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

Contents

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

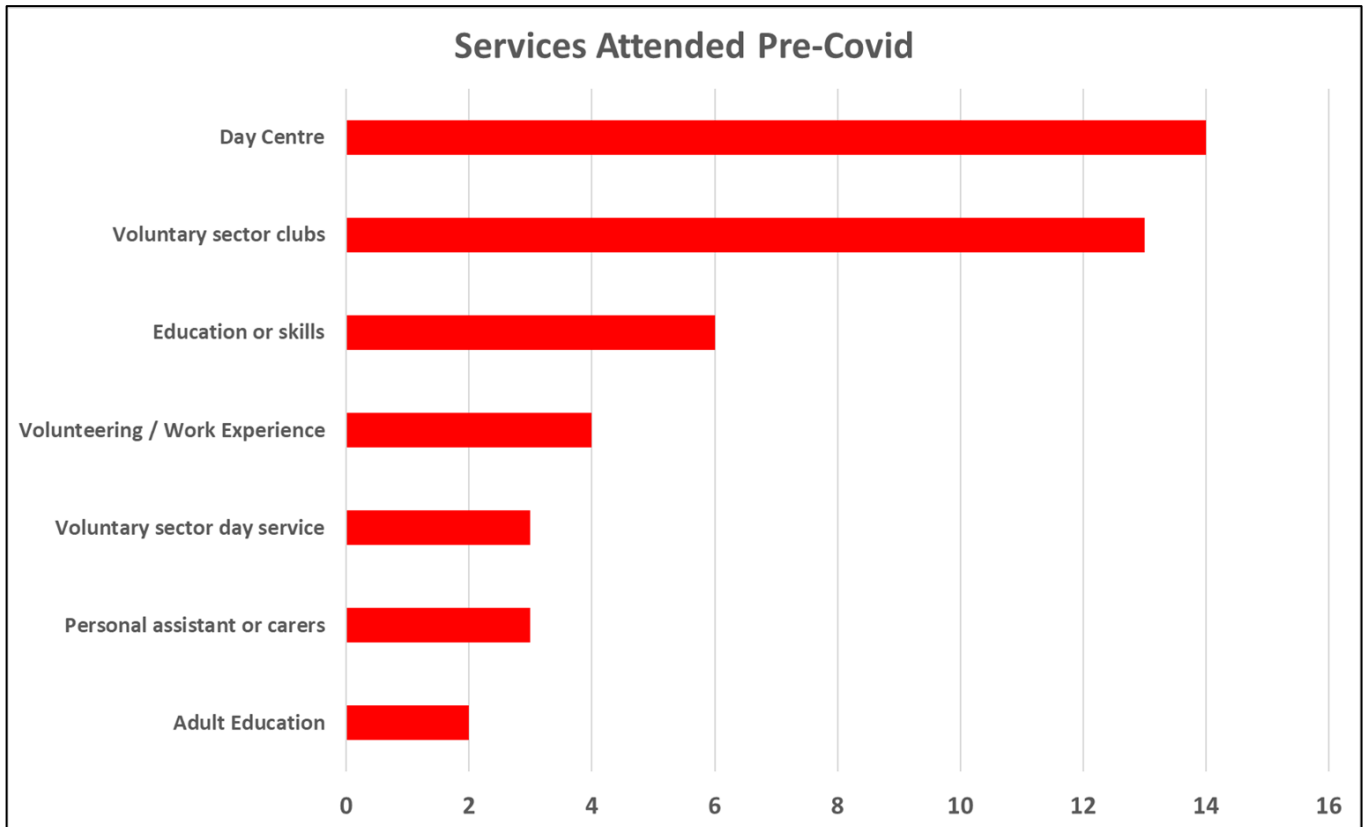| Who respondents live with	
With a family carer	30
Independently	3
Supported Living or Care Home	4

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.

Services Attended Pre-Covid

Service	Value
Day Centre	14
Voluntary sector clubs	13
Education or skills	6
Volunteering / Work Experience	4
Voluntary sector day service	3
Personal assistant or carers	3
Adult Education	2

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 <u>not independent</u> 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.
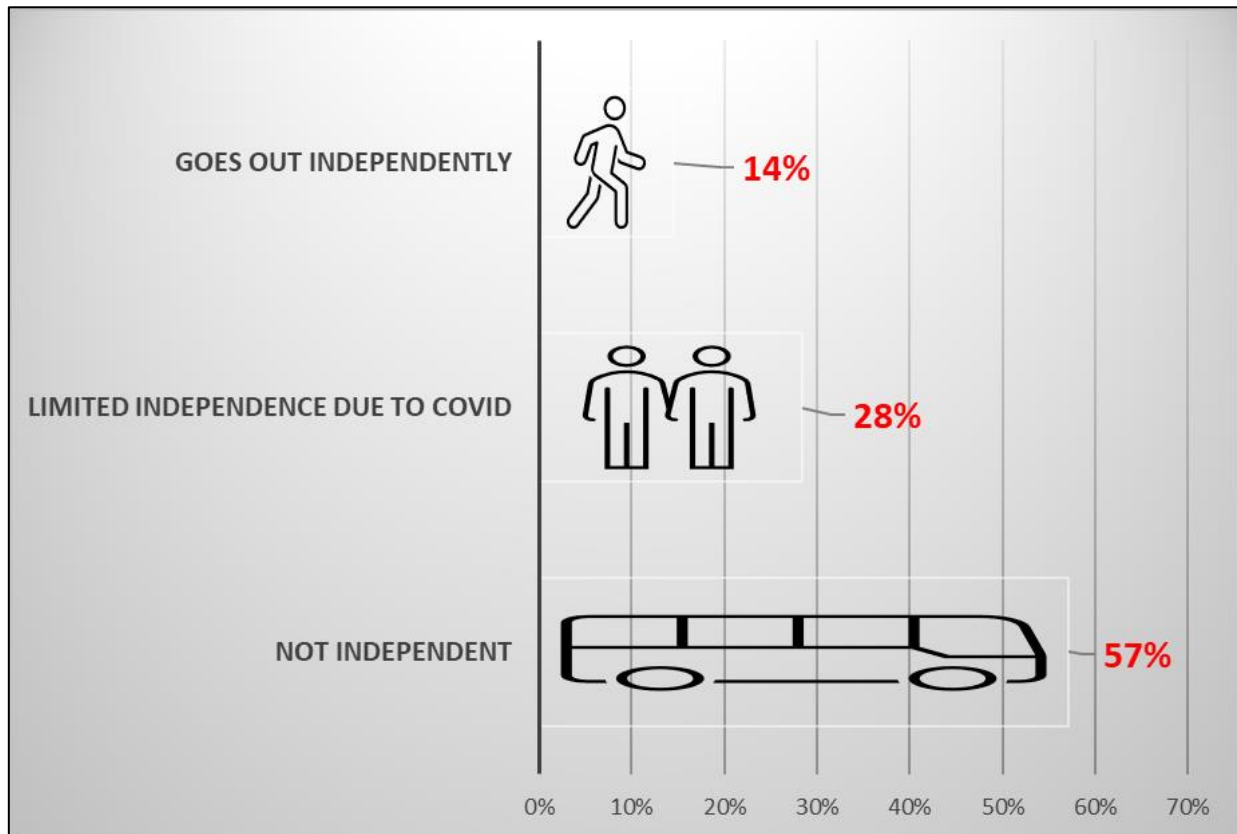
Reasons for reduced independence include lack of ability to implement safety rules, travel training on hold during lockdowns, self-isolation, reluctance to leave the house due to Covid, fear of travelling e.g., too many people without masks.

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.
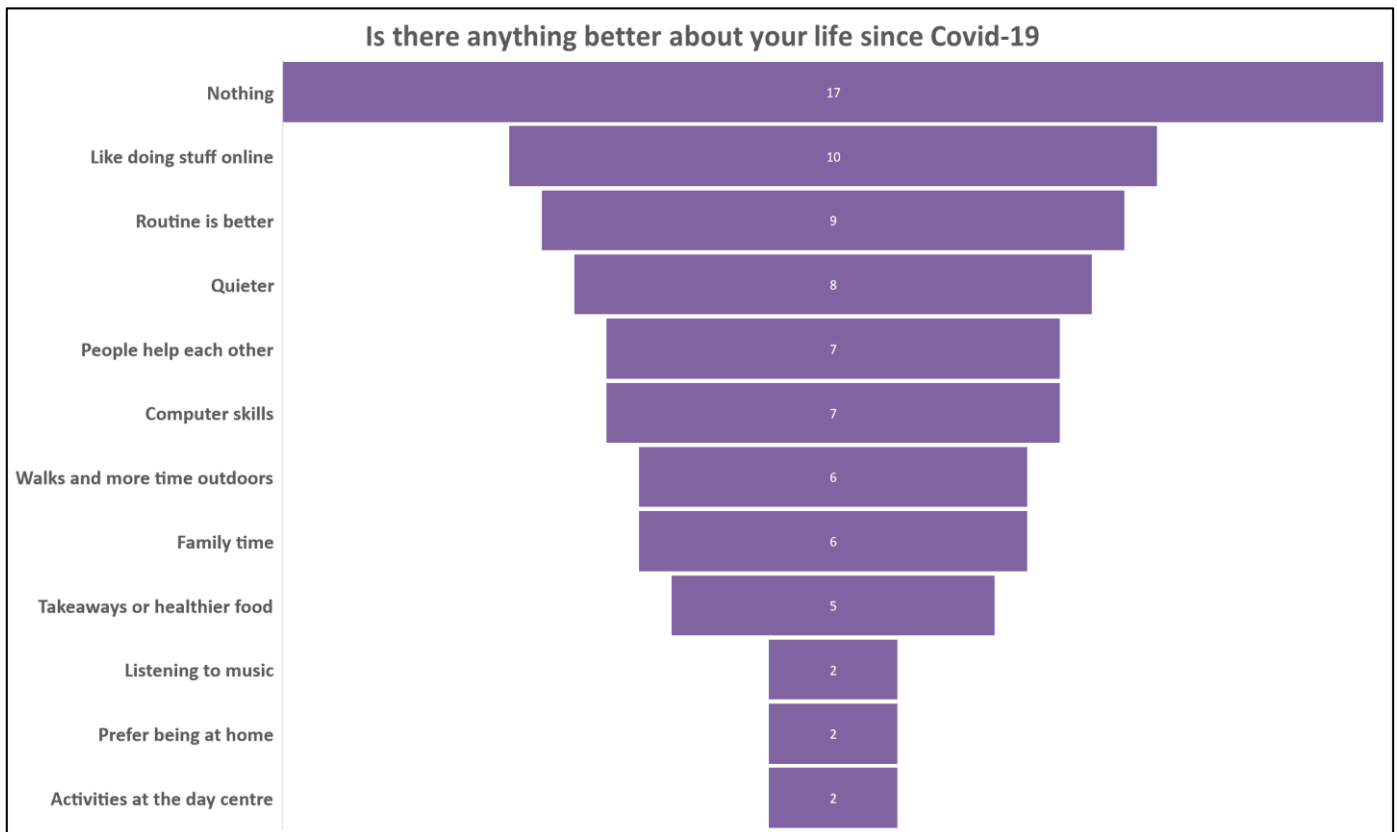
5. Support needs

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.

Is there anything better about your life since Covid-19

Category	Value
Nothing	17
Like doing stuff online	10
Routine is better	9
Quieter	8
People help each other	7
Computer skills	7
Walks and more time outdoors	6
Family time	6
Takeaways or healthier food	5
Listening to music	2
Prefer being at home	2
Activities at the day centre	2

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.

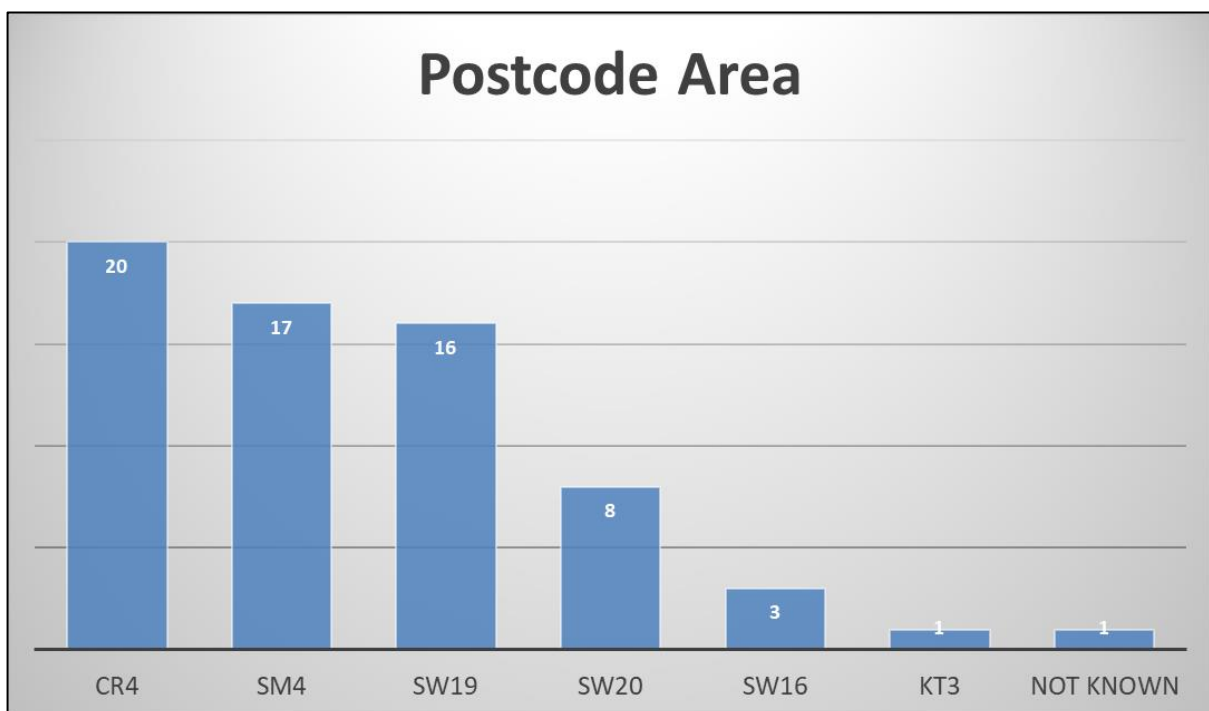## A.2 Results: carers of adults with a learning disability and/or autism

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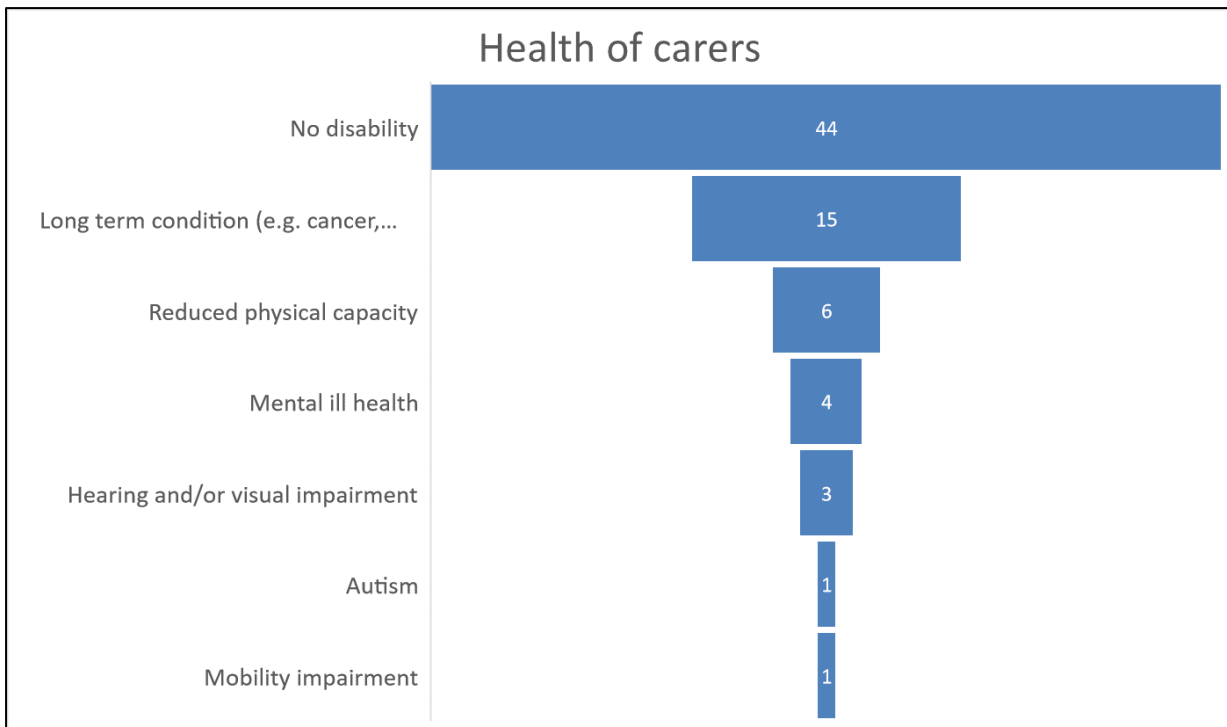
1. **Profile of respondents**

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)

Age Groups and Caring Situation

Legend: ■ Cares alone ■ Shares caring duties
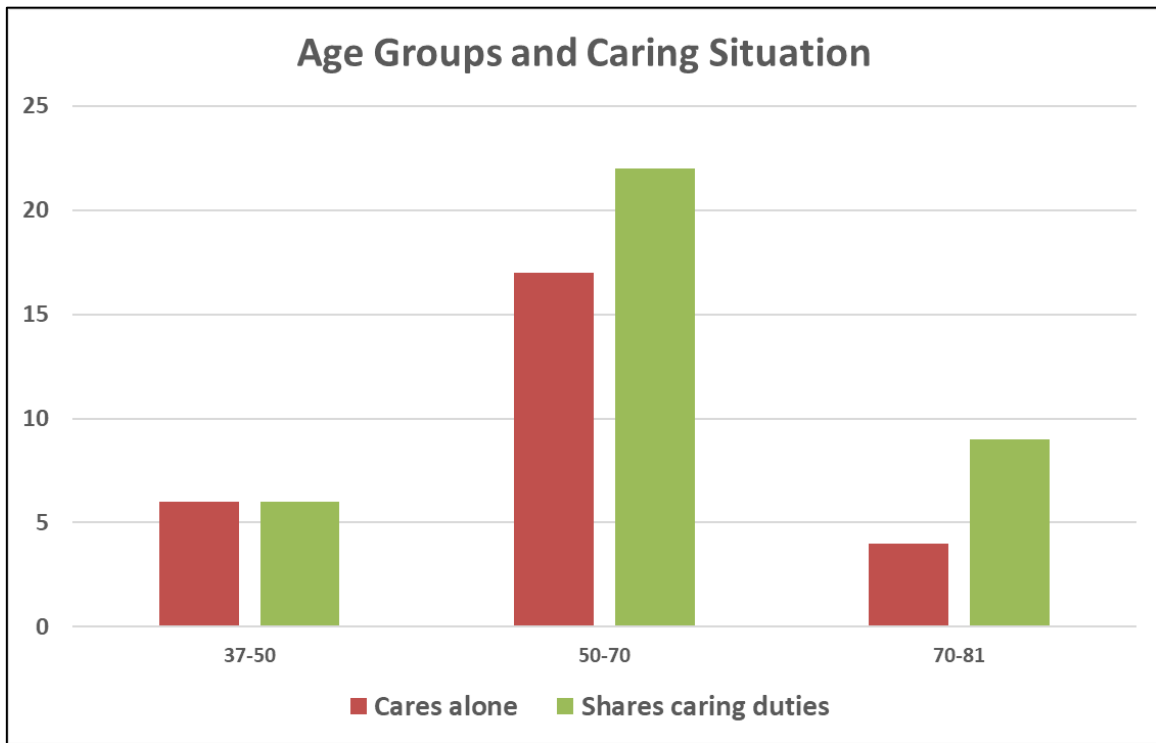
Respondents represent all areas of the borough

Postcode Area

CR4: 20, SM4: 17, SW19: 16, SW20: 8, SW16: 3, KT3: 1, NOT KNOWN: 1

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

Health of carers

Category	Value
No disability	44
Long term condition (e.g. cancer,…)	15
Reduced physical capacity	6
Mental ill health	4
Hearing and/or visual impairment	3
Autism	1
Mobility impairment	1

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.

Nature of Cared for Person's Disability

- Moderate learning disability
- Severe or profound learning disability
- Autism with a moderate learning disability
- Autism with a mental health condition/ADHD
- Autism
- Not known

16
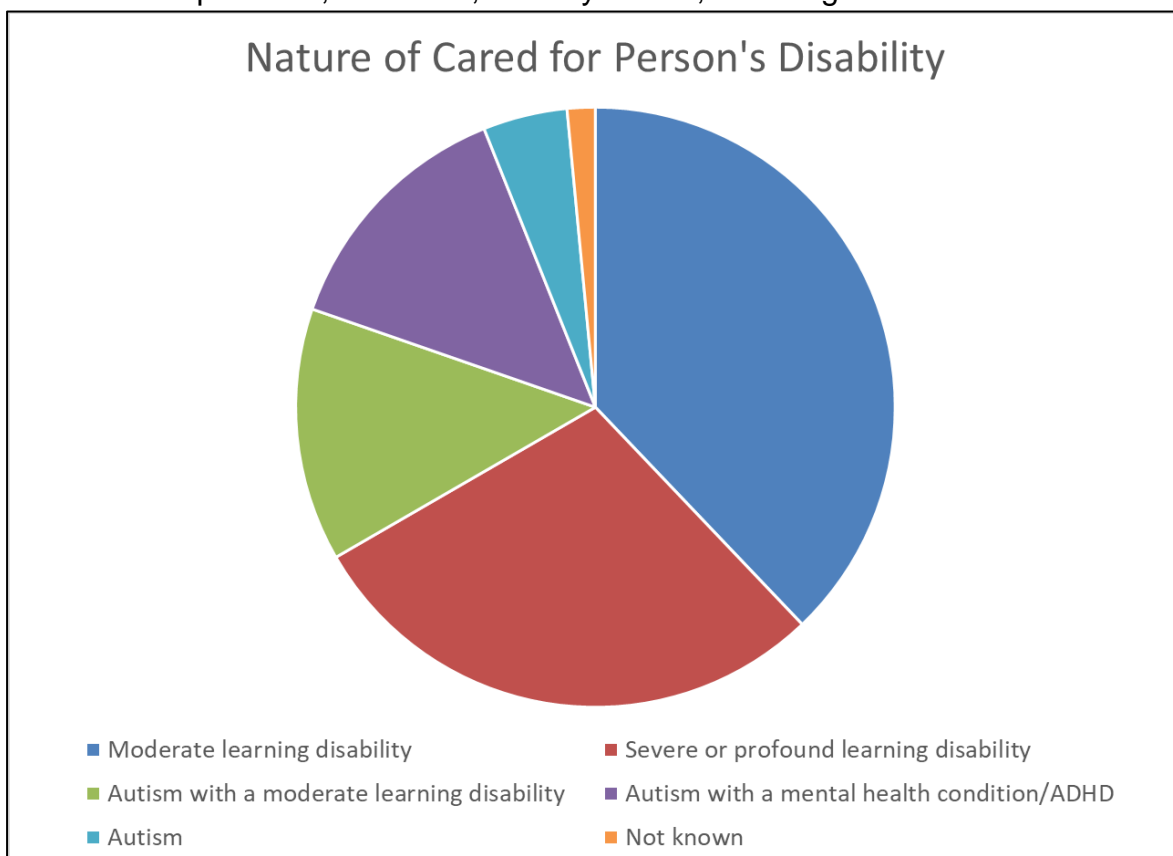
Gender: 90% of respondents were female, more than carers as a whole across the UK (60% of those caring for 50 hours+ per week are women and 75% of those receiving carers allowance are women).

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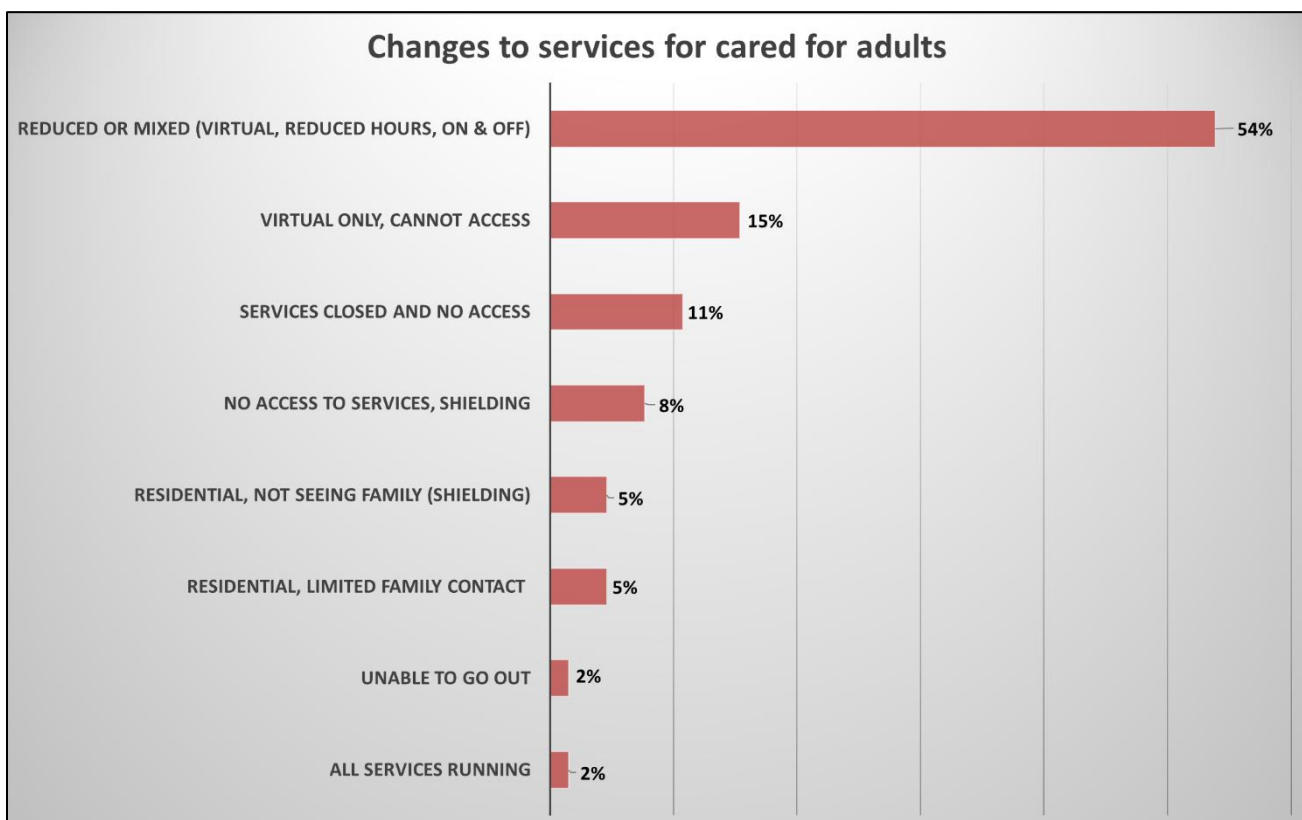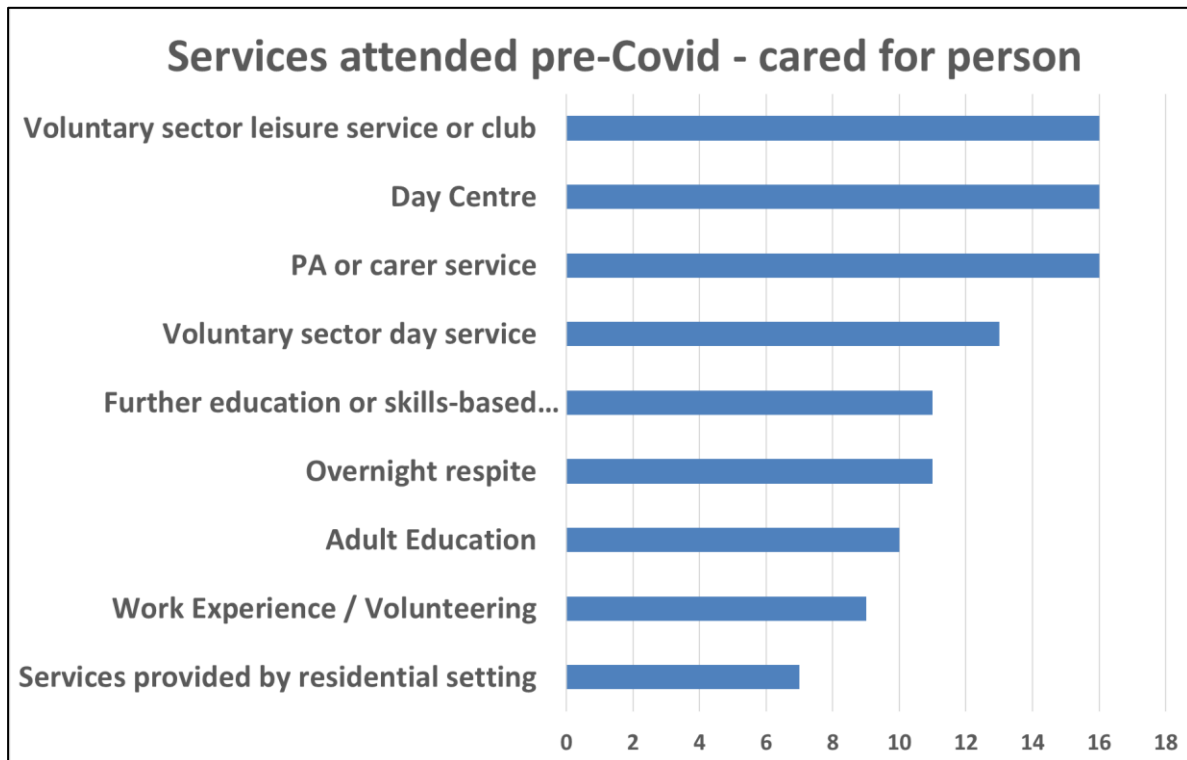
Caring duties before Covid	Number
1-19 hours	14
20-49 hours	29
50+ hours	19
No caring duties	3

Change to Caring Duties since Covid
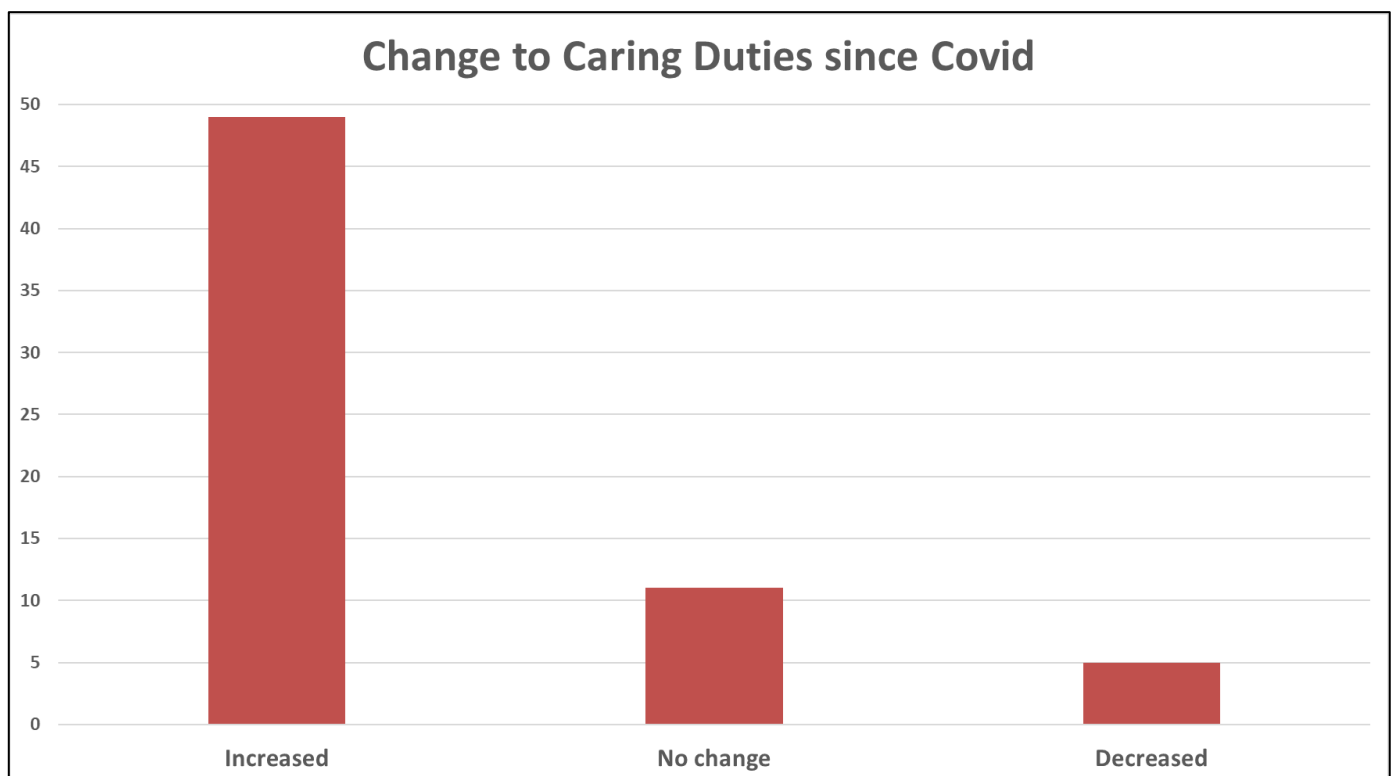
3. Access to services

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).
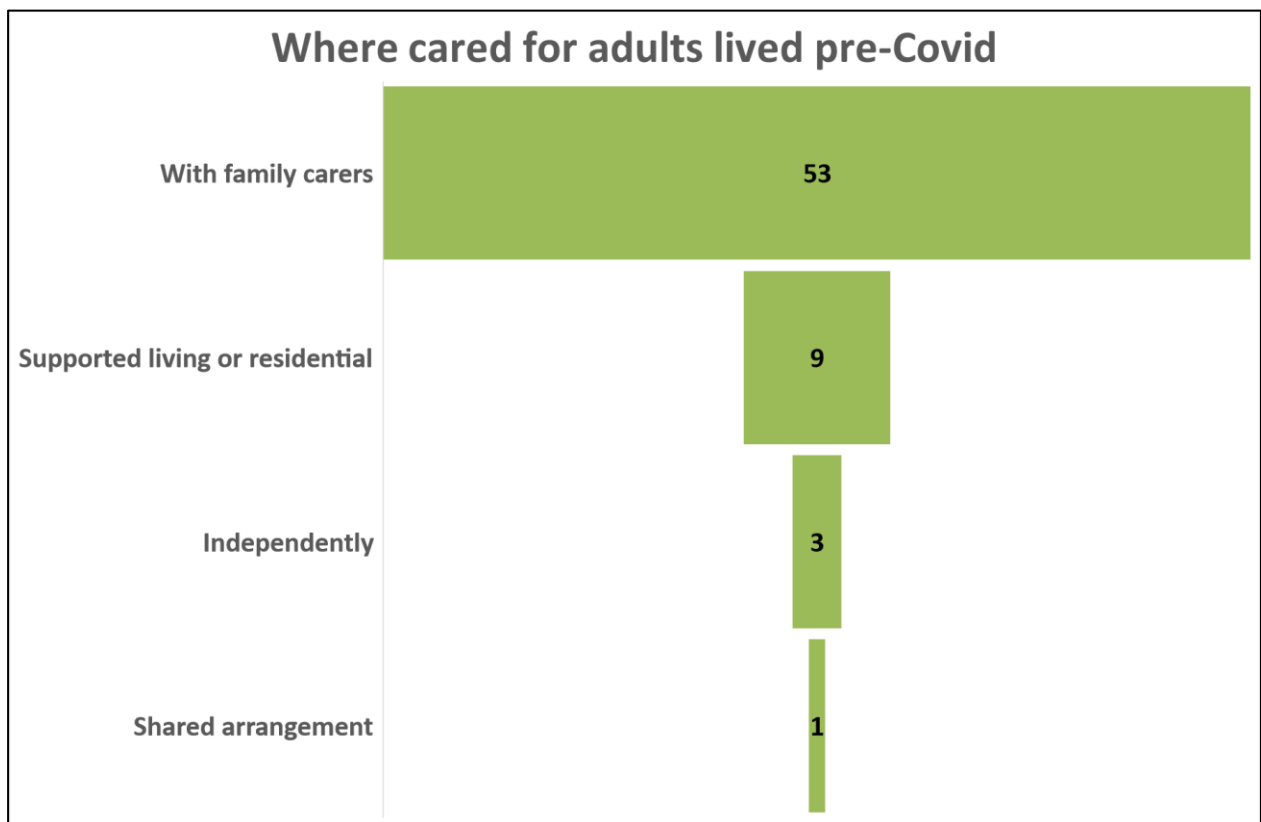
Services attended pre-Covid - cared for person

Service	Value
Voluntary sector leisure service or club	16
Day Centre	16
PA or carer service	16
Voluntary sector day service	13
Further education or skills-based…	11
Overnight respite	11
Adult Education	10
Work Experience / Volunteering	9
Services provided by residential setting	7

Changes to services for cared for adults

Change	Percentage
REDUCED OR MIXED (VIRTUAL, REDUCED HOURS, ON & OFF)	54%
VIRTUAL ONLY, CANNOT ACCESS	15%
SERVICES CLOSED AND NO ACCESS	11%
NO ACCESS TO SERVICES, SHIELDING	8%
RESIDENTIAL, NOT SEEING FAMILY (SHIELDING)	5%
RESIDENTIAL, LIMITED FAMILY CONTACT	5%
UNABLE TO GO OUT	2%
ALL SERVICES RUNNING	2%

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.

Where cared for adults lived pre-Covid

With family carers	53
Supported living or residential	9
Independently	3
Shared arrangement	1

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.

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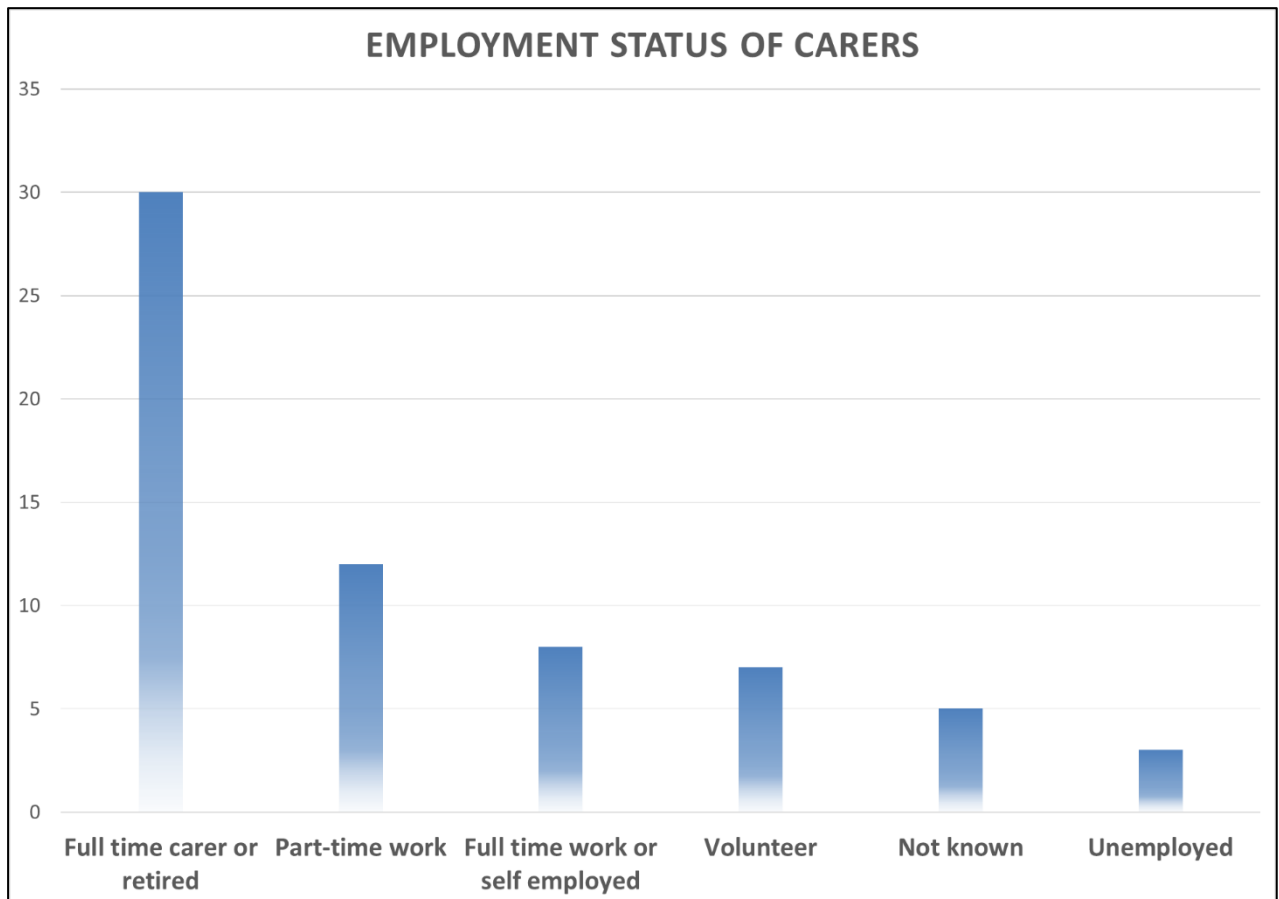
Of those who previously worked or volunteered, almost **1/3 have lost their role, been furloughed, or given up work to care** as a result of Covid. Covid is having an impact on carers' finances as well as increasing caring duties.

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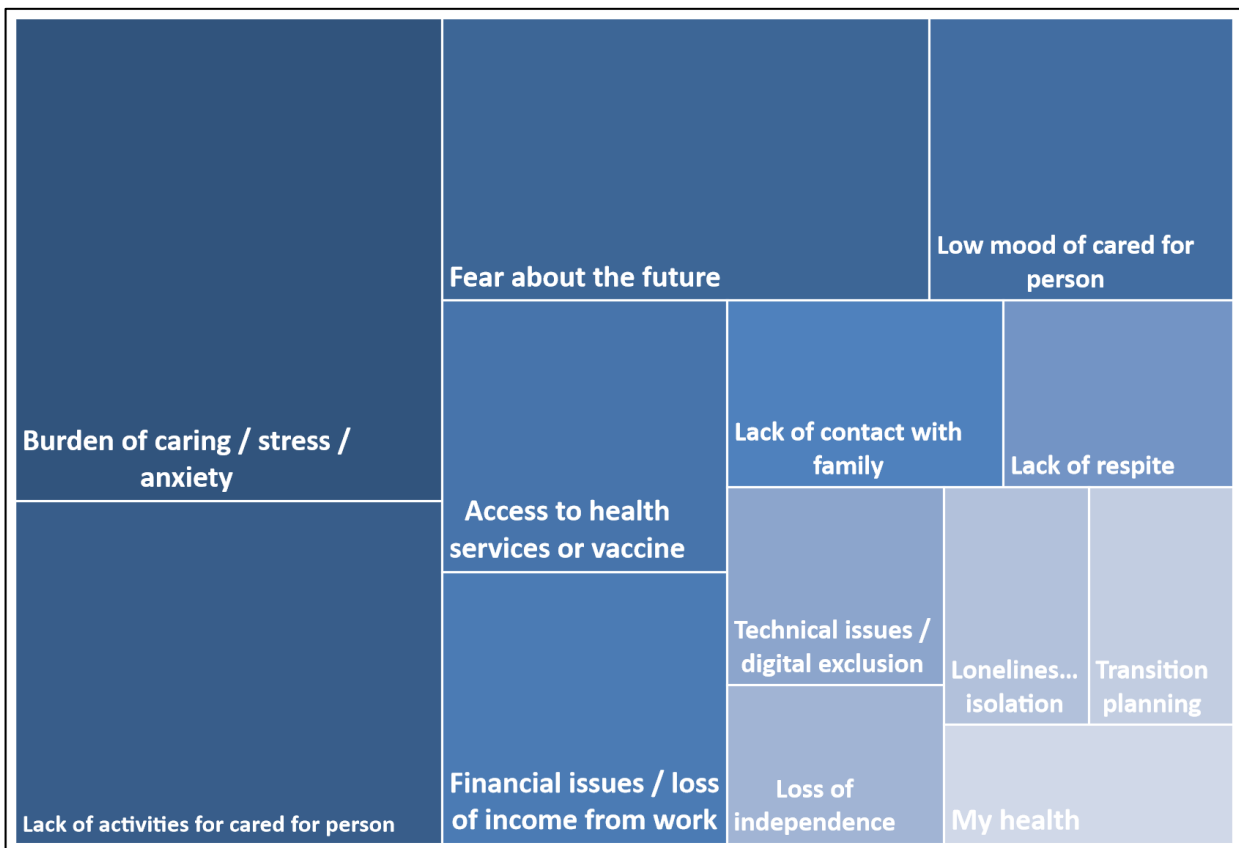
We are also able to report the following challenges which give **cause for concern** despite being lower numerically than those above:

- 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.

Health Impact of Covid
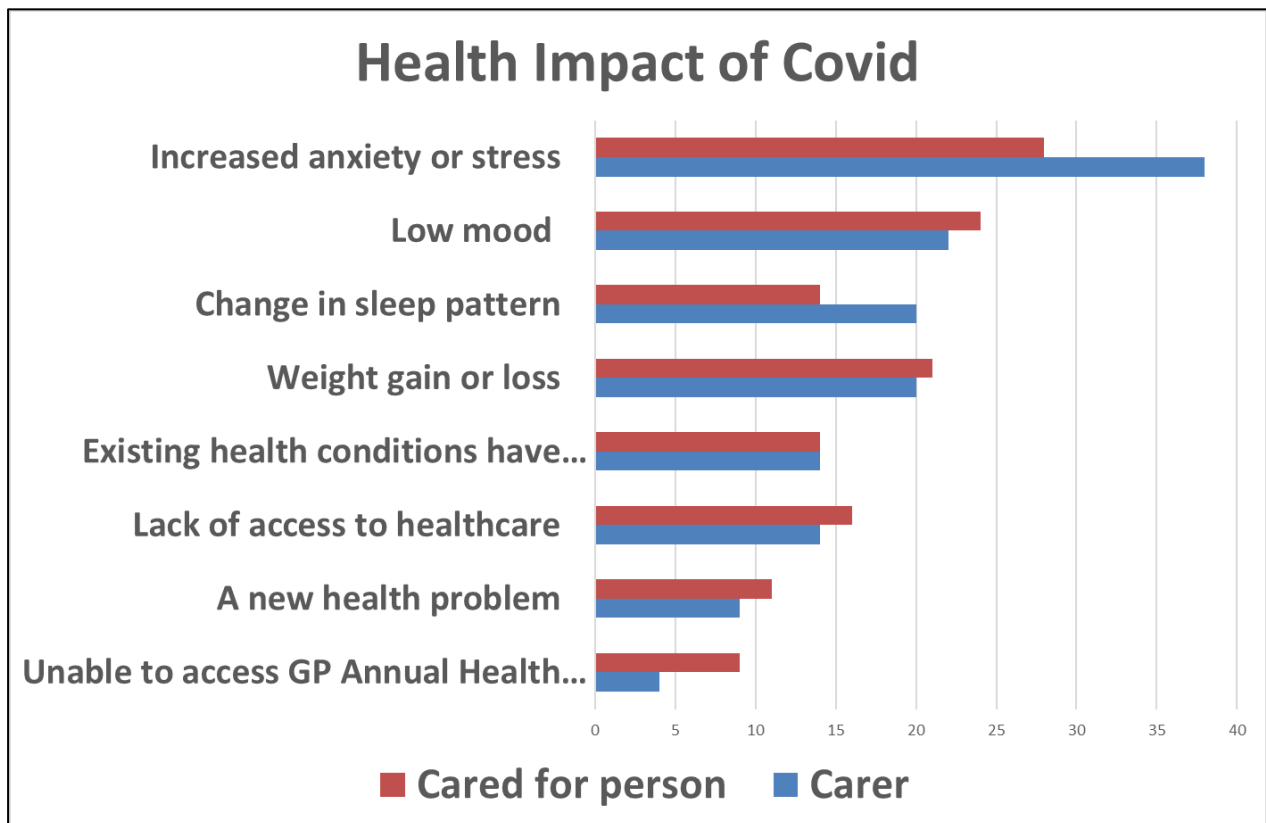
Other health experiences were:

- 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.


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**
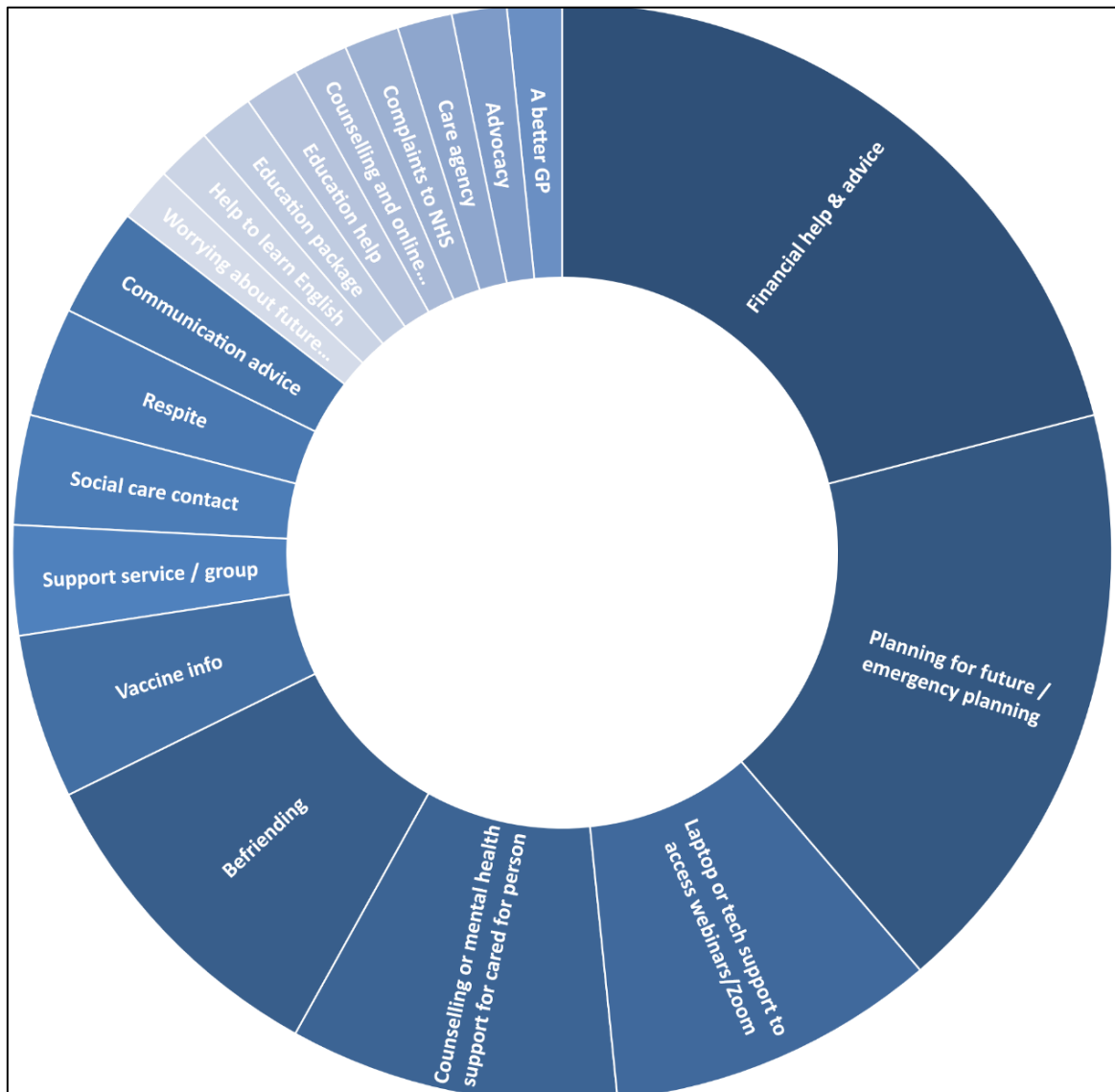
Much of the support requested by carers is available via:

•   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.
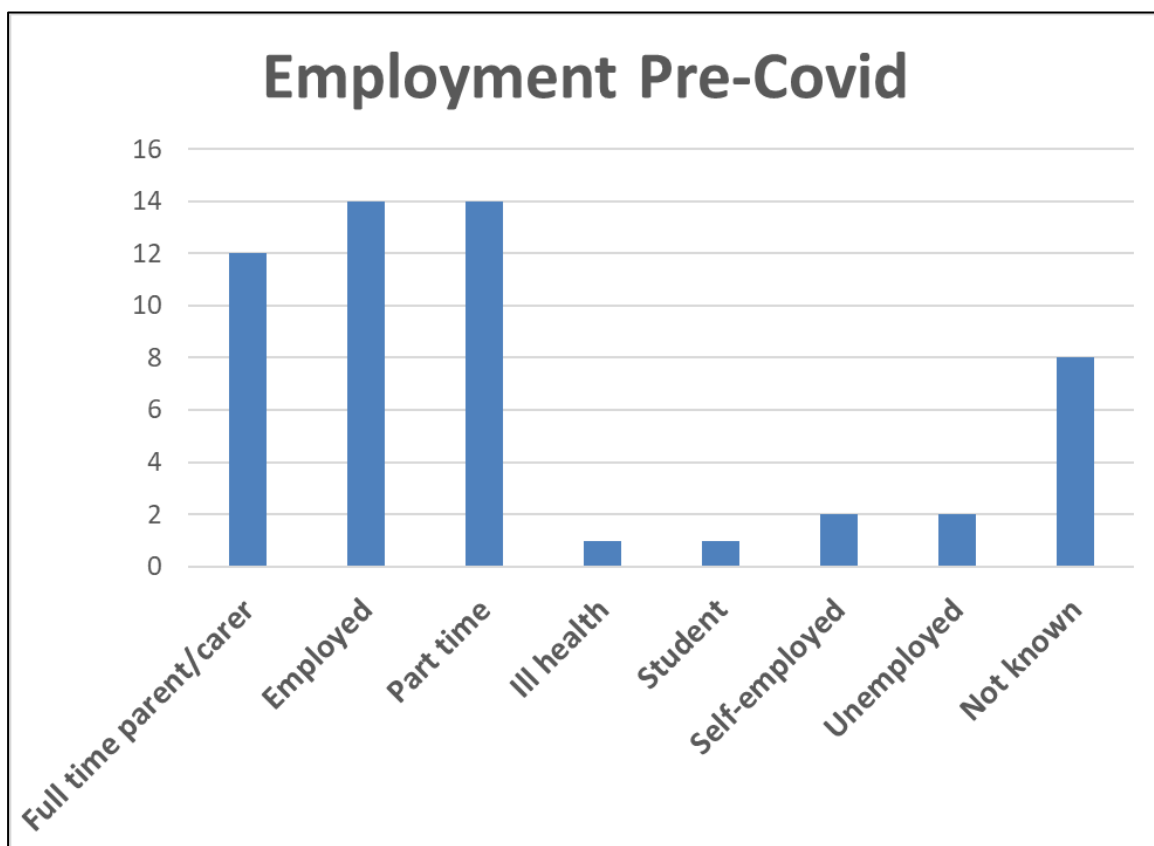
3. Type of disability or additional needs

26% of respondents have children on the autistic spectrum and 33% have children on the autistic spectrum with an additional diagnosis or 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.
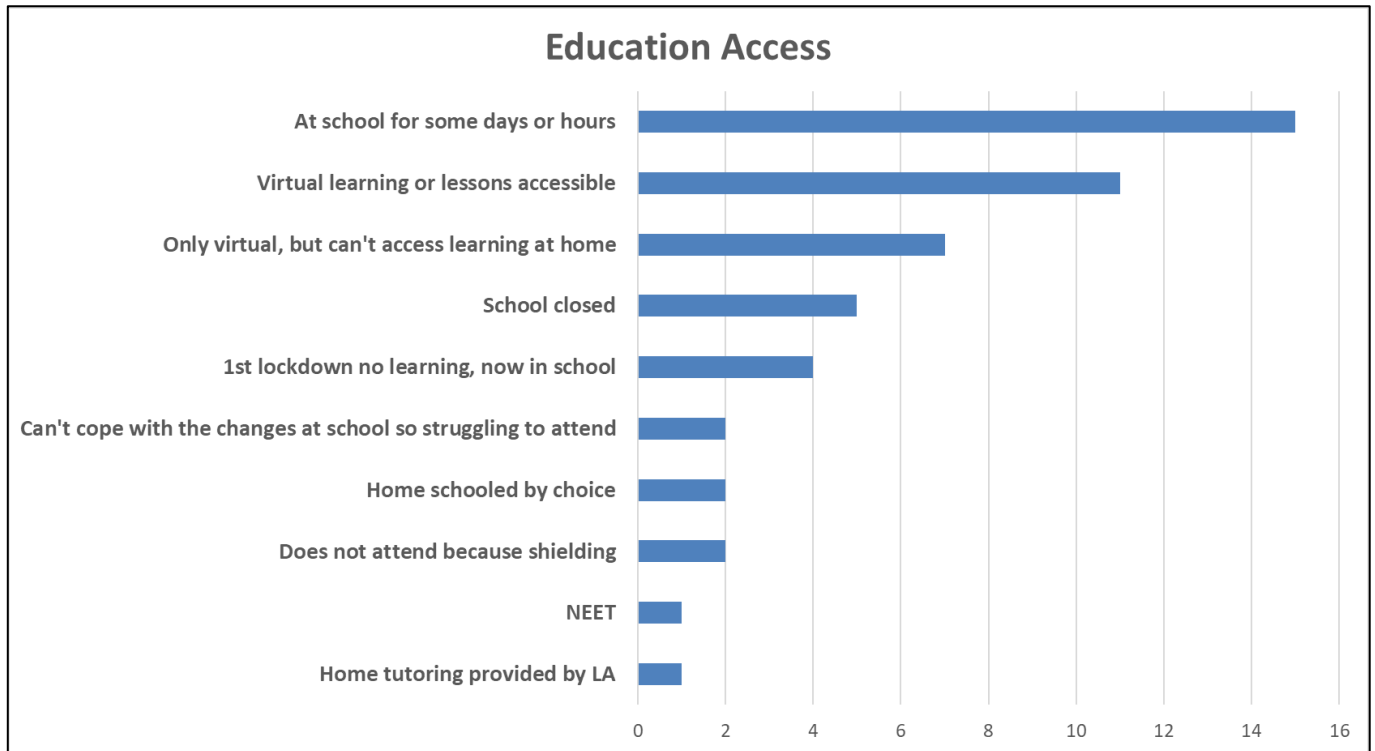
4. Independence
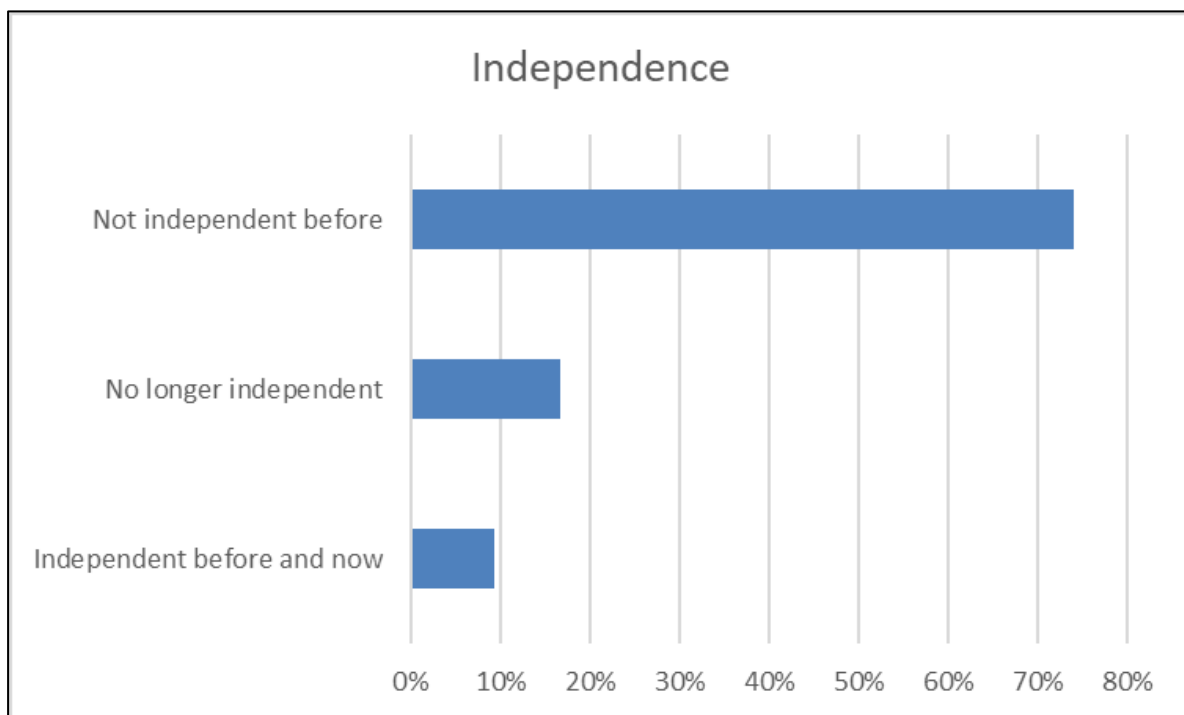
Children would be less likely to be independent travellers due to age. However, there is a similar pattern to adults with LD/ASD, namely, of those who were semi-independent before, 2/3 are no longer independent.

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).

Education Access

Category	Value
At school for some days or hours	15
Virtual learning or lessons accessible	11
Only virtual, but can't access learning at home	7
School closed	5
1st lockdown no learning, now in school	4
Can't cope with the changes at school so struggling to attend	2
Home schooled by choice	2
Does not attend because shielding	2
NEET	1
Home tutoring provided by LA	1

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.

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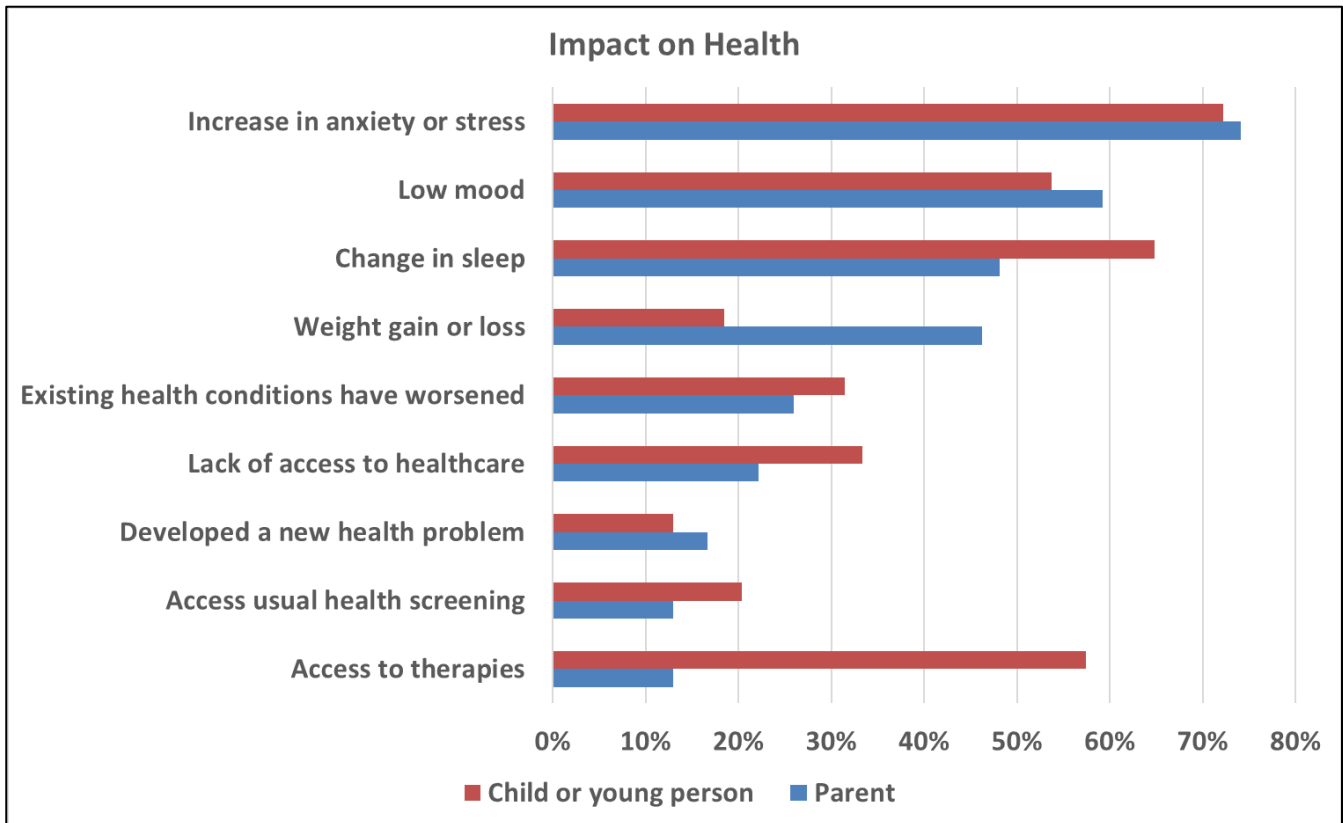
The individual examples below bring these figures to life and show why parents' own levels of anxiety and stress tend to be high.

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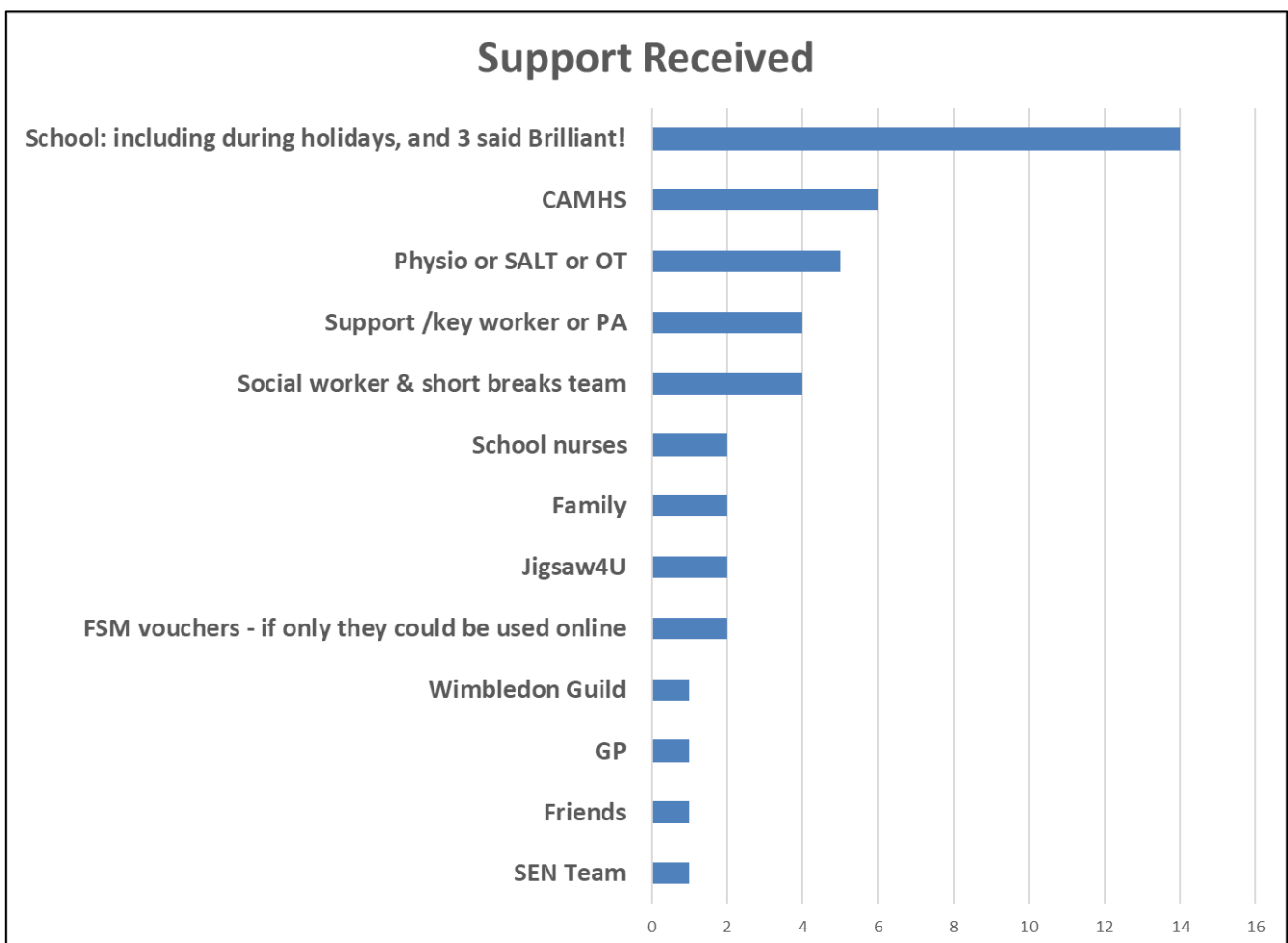
There is no doubt that, without such help and care from education settings, the situation in Merton could have been significantly worse for families.

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.

Support Received

Category	Value
School: including during holidays, and 3 said Brilliant!	14
CAMHS	6
Physio or SALT or OT	5
Support /key worker or PA	4
Social worker & short breaks team	4
School nurses	2
Family	2
Jigsaw4U	2
FSM vouchers - if only they could be used online	2
Wimbledon Guild	1
GP	1
Friends	1
SEN Team	1

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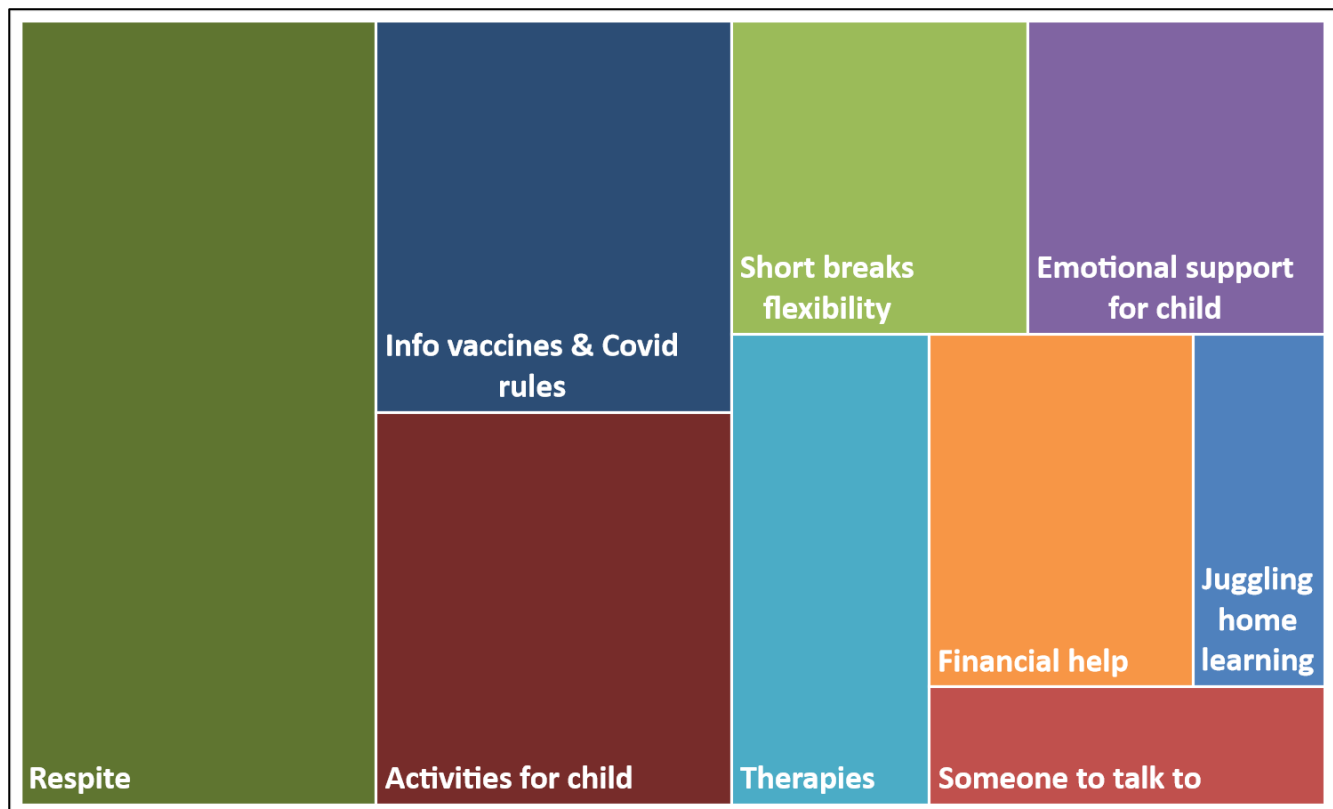
We received a few comments about Short Breaks, some grateful for services which continued to run or for the flexibility offered, but others asking for more flexibility in the they can use a direct payment.

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.

How do you prefer to receive information
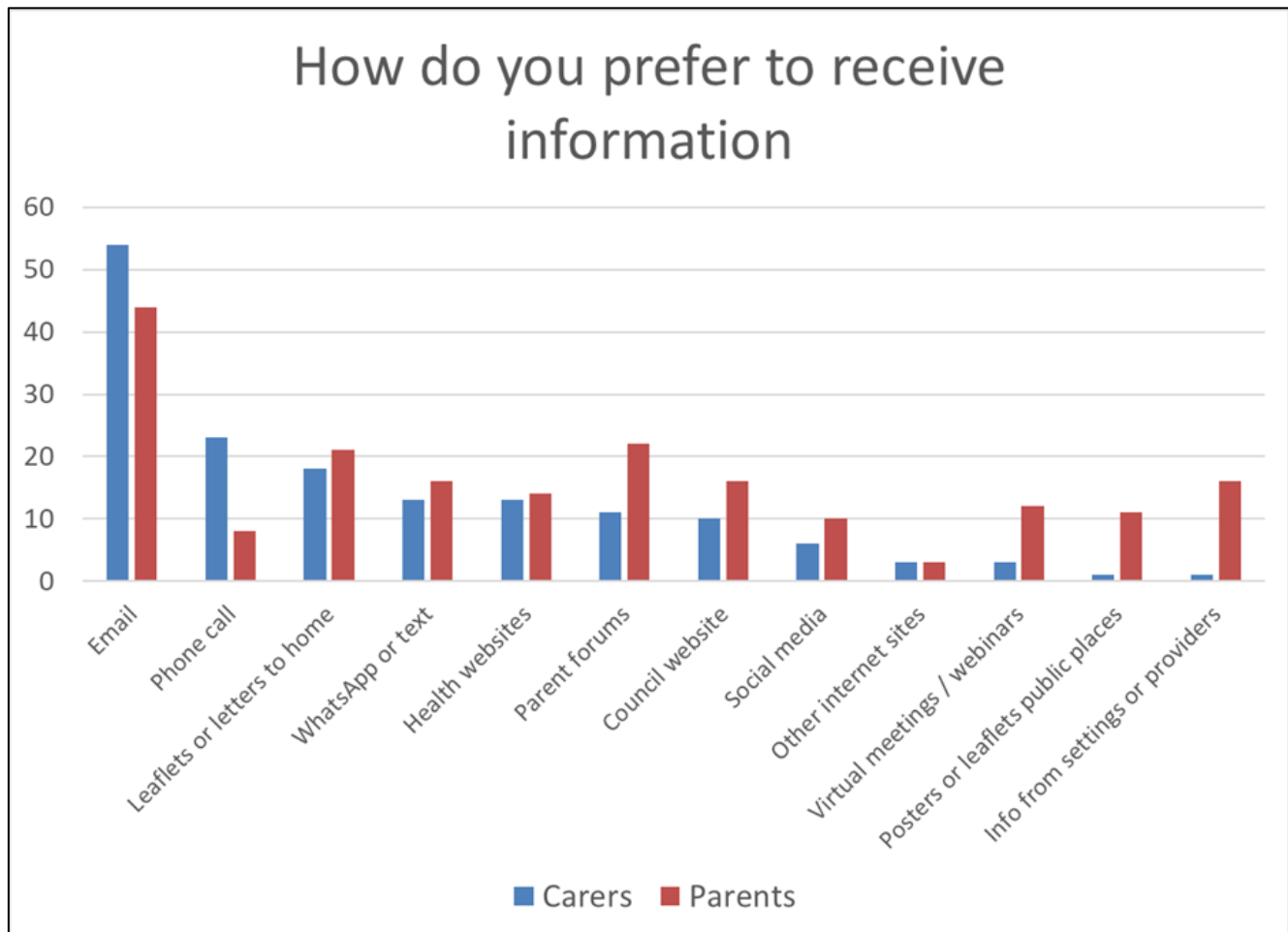
SECTION B   DIGITAL INCLUSION

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).
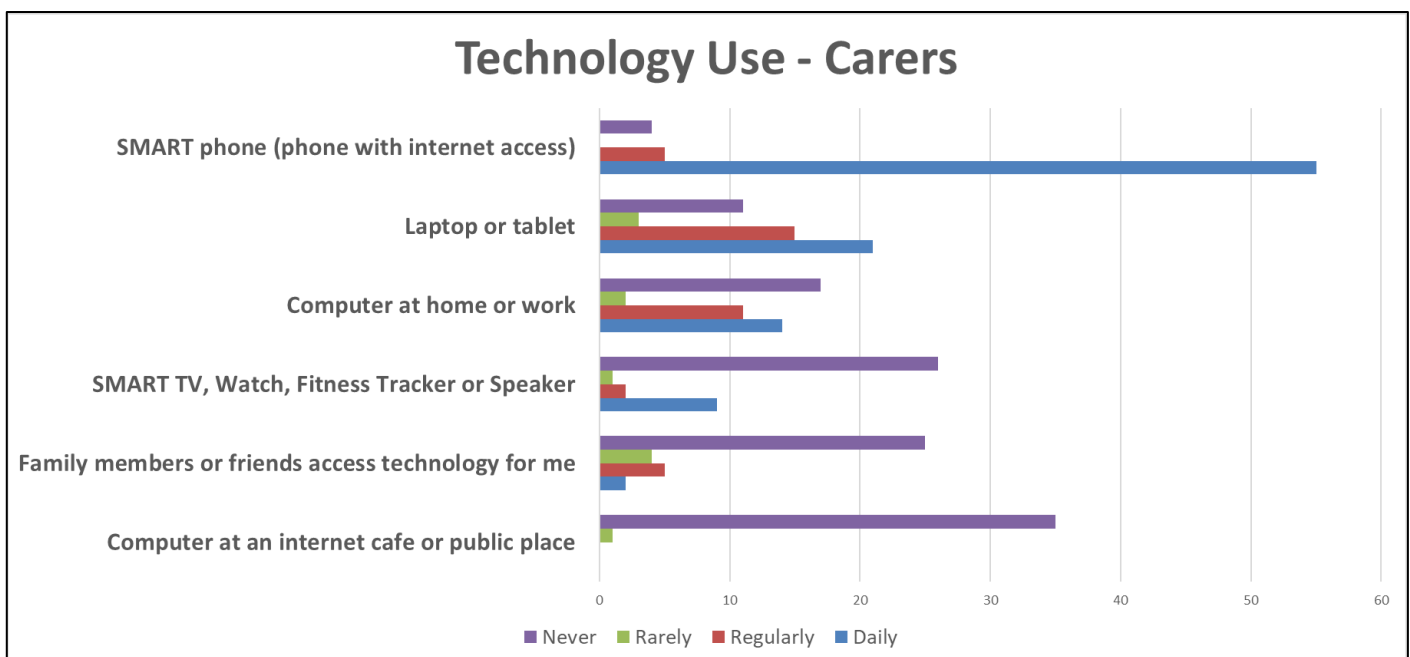
4. Purpose of internet use

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.

Internet Use - Adults with LD/ASD

Category	Value
Video	24
Music	19
Family and friends	19
Gaming	14
Finding out	12
School or College	4
Shopping	1

Carers - what are or could be the benefits of internet use for you and your cared for person?

Category	Me	Person I care for
Communications	52	23
Shopping	47	15
Finding out about things	39	13
Leisure activities online	35	20
Online education	22	18
Finding a job	17	11
Translation	2	1

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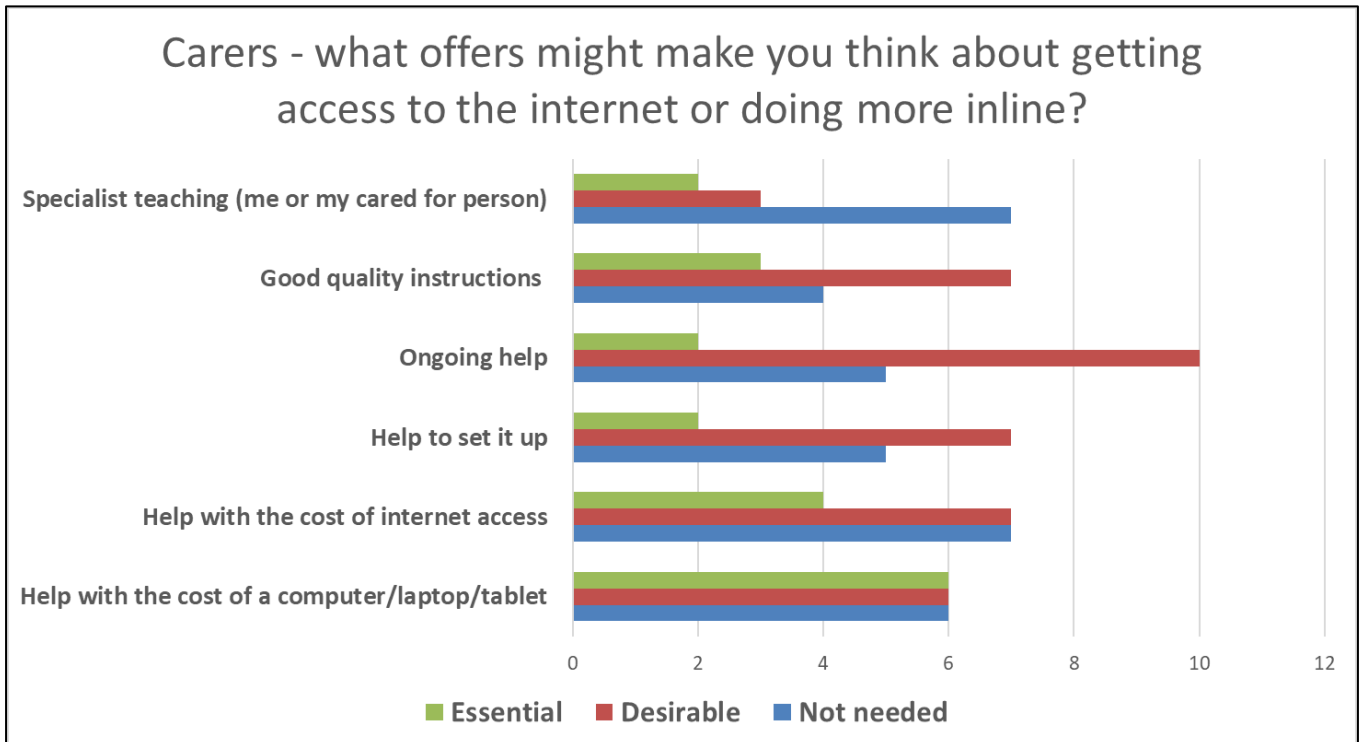
One carer stated, '*she just doesn't have the mental capacity*', another said '*he doesn't need it, as long as he has his TV, he is happy*', and one carer said, '*we have only just weaned him off videos*'.

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.

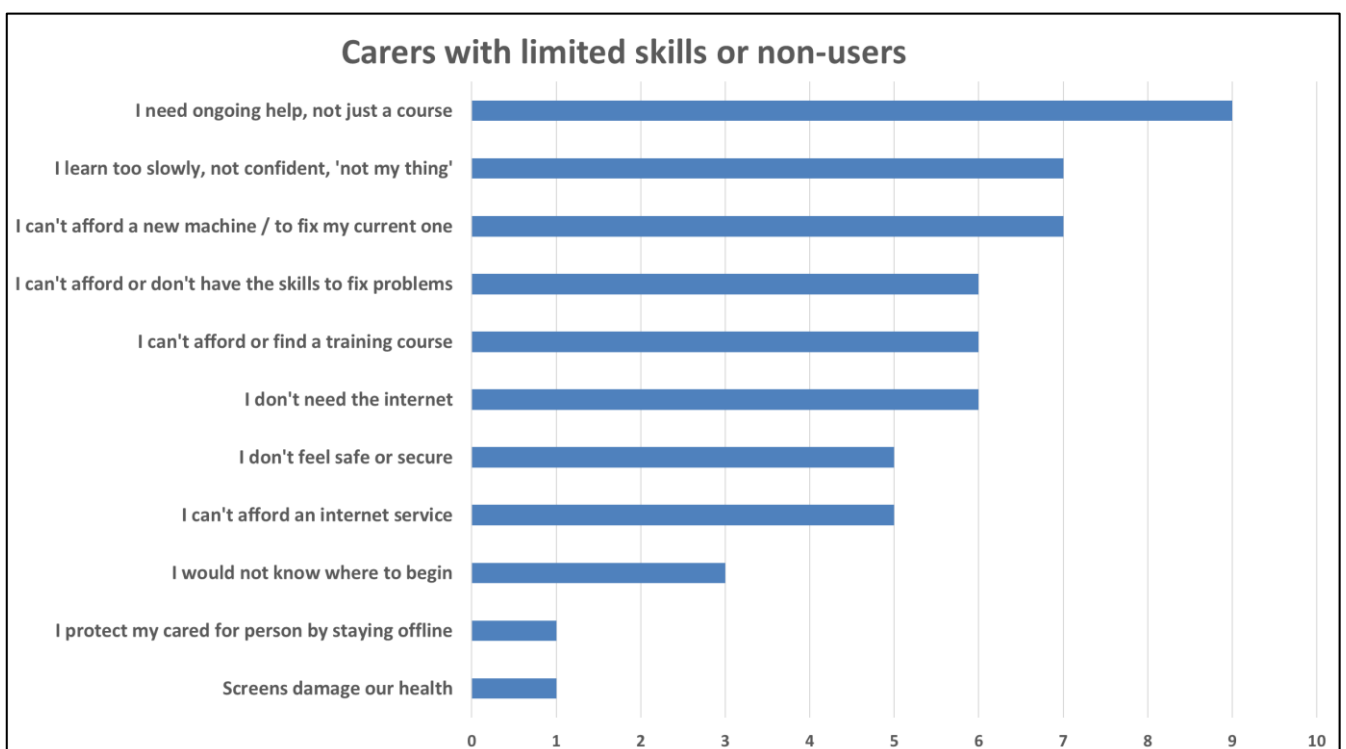**Gaps in internet usage**: even people who use the internet extensively, may need support to extend their usage in ways that could be important for them in the future. For example, in special schools, children are all digital to some degree and enjoy gaming and YouTube. Although they access online learning 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.

Carers - what offers might make you think about getting access to the internet or doing more inline?

	Essential	Desirable	Not needed
Specialist teaching (me or my cared for person)	2	3	7
Good quality instructions	3	7	4
Ongoing help	2	10	5
Help to set it up	2	7	5
Help with the cost of internet access	4	7	7
Help with the cost of a computer/laptop/tablet	6	6	6

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.

Carers with limited skills or non-users

Statement	Value
I need ongoing help, not just a course	9
I learn too slowly, not confident, 'not my thing'	7
I can't afford a new machine / to fix my current one	7
I can't afford or don't have the skills to fix problems	6
I can't afford or find a training course	6
I don't need the internet	6
I don't feel safe or secure	5
I can't afford an internet service	5
I would not know where to begin	3
I protect my cared for person by staying offline	1
Screens damage our health	1

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.

Carers - Assistive Technology
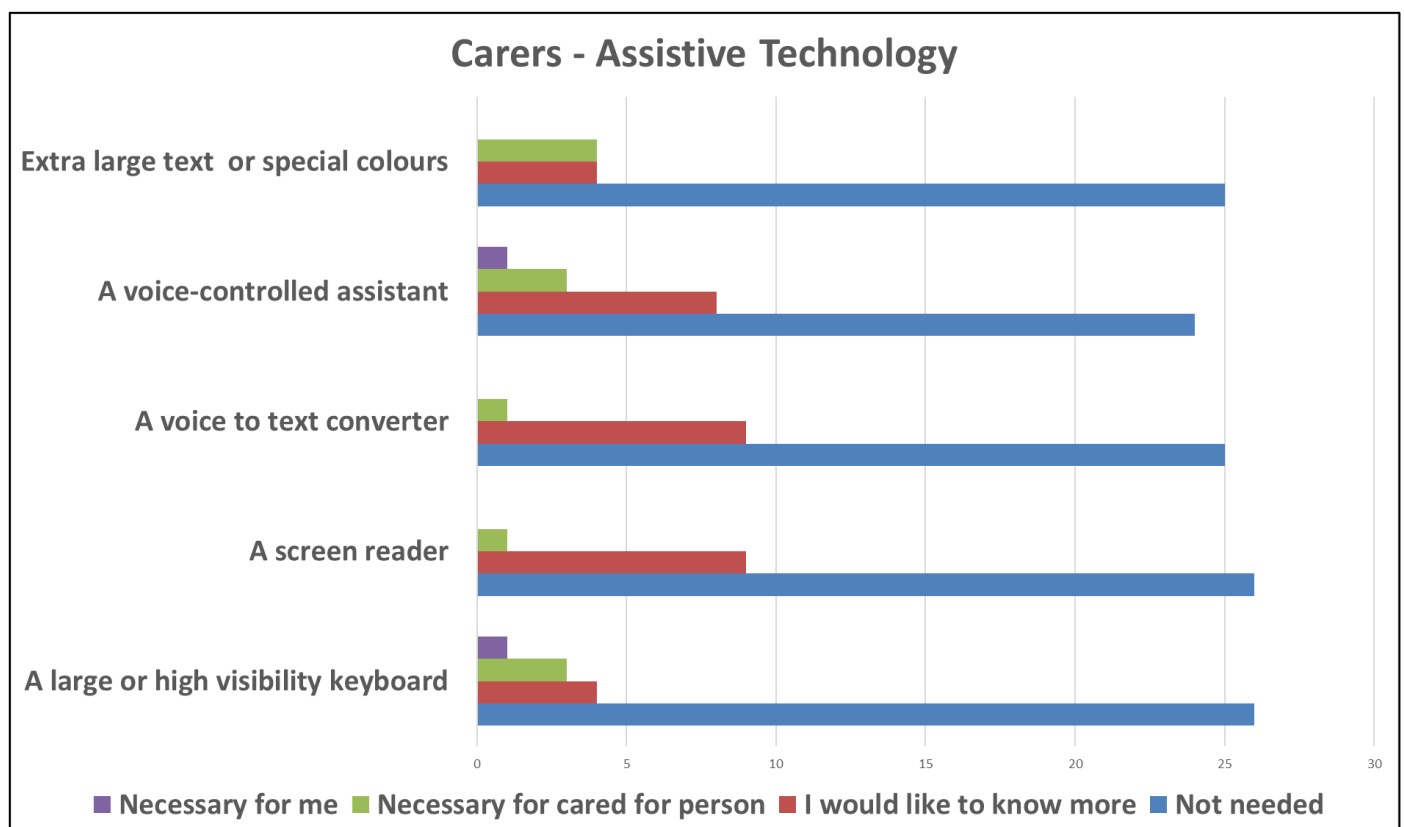
7. **Previous technical help (carers who are basic of non-users)**

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:

  o **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*'

  o **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)

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

  o **Practical considerations:** choosing equipment, setting it up, contracting an internet provider (we also note old machines can be counterproductive)

- o **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'*

- o **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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