

# Living Through Lockdown

# Lessons from Haringey's most vulnerable service users

August 2020



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### Introduction

This report is a summary of issues and concerns experienced by adult social care service users and carers during the lockdown in Haringey. Suggestions for service improvements are also presented. All points included were raised by the Haringey Joint **Partnership Board and** its reference groups, between April and August 2020.

During the Covid-19 lockdown, Haringey's pre-existing service user groups (termed reference groups) continued their work, where possible, through a variety of channels including Zoom, phone calls and email exchanges. They shared their experiences of health and social care services in Haringey during this difficult time; raising issues and challenges and making suggestions for improvements.

Feedback from the reference groups is invaluable in terms of hearing directly from Haringey residents about their experiences of health and social care. All feedback has been summarised in this report so local and national decision-makers can use it to inform their Covid-19 strategy and planning going forwards, particularly in terms of making plans for Autumn/ Winter 2020.

The report is divided into sections by the themes reported across all the reference groups. It sets out what has worked well, issues and challenges, and suggestions for improvements.

The following reference groups have contributed to this report:

- Autism
- Carers
- Dementia
- Learning Disability
- Mental Health
- Older People

- Physical Disability
- SCALD (Severe and Complex Autism and Learning Disability)
- Transitions

All information within this report was gathered between April and August 2020 through meetings held online and individual feedback over the phone and by email.

#### The Joint Partnership Board

The Joint Partnership Board was set up in 2017 to ensure that vulnerable groups in Haringey have a voice in the way NHS services and social care are provided for them. Public Voice, which runs and manages Healthwatch Haringey, was commissioned by Haringey Council to establish and support the running of the Joint Partnership Board and its reference groups.

The Joint Partnership Board consists of nine independent reference groups formed of NHS and social care service users and carers from the wide range of services in Haringey. The reference groups represent the interests of specific user groups, to ensure their voices are heard and their particular needs and aspirations are taken into account. Each reference group covers a specific thematic area: Autism, Learning Disability, Older People, Severe and Complex Autism and Learning Disability, Mental Health, Physical Disability, Dementia, Transitions and Carers. The groups are made up of adult members and focus on the issues of adult social care and public health. The transitions reference group focusses on the process of older children moving from being supported by children's services to adult services.

The Joint Partnership Board is committed to effective partnership working, with an emphasis on empowering service users, carers and other residents as equal partners in meaningfully contributing to, developing and achieving strategic priorities.

#### **Public Voice**

Public Voice is a Community Interest Company which, amongst other projects, delivers Healthwatch Haringey and supports the Joint Partnership Board. The mission of Public Voice is to improve neighbourhoods, the lives of the people who live in them, and the public services they use. This is achieved through community engagement, individual user engagement and community intervention, collecting the combined voices of citizens, gathering evidence and ultimately taking action to bring about positive change, now and in the future.

As the lockdown carries on and evolves, Public Voice will continue to support the Joint Partnership Board and its reference groups, cataloging concerns and gathering additional feedback and suggestions for service improvements. We will share this report with our wide range of stakeholders and partners including Healthwatch England.

### **Executive Summary**

The Covid-19 pandemic, and the unprecedented national lockdown, was an enormous challenge for health and social care providers as well as service users in Haringey.

Although many concerns were raised and the pandemic created a great deal of anxiety for Haringey's reference groups, some changes and action taken in response were seen as highly positive.

Some concerns and positive occurrences were expressed across all reference groups.

#### What has worked well

- **Community spirit and volunteers.** Both were highly praised by reference group members.
- Connected Communities. A programme established in 2018 by Haringey Council to improve access to council and voluntary services. During the lockdown, Connected Communities helped residents access essential items including food and other support they needed.
- Mutual aid groups. Formed during lockdown at the neighbourhood level and building strong links with statutory and Voluntary and Community Sector services and vice versa. These groups provided a wide range of support for others in their community – for example checking on neighbours and shopping on behalf of others. The mutual aid groups were praised and appreciated.
- Telephone support. Reference group members appreciated having someone to speak to on the phone when calling Haringey Council. Phone calls made from the Council, Clinical Commissioning Group (CCG) and other organisations to check on carers were well received. A telephone befriending service set up by Public Voice's Reach

and Connect service, was also seen as an important and successful method of tackling isolation.

#### **Concerns and points raised**

- Information and communication. Information about Covid-19 risks and service availability should be better communicated to residents, especially considering language barriers and disabilities.
- Digital inclusion. Digital exclusion is commonplace amongst vulnerable groups and therefore digital access (internet and email) cannot be relied on either as a means of communication or of accessing help and support.
- Digital enablement. A common concern was that there was not enough support for service users to access digital services where there was a will to do so with support.
- Virtual services. Over the phone and online appointments should not replace face-to-face appointments as it does not work for everyone. However, a combination of both could work. Language barriers and disabilities should also be taken into consideration.

- Provision for people with disabilities. New and evolving provision should consider the needs and requirements of all service users.
- Sustainability, community, volunteers and mutual aid groups. There are fears that the capacity of the Voluntary and Community Sector and mutual aid groups which has supplemented the statutory services during the lockdown may be short-lived when normality returns. Without serious work to retain this capacity, it is feared that big gaps will emerge in essential support for vulnerable people.
- Undetected vulnerable people. It was felt that many vulnerable people would be unknown to the Council and NHS, or may have been waiting for diagnosis at the start of lockdown. These people may not have received support they needed.

- Communicate more, faster and better. Across all reference groups it was felt that changes to services, actions taken, and future planning should be better communicated by the Council and NHS.
- 2. Provide digital and face-to-face access to services. As the lockdown is eased, it is felt that face-to-face access to services should be resumed but not at the expense of digital service provision introduced during the lockdown.

It was repeatedly commented on that, where possible and appropriate, digital service access should be offered alongside traditional face-to-face provision.

- 3. Greater coordination and consistency. In various ways the reference groups felt that services, communication, information and advice should be centralised between the NHS and Haringey Council to facilitate clearer and more tailored communication, guidance and service provision.
- 4. Digital enablement. It is strongly felt that more work should be done to enable those currently unable to access services digitally.
- 5. Default financial assistance. It was felt that where steps are taken to lessen a financial burden (e.g. possible suspension of council tax collection), these should be done automatically rather than expecting an individual to apply, which may be very difficult for a vulnerable person in a state of raised anxiety, depression or ill-health due to the lockdown and pandemic.

# Care Assessments and Annual Reviews

Care Assessments ensure appropriate support is provided to service users and Carers. Annual reviews are an opportunity to discuss what is working, what isn't working and what might need to change within a service user or carer support plan. Assessments form a vital part of care provision.

#### What has worked well

- Remote annual reviews. Some annual reviews had been conducted over the phone or via video call and some of those who had experienced this were happy with the process.
- Remote appointments. Over the phone and online video calls were seen as a positive outcome by some, particularly those with physical disabilities and parents of young people with learning disabilities and/or autism. They found these forms of virtual assessments removed the stress and anxiety involved in traveling to different venues for assessments. Service users reported feeling more relaxed in the comfort of their own home.

- Assessments and annual reviews. At the beginning of the lockdown service users and carers wondered if annual reviews and care assessments would continue and, if so, in what format they would be carried out. Concerns existed that delayed care assessments would create problems including a lack of care, backlog of cases and further delays.
- Care Act easements. The Coronavirus Act 2020 was met with considerable concern. As the new Act allows Local Authority's to disregard the Care Act without incurring any penalty and as such the new Act was seen as a backwards step.

In particular, it was felt that it would result in the timescale for assessments being extended and support plans already in place not being met.  Transitioning uncertainty. As many health professionals involved were drafted into the frontline fight against Covid-19.
 Parents of those moving from children's services to adult services care were worried and did not know whether the move to adult service care had stopped or been paused.

- Process and time information. Clear Information about ongoing processes, including timings, should be available to those involved in the assessment and review process where there is any disruption. This must be available in an easy read format.
- 2. Non-digital routes to care and assessment. Provision has to be made for those who do not have access to the internet. No assumptions should be made about access to the internet by vulnerable groups, and face-to-face options must continue to be available where required.
- 3. Appointment format choice. Moving forward, it would be good to continue offering over the phone and online appointments, in addition to face-to-face appointments, even when life returns to normal.
- Support for use of technology. Support workers need to help individuals access and use digital technology confidently.

- 5. Universal contact. Haringey Council should ensure they contact all those with learning difficulties living dependently.
- Communicating changes. Any future or ongoing easement of the Care Act to be fully explained to the wider community.
- 7. Share the backlog plan. Where Covid-19 has caused a shortfall in assessment and review targets, the Council should communicate its plan to address the shortfall, and any backlog, with both the Joint Partnership Board and individual service users.

### **Carers and Caring**

Carers play a vital role in supporting vulnerable service users. They are often family members, working unpaid around the clock to provide care for loved ones. During lockdown, carers have been under an enormous amount of physical and emotional stress as many day centres and supported living accommodation venues were closed, this led to an increase in the amount of care they were required to provide.

#### What has worked well

- **Digital peer support.** Some carers become familiar with meeting online and using WhatsApp groups to support each other.
- **Calls to carers.** Calls made from the Council and other organisations to carers were much appreciated.
- Letters to carers. Letters sent to carers from the Council at the start of the pandemic were also well received.
- **Closer family contact.** People with dementia have benefited from closer family contact.
- Quieter environments. For some, the lockdown created a quieter environment, greater routine and reduced levels of anxiety. For those with dementia in particular, this led to some reports of people sleeping better.
- **Mutual aid groups.** Many carers appreciated the extra voluntary support provided by community members.

- Carers' ages. Many carers in Haringey are over the age of 60 and many are also classed by the government as vulnerable to Covid-19. Many of the people they care for are likely to be part of the shielded group.
- Carer's database. It is understood that the Council's carers database is not up to date. Additionally, there is an issue with unidentified carers in Haringey.
- Personal Protective Equipment (PPE).
   Carers did not always have access to Personal Protective Equipment.
- IT support. Many carers are digitally excluded, and were therefore not able to obtain the information and support they needed promptly during the crisis.
- Respite care. With day centres closed during lockdown, many carers had 24/7 responsibilities with no access to relief or respite. This placed them at risk of "burnout" and those being cared for at greater risk from a safeguarding perspective.
- Do not resuscitate orders. Reports of automatic "do not resuscitate" orders for people with a Learning Difficulty being imposed, caused alarm and concern amongst carers and service users.

- Unpaid carers. Unpaid carers are not officially recognised and therefore not eligible for priority entry to supermarkets. At times of scarcity in shops this created difficulty in obtaining basic items for some carers.
- **Transport.** Carers' transport was also highlighted as an issue, as public transport was restricted and seen as a risk to use.
- Community support for all. Although mutual aid groups and neighbours were extremely helpful, concern was raised regarding some vulnerable groups, such as those with autism, who may be semi-invisible to their neighbours, or have unwittingly distanced themselves due to a lack of understanding of their communication styles. Neighbours may be less willing to help people they have considered to be "rude" or socially distant.
- Lack of voluntary sector support for autistic people. Concerns were raised that there is a lack of voluntary sector support for those with autism, which is a particular problem as many universal services are often inaccessible or inappropriate for those with autism.

- Identity cards for carers. Unpaid carers to have identity cards. Carers could use these to get priority entry to supermarkets. Alternatively, unpaid carers could be given headed letters to facilitate priority access.
- 2. Supply of essentials. Haringey Council could seek/obtain certain key essentials for carers, such as tissues, eggs, bread, milk etc. and organise delivery to homes.
- **3. Transport for carers.** Carers transport pick-ups could be organised.
- 4. Continued online appointments. Online appointments to continue being offered even after things go back to normal. Faceto-face appointments and examinations should still be available for those that require them.
- 5. Regular updates. Weekly 'check-ins' should be carried out by the Council or Clinical Commissioning Group (CCG) to check how carers are doing.
- 6. Pharmacy support. The Council/Clinical Commissioning Group (CCG) should ensure that at least one local pharmacy in the west of the borough and another in the east are stocked with the most common medications for people with special needs.
- Continuation of essential services. Ensure services such as rubbish and clinical waste collection continue during an emergency such as Covid-19.

- 8. Day centres and home care facilities. The Joint Partnership Board should assess which day centres and day-care activities remained open during lockdown and why those that closed did so.
- **9.** Support for vulnerable and older carers. Both Haringey Council and the NHS should reflect on the challenges faced by the many carers who are themselves over 60. Following this, the Council should communicate how the age of carers of those with learning difficulties or autism figure in the Council's Covid-19 policies (and in adult services policies generally).
- 10. Consider unknown vulnerable people. Haringey Council and the NHS should take into account the numbers of unknown vulnerable people in their response to Covid-19 and lockdown.
- **11. Future planning**. With a view to planning for a future emergency, data should be provided to detail:
  - **a.** How many carers have had Covid-19 and the support they received.
  - b. How many adults with learning difficulties and/or autism have had Covid-19 and the support they received.
  - c. How many families where both the carer and cared for had Covid-19 and the support they received.
  - **d.** The experience of families affected by Covid-19.

#### **12**. Do not resuscitate order legal

**assessments.** The Council should access records of vulnerable individuals to ensure blanket "Do Not Resuscitate" orders have not been put in place within the borough, and legal action should be taken if they have been put in place.

- 13. Refer inappropriate use of do not resuscitate orders. The inappropriate use of do not resuscitate orders should be seen as a safeguarding concern to be referred to the Safeguarding Adults Board.
- **14. Apps:** Apps could be used for people with autism.

# Mental Health and Wellbeing

Mental health and wellbeing are extremely important to a person's quality of life. People's experience of the lockdown has contributed to increased anxiety, worry and a feeling of isolation.

#### What has worked well

- Gardening. Residents with gardens, especially those shielding, considered themselves lucky as it helped them cope with lockdown.
- **Remote access to services.** Existing service users reported being able to access mental health services over the phone and online which was seen as positive.
- **Community spirit.** Increased community spirit was reported as contributing to improved mental health.
- Social media. Use of social media platforms for support was reported.

- Isolation. Feelings of loneliness and isolation contributed to mental and physical health problems. In particular it was felt that the impact of social isolation would hasten the mental decline of those with dementia.
- **Digital inclusion.** Access to the internet and technology are not available to all.
- **Substance misuse.** Alcohol and drug abuse rose during the lockdown.

- **Bereavement.** Losing loved ones and not being able to attend funerals.
- **Carers.** Mental and physical health impact caused by additional caring responsibilities and concerns.
- Shielding. Those shielding found it very difficult to not go outside and have human contact. This created additional pressures to their mental health.
- **Post-Traumatic Stress Disorder (PTSD).** After the lockdown is over, it was felt there might be a rise in post-traumatic stress disorder (PTSD).
- Young People. The impact of lockdown on young people's mental health, especially from vulnerable households, might have long-term effects.
- Self-care. As many autistic people may have been in a state of high anxiety due to lockdown, concern was reported that executive functioning was likely to have been adversely affected and the ability for self-care may have been negatively impacted.
- Increased risk of self-harm. Concerns were raised that self-harm may have increased during lockdown. In particular some vulnerable groups, such as those with autism, are already at high risk of suicide and self-harm. It was felt that accessing appropriate care, which is already difficult, would have become even harder in lockdown.

- 1. Provision for bereavement counselling. Bereavement counselling should be made available.
- 2. Bereavement counselling specific to those with learning difficulties. Bereavement counselling should be made available to people with a learning disability.
- 3. Public events. When possible, a public event should be held to acknowledge the suppressed grief felt by many.
- 4. Resources to target alcohol and drug abuse. Additional resources should be put in place to tackle increased alcohol and drug abuse.
- 5. Additional respite support. Respite arrangements for vulnerable carers should be increased.
- 6. Inter-service referrals. Mental health services should be able to refer people to other services for extra support; Haringey Reach and Connect, for example.
- 7. Make future plans available. The local Mental Health Trust should provide information on their plans to address postcoronavirus mental health issues.
- 8. Default financial assistance. It was felt that as vulnerable people would be highly likely to be experiencing enhanced anxiety, depression or ill-health, any assistance to lessen financial burdens (e.g. possible suspension of council tax) should be done automatically rather than individuals being expect to apply for relief - which they may not be able to do.

# **Housing and**

## **Sheltered Accommodation**

Appropriate, safe, housing and accommodation is of vital importance to all service users. Issues in this area were felt very keenly.

#### **Concerns and points raised**

- Monitoring of cleaning and Personal Protective
   Equipment (PPE). Members expressed concerns
   regarding the cleaning of communal areas,
   availability of Personal Protective Equipment
   and wondered about the monitoring procedures
   to ensure that those living in sheltered
   accommodation were being looked after. There
   were also questions about how external housing
   providers were being monitored.
- Visiting. Some members were concerned they could not visit their relatives living in sheltered schemes.
- **Hostels**. Concern was raised about whether people living in hostels are able to self-isolate or not.
- Evictions. Housing eviction of vulnerable people was mentioned as a point of concern which could become a serious question after the ban on public notice evictions is lifted.

- 1. Provision of Personal Protective Equipment (PPE) should be made for staff and residents.
- 2. Hand sanitiser should be available throughout buildings.

- 3. Information and advice regarding evictions within government guidelines should be made freely available.
- **4.** Haringey Council should inform the Joint Partnership Board on their plans to:
  - **a.** prevent and reduce evictions now these are possible again.
  - b. prevent vulnerable people, or people who have learning difficulties, from being evicted.

- 5. Haringey Council should report whether they have considered:
  - **a.** pausing Council Tax for those who are facing severe hardship.
  - **b.** repayment plans to enable people to catch up on overdue rent.

### **Care Homes**

Providing care and accommodation for people who need extra support in their daily lives in times of Covid-19 has been extremely challenging for care home staff, residents and their families.

#### What has worked well

Remote connections. Some care homes have enabled residents to contact their families, and vice versa, using social media which was reported as being very comforting.

- Infection rates. There were concerns about infection rates in care homes, and the discharge of Covid-19 patients from hospital back into care homes.
- Personal Protective Equipment (PPE). Concerns about Personal Protective Equipment availability were reported.
- **Contacting loved ones.** Not all care homes offered digital facilities for families to connect with their loved ones. Where they did, it was often the case that hard pressed staff could not be spared to support patients in using it.
- Safeguarding/digital technology. As some care homes now enable the use of technology for contacting loved ones, there is concern regarding safeguarding when using digital technology.

- Keep families connected. In all care settings facilities should be in place to enable families to remain in touch with family members.
- 2. Keep friends connected. Add friends to the list of those able to visit/communicate with residents as many residents no longer have living family members.
- 3. Resident digital support. Staff should support residents accessing and using digital technology to do things online and keep in touch with friends and family especially those residents funded by the Council. In particular, access to FaceTime, Skype, Zoom and Microsoft Teams should be facilitated.

### **Parks and**

# **Recreation Facilities**

Parks formed an important part of physical and mental health wellness provision during the lockdown. Where park access was disrupted a significant impact was felt by service users and their families.

#### What has worked well

- **Open parks.** Haringey kept its many parks open. Members reported using the parks for walking and exercise which had a positive impact on their health and mental wellbeing.
- Seating. Haringey did not cordon off park benches as some other boroughs did.

- Car parks within the parks. Even though parks were kept open, associated car parks were not.
  This was a huge issue to those with restricted mobility who could not use the parks for exercise.
  For many family members of people with a severe and complex learning disability, unable to access day centres or supported living units, this was a particular issue.
- Facilities in parks. Cafes and toilets in parks were closed, an especially limiting factor for many vulnerable people.
- Staff/security personnel in parks. Concerns about the lack of security personal in parks and issues of anti-social behaviour taking place.
- **Swimming pools.** Swimming pool closures was an issue for those with restricted mobility who benefit from aquatic exercise.

- 1. Free and open car parks. Car parks should be open and free of charge to those who are using parks as an alternative provision.
- 2. Consider health impacts. To consider the effects on physical and mental health of people who are already at risk because of being denied access to pools and parks.
- 3. Keep cafés open. Cafés in parks should be open (though people do understand why they were not able to stay open).
- 4. Keep toilets open. Toilets in parks should be open.
- 5. Make parks safer. Look at making parks safer for vulnerable people.

- 6. Park time for the vulnerable. The possibility of a quiet hour where vulnerable people could feel safer and more confident to go to a park was proposed.
- 7. Protection for vulnerable park users. Introduce voluntary patrols to safeguard vulnerable people against anti-social behaviour within parks.
- 8. Priority car park access. Car parks could be opened to blue badge owners only.
- 9. Share information on decisions made. Haringey Council should provide the rationale for closing car parks during the lockdown. They should inform the Joint Partnership Board about car parking arrangements.

# Parking

Parking provision during lockdown was seen as an essential part of enabling mobility and access for vulnerable service users. Disruption to parking was seen as a difficulty by many service users.

#### **Concerns and points raised**

- **Disabled parking.** Some disabled parking was given over to facilitate socially distanced queuing outside shops.
- **Poor communication.** Information on parking was very poorly communicated, such as the relaxation of many parking restrictions.

- **1. Extra parking for those who need it.** Extra parking should be made available for blue badge holders.
- 2. Improved parking information. Communication on parking and disability parking should be improved.

# Personal Budgets and Assistants

Personal budgets enable service users to have greater choice and control over the care and support they receive. Many service users employ the service of a Personal Assistant (PA), but during the lockdown this arrangement was particularly challenging for some service users.

#### **Concerns and points raised**

- Personal Protective Equipment (PPE). There were serious concerns that Personal Protective Equipment was not provided to service users, carers or assistants.
- Personal assistants. Some people decided not to allow their personal assistants into their home as some also work in care homes. They were worried about the risk of infection.

- 1. Free Personal Protective Equipment (PPE). Personal Protective Equipment, including visors, should be free for those with personal assistants.
- 2. Changes to care support plan rules. Spending on Personal Protective Equipment should be allowed even if it is not part of a specific care support plan.
- Add to the key workers list. Personal assistants should be regarded as key workers.
- 4. Introduce reserve assistants. Given the dependency of many on their assistants, a reserve capacity of assistants, who do not work in care homes, ought to be built up by the Council, who could be deployed if necessary, during a similar crisis in future.

### **Food Provision**

Many households have benefited from receiving food parcels for health or financial reasons.

#### What has worked well

- **Food parcels.** Residents appreciated receiving food parcels.
- **Food provision.** Food parcels have been provided to thousands of residents in need.

- Food shopping. Unpaid carers found it difficult to find time to go to supermarkets, especially when queues were long and they did not have priority entry.
- Religious and cultural diets, and unsuitable food.
   Food parcels contained food that did not always conform to the dietary needs of the individuals receiving them.
- **Poor advice on unused food.** Recipients of food parcels were unsure what to do with food they did not use, for example, could it be passed on to others or would this run the risk of spreading infection.
- Difficulties accessing food provision. Concerns were raised that amongst vulnerable groups, heightened anxiety would be very likely which would result in decreasing ability for self-care including an inability in some cases to access and organise food deliveries.
- **Rationing.** Many vulnerable people, for example those with autism, have restricted diets and only eat certain types of foods. If rationing occurred, formally or informally, this could have had a negative impact on individuals health and the health of those they care for.

- take into consideration an individual's specific dietary needs.
- 2. **Review food-aid.** A review should be undertaken to ensure that all eligible vulnerable people were allocated food aid.
- 1. Tailored food parcels. Food parcels should 3. Unpaid carers ID. Unpaid carers should be supplied with temporary ID cards to allow entry to reserved slots in supermarkets.
  - 4. Advice on food use. Advice should be given on what to do with food that is not used.

# NHS and Primary Care Services

As a substantial element of care provided is through the NHS, changes to service provision during lockdown often had a substantial impact on service users. Positive changes and continuation of services were greatly appreciated.

#### What has worked well

- Phone and online appointments. Appointments being offered over the phone or online during the lockdown was seen as positive.
- Hospital phone contact. Contact with hospitals by phone was reported as being very good.
- **Podiatry services.** Urgent podiatry services remained accessible.
- **NHS 111.** It was reported that the NHS 111 service worked well, particularly during out of hours times.
- **Pharmacy services.** Pharmacists stepped in to support the community with emergency and non-emergency advice when GPs were unavailable.

- Blood tests. Not all GP practices offer blood test services, those that do usually only do so for people aged over 65. This is a particular issue for those who require regular blood tests and those shielding.
- **GP** access/clinical provision. A number of people were unable to get through to their GPs by phone. Some practices only provided very minimal services, in some cases only admin and repeat prescriptions. There was also a concern that lack of physical examination could lead to misdiagnosis and medical needs going unnoticed.

- Appointments, treatments and operations. Issues with cancellations and treatment/operation delays were reported.
- GP and hospital appointment rescheduling. Hospitals were sometimes slow to reschedule appointments. Some appointments, for example screenings, were cancelled without any follow-up appointment being booked.
- Access and knowledge of pharmacy deliveries. Concerns were raised that some pharmacies did not increase, or promote, deliveries of medications. Although delivery services exist it was felt that few people knew of them.
- E-consulting. Moving to virtual appointments is an issue for those who are digitally excluded, and for those who are vulnerable, for example - people with mild to moderate learning difficulties, who may not have carers to support them.
   Face-to-face appointments should be available once they can be done safely.
- Delays and difficulties with health assessment. Concerns about health assessments for vulnerable people and over 60s not being done on time. Additionally, it is understood that health assessments for over 60s are not being undertaken in the west of the Borough. Cognitive testing can be difficult to do remotely.

- Fear of accessing services. Concerns were raised that the fear of going to a hospital may have deterred people from seeking the help they needed. For example, the fear of sensory over-stimulation may deter someone with autism from seeking medical help, i.e. the fear of being taken into a noisy and crowded hospital may have been too overwhelming to face.
- **Community care assessments.** Concerns about community care assessments not being undertaken.
- Hospital visits. Those who are told to attend hospital appointments, or to have blood tests done, worried about the risk of contracting the virus.
- Remote hospital assessments. There was a concern that remote assessments, by phone or online, do not have the same holistic approach to assessment that inperson appointments do and are therefore not as thorough. Therefore, it was felt that these should not become the only way of accessing medical assessments.
- **Covid-19 tests.** Confusion as to who could be tested and where.
- Covid-19 recovery. Though an evolving area of medical knowledge, there was concern that not enough information existed on pathways of recovery from Covid-19.

- Shielding letters. Concerns were noted that letters instructing vulnerable people to shield arrived late, with some users reporting letters arriving in May. As a result, some vulnerable people (who often knew they needed to shield themselves) could not access help such as food parcels and reserve delivery slots unless they were identified by a mutual aid group.
- **Disagreement on who needed to shield.** In some cases, users were concerned that there was a disagreement between the NHS and their GP on the necessity of shielding or not.
- Contacting and triaging difficulties.
   In the case of autistic people, concerns were raised as they may require a variety of ways to contact services. Using the phone can be difficult or impossible, as can pro-actively getting in touch for help during a time of increased stress. If autistic people do contact service providers, they can be in danger of being 'triaged out' of getting support if frontline staff do not understand autistic needs, or if the criteria for eligibility are insufficient to cover autistic needs.
- Memory assessment services. As these services closed across London during lockdown, it was not understood what was being done for those on the waiting list in terms of identifying who on the list needed help and sharing this information appropriately.
- Classification of dental treatments.
   Concern were raised that there was no clear explanation of what constituted a dental emergency.

- Difficulties accessing dental services. Concern was raised that there was differing access to treatment appointments.
- Undetected vulnerable people. Concerns were raised that those who are considered 'hidden' - cohorts of vulnerable people
   may be unknown to the Council and NHS, for example those with early stage dementia, would not have received support they needed.
- **Covid-19 related delirium.** Concerns were raised that planning would be required with regard to Covid-19 related 'delirium,' which would be likely to affect people with dementia in particular and could cause a rise in the number of dementia cases in the near future.

- 1. Universal blood tests. GPs should offer blood tests to those shielding regardless of age.
- 2. Consultation protocol. Protocol should be developed to ensure that different GPs and hospitals offer a consistent and appropriate route to care.
- 3. Post Covid-19 care advice. A Clinical Commissioning Group (CCG) inspired statement, or widely available advice, on what to look out for after someone has recovered from Covid-19.

- 4. Ensure test availability. The Council/ Clinical Commissioning Group (CCG) should ensure information on local tests is accessible and available.
- 5. Share health assessment plans. The Clinical Commissioning Group (CCG) should provide more information on health assessments and plans to address any shortcomings, if there are any.
- 6. GP clinical care review. The Clinical Commissioning Group should review what GPs have provided in terms of clinical care.
- 7. **GP home visits.** GPs should offer home visits for those who need them.
- 8. Consult on e-consultations. An ongoing consultation should be arranged with patient groups in regard to e-consolations and phone assessments.
- **9. Understand e-consultations.** Statistics should be gathered on the success and failure of e-consultations.
- Improve follow-up. Better follow-up on rearranged appointments and screening by both hospitals and GPs should be put in place.
- Free Personal Protective Equipment (PPE) for dental care. Free Personal Protective Equipment should be made available for NHS dental care.

- **12. Share future plans.** Information should be shared with the Joint Partnership Board on the strategy and vision for opticians and dentists in the new normal.
- **13. Provide recovery information.** Pathways to recovery should be set out.
- 14. Universal shielders list. A common list of local shielders should be established and shared between GPs and the NHS. This should be kept up to date on an ongoing basis.
- **15. Consider unknown vulnerable people.** The Council and NHS should take into account the numbers of unknown vulnerable people in their response to Covid-19 and lockdown.
- 16. Dental paths for non-emergency treatment. A path to advice and treatment should be made clear to those with nonemergency dental needs.
- **17. Share information on digital inclusion.** The Clinical Commissioning Group (CCG) should provide information on:
  - **a.** how they plan to ensure digital enablement.
  - how they will ensure the digitally excluded can continue to access services and receive care.

#### Appendix

#### **Joint Partnership Board**

Co-Chairs: Sharon Grant Helena Kania Andrew Carpenter

**Reference Group Chairs** 

Autism Reference Group Chair: Andrew Carpenter

Carers Reference Group Chair: Isha Turay

**Dementia Reference Group** Chair: Tim Miller / Paul Allen

Learning Disabilities Reference Group Chair: Debbie Floyd / Patricia Charlesworth

Mental Health Reference Group Chair: Sue Wedge

Older People Reference Group Chair: Gordon Peters

**Physical Disabilities Reference Group** Chair: Graham Day

**SCALD** (Severe and Complex Autism and Learning Disability) **Reference Group** Chair: Mary Langan

**Transitions Reference Group** Chair: Public Voice (the group is in the process of electing a new Chair)



# **Contact us**

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