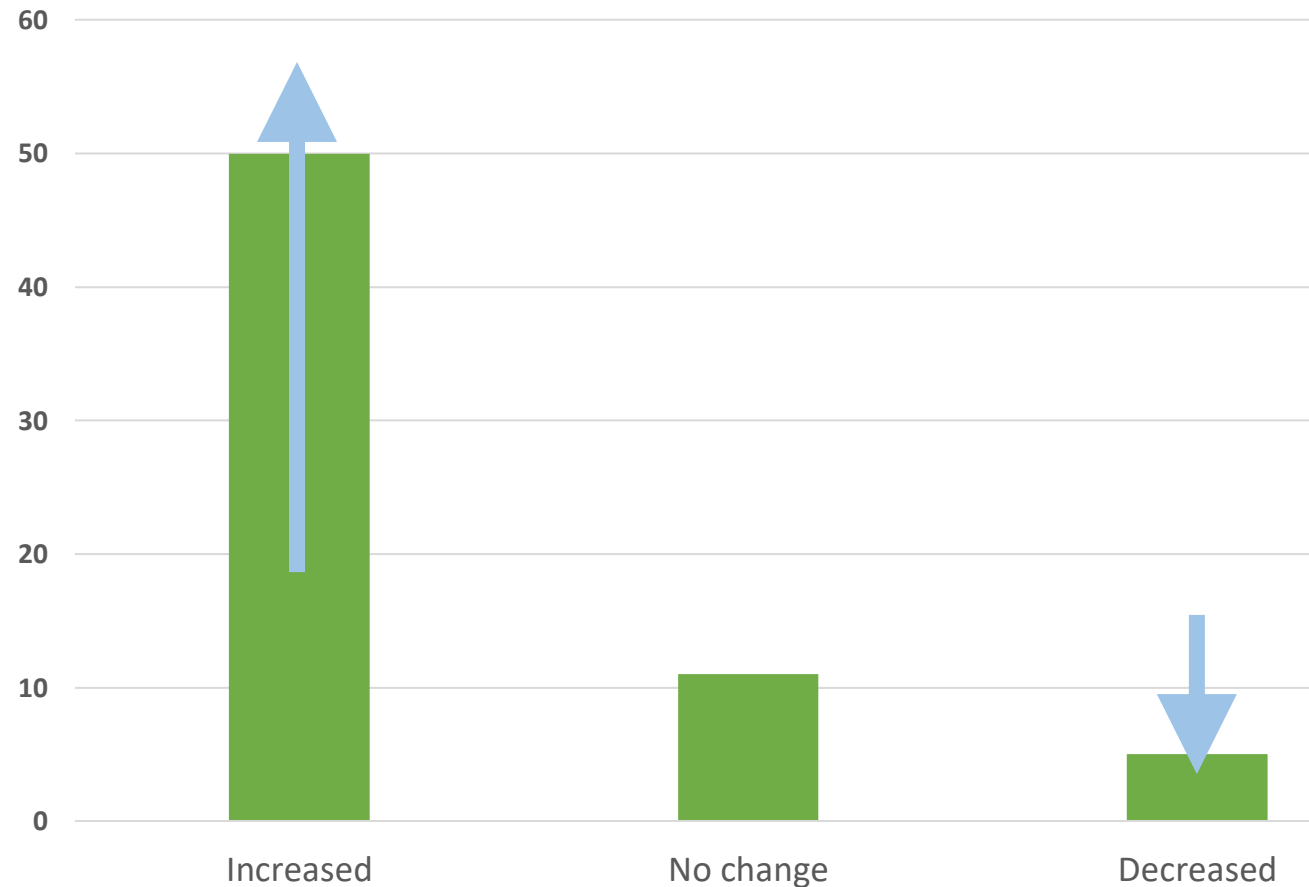
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Over 1/3 access NO services

- Virtual but unable to access
- Service closed
- Shielding
- Unable to go out / leave the house due to fear of Covid

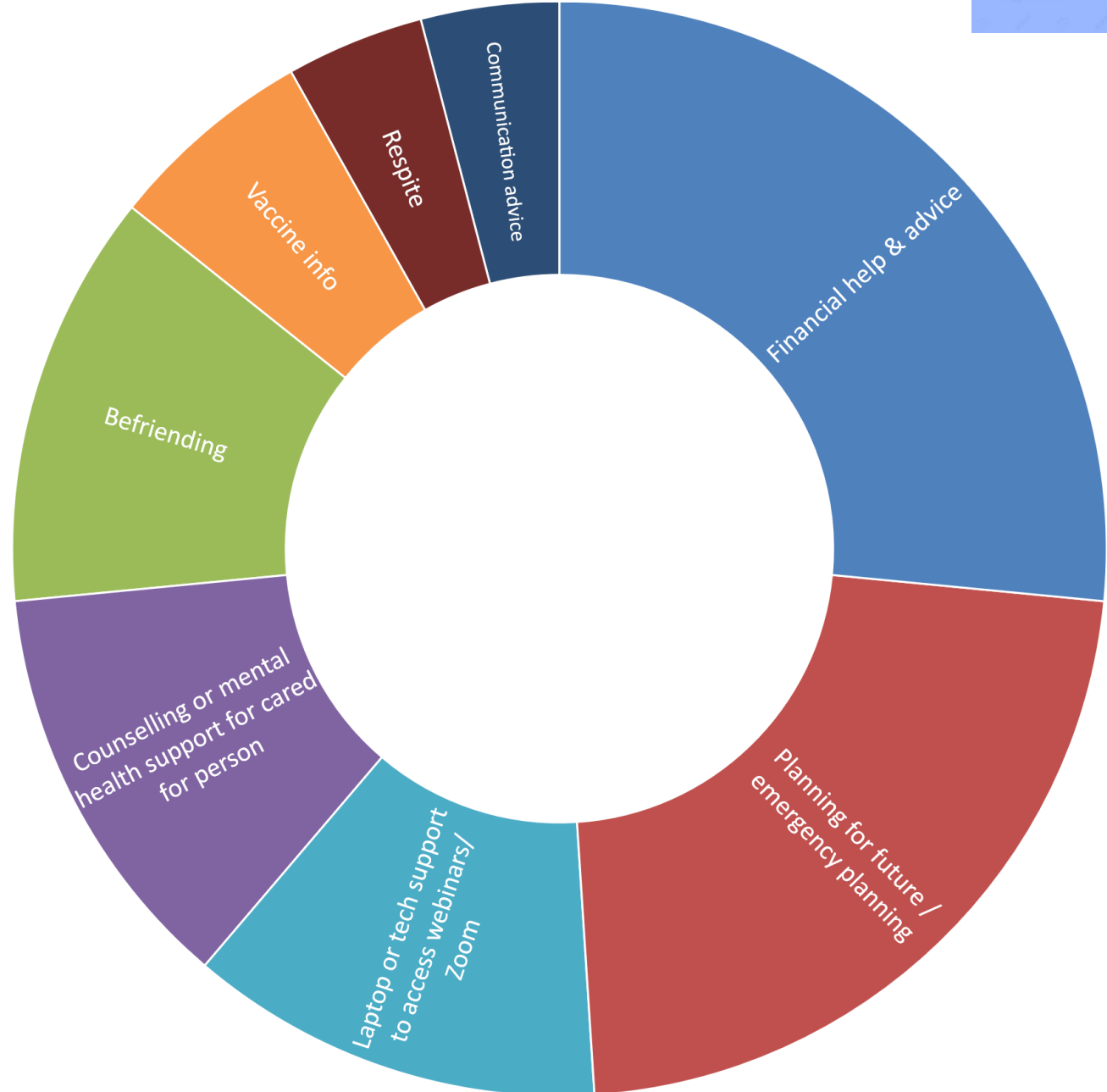


82% of carers say their caring duties have increased





Main support needs



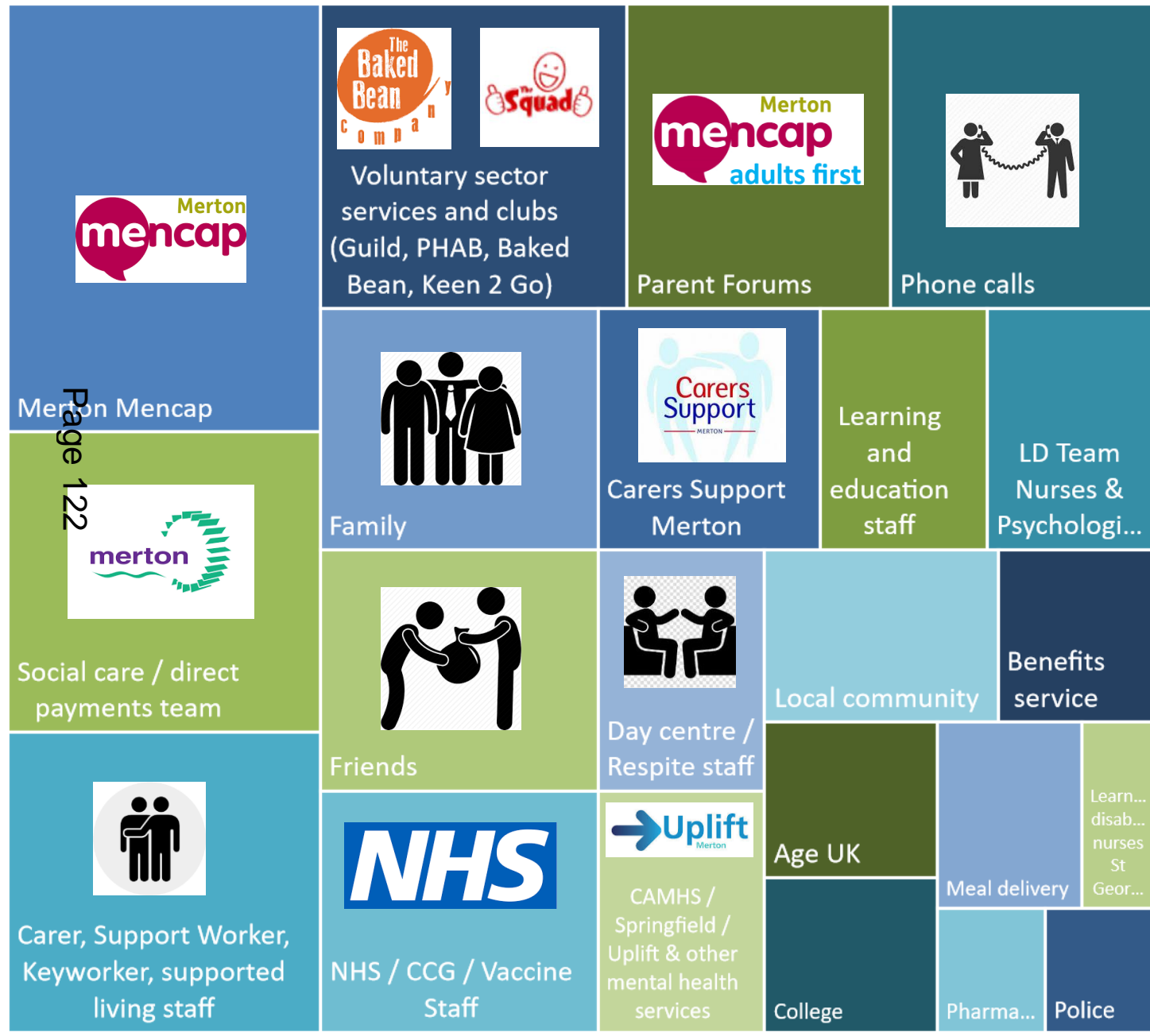
Main challenges

- **Caring role / stress**
- **Lack of activities for cared for person**
- **Fear about the future**
- **Low mood of cared for person**
- **Access to health services**

Who has supported carers so far?



Carers



Positives

- Wide range of support services accessed



- Praise for NHS vaccination services



- Praise for staff at day centres & supported living





Carers' Mental Health Indicators

65% of carers experience low mood, loneliness, stress or poor sleep

"I struggle every day as I feel I can't allow myself to feel either physically unwell or mentally worn out."

"Loneliness – dependency of [person cared for] has increased"

"Stressed, haven't had a break"

"Extremely difficulty emotionally - walking on eggshells"

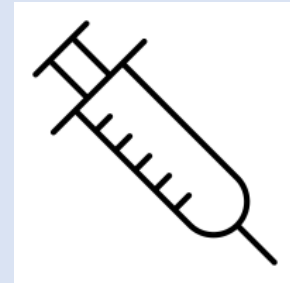
"I am lonely"

"Can't sleep"

"I cry daily"



9 have a new health problem and 14 say an existing condition has worsened



- *6 carers were not sure about the vaccine*
- *14 carers thought their cared for person may not have it*
- *7 people who are cared for were not sure about it*

Main Challenges

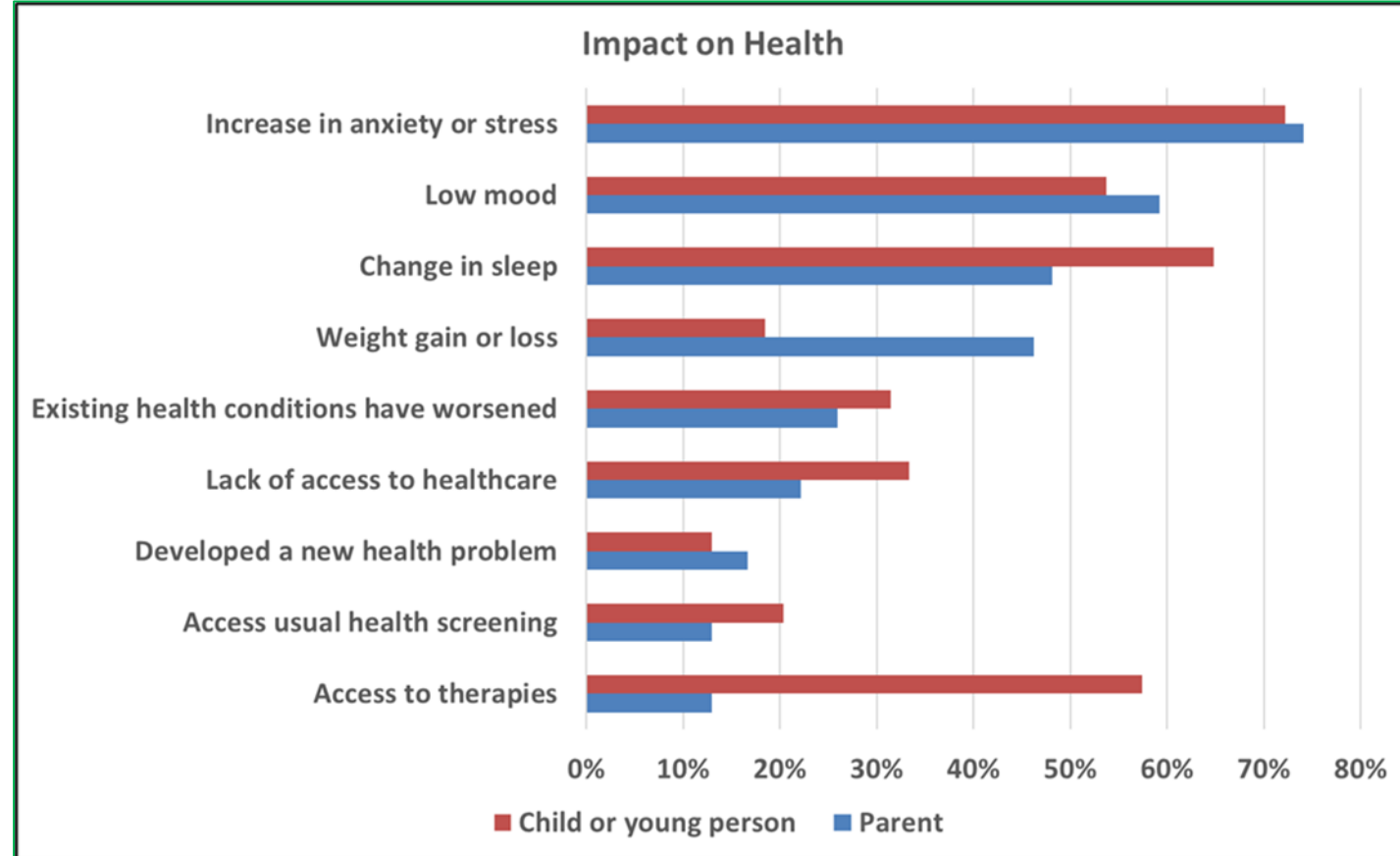


Parents

- Child's anxiety or mental health – significant issues arising for nearly 1/3 of parents
- Parent's anxiety or exhaustion
- Child's worsening behaviours
- Unable to meet sibling's needs due to demands of child with SEN/disability
- Anxiety about lost skills or educational disruption
- Parent's isolation
- Lack of respite
- Financial worries
- Fitness
- Too much screen time
- Sleep
- Access to health
- Other education concerns
- Emergency planning

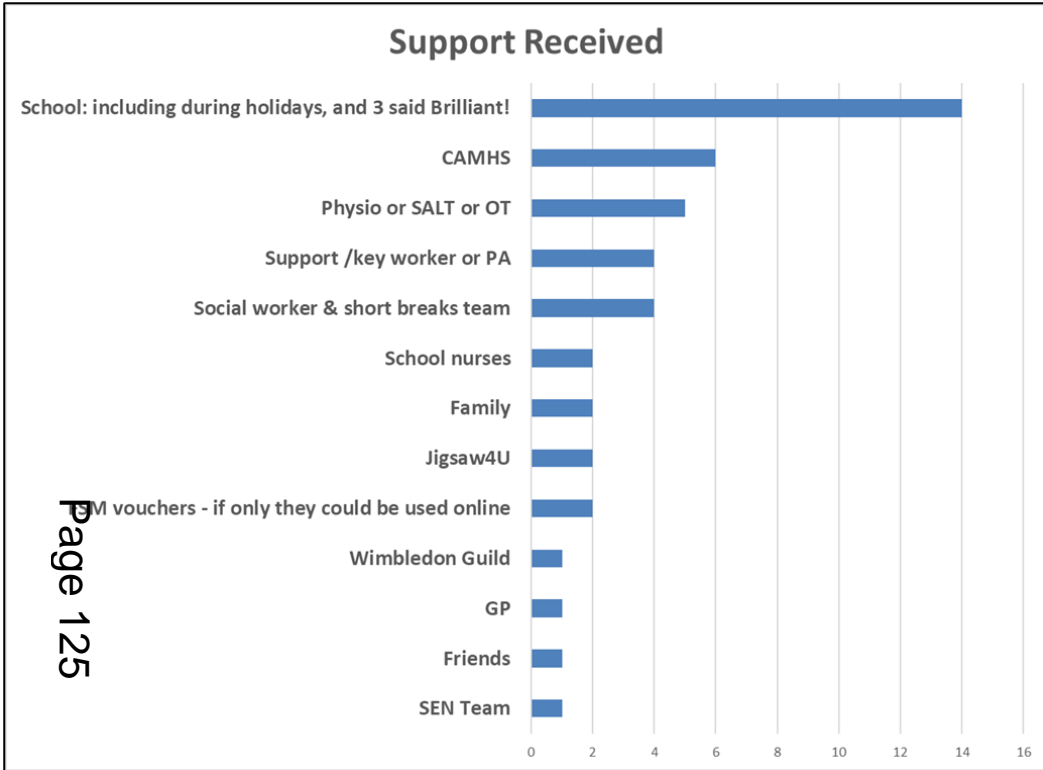
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Mental health is the most significant health issue





Support received



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- Support from schools has been good
- Support from CAMHS and specialist services is good for those who are eligible

Hopefully, pressure on parents has now eased as they are back at school

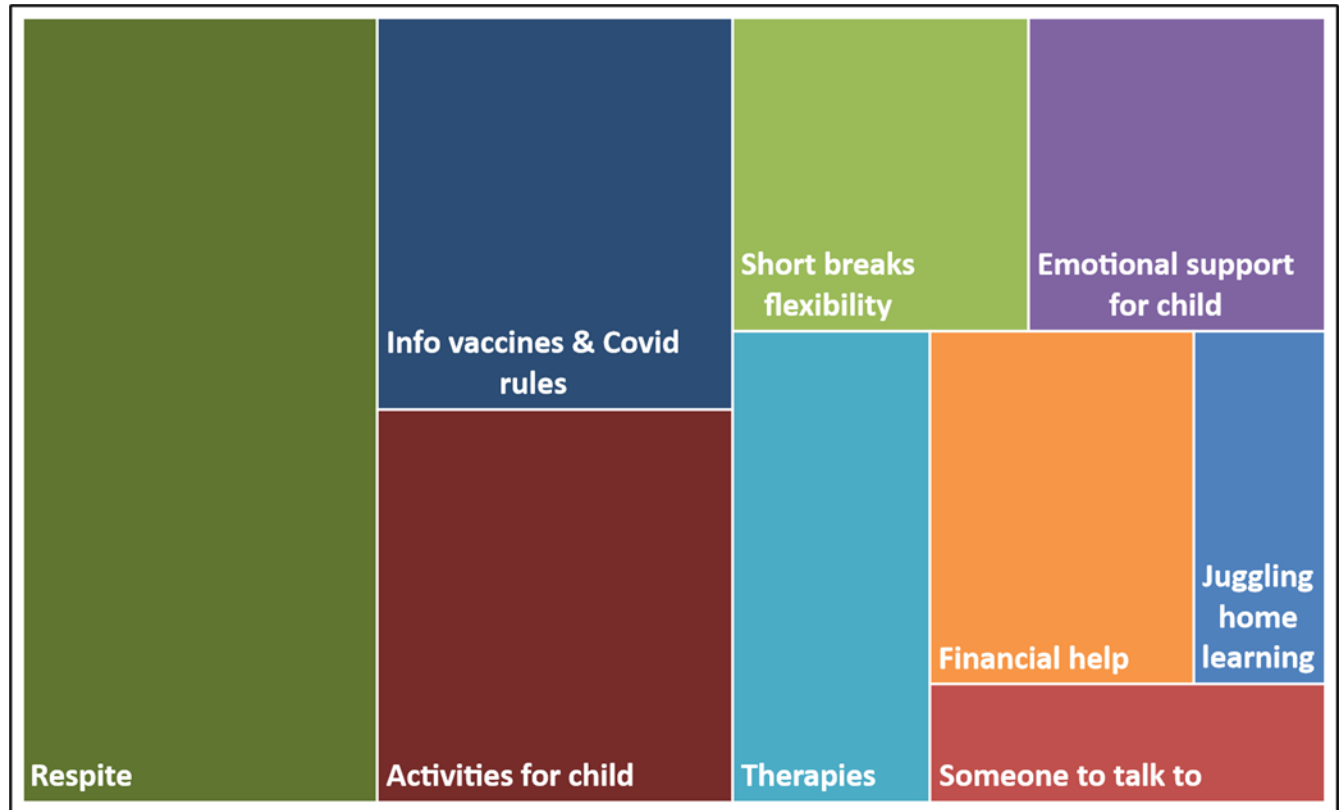
Positives?

Most said none

20% said learning or anxiety about learning is better

17% valued more family time

Support needed



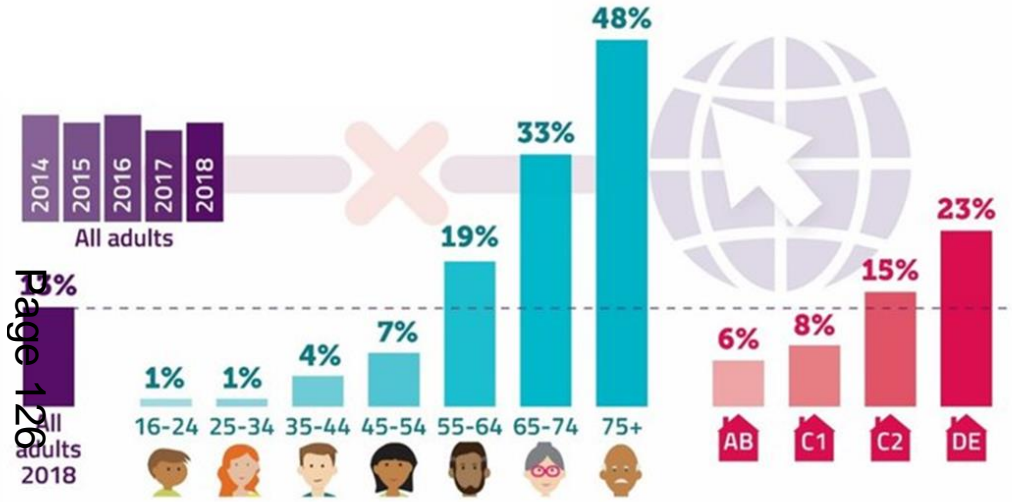
Digital Poverty

What do we know about digital poverty in the UK?

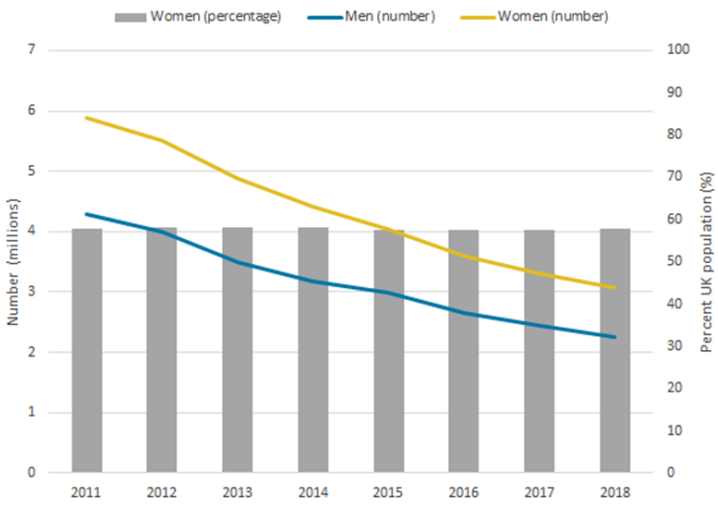
22% are digitally poor (basic or no skills)

What do we know about carers?

60% of those caring for 50 hours+ per week are women
72% of those receiving Carer's Allowance are women



Page 126
All adults 2018



Most likely to be digitally poor are:

- Women
- People over 50, increasing with age
- People on low incomes below £17,400 and people who are economically inactive
- Benefits claimants
- People with an impairment or disability

What do we know about our Merton carers?

88% were female

81% were over 50

34% have some form of illness, condition or disability themselves

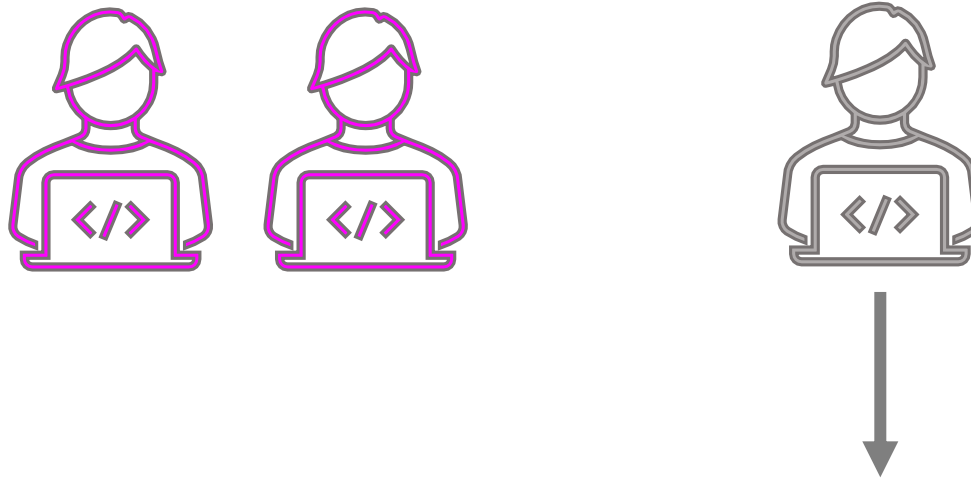
58% live in the more deprived postal areas

41% care on their own and 63% are economically inactive so are likely to be reliant on benefits

38% are digitally poor



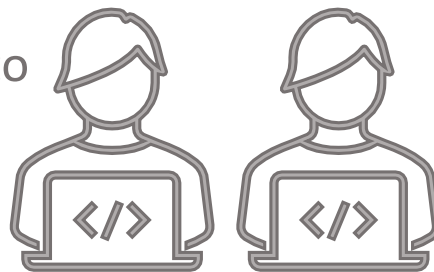
Over 1 in 3 carers are basic or non-users of the internet



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2/3 DO NOT feel they are missing out

- ✓ May not become digital
- ✓ Need alternative ways to obtain important information
- ✓ Their right to choose



1/3 feel they ARE missing out



- ✓ need ongoing help
- ✓ help with set-up
- ✓ good instructions
- ✓ help with costs



Digital Poverty

Impact

8 out of 10 carers have felt lonely or socially isolated as a result of their caring role

Carers UK

Merton Carers

Isolated and lonely

Unaware of services available to them

Unaware of all Covid rules and guidance, including 'exceptions' that could improve their lives

At a financial disadvantage by not being online

Getting online is estimated to be worth at least £1,064 a year per individual due to less social isolation, financial savings and opportunities in employment and leisure

BT, 2014

Merton People with LD/ASD

Socially isolated

Lack engagement and stimulation

Digital Poverty

Each individual has a different combination of barriers
Each person needs each barrier addressing

BARRIERS

Motivation: 'managed up to now', not a priority, only an issue for me, exhausted by caring

Understanding: belief that access requires good motor skills, cognition, problem-solving, literacy; poor understanding of benefits for others e.g. music, podcasts, video, catch-up; poor awareness of adaptations available

Lack of exposure / awareness: limited opportunities to see what can be achieved (with or without assistive technology), or see others using the internet successfully

Practical Issues: what, where, how, internet contracts, terminology, language issues, time learning is not respite time

Confidence and emotions: may be a dead end, fear of failure, may not retain skills, scams, 'visibility', risk

Money: can't afford machine and/or can't afford provider, not a financial priority compared with daily living

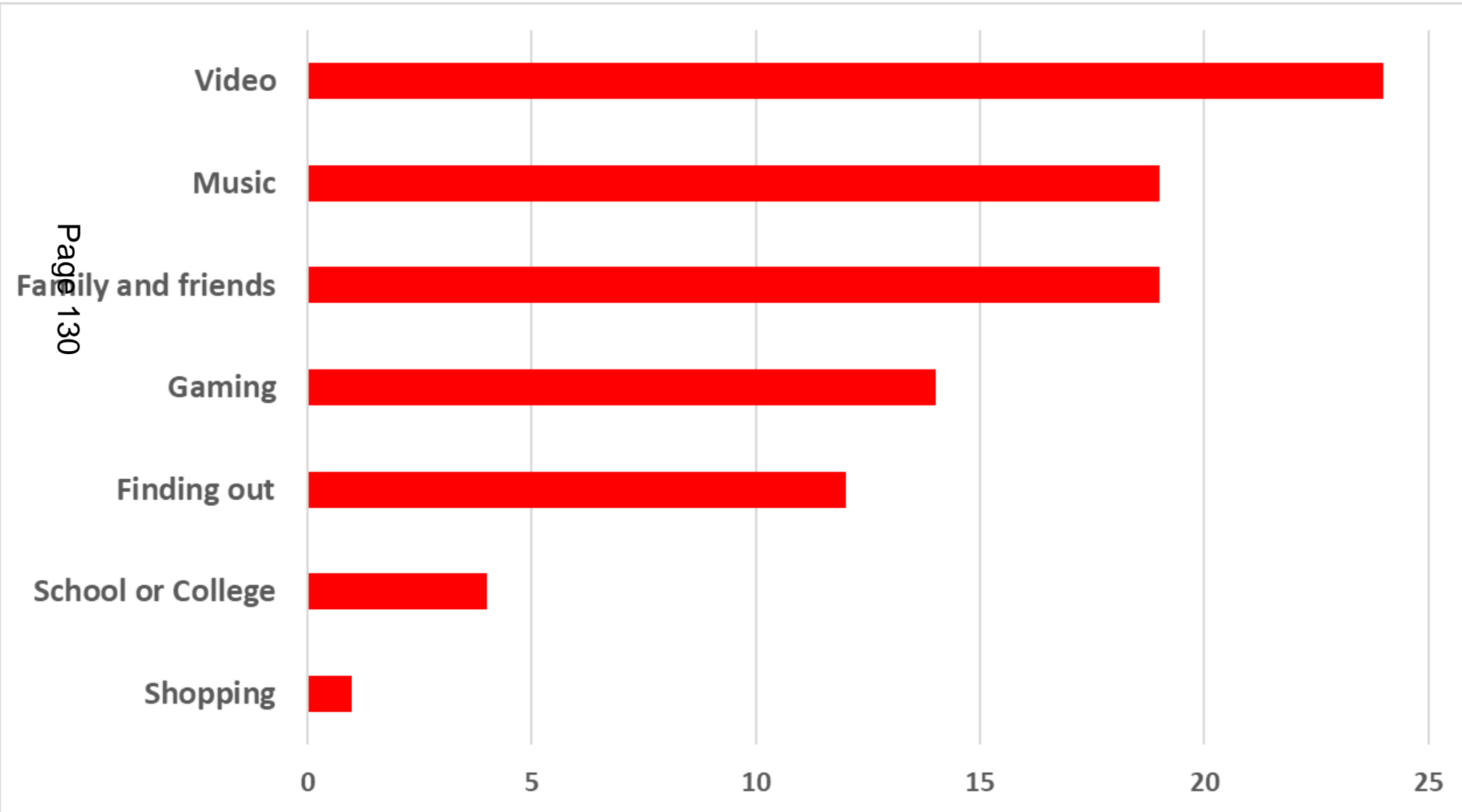


Care professionals are not automatically digital professionals

Digital Poverty



80% of people with LD/ASD internet users, ¼ require some support to do this



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- Main interest is entertainment
- Valued also for social engagement

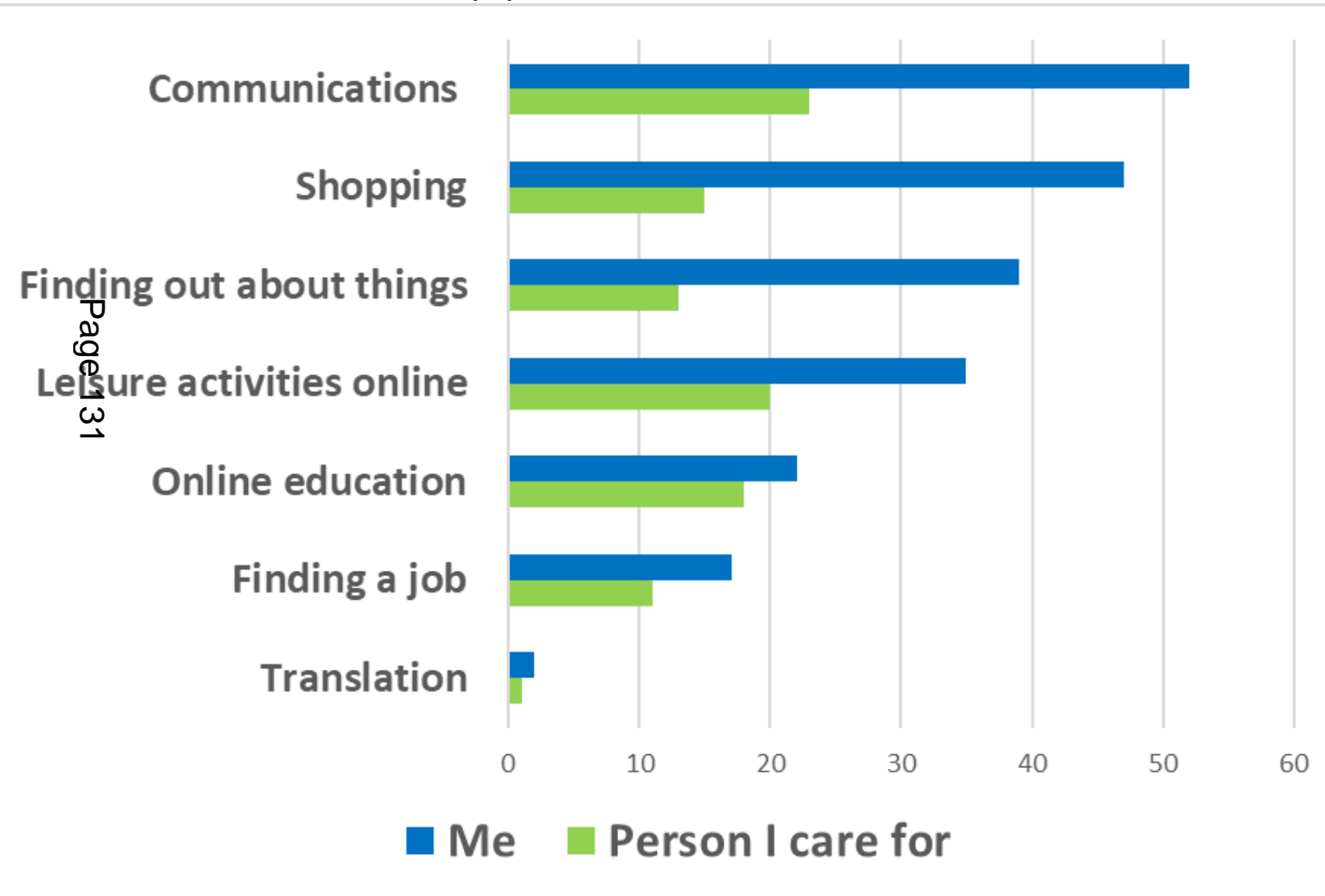
Zoom activities were mentioned by many

Digital Poverty



Carers were asked about the benefits of the internet for them and their cared for person

Their own interests are mainly 'practical'. Less than 1/3 feel the internet does or could benefit their cared for person



- Almost all carers **manage their cared for person's finances**, even those who live in supported living or residential care
- Most carers influence their cared for person's **access to daily activities**
- Most family carers are the **main advocate** for their cared for person

Adults with LD can be digitally excluded because their carer:

- Has different interests
- Has to set financial priorities
- Believes the internet is 'hard' to use

Support provided so far by Merton Mencap



- Learning Disability Carers Advisor
 - ✓ Small grants
 - ✓ Financial advice
 - ✓ Emergency planning
 - ✓ Referrals (benefits advice, activities for cared for person)
- Merton Mencap ZOOM activities
- Referrals to parent forums (vaccine meeting, planning for the future, assertiveness & wellbeing sessions)
- Referrals to MAPS (Merton Autism Parent Service)
- Tailored fact sheets (Covid rules about outdoor exercise, needle phobia, mental health support services)
- Phone & email advice (communicating about Covid, accessing support groups)
- Pilot: Companion Service (walk in community for adults unable to access digital services)