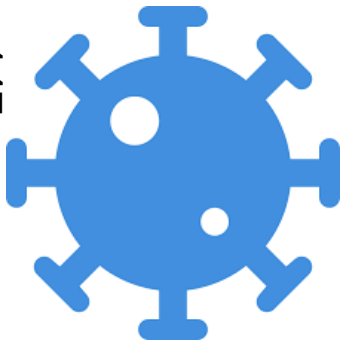




Engagement Work for Public Health Merton



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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



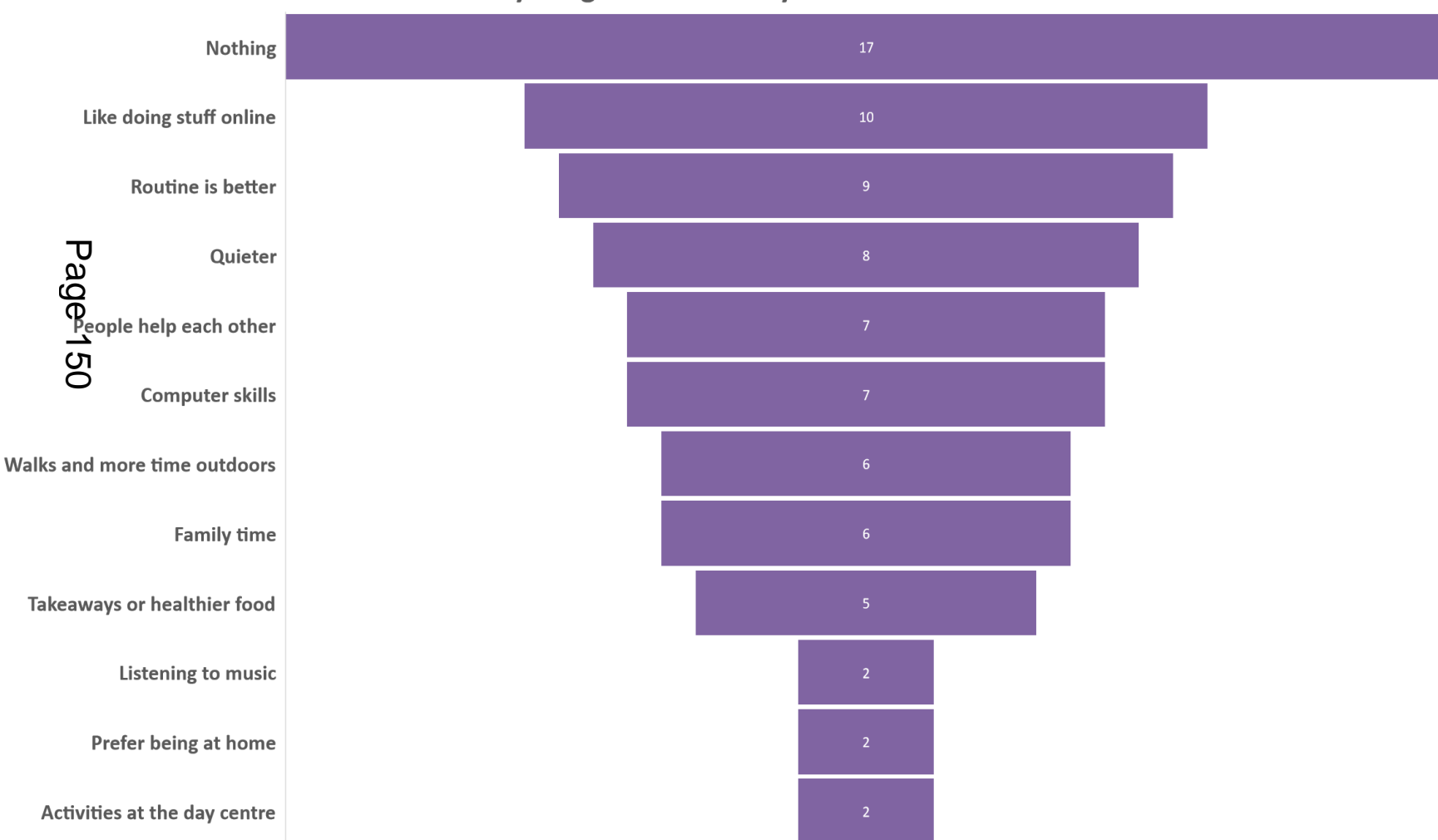
People with LD/ASD miss outings, friends and activities

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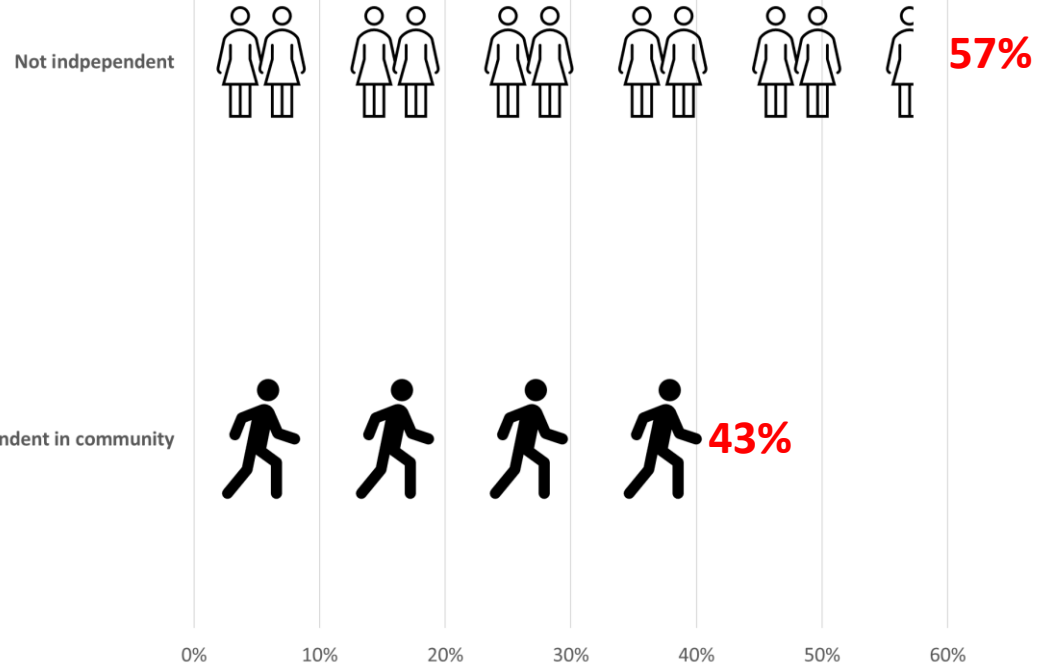
- Nearly half say nothing has been positive
- Being online or computer activities are enjoyed by some people
- For some, virtual health appointments are easier

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

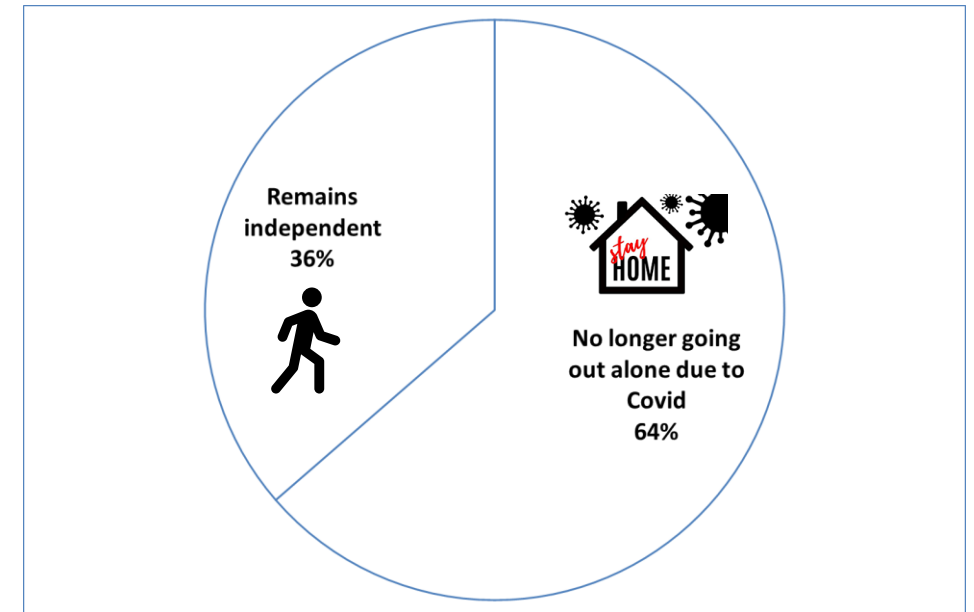
Nearly 1 in 3 no longer go out alone because of Covid



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



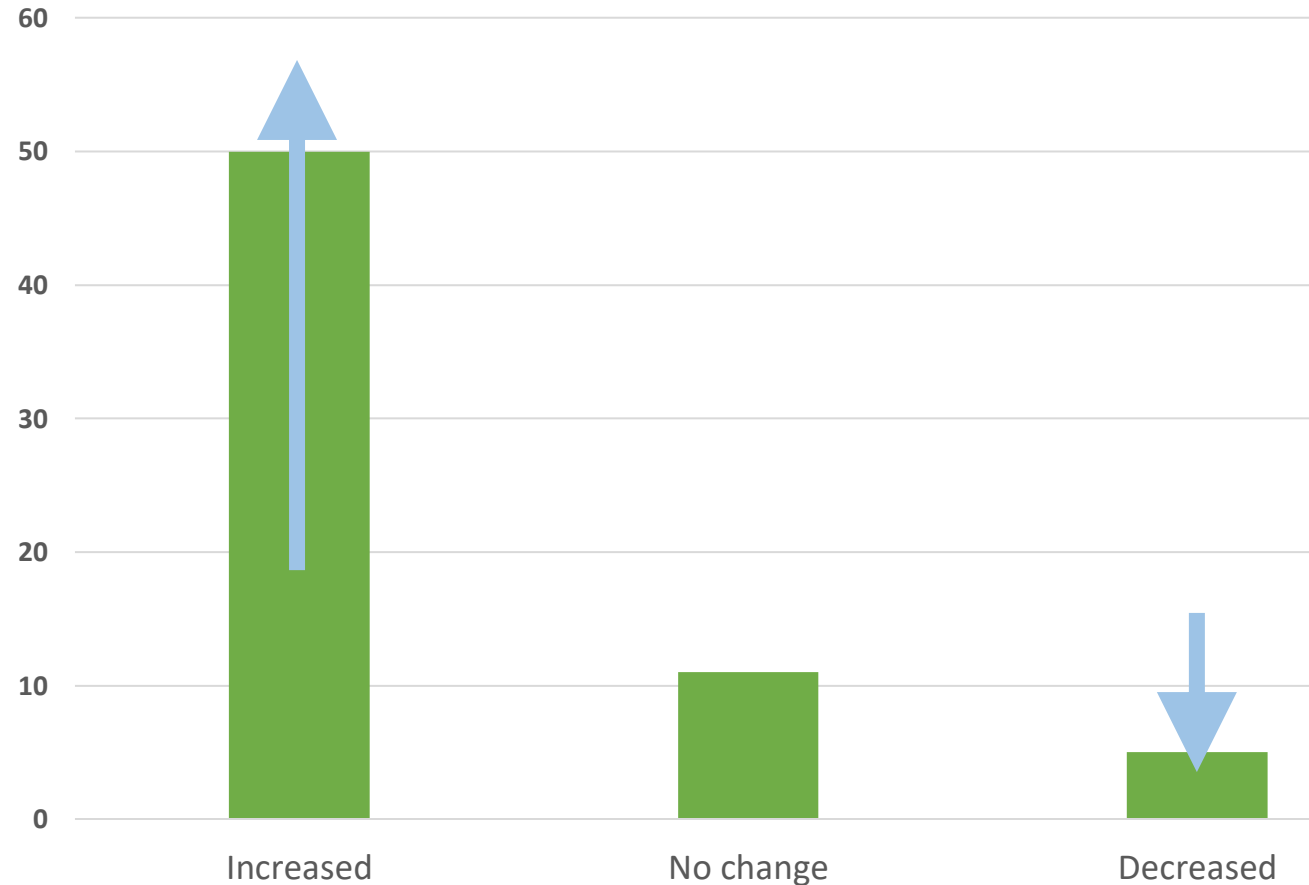
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Over 1/3 access NO services

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

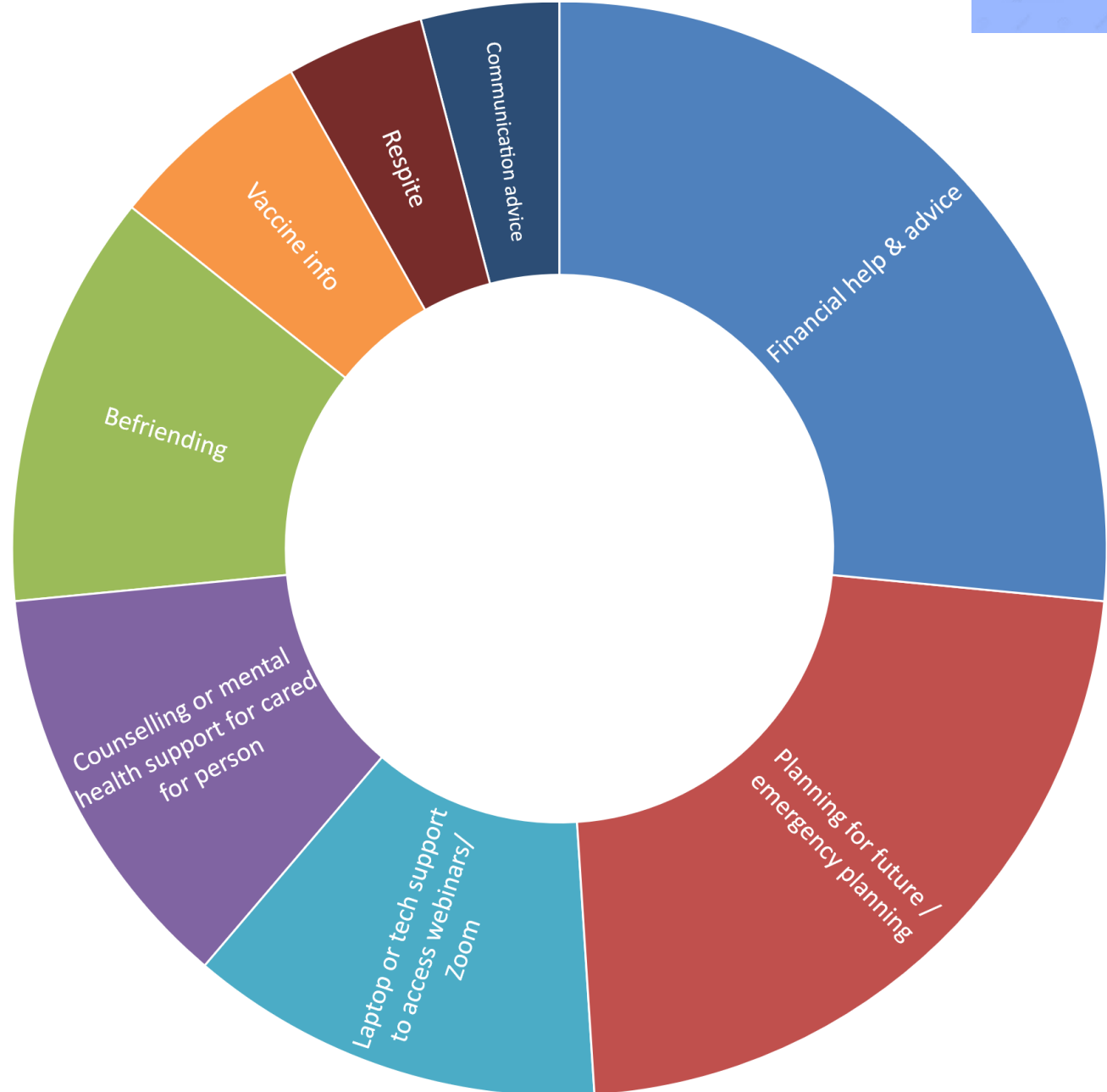


82% of carers say their caring duties have increased





Main support needs



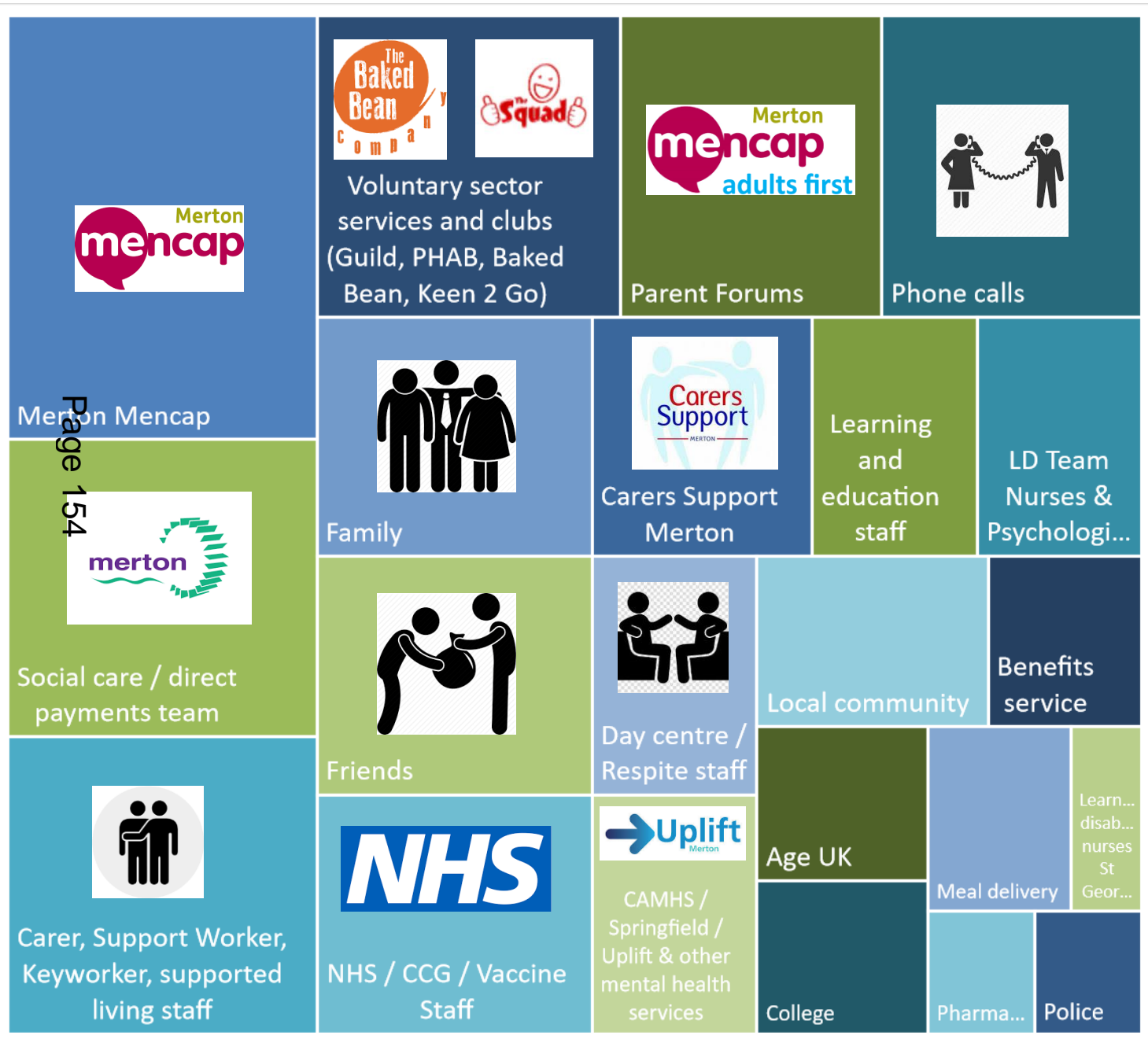
Main challenges

- **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”

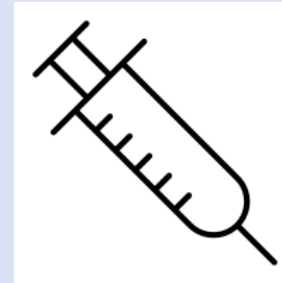
“I am lonely”

“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

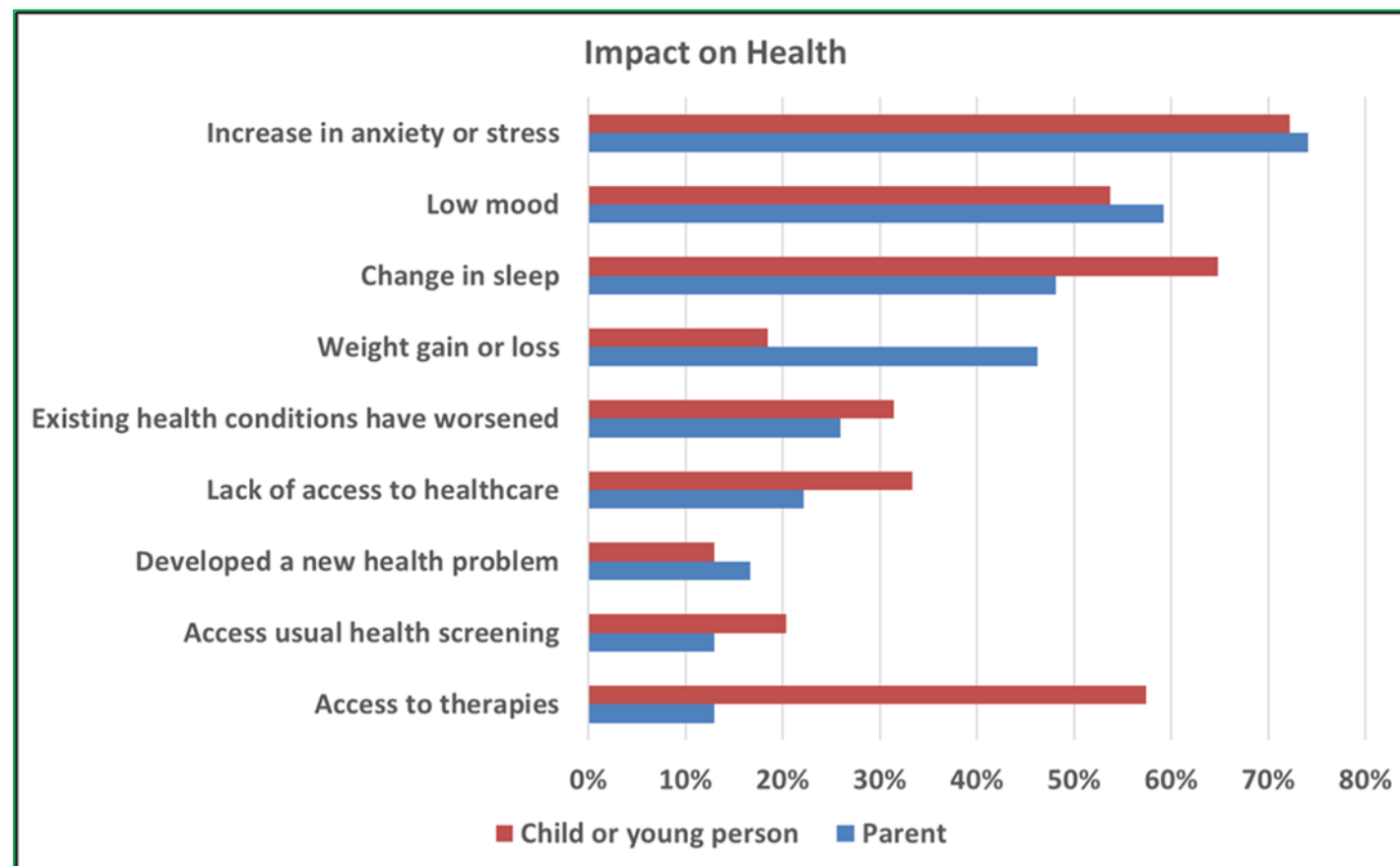


Parents

- 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

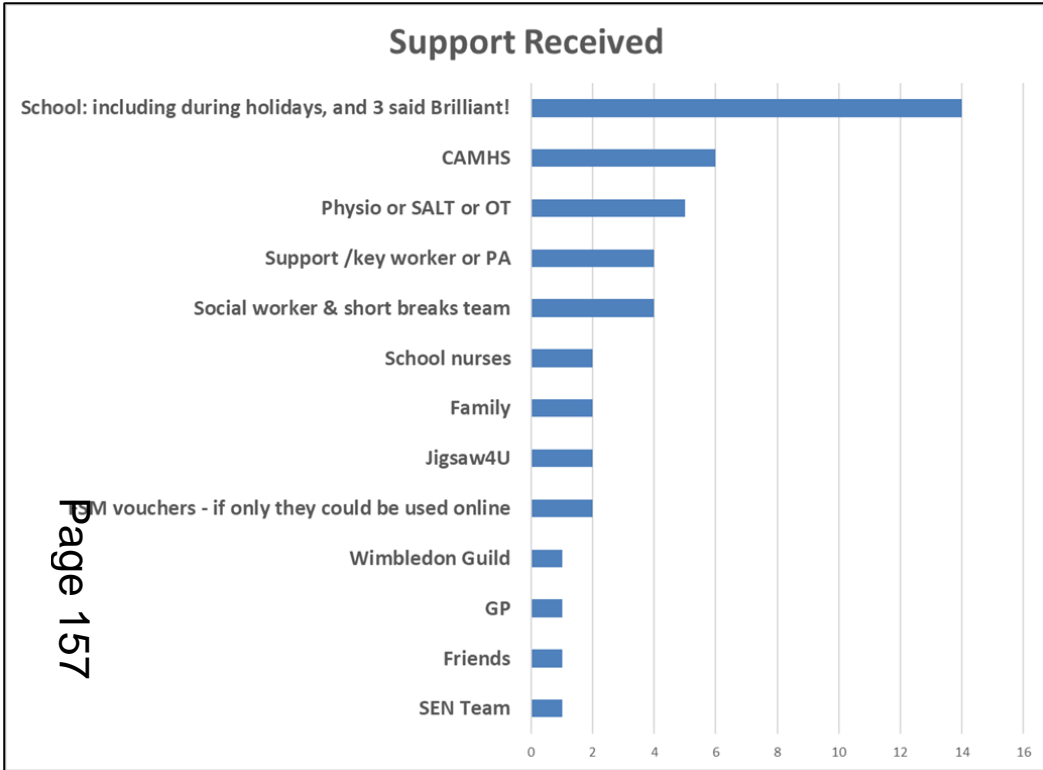
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Mental health is the most significant health issue





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

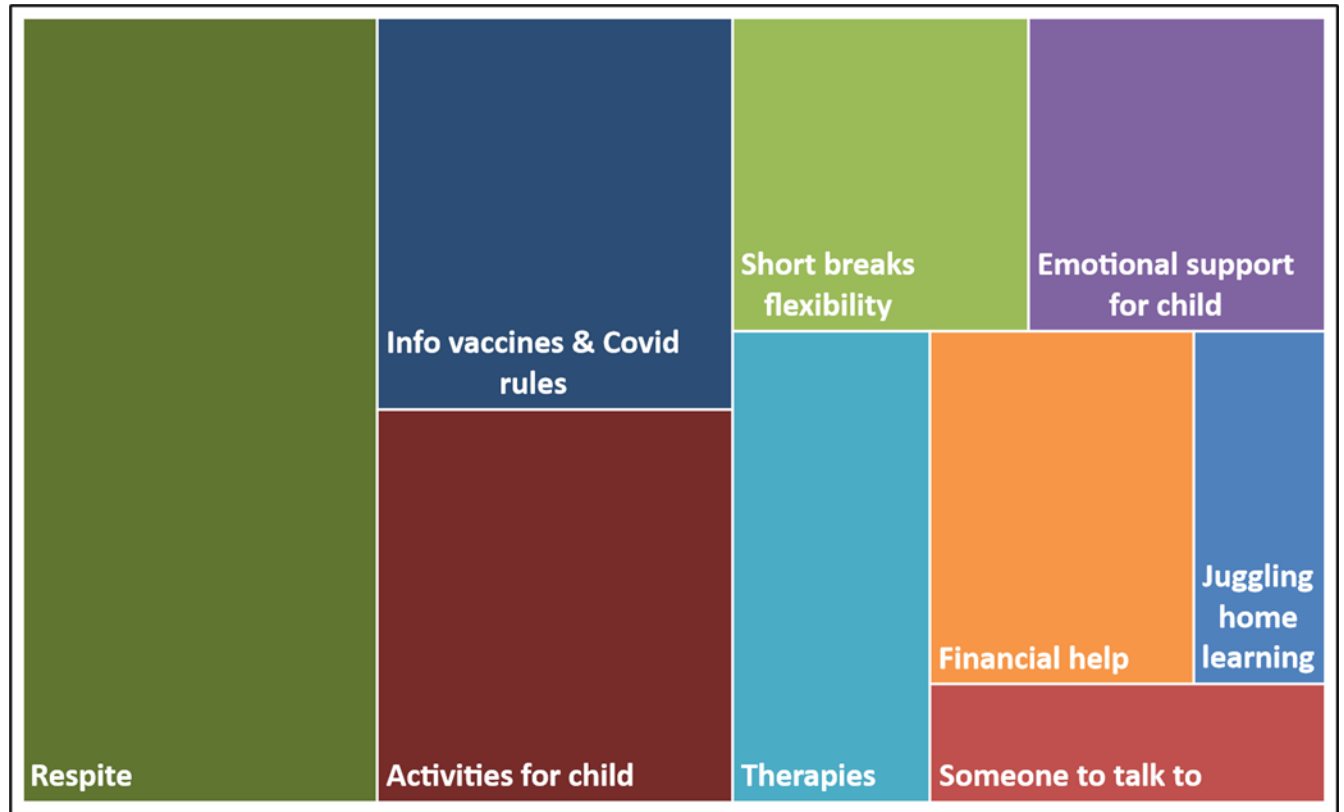
Positives?

Most said none

20% said learning or anxiety about learning is better

17% valued more family time

Support needed



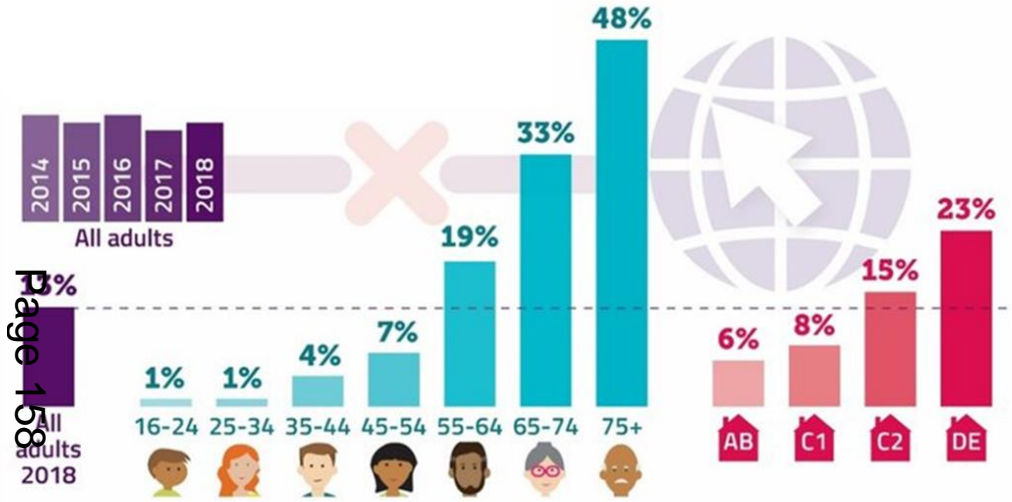
Digital Poverty

What do we know about digital poverty in the UK?

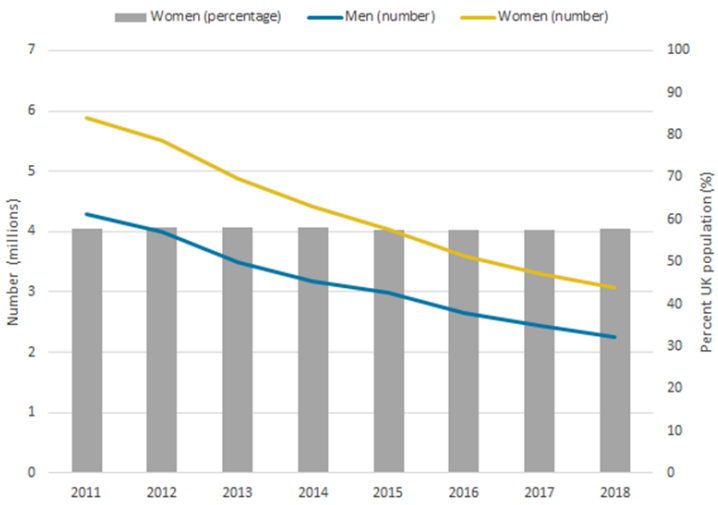
22% are digitally poor (basic or no skills)

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 158
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

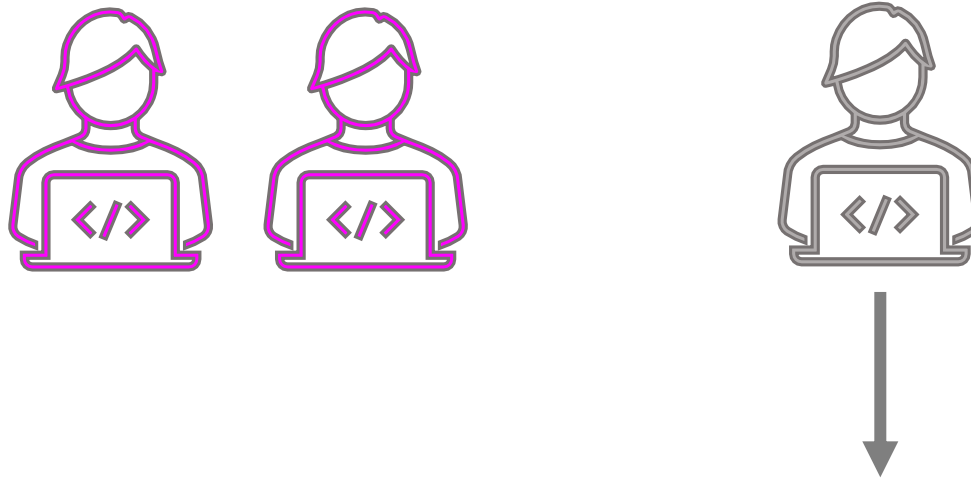
58% live in the more deprived postal areas

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

38% are digitally poor



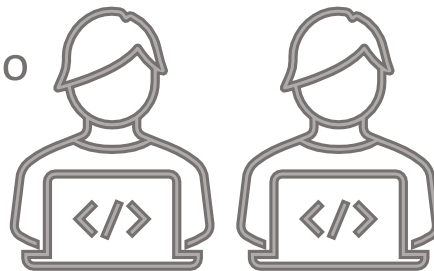
Over 1 in 3 carers are basic or non-users of the internet



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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

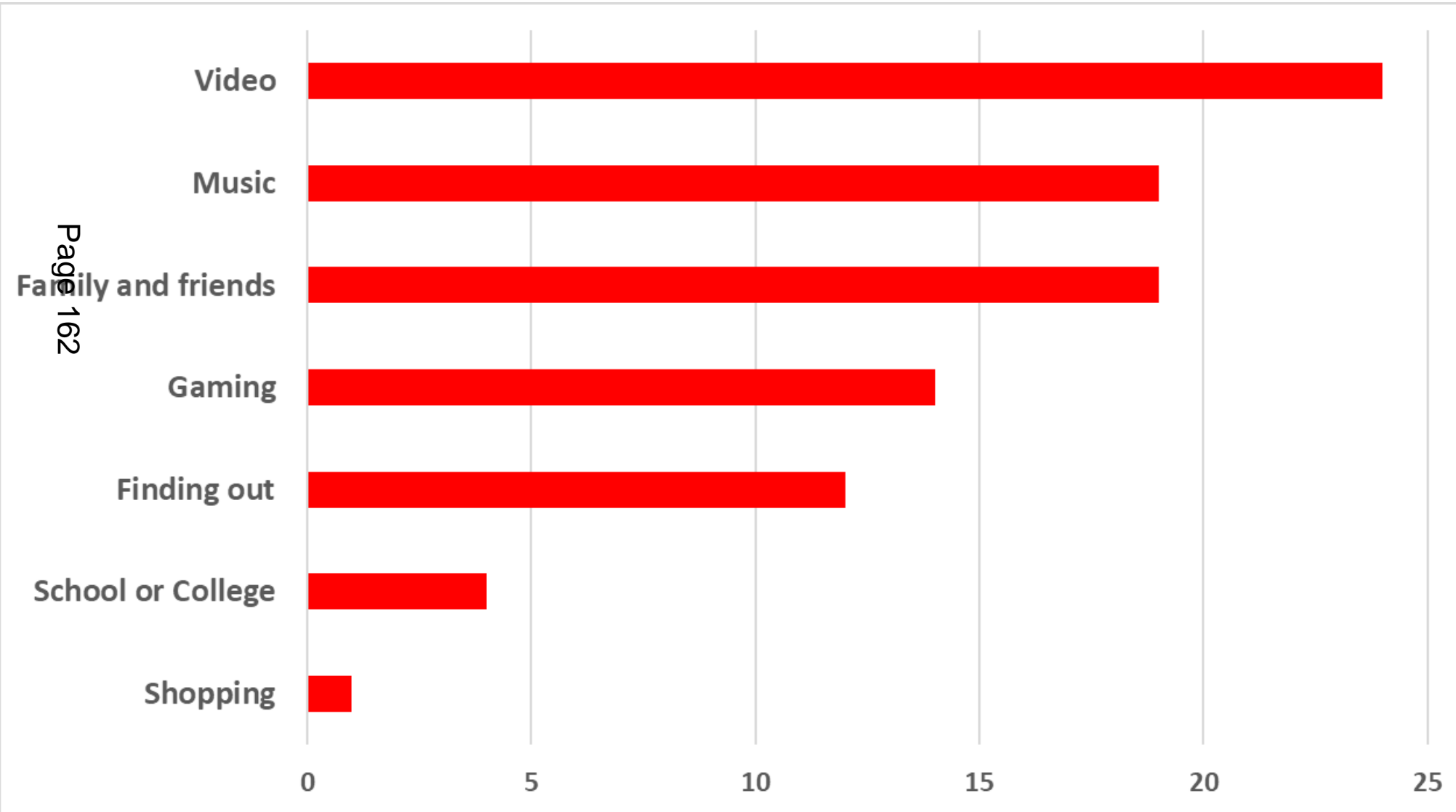
Money: can't afford machine and/or can't afford provider, not a financial priority compared with daily living



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

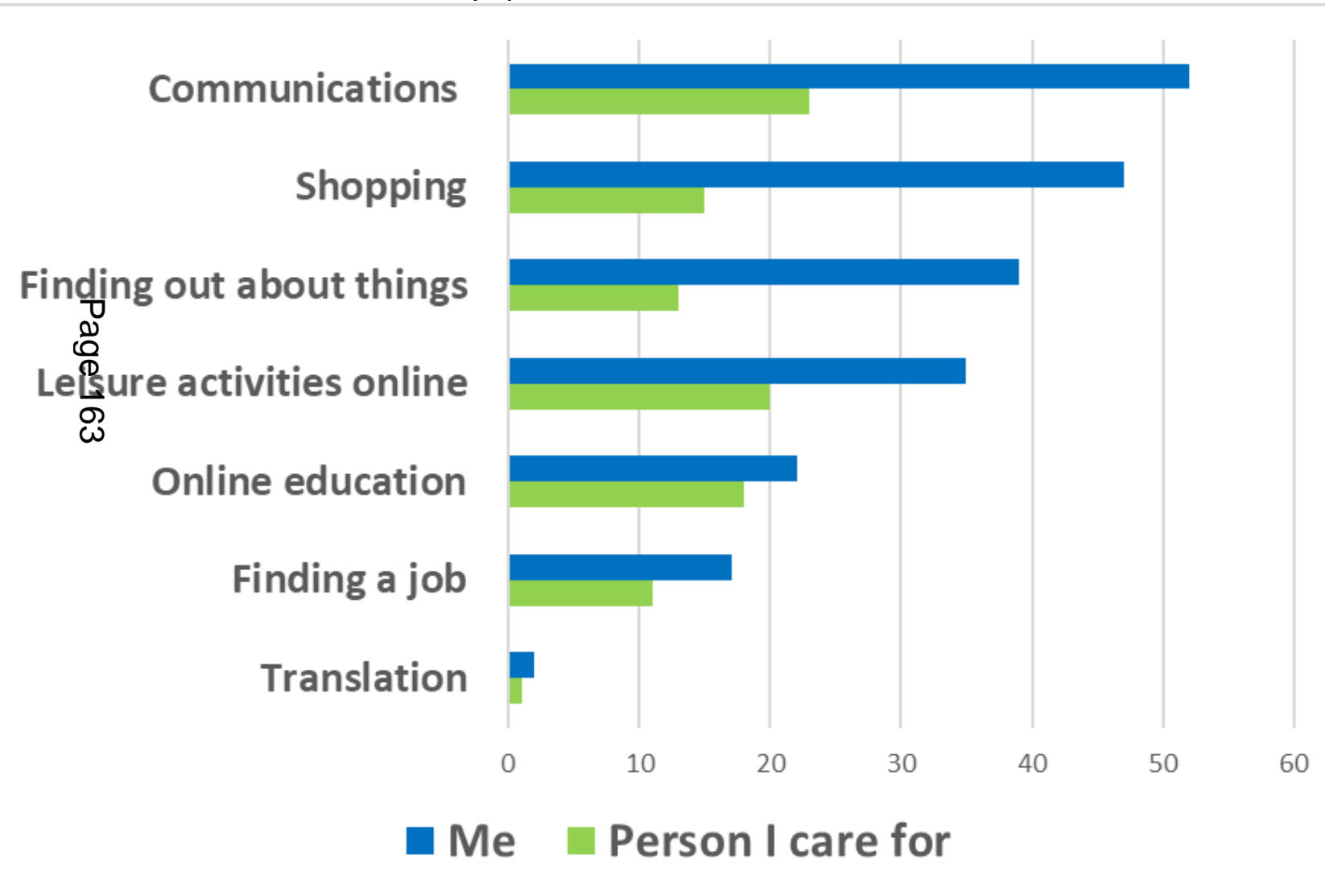
Zoom activities were mentioned by many

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)