



In partnership with



The challenges facing Portsmouth residents: a community-based research study



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Citizens Advice

Solent MIND

Special Care Dental Service

Advice Portsmouth

Age UK

Holiday Activities and Food programme (HAF)

SUMMARY

This project sought to explore the experiences and unmet needs of individuals living in deprived areas of Portsmouth with regard to access to health services, education, housing, good quality employment, support networks and social arrangements.


Whilst the Portsmouth Health and Wellbeing Strategy 2022-2030 aims to make Portsmouth a healthy and happy city, several areas of Portsmouth are some of the most deprived areas of the country. Those living in more deprived areas or experiencing health inequalities are more likely to live more of their lives in poorer health and experience lower life expectancy and productivity.

Conversations were undertaken with people living in postcodes PO1-PO6, and with those who work with people living in these areas.

Challenges were identified in all areas:

- Access to healthcare: accessing primary care and specialist services was difficult for Portsmouth residents, mental health services were often inaccessible and did not provide appropriate, ongoing care; dental care was not accessible for many.
- Access to support networks: Portsmouth has a strong community spirit and support groups, community centres and the like are valued. However, public transport limits access and local politicians are considered to provide little support.
- Access to housing: there is a lack of appropriate social housing and insufficient information about housing options. Not all housing offers suitable living conditions.
- Access to education: parents need to be both willing and able to get their children to school. For older children, there is insufficient information about the transition from school to college, and, for those with learning disabilities, there are safety concerns at this stage. There are financial implications for those wishing to ensure their children have education-related opportunities.
- Access to employment: there is a lack of understanding of additional needs by employers, with participants facing discrimination in the workplace. Local transport availability does not support access to employment. Parents of young children, those with additional needs or people facing health problems experience challenges accessing suitable employment, but are keen to work.

A further additional area, of access to health and education for children with special educational needs or disabilities, was identified. The limited health services available were



considered to be disconnected, and people were passed from one service to another. The lack of mental health support affected the ability of young people to engage with education, and there was inconsistent support provided by schools.

A number of solutions are presented, informed by the discussions with local residents. Key to these is ensuring that people are placed at the heart of services in Portsmouth, and their views sought and acted upon. This includes more joined-up thinking by services, enabling access in ways which suit different groups, including those who are unable to access or use online mechanisms, and more information about the services available and how these can be accessed. It is recommended that existing good practice, particularly support provided through community groups and centres, forms the foundation for future changes.

As a follow-up to these findings, Healthwatch Portsmouth and the University of Portsmouth hope to organise focus groups with interested communities in the city, to discuss how the solutions suggested could be achieved and to identify next steps.

1. Background

The Portsmouth Health and Wellbeing Strategy 2022-2030 (Portsmouth City Council n.d.) has an overall aim to make Portsmouth a healthy and happy city, in which people have the education, care and support they need for their physical and mental health. However, of the 115 areas of Portsmouth listed in the Index of Multiple Deprivation (Ministry of Housing, Communities and Local Government 2019), 15 areas are in the lowest decile, meaning they are some of the most deprived areas of the country. People living in more deprived areas are more likely to not only experience lower life expectancy but live more of their lives in poorer health. Unfortunately, these inequalities have been exacerbated by the Covid-19 pandemic (Marmot et al., 2020; Portsmouth City Council n.d.).

Determinants of health include access to healthcare, employment, education, housing, income, and other social factors (CSDH 2008). According to Marmot et al (2020):

“In England, health is getting worse for people living in more deprived districts and regions, health inequalities are increasing and, for the population as a whole, health is declining.”
(Marmot et al., 2020, p.149).

Inequalities in health not only lead to differences in health status, but also to differences in life expectancy and in productivity (Marmot 2010). Reducing inequalities in health improves the life of individuals, their families and also society as a whole (Marmot 2010). However, repeated attempts to achieve this have been, at best, only partially effective, with healthcare organisations in particular adopting the viewpoint that their role is in treating those who are ill rather than in taking action to reduce inequalities (Allen et al 2023). However, recent work in London has demonstrated that change is possible and that small changes can positively influence the wider determinants of health, such as employment, education, environment and income (Allen et al 2023).

Against this backdrop, this project sought insights into the experiences of those living in the more deprived areas of Portsmouth, with regard to some of the determinants of health. In light of the remit of Healthwatch Portsmouth, this encompassed the following areas: access to healthcare, education, employment, housing and social support. Income and finances were specifically excluded as this area does not form part of Healthwatch Portsmouth’s remit.

2. Aims and Objectives

The aim of the project was to explore the experiences and unmet needs of individuals living in deprived areas of Portsmouth with regard to access to health services, education, housing, good quality employment, support networks and social arrangements, together with any other areas of concern identified by this group.

The objectives were:

- To gain insight into the experiences of access to health services, education, housing, good quality employment, support networks and social arrangements, and any other areas of concerns for those living in deprived wards of Portsmouth;
- To identify unmet need for services and support for those living in deprived wards of Portsmouth;
- To identify potential solutions to the unmet needs and concerns identified by those living in deprived wards of Portsmouth.

3. Methods

A favourable ethical opinion for this study was received from the Science & Health Faculty Ethics Committee at the University of Portsmouth (SHFEC 2023 - 035).

This qualitative study collected data through one-to-one conversations with people aged 18+ living in the PO1-PO6 postcode area. We also held an event at which several people discussed their experiences - or those of people they knew - of accessing health services, education, housing, good quality employment, support networks and social arrangements. Solutions to the issues were also identified.

The data collected was first grouped according to topic area (access to health services, access to education and so on). We then reviewed the data for themes within each of these areas. These are presented below.

4. Participants

We carried out one-to-one conversations with 18 people and held one event (six attendees). Those involved either lived in or worked with people in the deprived areas of Portsmouth. We have ensured that contributions do not lead to individuals who took part in the project being identifiable.

5. Results

Eighteen participants took part in the study, three men and fifteen women. All lived in Portsmouth, with postcodes across the city centre (PO1 to PO6). Ages ranged from 38 to 76 and fifteen disclosed that they had long-term health conditions or disabilities. In addition, we collected data from one group who worked with people in the city. Of the six attendees, one was male and five female. All participants were invited to share their experiences and thoughts about access to healthcare, good quality employment, education, social support, and housing.

5.1 Access to healthcare

Several barriers were identified to accessing healthcare, including accessing primary care (GP practices), emergency and specialist services, dental care and healthcare for children with special educational needs and disabilities. Overall, participants thought that healthcare was in crisis, that it was set up according to the needs of healthcare professionals rather than patients and that services assume that everyone can access and use technology. Several people indicated that they had '*given up*' seeking medical care.

5.1a. Access to GP appointments

Participants described how simply trying to **book an appointment** with their general practice (GP) was a challenge. Those from Minority Ethnic Communities often found the system challenging and it was not clear how to register - the information available to them was inaccessible:

"People ... from other ethnic groups, ... are not very familiar with the health system in this country, especially if they're new ... sometimes what they're supposed to do is not clear enough. ... You really have no clue, because things are very different where we all come from. And so just making information more accessible for people, especially with registering, with the GP, with the dentist ... They really don't know what to do. They've checked the website, they're not sure, and all of that. So just making

information a little bit more accessible for people from other cultures, I think that will be helpful.”

It was acknowledged that participants might choose to **register at a different practice**, however, this presented different challenges as people would then need to share their information all over again:

“I almost feel like, do I just go over to [name of different practice]? But then it’s having to repeat everything all over again ... If I don’t get any answers, I will feel like leaving”

Participants struggled to arrange an appointment to see a healthcare professional at their GP surgery, as they were required to either **complete an online form or telephone the practice at a specific time**. Some were unable to complete an online form because not everyone had access to or the capacity or knowledge to use the internet. Other times the forms simply did not have the options the individual was looking for:

“So that if on the list you’re not on there, say, like, you’ve got an earache, and actually ear isn’t on there, there’s no way you can then go ... well, you can’t carry on with it, because it won’t let you’

and some people found it **difficult to write their health complaint on the computer**:

‘I find it difficult to convey things on a computer”

particularly if they had multiple symptoms:

“It’s taken about half a year. It’s taken quite a long time for them to get hold of me, because you can’t get through on the phone, so it’s e-consults, and then, pick a particular thing, and it’s not one thing.”

For those booking appointments by telephone or online, they needed to contact the practice at a **specific time or within a specific timeframe**, when not everyone was available.

“I’ve actually just managed to get an appointment last week, which I was amazed by. Because I have been trying eConsult and it shuts within about 10 minutes. And unless you get there at half past six (in the morning), you can’t get anywhere.”

“The other thing about the GP at the moment, for older people, it’s a nightmare. My own GP surgery, you either have to submit an electronic form online to get

something on the day, or you have to stand outside and queue or you have to make 200 phone calls at 8am in the morning. How's it come to this? ... There's something wrong. And for older people navigating that, it's absolutely impossible. Absolutely impossible. How the hell is someone in their 80s going to sit on the phone for 80 phone calls first thing or queue up at 8.30 in the morning waiting for the door to open when there's another 16, 17 people - and actually lots of them can't because they're with their person with dementia at that time in the morning. It's absolutely ridiculous."

For those who are able to book an appointment by telephone and are able to do so at the allocated time, there was often a **long wait for the call to be answered**, and by the time they managed to speak to someone, all the appointment slots had been filled:

"Jumping through hoops and half the time you've wasted your time"

"It's almost impossible to get hold of any appointments with the GP ... And it's a bit difficult because to find the time to book the appointment is really ... with a tight schedule ... on the phone ... what normally happens is that, if you ring to make an appointment, they will then say all the appointments are booked. If you want an emergency appointment ring at 8 o'clock in the morning. If you don't get to the phone dead on eight, you have no chance. If you get there at 8 there's still a long queue because thousands of us are trying to get on the line at the same time. And then you get the emergency appointment and you still have to sit and wait. ... Yeah, it's just waiting on the phone. So you wouldn't want to lose your place in the queue. So everything else has to stop for that period of time while you're waiting."

"Trying to get a GP appointment is very, very challenging ... You can ring up and you're about number 30, it is just so difficult ... It is just a nightmare, absolute nightmare, and not just for me, for everybody, really .. I tried the online, I gave up with that, it's impossible. The minute you click on they're gone"

All methods of booking an appointment were often considered **impractical for those who work**:

“So I work full time, so when am I likely to be able to have the time? I haven’t got time to spend an hour on the phone, unless I do it in my lunch hour, assuming I’ve got a lunch hour... You can’t do it at the weekend, which is when I’d want to do it ... So normally it’s nine to five really, isn’t it? Which is your work hours ... So it’s not accessible to people who work”

This was exacerbated by the lack of **availability of future appointments**:

“Now you can’t even be proactive ... We can’t phone and say, can we book this appointment for this person in two weeks time? ... (We’re told to) phone on the day you need it. But you can guarantee, on the day they need (the appointment), it’s not there, there’s no appointment”

Using the telephone and the internet require a degree of **physical dexterity and ability** that not all have, and so those with physical disabilities face additional challenges in trying to get a GP appointment:

“We’ve got people who can’t hold a phone, so they don’t...they can’t hold a phone so they don’t have one.”

Participants described how, even if they were at their GP practice, they had been told that they needed to call to book an appointment:

“Even if you’re in the doctor’s, and you say, listen, can I talk to someone, they will tell you to phone the doctor’s, while you’re stood in the doctor’s, to call to talk to someone ... You can speak to the receptionist, but you’re not allowed to make an appointment, you have to call, while you’re stood inside the doctor’s”

Whilst there was an understanding that reception staff were trying to ensure they saw the correct person, participants were discouraged from making appointments by the need to **share full medical details**, potentially in an open space:

“At the reception when you get there and you want to speak to the receptionist, it’s really open. Like many times you don’t want to share your business out loud where many other people are waiting. I find it a little bit embarrassing sometimes. And they want to know everything. I guess so they can let you see the right person. But it’s

really.. I really don't like that. Or maybe if I'm in the queue and somebody else is trying to speak to the receptionist I don't really want to know what they're there for. I don't want to know. So I find that really uncomfortable ... I really need to book an appointment now and I don't want to because I don't want to.. The only reason I haven't booked it is because I don't want to stand there and blurt out all my stuff at the reception"

Participants discussed the **possible impact** of poor access to appointments on their health:

"These delays must be contributing to mental health conditions for people because it just seems unjust and unnecessary and leads to anxiety. I suppose I'm quite lucky because I've got, you know, I'm not poor and I'm not living in unstable conditions and things. I mean, for others I don't know what it's like"

"Then little things will end up being bigger things if they're left. But it's all about at that moment in time, prioritise it, so if they've got a little thing and a big thing, the bigger thing will take priority, which is understandable and right but it doesn't mean the little things shouldn't be looked at as well."

Other participants experienced the **negative results of being unable to gain access**, with one participant having had their medication changed without consultation, and another requiring emergency treatment:

"They did say they'd rung me and I never got a phone call, so I did ring them back and I said I've noticed that my medication had changed, can I just ask why? Oh, well, you've had a medication review. And I said, but nobody rung me, and they said, oh, well, they couldn't get hold of you, so they've done it. And I said but that's not very good, they should speak to me. I don't want that done behind my back. So I was a bit annoyed about that, to be honest."

"I'd been going backwards and forwards to the GP saying, this isn't right, and they kept fobbing me off and fobbing me off. Then when I was really poorly and they rushed me into hospital, they actually asked me at the hospital, why didn't you get any treatment if they were that bad. I was like, well I've been trying to get.. That's the state of how bad my health is because you can't see a GP or you phone up and three and a half, four weeks ..."

Another had been **seeking a face-to-face appointment** for some time to discuss their long-term health concerns which were not being addressed appropriately:

“And then I did get told to reduce my medication, I was on an antidepressant and I got told to half it, and that went on for about a year and I actually began to feel worse mentally. And then when I contacted the doctor to say this, I just got an abrupt phone call back, saying, well, they shouldn’t have said that, that’s not even a regular dose, that’s not even a proper dose, go back on it, as though it was my fault. ... I just feel like I would like to speak to the doctor [about other health concerns]. And I have kept putting that in the e-consults, I’ve kept saying, I would like to physically speak to someone, and then they just say, your e-consult has been received and this is your reference number”

Further challenges faced those who were able to get an appointment. Participants disliked the **lack of confirmed time** for telephone appointments, which meant those who might need support with such calls were unable to access it.

“In the old days if they needed to go to something we could go with them to the appointment, put it in our diaries, three o'clock meet so and so at the doctors to go with them to be able to explain what it is that they’re needing help with. And now it’s like, well, I’ll sit with someone and we go through to getting a phone call; if you sit and do all that, they’re going to get (told) that the doctor will phone you this afternoon. So, we can’t be sat in their house all day to support them.”

They spoke about how low literacy levels meant that some patients could not read through any notes made to support the conversation. Participants also highlighted how some people with mental health issues could struggle if they saw someone ‘official’ (the doctor) calling them. Moving to telephone appointments also led to **those who might be struggling to slip through the net**, as in-person appointments allowed healthcare professionals to gain further information about a patient, for example through their body language, state of attire and cleanliness and so on. Telephone appointments did not enable such insights.

“Whereas if they could actually have an appointment, they go, their doctor can see their body language. Yeah? So, they’re not getting the whole picture. Are they in their pyjamas? They don’t know they’re actually on the phone, do they, if they’ve not left the house for weeks, you know, you can’t get all that into, you get a ten-minute slot, don’t you?”

This was reinforced by another participant, who felt that mental wellbeing required not only access to medical care but also to social support:

“When it comes to mental health issues there’s so much missed. I think there’s so many people at home that never leave the house. They have loved ones looking after them and I don’t think you’ll ever know how many people don’t leave their homes. Yeah, they spend a lifetime at home and then they get health problems because they’re not going out, like, and using their body. Yeah, because I think when you go to the doctor, the doctor will give you some pills to take and that’s not the answer, it’s not. I think counselling and talking is really, really helpful, but it’s still not enough. No, I think it’s halfway.. being able to share, I think it’s.. you know, you’re halfway there, but there’s more needed.”

Short telephone appointment slots meant that patients had to tell a GP - who usually did not know them - their health history within ten minutes, often in an inconvenient place, whether at leisure or their place of employment:

“It’s not a local service, you don’t get the same person that you’ve had who knows about you and your medical conditions”

“They’re assuming you’re accessible, like, I can’t answer my phone when I’m working and a lot of people can’t. So they’re 8-hour shift, they’ve not got jobs where they’re sitting at a computer and just answer their own phone. If you’re working in Tesco’s you can’t be stacking a shelf and having a consultation on the phone ... Driving around the area, even if you can have it through your car, the doctor cannot speak to you while you’re driving. You’re not allowed to.”

Participants were not convinced that speaking to the doctor by **telephone could replace in-person appointments**:

“If you phone, there’s so many people in front of you that it costs you more on the phone. So I end to go down there, and they say, a doctor will phone you. So to me, that isn’t what it’s all about, you want to see a doctor, or you want to see somebody medical. I don’t see how they can diagnose anything over the phone.”

Participants were **not aware** that there is an option to request a face-to-face appointment:

“Are you going to sit around waiting for them to phone you back or get on with your life, go to work, go shopping and then have to talk all your personal stuff in the supermarkets. It’s not really.. I think people should have more of a choice”

Participants also described how their practice would no longer see them in connection with some health conditions, because their care had been assigned to the local hospital:

“If I’ve got in contact with them, the diabetes nurse at [practice name] will not deal with me now, because I’m under [local hospital]. Which, she still should deal with me, because my Hb1A - if that’s the correct word - last time I had it done, it was 104 ... That’s really high ... They say to me, because you’re under [local hospital], we can’t do anything about it”

As a result, they found other ways to get the care they felt was required:

“Participant One: I need to know whether I can have a blood test, or not, so I’m going to message my asthma nurse, because we’re really close

Participant Two: but you shouldn’t have to, because you’re not really messaging about asthma, are you, she’s just doing you a favour really”

“If there is any time I think, actually, I need my chest listened to, I would ring the nurses and I’ve done that many.. I said I think you ought to come and have a listen, and then they’ll listen and say, oh, yes, I can hear some crackles, we need to get on top of that ... I think, yes, if it’s something I feel I need to be seen, then I will push for that.”

“It’s like they say, if you want an appointment, a routine appointment, it’s three weeks, if you need an appointment on the day, phone up and say you’re an emergency. I’m the sort of person who won’t class myself as an emergency, but you have to, don’t you, that’s what you have to be like. You have to kind of play the system, which is wrong”

Despite this, participants also spoke of some **benefits to having online access** to arrange prescriptions:

“With the prescriptions, because my daughters, both of them have eczema. So normally in the past, have to ring to make.. book a repeat prescription of their cream. But because now there’s an app that you can do that on the app, that’s taking a big chunk of the pressure off, which is really good”

As a result of the merger of many practices in the local area, participants spoke of the **challenge of physically finding and accessing their GP practice:**

“He’d go to the doctors if he needed to, he had learning difficulties, he had mobility problems and he was partially sighted. So, he would go to it, across the road where he’s always gone to the doctors and then he would go once a week to the chemist and get his medication. They knew him, that was his little circle. As soon as the pandemic changed everything, he couldn’t get himself to the doctors, he didn’t know where it was”

This included the **need to travel to their practice**, where previously it had been close by, necessitating the use of public transport in some cases, a particular challenge for those with mobility issues.

“One of my friends, she lives on the main estate and she’s got COPD and she’s got a problem with her leg. Her GP got shut, I think and she showed me the letter she got to go because she needs to see a podiatrist and things as well. She showed me the letter she got and she got told to go and register at a surgery in [name of street]. Now for someone who can’t drive anymore because of her leg, she was expected to get on two buses and all that travelling and buses aren’t always that comfortable. She was absolutely gobsmacked that she couldn’t get one in [place] or [place] or [place], which would have still been a bus journey but it would have been not quite as problematic for her. ... it’s unreasonable to expect a sixty-three-year-old woman with mobility issues and breathing problems to do that once a week.”

Participants described how they had **given up trying to seek help from their general practice:**

“Most things I don’t go to the GP now, I just ride through them and let them heal up on their own”

“I find it very stressful (trying to see a GP in person) ... I don’t really want to talk about it, because there’s no point, because it’s a shut door, you don’t get any further. So, what are you supposed to do then? Keep trying, every day? All day, every day? ... I just don’t feel it would be worthwhile. It’s the system that’s wrong, or lack of, lack of doctors, lack of trained nurses.. despondent would be the word, anxious, frightened.”

“A lot of people I know actually give up. They think, oh, and then they’ll become really unwell, and end up going up to QA, or the walk-in centre. ... Then, they’re using up services and resources when they need to save money.”

“It’s so hard to get a GP appointment that I’m finding more and more that people just don’t bother.”

5.1b: Accessing other types of healthcare

As well as speaking about their experiences of accessing GP appointments, participants spoke about challenges in accessing other kinds of healthcare. Some of these related to practical aspects of physically getting to required locations, in other cases they spoke of long waits and delayed responses.

Participants indicated that the lack of ability to get a GP appointment was having a **negative impact on local walk-in services** such as Emergency Departments and Urgent Treatment Centres:

“Walk-in service, that is meant be like an emergency. So to reduce I think, I guess to reduce the pressure of A&E and things like that. It’s almost a nightmare, like I’ve sat there for six hours before. It’s a really long wait. And I guess there’s a big need and probably they’re short-staffed, but yeah, that’s another big challenge accessing that. You still find people going to A&E because it’s almost better to go to A&E. It does put me off.”

“They’re needing to go into hospital to access any services ... you need a crisis (to be seen by a healthcare professional)”

Similar to general practice, **wider health services were seen to be struggling and unable to provide support** to patients:

“Everything’s in crisis management”

“I know that they’ve tried really hard to provide a service but it just seems like it’s at breaking point, isn’t it, at the moment”

“We can contact adult social care, mental health, whoever, and explain that, and they’re like, well, there isn’t anyone to help”

One participant described the **challenges experienced during a relative’s hospital discharge** following a series of strokes:

“My [female relative] had a stroke at some point last year ... and the whole discharge process ... They were trying to send her home with no kind of care package ... She really wasn’t well, and not capable of doing a lot of stuff ... Although my [male relative] is her carer, he’s [50+] years old, it’s not appropriate for a male [50+] year old to care for your [80+] year old mother, you know when it comes to personal care ... They tend to go, oh well, you’ve got family at home, off you go, bye bye ... I was speaking to the OT on the ward ... ‘We can’t come out and assess the home’”

One participant, who had physical disabilities, experienced **challenges in gaining access to appropriate equipment** at the local hospital, saying:

“Some of the appointments, they can be challenging, especially having a scan, they don’t always have the hoist available. That can be difficult. I’ve been quite a few times where we’ve booked it, and you get there and they’re, like, oh, you’re in a wheelchair, and it’s like that should be on my notes. I’ve been in a wheelchair all my life, it’s not a new thing ... And another issue that keeps coming is ... I have guided injections with steroids into my joints and I should have it by ultrasound. Several times I go and they try and put me in for what they call a fluoroscopy, which is a big machine and you’ve got to lie on the bed, keep still and I can’t get in that position, so I’ve said to them I don’t have it like that, I stay in my chair. But then again I’ve had to go home and rebook.”

Similarly, another participant had been **waiting several months for appropriate equipment** to get her daughter into and out of the bath, delays in which had caused her daughter to be injured:

“I have a problem with my back just from lifting her in and out of the bath, I have physio for that. And she was given this bath board ... She doesn’t have the strength, she can’t do it. So I’m still having to scoop her out of the bath ... I was told on the 8th of December it would happen and we’re nearly at the end of February ... She was referred in July ... And then last night [daughter] ... She fell and she slipped, and she hurt her legs, and her foot, and then she was crying because she scared herself

because she was hurt ...It's just like if somebody had bloody done what they're supposed to do back in December, then we wouldn't be having this problem. And that's the other thing that just annoys me, if you say you're going to do something, do it. Don't say you're going to do it and then not, because it affects people's lives, people are getting hurt, because people aren't doing their job. Or if they can't do their job, pass it to someone else who can."

One participant spoke of **positive changes in the attitudes of staff** towards young people with disabilities, despite the challenges this posed:

"It's been a huge swing, a brilliant swing towards supporting the patient, meeting them at their needs. But sometimes I find that the staff will talk to my son almost ignoring me and I'm, like, any minute now they've got to twig he's got learning difficulties, they've got to twig that, like, don't ask him 'cause it's ridiculous. And that sounds rude, and if I've said this to people before they're, like, oh, you know, don't put your son in a box or whatever. But you can't let him make decisions of his medical needs. ... So, of course, you've got to meet the patient's needs and, of course, the patient should have rights and a voice but, wow, sometimes I go and I'm, like, you can't let him, I've had to say, I've had to step in before and say no, you know, one time they said we could do the operation today and he's, like, yes, brilliant. And I was, like, no, hang on a minute, I've got to go back to work in a minute, he can't have that done now. Let's just take a step back, we need to plan things a little in our house and he'll need a lot of preparation for this. Whoa, you can't just do it now."

Some specialist services were unavailable in the local area, with participants mentioning support for those with drug and alcohol addiction, for those with functional neurological disorder (for which there is a small number of specialists in England) and for children with Avoidant Restrictive Food Intake Disorder (ARFID). For ARFID in particular, people were passed around the system without necessarily gaining a resolution, with one participant describing referrals to paediatrics, a dietician, Child and Adolescent Mental Health (CAMHS), the Evelina Children's Hospital in London and Great Ormond Street Hospital, also in London, in addition to an existing wait to be seen by the Neurodiversity (ND) team locally :

"We don't support ARFID in Portsmouth, you need the Evelina (Children's Hospital) in London. To get to the Evelina you need a paediatrician to refer you. I can't refer you to a paediatrician, your GP has to refer you to a paediatrician. So I then went back to the

GP, explained all the situation ... She immediately wrote to the paedes (paediatrics, children's medicine) team, paedes said, I can't help unless she has a psychological assessment, you need CAMHS. So, we then went to CAMHS., CAMHS said we can't help you because she's on the wait list for the ND team. So, paedes wouldn't help., CAMHS wouldn't help and the doctor just wrote directly to the Evelina herself. Evelina came back literally like a week before Christmas, so bearing in mind this started August/September 2001 and I'm talking December 2023, we get a reply from the Evelina, and they said we're out of catchment,. They've changed their criteria because so many people are going to them we're now only...the only place available to us would be Great Ormond Street - GOS. So, the doctor wrote to GOS. GOS came back to me last week basically saying we're unable to accept this referral, we only accept referrals from CAMHS and paediatrics."

Those requiring specialist eye tests are unable to make appointments for these to take place in Portsmouth, despite there being a screening centre in Portsmouth, and were forced to go to Havant instead:

"Now they just use [community centre] for eye screening. Which, and this is the ironic thing, I take people to their eye screening, but I've got other clients who ... have to go to Havant ... If you are under QA for your eyesight, you have to go to the Havant.. ... If you've got no transport you've either got to get a taxi there or you've got to get the train to Havant and walk up to it"

5.1c Access to mental health services

Mental health services were discussed by several participants, and were often considered to be **unable to offer adequate and appropriate support**.

"I went to the place up Albert Road way for a bit of talking therapy, but they don't understand, they don't go deep enough. And children are never spoken of. Because a woman to lose her mental health is always connected to the children, because the children and her are one, so if she loses her mental health... And yet they don't mention the children, it's not mentioned ... they don't understand enough about mental health issues. I think there's so many mental health issues out there, so many people just do their own thing, don't they, and survive"

There was a **perceived gap** between the support which could be offered through primary care, and secondary care, and participants spoke of feeling dismissed by those who were supposed to help:

“Talking Change (mental health service) don’t want to know. I’m too bad ... I did one course with them, and you have an interview at the end, and they said, oh you’re too bad, I don’t know why they ever put you on the course, you’re not suitable ... I’ve been to a psychiatrist and they said, you’re not bad enough, because you’re not self-harming, and suicidal. So you’re left completely in the middle ... In the end, I got in touch with a charity that helped me ... There’s nothing out there for people in the middle.”

“They kept putting it down to, my mental health down to, oh, because your mum’s been poorly. Don’t always blame my mum, don’t always put it down to that ... 24/7 my legs hurt and obviously we’ve put it down to my nerves in my legs have just gone”

Whilst some participants highly valued the support provided by CAMHS (see section 5.6 for further information), there was acknowledgement that there is a **long wait for support** and, for those aged 16-18, it was not clear what route was available to them, given the long waits to access CAMHS:

“And obviously trying to get her on CAMHS is useless because she’s 17, so by the time they will do that, I think they only work with people until they’re about 18”

It was not always clear to anyone involved whether it was possible for adult patients to **self-refer into mental health services**:

“For clients it’s quite difficult for them to access mental health services, really you just have to go through your doctor. It’s difficult to get any ... I found something ... called The Hub that’s just started. But I’m not sure whether you can just self-refer to that or whether it’s GP. But I’d obviously screenshot-ed it, because I thought oh that’s useful for people, obviously ... I’m not sure whether you can just go there yourself.”

“Even if I need to, I’m not sure where to go or who to speak with. And if they will understand me”

“But to be honest, I don’t really know enough about that at all. I have been looking into it [access to diagnosis of neurodivergence], especially the last couple of weeks, I don’t really know enough about it. I did ring up, there was a number they gave me to ring up, but when I did ring up, it was the same sort of thing. Oh no, we can’t really do anything, it’s not done that way anymore, go to your doctor ... Yeah, because she’s not at school, how it was said to me was, because she’s not in school education anymore, they wouldn’t do it through the NHS, but then I don’t understand, because not everyone can afford...”

Where it was possible for patients to self-refer, **the means to do this were digital and therefore not always available**, similar to accessing a GP appointment:

“I had someone that was told they had to do an online thing first, so that’s assuming you’ve got access to that ... And some of them, they haven’t even got a phone... Some haven’t got a phone, they definitely haven’t got a computer. And a lot of ours don’t have wifi, they have no idea about internet”

Participants indicated that the lack of funding for mental health services had resulted in most services changing to **provide care remotely**, again similar to primary care, and that this was not necessarily effective:

“The government keeps saying that they’re going to fund mental health. I mean, after COVID, it was obvious there was a, sort of, tsunami of mental health issues and they’re just not funded. I mean, I have experience of people who have used some of the online services that are available but probably with the best will in the world but are just no good. Just not meeting the needs of anybody really. It seems like a tick box exercise.”

Others had managed to access **appropriate care which was effective for them**, only for this to be **withdrawn** and for them to be suddenly left once again without support:

“I was with the [mental health] team, I had like an event with psychosis and I ended up in [hospital] for two months. And that meant that I was registered with the [mental health team], but their funding only lasted three years ... So I no longer have access to the service. So I was getting a nurse visit once a week and he would be monitoring my health and my wellbeing and we would go out and spend an hour talking about how I was getting on and that sort of stuff. So that just stopped when

the three years ended. ... It's like having a carpet pulled out from under me really ... It's been very difficult ... Just having a regular weekly visit provides stability I think."

"So, say you get a social prescriber, well, in my experience when clients have had a social prescriber, they never actually saw them, it was all on the telephone and they could only have eight contacts with them. So a lot of services ... You can only have it for so long and then it closes and then you lose it"

"I was under social prescribing at the doctors ... I've never met her but she'd ring me once a month and the kids would be like, who's that mummy? And I was like [name] checking I haven't lost my mind ... and then about a month ago she rang to say that she couldn't talk to me anymore, I've gone all teary, and she's like, we're not allowed to talk anymore because I'm not really doing anything for you. And I said, what do you mean? And she said, well, we're just talking and that's not what this service is supposed to be. And I said, okay. And I've never met this woman or anything, but it was just nice to have someone check ... So basically she'd been told off for keeping us on her books. She didn't say it in these words, but that's how I interpreted what she said. She'd basically been told off for keeping us on the books because she wasn't prescribing anything ... I think just having the contact with that person and them checking in on me made a big difference to me. But on paper that wasn't what her role was supposed to be."

The lack of access to mental health support was seen to have an **impact on family members**, who were expected to provide care, although some people were known to not have such support:

"They kind of expect the family members to do the care; whereas a lot of the family members can't do it. And they can't be awake, one person, it's like ... that one person could not stay awake 24 hours a day looking after [person's name] ... Somehow, they try and keep each other alive"

"They haven't got family members, it's very sad, they've got no-one"

Whilst some of those who had eventually managed to access mental health services had positive feedback, participants felt that **more was needed for those with mental health conditions**:

“They suggested to refer myself to Talking Change, which I did, and they were amazing. They were so good, and they really helped me a lot. But the waiting list was phenomenal and by the time I got there I was in a hell of a state. I wish I could have seen someone sooner ... I think for a lot of people with mental health they need other things. So I’ve now found a wellbeing group that I belong to, it’s amazing. The lady that actually runs it, I’m not going to obviously mention names but she had a lot of issues and she found there was nothing out there for people with mental health and she went through a lot, and she thought I’m going to set something up.”

Several participants spoke of the **stigma which is still attached to seeking support** for mental health concerns:

“You’ve got someone you can talk to about these things, because you just can’t really talk about mental health to anyone. It’s a lot better than it was, I think, but there’s still a stigma attached to it”

“Regarding mental health services, I’ve never personally accessed any mental health service. Not because I’ve never needed it, but because I don’t know... It’s just really hard. It’s just really hard to almost own up to the fact that you need it and you just find ways around it. I mean this is not even to blame anyone. But for me personally, and I know definitely for a lot of people from my kind of background, it’s almost like a thing of shame. A sign of you being inadequate if you’re... You just have to get on with stuff. You can’t just...almost a sign of weakness.”

5.1d: Accessing dental care

Participants were often unable to access dental care, including those who had managed to join a dental surgery’s patient list locally. There were multiple challenges, including physical access, closures, delayed and cancelled appointments, alongside dentists closing their books (i.e. not allowing more people to join their list).

Those who were included on a patient list with a dentist experienced **delays and cancellations**:

“My son had, last year, 14 months ago, he had an infection in his tooth, so he went to the dentist, and he had antibiotics. And he's been waiting now, for a year, to have an appointment for a filling, a whole year. And then, he went to a drop-in in Fareham, that's the only drop-in I've heard of, actually, but they've got a drop-in in Fareham ... And so, they're going to keep giving him antibiotics, now, until he can be referred to the hospital. But this should have been done a year ago. If they'd have referred him a year ago, it would be nearer to having it done”

“I got there eventually, but after two cancellations ... You make an appointment, say, six months, and then it's cancelled, and then it's cancelled again, so it goes to about a year”

“That was one thing I kept thinking, when I was getting bumped with, oh, you're, at my one, your dentist has left but I kept thinking, but at least I'm registered with you. So, we'll text you when you can have an appointment. So, I wasn't having an appointment every six months but I knew I was with them”

Experiencing delays and cancellations was considered to be **better than having no dentist at all**, as at least emergency treatment was then possible:

“At least I knew if I had an emergency I could phone them up and say”

Dentists weren't always accessible to the local population, for different reasons, including the need to be accessible to wheelchair users and via public transport:

“But he's disabled, and you've got to go upstairs. ... Obviously he got upset and left, but then we've called back they said they have got one that he could access, but it was in Havant. Then, he had no means to get over there ... But if we hadn't done that he would have just said, oh, I can't go there because it was stairs; and it would have been the end of it.”

“Then if they do have an emergency they have to go to Fareham”

“A dentist has just opened up down by North Harbour, which is great if you can get there because again, yes there is a bus route but only if you're coming from Fareham

or Portsmouth. There is no direct bus route from here, what you would you have to do if you were from here is, you would get a bus outside the main schools down here, then you would get a bus to [name of road] shops. Then you would have to walk down [name of road] over the bridge, walk down to the bottom main road, then cross over and go. Then obviously you would have to come all the back and do that as a repeat journey. Well, that's a lot of faffing."

Some participants were simply **unable to find a dentist with availability**, even with support from other health services:

"I haven't been able to get access to dentistry at all, so I don't have a dentist ... That's been impossible, just nobody taking NHS patients. I do actually have toothache but I'm just coping with it at the moment and chewing on one side. I was with the [mental health team] ... at [hospital], and they tried to get me access to a dentist but they couldn't."

5.2 Access to social support

Experiences of social support varied between participants, with some describing people as having given up whilst others gave positive reports. Support groups were valued. Accessing support was considered a challenge, with transport and funding being the main barriers to engagement.

Some participants spoke of how friends and neighbours supported one another on an informal basis, and there was a sense of **community spirit**:

"This is the way it would be, he probably has to say to the guy with a dog, if you go and get me some shopping, i'll give you tea tonight. It's normally some sort of, it's normally like a trade-off ... There's normally something, you did this and I'll do that"

"I'm lucky, there was plenty of people in my life who were like, if you need to go somewhere, phone us, we'll come and get you, don't worry about it. Now if I wasn't in that position or I had a mobility problem, I do not know how people manage to get around in this area."

However, in some cases this brought some **disadvantages**:

“The one thing that this place does have is a community spirit, people will pull together, not always necessarily in a good way when we had the riots because somebody misread something and though it said paedophile when it actually said paediatrician, which then goes back to if somebody had learnt to read, maybe that wouldn’t have happened. But there is a sense of, well if nobody will look after us, we have to look after ourselves and I really picked that up”

“They are within a community quite often, they come here and they try and, they look after each other, try to look after each other, so they borrow money from each other. And that has a knock-on effect with other families because, you know, they are impoverished by helping their friends. But they do it. ... There is a lot of goodwill in Portsmouth, there’s a lot of people who are really, you know, brilliant and do what they can. ... People want to help, don’t they? But the state should be doing so much more...”

In contrast, local services were considered to be generally poor, with **little support provided by local politicians:**

“You go to your MP, I mean the complaints we have about this place, and nothing is ever done about it. We’ve gone to our local MP ... Here in this block, we have gates that don’t work. We have safety doors that are left open, and I came here for security. And we’ve been to the local MP about it, and that’s about as far as it’s got. You see it’s the typical political thing. They say they’re going to do things, and they don’t.”

“The MP is absolutely awful. You go to him, and you get nowhere ... I’d written to him, I’d emailed him, I’d phoned, nothing, about four or five times ... He said, it’s nothing to do with me, he said, nothing ... It’s not just the services, but no-one’s there to help you to get into the services, no-one will fight your cause ... There definitely needs to be more access, and more ways of complaining and more ways of getting things done ... There should be something there, there should be someone listening, and someone fighting for you”

“I contacted local MP (name) about it and was basically told, oh well you’ve got to do something about this, I was like what do you think I’m ... doing, what do you think I’m

doing... 'cause I contact my local MP... and was basically told by her that she didn't care"

and local people were described as being 'fed up' of **trying to improve local services:**

"It's really hard to get community engagement, it seems. I don't know if it's because people don't want to be engaged, I think people are unsure, they're a bit like, what if they start talking to me about something I don't know about. ... One old dear said to me, she said, look love, we've been surveyed to death up here, over the last seventy-odd years, just leave us alone. I was like, okay that's a fair comment, so if you feel like that and you're obviously an older resident, how many other people feel like that. ... Over the years, I've heard all these promises of all these wonderful things that are going to happen here, prior to me even having children and it's the same rhetoric year after year after year, we're going to do this, we're going to invest, we're going to make it better. Then it never, ever materialises and people have got used to their, oh well we'll listen to you but we know it's not going to happen ... When we spoke to people afterwards about it, it doesn't matter which party get in, they're not really going to do anything for us up here. So, when you look at the lack of services, whether that's transport or health or just being able to find out information and then that's how people feel about whoever gets in up here, well they're not going to do anything anyway, so what's the point in voting for them and you've got people saying, don't survey me anymore. You just think people are just fed up."

Where support was available, for example through social prescribing, it wasn't always **accessible for the duration needed:**

"Most services are time limited aren't they ... For some people, they're always going to need that support"

and for others, physically getting to venues was made challenging through the **lack of accessible public transport:**

"The bus services, they are non-existent and I run the community centre at the top of the hill and our main problem, I can't get groups running successfully is because if anyone doesn't drive, they can't get there. I've just recently had a dementia group contact me via work saying, what's your centre like, what does it offer, do you have tea and coffee-making facilities and, and are you on a bus route. I was like, I can accommodate everything for you but I'm really sad, I'm nowhere near a bus route."

Support groups, community centres and similar (e.g. food pantries) were valued, even by those who had not yet attended:

“I need to look into that a bit [Portsmouth Parent Voice]. Apparently, they do meet once a month and you don’t have to be diagnosed but they can help you. I think I’ve just missed the last one, but that would be something that, if I can get down there, that will be excellent, because I don’t think it’s too early as well. That would be something to look at.”

“That’s what I like about the [support group] actually. Everybody’s there to support each other, that’s the sort of thing. That’s brilliant. ... The ladies that run that, wow, they know everything, so they’ve been fabulous”

For those who did not feel they should be spending money on themselves, they were considered an opportunity to be sociable, to maybe undertake some exercise and to maintain mental wellbeing:

“There was other stuff to do with community things that were quite useful, that I knew were going on, but I didn’t really know how to approach it, or if I could approach it, I suppose. Because with certain things, I do feel a bit like, oh, I’d love to be able to do that and help, but I also don’t want to commit to something and then let people down. Especially as I’m not working, I would like to pay something forwards, sort of thing, in some way ... Yeah, there was a bit of an all round fitness, mental health, community ... And most people were quite approachable, so I did think that was ... Sometimes it’s like, oh no, I don’t want to ask for help, it can be a bit like that. ... I do feel like, oh, I’m on benefits and I shouldn’t ask for help, because I’m already getting help, sort of thing ... And I do think physical exercise and stuff like that, coupled with other things, just really does make a difference. Well, it does to me, to my mental health, as long as I don’t overdo it.

For those with ongoing mental health issues, who were often unable to access ongoing healthcare in this regard, **support groups offered an alternative way of supporting their mental health and wellbeing;**

“We meet once a week ... It’s just two hours a week and it is just brilliant, I love it. I’ve met some really lovely people, made lots of friends. We’re all very like-minded, you know? Some have got bigger problems going on than others. We can chat to each other and help ... There should be more things like that around for people, because

mental health is such a big thing, you know, mental health and wellbeing, keeping people well ... It changed my life massively."

However, several participants felt that there is **insufficient support available in the community**:

"But it made me realise there's not enough out there. Sadly, one of the answers would be, well, we could give you a tablet. I don't want a tablet ... I know I don't need it, I just need to be around other people that can actually relate to what I'm talking about, which is luckily what happened for me."

"It took me a long time to realise when I've been looking for different support groups, I'm not going to find a support group that's for mum's that are [age], with children with special needs and who are adopted. You know, I go to an adoption and the children might have special needs and then I go to a special needs group and the children aren't adopted. And that took me a long time to realise, I'm not going to find that. And that's what took me a while ... So, you're not going to find that group, you've just got to pick from what the groups you go to"

"There's very little support for parents out there ... You hear from various services, oh you know, you need to look after yourself and if you don't look after yourself you can't support. Yeah, that's great but how am I supposed to do that? ... I'm getting to the point where I'm totally overwhelmed ... People are at their wits end"

"There isn't anything for, specifically for dads, I don't think ... I know men don't always want to talk"

"The thing that there is nothing for at all is your people with early onset dementia. Everything that is geared is towards older people and although a smaller minority, they have nothing. They don't wanna sit in a room with a 90 year old"

For those caring for someone with dementia, there was a view that further support was needed, which met the specific requirements of this group:

“The biggest thing is carer’s support that we need ... It’s completely underestimated how valuable peer support is between carers ... There’s not a lot out there ... The biggest barrier to attending a group, a carer support group is that you are looking after someone that can’t be left alone”

Some participants had found **support through people at their church**, which they also considered to be a safe space:

“It’s very isolating having [mental health conditions], it makes you feel different and left out, but it’s just one of those things. That’s why I’ve come to the church, because when you belong to the church, everyone, you know, everyone asks how you are and it’s nice. You don’t have to talk about that, you know, it’s just nice. It’s nice, there are lots of lovely people there, they’re really nice here, really nice ... I think coming to church keeps that continuity, if you know what I mean. And when life can get a bit crazy you can come to church, and even when you’re sitting down listening to the sermon it’s like a quiet time, you can gather your thoughts ... You have the people care, which is great. I just feel safe at the church, I just feel safe, because there’s no other place where you can feel safe, apart from at home”

“Oh, the church is, yeah. I still don’t think they understand mental health completely, but they’re willing to help, and they’re open-minded and accepting. And if you have got a need, they will help you if they can, do you know what I mean, but yeah, I’m not sure they completely understand. But then, who does with mental health?”

They had also found support through **different mechanisms, by finding people they found to be nice**:

“There’s the libraries. Libraries are good, yeah, when the people in the library are kind, because some of the libraries the people are not kind, so I don’t want to stay ... To go somewhere and just have a chat, you know, chats and talk. And go there each week and then it builds their confidence and then they feel that they can do more things ... And the food banks are great, because people are struggling and they chat and they’re friends with each other. Yeah, food banks are great.”

Unfortunately, a **lack of funding** meant that some support groups and venues such as the healthy living centre were unable to continue indefinitely:

“That’s run by a charity, she’s running out of money at the end of the year. So all, me and all of the people that benefited from that group, I don’t know what’s going to happen really ... It’s very precarious always”

“They don’t get a lot of funding ... And unfortunately again that’s getting quite low”

There was also a perception that **information about local services which would once have been provided as leaflets was now only provided online**, although this isn’t accessible to everyone:

“You used to be able to go in the Civic and they had all (these) leaflets about all services. But now because they’re so brilliant, it’s all online, but they just assume that everybody can go online and do stuff, and that’s not the case. Youngsters think everyone’s doing it but it’s just not at all the case. And it’s all right saying, well, I could teach these people, some people are not going to ... they’re either ... if they’ve had a stroke, their memory’s poor, if they’re elderly, their memory’s poor. Some people can’t physically hold and work the technology because of their disabilities. So, maybe going a bit back to having leaflets and things for the people who want it

There was also an assumption that **literacy levels** in Portsmouth are maybe higher than they are:

“Maybe they can’t even write and read very well, they’re not going to go for that, are they? Because even if they can, they’re going to be going ... and then it says there: click on the one that says ... and they won’t know how to do that ... I think some people don’t realise there are people that can’t read or can only read a little bit and they’ve managed to get through pretending. And I think some people think, no, there can’t be anybody left that ... can’t read, but there’s a lot of people. They’ve been getting by ... To do online you do need to be able to read, don’t you?”

Participants did not always have **access to social support in the local area**, in some cases impacting on the health of participants:

“I’m on my own, there’s no-one to help me”

“So, we have to have biannual colonoscopies and things like that. But I can't have that because I don't have anyone to look after the kids ... And even like the colonoscopy, you're supposed to have, because they knock you out, you're supposed to have an adult with you for 24 hours after you're home from the anaesthetic, and I don't have anyone. Because my dad is my mum's carer ... So it's not like I can farm my kids off to grandparents and their father is useless ... My dad's like, well, you're just going to have to wait ... But I don't want to have to wait, I want to get this out ... Because what happens if I get cancer, then who's going to look after the kids?”

For those who were seeking local friendships, there was a **lack of one-to-one befriending services** particularly for those with specific needs:

“I had a client ... she wanted a befriender and I wanted her to get someone, and I thought there must be someone out there, but there's not a service in Portsmouth that you can get a one-to-one befriender. You can go to groups, because she had a head injury, Headway, they said she could go to groups but could not find a service that would do a one-to-one, because she can't be in a room with a group or a lot of people talking at the same time. So that was difficult to actually say there's nothing available.”

Even where support was available, it was not always visible to those who needed it:

“And then one day, I'd gone somewhere and this lady told me about this group. It was all by chance. I said, oh, what's this group? And she said, well, it's a mental health wellbeing group. And I just ... It all came about like that, and now I'm part of it, it's just changed my life”

A small number of participants described a **feeling of hopelessness**:

“It's always been like that in [area of Portsmouth], it's because people just always felt abandoned, so they've given up and there have never been any services ... I think a lot of people just feel there is no hope sometimes, they just have to plod along and accept plodding ... What I've experienced working in the community is, there is a lot of families here who've just struggled at school, come out of school, maybe done some college or gone straight to working in a shop or whatever and they've just plodded and they've never really been given any reason to not accept it.”

5.3 Access to housing

As with access to healthcare, there was an expectation that to access housing, individuals needed to be able to **access and use online platforms, complete forms online, and send and receive emails.**

“I had to answer all the questions on an email to the housing officer, to get him to explain why he needed ... and send photographs, that it wasn't suitable housing, was it? He could not have done that himself, there's no way. He'd had a stroke, he's partially sighted, partially deaf, he couldn't have done that ... He couldn't do it without us because he couldn't use the technology, because you've got to order it online and then use a payment card... I think people don't realise that there's a lot of people that still don't have technology, or would be able to work it even if they did have it ... They're not going to have the money to buy the technology and have the stuff ... They might have a phone, but they just have a normal phone for phoning people”

Locally, it is believed that there is a **lack of suitable housing**, exacerbated by immigration and university students living in the city:

“Especially in the last two or three years, because I don't know if you noticed that there's been a lot of ... because of work, especially in the NHS, there's been a lot of immigration from other countries of the NHS, health professionals, and of course students which has always been. And I know that last year it was really ... housing was really terrible, I will put it that way. And that's putting it mildly. Because there were so many people and not enough housing ... Many people get here thinking that at the end of the week ... So they come in, lodge into a hotel, hoping that within a week they'll be able to get accommodation. Three months down the line some people are still ... I know of somebody who had to pay a whole year's rent, just to secure ... Yes. A whole year. Which I mean where do you get that kind of money? ... I think it's a little bit better this year because I don't think as many people came in this year as they did last year. But last year was really, really bad. It was really bad.”

“They do build an awful lot for the university. They do seem to ... Everything you hear it's university, university, and you think, we need more disabled properties.”

“Housing is quite difficult. The housing stock, there isn’t obviously much housing stock”

In order to meet the requirements for social housing, people must comply with **multiple categories of need**:

“Just being homeless is not really, you know, to get housed you need to fit, like, have a child, you need to have a vulnerability, a disability ... That’s why there’s a lot of men that are homeless ... They can’t give you housing if they haven’t got it”

Despite multiple needs, one family was informed that they had to be evicted by bailiffs in order to fulfil the requirement that they were homeless:

“We were evicted in [month, year]... you get put on a housing register, if you’re accepted as homeless, and that in itself you have to jump through so many hoops to do that, and your landlord has to sign this document, you have to get all the documents like this up-to-date tenancy agreement, it’s up to date this, its up to date that, you have to present them in a way that they want it to be presented ... You get all the paperwork together and they accept you on the housing thing, but their advice is, you have to stay. On your eviction day, you have to stay and squat, you have to stay there, and you have to wait for your landlord to evict you, they have to take you to court ... and get an eviction notice. Then, and only then, will the local authority agree to help you. And if you go before your eviction day, if you go on your eviction day, you are making yourself intentionally homeless ... You could end up anywhere in the city, we don’t have 4 bedroom houses, we have very few 3 bedroom houses, you could end up in temporary accommodation. I’m at that point just out of a wheelchair and my daughter’s autistic, and my son’s got ADHD and one of them goes to primary school, one of them goes to secondary school and one of them goes to college, what am I supposed to, how am I supposed to do this, but there’s nothing, there’s no housing.”

Participants indicated that there was a need for appropriate housing, and for **information to be made available that enabled individuals to make informed decisions about the housing available**. For example, one participant had experienced a mental health crisis, following which they were made homeless. They only found out by accident - through staff at a night shelter - that the council was obliged to house people in his circumstances.

“But as it turned out, because I had a mental health condition, they legally are obliged to provide me with emergency housing ... I had to turn up at the night shelter

and sign in there, and it was only them that said, because you've got a mental health condition, the council have to provide accommodation ... So it was only by the luck of the wonderful people who work in the night shelter, who I think are volunteers, who said that it's necessary to give me, the council are legally obliged to give me accommodation"

Another participant lived in a 'house in multiple occupation' and described how, despite improved conditions in their own room, **they were unable to change the living conditions of others** in the house, despite its impact on other residents:

"Two people smoking crack here, and with that comes a traffic of just people you don't want in your house, I mean, I just felt so vulnerable ... I've had to fight tooth and nail to get any peace in this house ... He could make us ill. He's so dirty and he just will not clean himself, he won't clean his clothes. I mean, his clothes are shiny, they're that dirty and smelly, and we've all got to put up with that. Even though we've all gelled together and become quite a nice house ... He isn't entirely responsible for the nightmares in this house ... He was with the filth and the fleas and the mice and stuff"

For those requiring wheelchairs, the **housing stock in the local area was not considered appropriate**:

"I think there needs to be more accessible properties in Portsmouth ... For example, where I'm living now, I had to wait just over three years for it, so that gives you a flavour, and that was about five years ago. But now it's even worse. I think you're waiting four or five years. We were living somewhere very cramped. Our daughter was getting older, my health had changed and I had a lot more machinery and we didn't have a lot of space and we needed somewhere bigger."

"Where he has to come out of his house in a wheelchair and get into a taxi that he can use, there's no dropped curb is there? And yet it's a disability ... flat"

Similarly, the lack of housing impacted on families:

"They've got to have a criteria because they haven't got enough housing. So, if you don't fit the..., and even if you do... I've got a girl, a client who she's got two children,

a boy and a girl, the girl's 16, the boy is, I think he's just gone into senior school, what's that, 11? And she's in a two-bed flat. So, she now has her bed in the lounge to give the daughter a bedroom and when I tried to get her, surely this isn't, they just said, the waiting list will home swap her. She won't get anywhere on the waiting list, the girl will be over 18 by the time that she gets.."

For those renting privately, **landlords were not always taking appropriate and effective action to provide suitable housing**, with one participant describing how the damp in her home had been reported but not addressed:

"Housing ... it's not great. It's a very damp house, I have a dehumidifier running 24/7, which chucks out so much water you wouldn't believe, even in the summer. It's a private rent. There are things, like the double glazing gone, stuff like that, he won't do anything about because it costs him money ... I've been asking him, like this carpet is coming up on the stairs, the carpets were old when we moved in, in 2010. There are things that I keep on that he should be doing, about the damp and about the damp coming through the ceiling in the bathroom and in the kitchen, and he just won't do anything about ... But I am aware I can talk to the council about this and there are a couple of things recently that I have said to him, look, I feel like I have asked you this before, I don't want to keep going on about it ... I don't mind doing certain things, but there are other things that I think, yeah, I can do, but then he doesn't, because of the damp, it will just be ruined."

As with healthcare, participants spoke of the **potential impact on their health and wellbeing** of being unable to access appropriate housing, based on their own experiences:

"The impact's great. I mean, it could be massive because it could be something like not enough space for someone to move around. It could be that they've got problem neighbours and when you've got disabilities, you know, the reality is there is still a lot of hate crime out there for disability ... If the property isn't suitable anymore, it might be that they're living somewhere but then they developed a disability or they might have had an accident and then become disabled and then their property isn't suitable. So it can have a massive impact. And then what you're looking at is a knock-on effect of then the mental health creeping in, because it might be that someone's then confined to the house. They might not be able to get in or out. But it is a challenge because you can't just magic properties out of thin air, you know?"

5.4 Access to education

As with other areas of interest, there was a requirement for **education-related issues to be dealt with online**:

“If there’s a reason they cannot be at a certain school, again, it’s all online, you have to do an online form”

With regard to children actually getting to school, participants commented on the need for **parents to be both willing and physically capable of getting their children to school**, something that wasn’t always possible:

“They keep moving the schools along because they keep banging them down and building new ones which is great but when we first moved here, all the schools were up this end. All the schools got further away, that’s fine, again if you’ve got no issues of walking and things like that ... You would hear comments in the playground like, oh well I can’t really read and I’m alright. You would be like, but why would you want your child to be like you and that’s how I think people in the area have always felt. They feel a bit like, well no-one really cares about us, so what’s the point in trying and you see that with parents ... There are a lot of schools along here which are all easy to get to if you’re a young, fit mum.”

“Some can’t even get their children to school because of their own health conditions ... One lives ... at the top of the hill; school is at the bottom of the hill. She can’t walk, so she cannot get down to the school. The school won’t put on transport because it’s within a mile”

Much of the discussion around education was focused on children with disabilities or additional, specific needs, although finding the right kind of education was also important to other parents.

One participant found that **her child struggled with the rules** during the Covid-19 pandemic, and as a result had moved schools, saying:

“I said, what are you doing sitting on the floor, you’re supposed to be at school? And he was just like sort of mumbling. I thought, he’s really... Because I’ve got mental

health issues, I think it comes down in families and I thought, oh he's losing it, I thought, he's losing his mental health, it's not worth having education if you lose your mental health, it's not worth it ... So many rules that the children's personality is just crushed, it's just crushed by rules. So, I got him out and things lightened up and he's so much better now. So, he goes to a different school and he's really getting ahead because at that school he was just falling back, he's really getting ahead, he's doing really well now... School does help I think, you know, because the children are out and about, they get friendships and they're learning. And, you know, and then they come home and I think school really does help with, you know, the running of the family – when the school's good and works with you, yeah.”

For one participant, ensuring that her daughter, who has severe learning difficulties, was **kept safe during college hours** was challenging:

“She's just started college and my husband and I are going to be getting a meeting because there's already challenges there, you know? They let her go early and things like this, sometimes an hour and a half, two hours early, and what they don't get is that she can't be on her own. So, my husband or me have to be at home waiting for her ... She's supposed to be on a full-time course. Sometimes she's only there two hours ... She's treated like an adult but she's an adult with severe learning disabilities. You've got to think of it like would you let an eight-year-old do that? That's what they're missing. No, you wouldn't. Although she's 16, she's vulnerable.”

Their child's safety **impacted on the participant and her husband**, as they needed to leave their workplace to get home to their daughter:

“It's not only having an impact on her, it's an impact on me and my husband. It's like, okay, where are you? Can you get back? As I say, I've got my work with [employer], my husband works.”

They described a **gap in provision for those older teens, who were no longer of school age** with the associated responsibilities assumed by the school, but who were not able to look after themselves.

“So yes, that's definitely a big gap between 16 and 18. Services, you know, social things.”

Information about provision was sometimes considered to be lacking, particularly for those parents whose children were moving from secondary school to college:

“My 16 year old, he still doesn’t know which college he’s going to go to. It’s sort of up in the air at the moment.... He thinks he might be wasting his time doing something he shouldn’t be doing with the wrong college, yeah, so... And I don’t really know which is best for him, which has got what he wants to do. I just need more information really, yeah. ... I think the schools, because just before Christmas they said to him, you’ve got to pick a college and I thought, what? We need more information. I was waiting for some information to come across but I haven’t heard anything.”

“I think I was saying to someone yesterday, this is the first time that I will struggle with the next steps, because I don't really know. And I think also because I want to get it right for her, it's really stressing me out. I don't think there's enough... I know the city council, they're doing so much to improve the post-16 information and provision. There's a lot of work going on with that. But I still feel like I don't know enough to make a good decision for her”

Physically being able to access educational settings such as colleges could be challenging, in terms of both getting buses from college sites and paying for the necessary bus passes, thereby potentially limiting access to education for some young people:

“I would say more moving on from secondary school is hard, particularly if, like we were, when our eldest came to go to college, we were just above the threshold by about six pounds to be able to get a bus pass basically for our daughter, six pounds ... We couldn’t buy a bus pass, we had to buy two bus passes because she didn’t want to go to Highbury, she wanted to go to South Downs. That meant we had to get a pass for Portsmouth to get up to Cosham and then because she had to get a bus from Cosham, which I think was Stagecoach, which is a completely different bus service to get her to South Downs. It was costing us nearly six hundred pounds a year and then you go, well I’m only six pounds over but now that’s going to cost me five hundred and ... because of six pounds. So, I did extra shifts at work ... To have that choice is a luxury and most children, I think who do have to rely on the buses, I feel they end up going to Highbury, just because it’s on the doorstep, it’s easy to get to, you don’t have to buy two bus passes.”

Similarly, the **price of school trips could be prohibitive** to those who were working, but not on a high salary:

“We had this with my son, he got to go to Russia, it was nearly a thousand pounds and my other half was going, we can’t afford it, we can’t afford it and I said, I will literally work seven days a week, he is going. This is a fantastic life experience for him ... If you’re on benefits, you don’t have that luxury, so your kids miss out on that higher experience. So, not only is it a struggle to get to these colleges sometimes, but it’s then the expense of college”

Paying for holiday clubs was difficult for those who were working but earning limited amounts, and this was considered unfair by one participant:

“With the holiday clubs coming up, the children's holiday clubs, because the thing I completely disagree about that is, is that they're free for children whose parents don't work. But the people who work have to pay. And they're just as hard up, and also, they need to have the holiday clubs, so they can work. They haven't got that extra money; they've got to have someone to look after their kids so they can work. Whereas, you know, if the people are just not working, they're actually there to look after them. So, I think there should be a way that, maybe, the people on Universal Credit just get free meals, and then the other ones on low income get the activities free, and maybe pay for lunch. But I don't think it's fair, it's a cut-off, because it ends up, the people that are working are worse off than the ones that are on Universal Credit, and that's not fair.”

For adults wishing to access education, **finances were often a barrier**, with those who were earning needing to pay:

“Everything is free for people on, like, income-related ESA (employment and support allowance), but for other people, you have to pay. And the thing is, it is really difficult, just because I'm on income, I'm on ESA, but not income-related. But when you're home all day, you can't keep paying to do things every day, it really adds up, do you know what I mean?”

5.5 Access to employment

Several participants spoke of how **gaps on their CV, or employment overseas if they were new to the UK, made it difficult to access employment**, forcing some to work in roles they did not want to be employed in:

“People don’t like the gap on the CV so I think that’s been a problem ... They like recent experience, and if you’re not in work, then it’s really not easy to find work.”

“A lot of people are having to do jobs that they really don't want, because they need to put food on the table. But they have skillsets that are just lying dormant because there is no way ... Especially those that are new in the country as well. It's more difficult for them to find a job that matches their skillset. Employers ask for UK work experience which of course if you are new there's no way you will have UK work experience”

Those with disabilities spoke of the challenges they faced in gaining access to quality employment, and some spoke of the **discrimination** they felt they faced:

“In the workplace, I’m a good employee until they find out I’m autistic and then like suddenly you’re not. And you’re viewed as an idiot or a hindrance or, even though nothing’s changed ... Jobs where I’ve applied for skilled work and I’ve been open about saying I’m autistic, you either get treated like a simpleton and made clear you’re not getting the job, or just plain ignored.... You ask for ... things like getting the questions in advance, I forget what it’s called, and people will fight it ... It’s sort of a case of if we ignore it, now we’ve found out, if we ignore it, it’ll go away. ... Once companies find out, jobs I’ve applied for and got, I have not disclosed my disability at all and when it has been disclosed, it’s like somebody has flipped a switch ... Like the (government department) one, the woman said to me ... ‘Ah well yeah, there’s basically two systems and we only employ autistic people through that like, we’ve done it 2 or 3 times in the past 5 years’, and it’s like, why are there two systems, why can’t I apply through the same system as everybody else? I apply for the same jobs as everybody else, have access to them, skilled work”

This was supported by another participant, who felt that employers might fulfill their legal duty, but that **discrimination** against those with disabilities still existed:

“I think there’s still a lot of ... people ... a bit of ignorance about it, I think. About people that are disabled. I know obviously employers have to take one in three people with disabilities ... but I think there’s still a lot of ... what do they call it ...

stigma about it ... Discrimination, yes ... It doesn't mean that they're not behind their backs thinking, you know, we've got to do this, we've got to do that, because I think it's still there."

There was also a belief that neither government nor employers understood the **practical elements of accessing work for those with disabilities, including arriving at a specific time:**

"It would be really good, and I think what the government need to also get their head around is to help people with disabilities, it's a bigger picture. It's not just getting a job, it's how do they get to that job? How do they get there on time? Because you're then going to have complaints about tardiness. How do you take into consideration somebody may need carers to come in and get them up or dressed to get to work before you're even getting in the taxi? You've then got to allow that carer might be delayed. She might be late getting to you, so you're then late even starting having your wash ... Do they need some medication? I have to have a nebuliser every morning that takes me half an hour, you know? I've got to allow for that. If I was working on a morning, which I can't but if I did, I would never be able to get to work for eight o'clock in the morning. It would mean me having to get up at five. It just wouldn't happen. I couldn't. So okay, yes, get more disabled people back into work, that's brilliant and positive, what else are you going to do to support people with disabilities?"

As has been mentioned elsewhere, the lack of **accessible public transport or taxis** in the local area meant that some struggled to access employment:

"You couldn't even get a taxi to work. I could never get a taxi when I worked at [organisation]. I always had to get the bus. Because you could never get a taxi ... [Taxi company] don't do wheelchair taxis. They do something ... where they'll link someone's arm or assist them if maybe they've got sight impairments, things like that, but they don't have the wheelchair accessible taxis ... So [taxi company] have a monopoly, they've got loads and loads of taxis, but I don't know what on earth is going on, they just haven't got the capacity for a wheelchair apparently. So here it's very frustrating"

Others felt they were unable to access employment as their disabilities meant that they would **not be able to work in the required way:**

"I've got this [mental health condition], that's why I wanted to start the soup kitchen. So that anyone that's in my position with mental health issues can talk about it and not feel on their own, because if it wasn't for the church I don't know what I'd do. Yeah, I can only... I can go to work but not raise a family, or I can raise a family and not go to work. I can't do both, because PTSD, what it does, everything I do, I have to ... It's like, if you go and do something it takes ten minutes, but for me it would take about 30 minutes. I get there in the end, it just takes so much longer. And if I was at work and they asked me to do something I'll take too long and it won't work, it just won't work out, I'll take too long."

Ongoing health issues were a **barrier to accessing employment to match their skills**, as was being a **parent** to young children, or children with additional needs:

"They were helpful, but it was stuff that I wasn't able to do, like night shifts. All the stuff they were getting for me was stuff that I wasn't ... I'd literally, without being funny, I couldn't cope with that. And what with the girls, it's not like they'd get themselves up, and they're still young, if you know what I mean, I can't expect them to totally look after themselves ... The job description that they said about wasn't the same as what was advertised. Like they say flexible hours, but then they say, no, you've got to work all ... every ... like this sort of thing. Which I understand, in certain places, you've got to be flexible, but I wouldn't have obviously gone for the job if I had known that wasn't, you know ... Like I say, all the people at the last jobs fair I went round to do with the hospitality, anything you didn't need many qualifications for, it was, you couldn't be part-time. And some of it was night work and stuff that is just not doable at this present moment with my situation, unfortunately"

"For universal credit, children don't really get a mention. Like, how can I go to work if I've got children? How can I? Because they come home from school and they have days off and it's half term, because we've got ... in two weeks we've got half term, we've got Easter and Christmas and summer holidays."

"My job is so flexible ... So, when I say my job's flexible it's because I've got a paper round. I mean, it is the only job I can do really, it's quite funny. I have worked, obviously, even with the boys I've worked ... I need to work, I need to have some money, so I do a paper round because they can come with me, I take them with me in

the holidays. We walk it together. And I only have to do two hours a day, anytime between, sort of, eight and five, so you can ... I mean, I've never heard of such a flexible job in my life but, of course, I don't earn a lot but I'm on universal credit ... Without universal I couldn't survive, no way, I could never earn ... I could never have the time or the flexibility to work in a job that would cover the three of us, no"

"Which is then putting the problem onto wider areas, because I can't work because I'm too ill. If I'm having a day where [daughter] isn't in crisis, I'm exhausted, so this is making a wider economical problem by not dealing with the problems before they happen ... I can't even look for work. Even if I was well, I've got to care for a child 24/7 and my main job at the moment is just keeping someone else alive, so that's it"

"What job can you do for three hours a day? It's just not possible"

Despite this, participants indicated that they themselves, or those they knew, **wanted to undertake some form of either paid work or volunteering if there was the right support in place:**

"But I know there's stuff out there, and like I say, I would like to be able to do something useful, because I don't feel like I am at the moment. ... I do feel like I want to be able to do something for somebody, even if it's just keeping someone company or something. Something that doesn't involve academic stuff and that's something that could make a difference ... Like for me to just go flat into full-time work with no support wouldn't help anyway and I'd just get burnt out. But it would help me and it would be nice... Yeah, I suppose I do feel like if I could just do maybe part-time, but there doesn't seem to be anything out there."

"My experience of working in the community, is that there is a lot of people who want to work but don't know how to. I've experienced the job centre, again in Cosham, so you've got to get a bus and they're horrible to you in there, they treat you like you want to be there, like you don't want to earn a wage. That's not the case at all, there are a lot of people who do want to go to work, but they have limited skillsets and minimum wage, quite often is less than what people can claim."

5.6 Health and education for children with Special Educational Needs or Disabilities (SEND)

For those participants who had children with special educational needs or disabilities, their requirements crossed over between education and healthcare. As a result of the complexities involved, this group are discussed separately in this report. However, the findings should be considered in light of the issues with accessing healthcare and education identified elsewhere.

Parents of children with special educational needs or disabilities were **given incorrect or not enough information about what support could be offered**. This prevented them from accessing appropriate care:

“Right in the middle of it at the moment with my son and his mental health. Been trying to access support for him since November ... So I approached the school SENCO (Special Educational Needs Co-ordinator) and said that I felt his mental health was deteriorating, and he’s neurodiverse anyway and he’s got support in school ... I’d found out myself ... Spoke to the mental health support team because I didn’t realise that he could be referred to them. I’d, when I first heard about them, I’d been told that they were a sort of like a stepping stone between school and CAMHS...it wasn’t for children who were already identified with needs”

The limited services which are available were considered to be disconnected, even where there was a clear overlap, for example between CAMHS and the mental health support team:

“None of these services join up, it feels like there’s a whole disconnect between them all, even though they all come under CAMHS..”

“She needs help, she needs to talk to a psychologist, she needs some strategies ... She’s got 8 weeks of counselling with [organisation] at the moment, play therapy, and that’s all she’s had ... Just nothing, there’s no service for suicidal children in Portsmouth. That’s what I’m told anyway ... CAMHS is a mental health service and we don’t deal with neurodiversity, we just deal with the diagnosis and then it goes to an ND team. The ND team say this is a mental health crisis, she’s trying to kill herself, that needs to go back to CAMHS. Then you go back to CAMHS and then they say, we don’t have this service, and other clinicians have seen her and she seemed quite

happy so ... I'll take her home and stop her climbing out the windows ... the support has been abysmal, really abysmal. ... It's fractured, no-one knows what they're doing and everyone blames everybody else, all the other services just push it back to each other, so it's like ping-pong."

"Because there's like no help from anybody, you just have to do it all yourself. Well, I feel there's no help from anybody. The doctor re-referred him to CAMHS and in big fat writing wrote: ignore autism diagnosis, focus on depression and anxiety. Got declined. She did it again. Got declined. And it was just ... And they just kept coming back. And I'd be ringing up the single point access number going: can you not hear him? He'd be headbutting cupboards or whatever. And they just kept going: we can't help him because he's autistic. And I was just like, oh my God, this is nothing to do with his autism, his needs aren't met because he's autistic, but what's happening is because he's depressed and he's anxious. If this was an adult you would have given him antidepressants months ago. It was just absolutely ridiculous."

Young people experiencing mental health challenges struggle with being **passed from one person and one service to the next**:

"For his initial assessment ... when we got her report after the appointment ... so we want to refer him on to somewhere who can give him, she said, he needs one-to-one support rather than group, and she said there's a charity called Winston's Wish who can do that, she said, but you have to refer to them and she said and then we'll close to him ... My son hadn't understood things the way that she'd meant them ... He was furious because he thought that she was going to carry on supporting him and not just refer him on somewhere else, and we left the appointment and he was saying to me, she's just dropped me, she's stabbed me in the back"

"The lead of the team [name] is lovely ... but my ND coordinator I've never met ... It seems to be a very stressful job ... I think it's a great idea on paper but the resources aren't enough for the amount of kids that they need to deal with and the amount of stuff they need to do. They deal with ND kids and they are needing to refer back to CAMHS for mental health reasons but CAMHS aren't accepting the referrals because they're ND kids so they're your problem and actually their mental health is being seriously affected ... There's a percentage, I don't know what it is, of autistic children who present with very violent and controlling and challenging behaviours and there

are you know, it's a really difficult problem, but the local authority and CAMHS just seem to have the opinion that it's not their problem"

"He'd be wrapping his arms around the railings and screaming, and crying, and stuff. And at that point, I started to try and get him help through CAMHS. He was eight the first time he tried to kill himself, he ran out into the busy traffic on purpose because he wanted to get hit by a car. And they saw him but said it was due to his autism and it was school's to deal with. Because obviously school was causing the issues for him to get stressed and anxious, and then that's how...So, CAMHS discharged him. That was the first time he's been discharged. It's about eight times now"

Even where parents had a **care plan in place which recommended that they use 111** for support if their child experienced a mental health crisis, there were challenges in accessing such support:

"The care plans you get, they don't work. The latest... it's call 111 for mental health advice if she's trying to kill herself, don't bring her to [hospital] in an ambulance, because you need to break that pattern. Right ok, so you call 111 and they want to go through medical questions with you. And they will not put you in touch with a mental health person, they won't refer it to mental health, they won't do anything mental health-wise until you've gone through the medical questions. And they get really horrible to you, they're kind of like, well you have to go and touch her back and see if it's cold, and you're like, i'm going to get bitten if I do that, do you not understand? I've got a child in crisis who's trying to kill herself and I need to speak to a mental health ... These services are meant to help you ... There's no crisis care for children in Portsmouth at all so it's just on to the families to deal with"

The lack of mental health support **impacts on the ability of young people to engage fully in the educational setting:**

"He's on a reduced timetable at school, he is not in lessons in class. He's actually doing them in a sort of personalised work area, so, and he's not coping and the school have been, you know? They're supportive but they were saying they wanted to integrate him back into lessons and I said, but he's had no support, he's not ready ... I did some chasing, got hold of the ND team manager and said, look, you allocated him a support worker on x date, ... What's going on ... But it's all this waiting

around. In the meantime he's just in limbo, he's languishing, he's not coping there ... it just feels like you're going round and round in circles. So, there is no joined up approach."

"She's out of education, I don't know how long for. She doesn't ever want to go back herself, she hated it. She doesn't want to go back to school. They're saying she won't survive in a mainstream, she can't cope with a mainstream ... And they don't know of any specialist provisions that would be suitable for her, because her needs ... The specialist provision, from what they're telling me, won't be able to stretch the intelligence in the way that she needs it stretched."

"I then rang the ambulance service and he's still trying to hurt himself, he's still trying to climb out the window. And they said, well we can send you the mental health car ... They were the nicest people I'd spoken to for like over a year honestly, and they said to me that obviously he needs CAMHS help ... We had them out another two times that summer and, by September, I knew there was no way that he could go back to school. He should have been in [school year]. I contacted school on the first day of term to explain the situation, because obviously, his anxiety had got worse and worse, and worse as school got closer. And I said you need to help; you need to revert to CAMHS. No, we don't see any issues, blah, blah, blah, blah, blah. And I was like this is ridiculous. So, I went to the doctor's ... She wrote him a letter ... basically saying that he was in no fit state to do anything and that he couldn't attend school. And then I went to the school with that, I went to the council and said he needed alternate provision because school weren't meeting his needs"

For young people in education, **autism was considered to be a hidden disability**, which could be missed until the person experienced a crisis:

"The other difficulty we've had from an education point of view is that he's highly academically capable, but his main thing is, social, emotional and MH ... and obviously he struggles with the sensory side of school and things like that. So he doesn't need a lot of academic support, but when he's struggling, he needs that emotional connection. So, they're within their resources, they are, they've been very good and very helpful, but I still feel that they don't fully appreciate it from his perspective, you know, when I was talking to the SENCO ... because he appears

capable, he's very articulate, he understands things, it gets missed, it's the typical, as they call it, the hidden disability, you don't see it - until he reaches crisis point"

"To a degree, schools are supportive, but it's hard because they are a mainstream provision and although they are used to dealing with children who've got additional needs, actually I hadn't realised ... There are only 18 children in that school with an EHCP (Education, Health and Care Plan) which is a very small amount, it's under the national average, and no two children are the same, so if they've not encountered that level of need before.. They're working with their constraints ... I trust them, but I'm getting to the point where I don't think they really appreciate what he needs."

Whilst **children with an EHCP should be provided with appropriate support for their learning**, this was inconsistently applied across the local area:

"Predominantly he has LSA (learning support assistant) support in core lessons. They did just before half term give him LSA support so he could go to one of his art lessons, and that was really successful, but again it's that juggling isn't it, and I know when we've asked for support in other lessons prior to this, the SENCO said that if, to do that, I've got to take the support away from somewhere else and, and that's the trouble isn't it, again where mainstream is not geared up for it even with an EHCP."

"There is funding because, for starters, they both receive pupil premium, they both receive pupil premium plus which nobody seems to understand, that's a real bugbear of mine, nobody understands what pupil premium plus is. And I've told ... Eight years I've been telling them, every school that I've ever come into contact, what it is. Nobody listens or understands it. And then they get funding through EHCP ... My son receives the highest level of funding there is, he receives 25-plus hours a week one-to-one support, there's no reason for him not to be getting it."

There is a **lack of consistent support and understanding by staff in mainstream educational settings**, negatively impacting on young people:

"The trouble is within mainstream secondary the SEND department are amazing and they coordinate the support he needs but what they can't coordinate is the response of individual teachers. And although the majority of them have been fantastic when

I've spoken to them at parents' evening ... The odd one or two, really don't understand it and when we were discussing this at his annual review, the SENCO said, yes, absolutely, he said, that's where things are difficult because you've got the individual personality of the teacher and their understanding of the situation."

"Secondary schools are really diff...well, no that's not fair, all schools have been very difficult for my youngest son. So, he's mainstream with a full EHCP. But it's not good enough. There's not enough special needs cases in Portsmouth in any way, shape, or form. Quite honestly he should be in a special needs setting ... The children that might have found themselves having a place at Cliffdale (school for children with complex learning difficulties), generally are in mainstream school with an EHCP, but it's not enough. My son now goes to senior school, there is no one-to-ones at senior school for him. He's really really struggling ... And it wasn't till the other day, my partner said to me, he's basically being babysat at school. And that really hit home to me and I thought, yes, and I'm just thinking great, we got through today, phew, we got through this week, it's been awful but we've got through it. I've only been called in three times and he's only had 15 detentions and four isolations and, you know, he's still there, they haven't expelled him, it's brilliant. And I, sort of, he doesn't actually do any work though. He's done absolutely no learning."

"Then, I was going to the school and they were like, oh, well, he's fine here. I'm like, he's really not, he's masking. He's punching holes in walls, he's smashing windows, he's doing all these things ... And I told them what happened and the SENCO basically turned around and said it was my fault. I should have kept a tighter lead on him basically, not an actual lead on him on the way home and blah, blah. But I was like if he hadn't got to that state at school this wouldn't have happened, it's your issue. And, yes, just since then it just spiralled and he'd be like hiding under the trampoline, he'd be in the cupboard, he'd be under his bed, he wouldn't come out. I asked school to refer to CAMHS, they wouldn't because he's fine. I asked them to sort out MHST (Mental Health Support Team) but again, they said, no, he's fine, it's like an at home problem"

When an appropriate educational setting was finally found, **parents appreciated how the flexibility offered together with access to staff who were knowledgeable and prepared to work with the family** had a positive impact:

“She can’t go to school because she’s a risk, she’s drinking substances and she’s trying to eat the berries off the bushes at the back of school, sticking forks down her throat and attacked people. So she can’t go back to school, so she’s on a dual register now with the medical school and they’re being brilliant, and I think they might actually be able to help her ... At the moment, she’s accepting that the tutor comes round twice a week ... She’s (the tutor) the first person in 4 years of me saying I think my child has autism and I think she’s got a PDA (pathological demand avoidance) profile ... She is the first person who has gone yeah, she’s clearly PDA and here’s this strategy and here’s that strategy and this might work and that might work, and it’s like, well that’s quite nice, that’s quite refreshing, thank you.”

“[Son] goes to a special school now, he was out of education for nearly 18 months, he's not suicidal anymore ... They're really good, he's struggling, so they tailor it to fit him and there's only like 25/30 kids in the whole school, which is what he needs ... Him, me and them have both said we'd rather he go for three lessons and it be a positive three, rather than it be six and it be dire. So, they're really good like that”

Parents were not convinced by the claim that Portsmouth is a **needs-led city**:

“Portsmouth is meant to be a needs-led city, but the reality is, until you get a diagnosis, nobody listens ... It relies on you having a very supportive and good school ... There is definitely an imbalance of power at school. ... School believe that parents are asking for things that they shouldn't have”

“I've been chasing up so much because she needs help and support at school, and although Portsmouth always bang on about how they're a needs-led city, it's a load of crap, excuse my language. But even when you have a diagnosis, like my son, it still doesn't bloody help if you're at the wrong place”

Even where parents were able to identify an appropriate way of accessing education, **providing the resources to do so could be challenging financially**, particularly where children were likely to 'lash out' and damage equipment:

"Now we're in a situation where she hasn't been to school since November. She's dual registered with the medical school, I have no equipment for her home learning ... I don't have the resources and the money to buy her her own laptop ... I can't afford to buy a laptop that gets thrown on the floor next week, so I'm just having to risk mine"

Overall, parents could feel **overwhelmed, alone and unsupported**:

"Nobody will help. I'm going to have to crowdfund money to go to a private psychologist with my child because the local services are all sat in their separate little boxes, gatekeeping their funds ... It's so awful, it's so awful sitting in the middle of all of this. If you are one of those people who've got health problems yourself and your child has got health problems, you're screwed ... There's nobody helping ... the only person who has been on my side ... My adult assisted living support worker is amazing"

"I don't think there's a service that helps, not that I can find"

and some had given up trying to access support:

"I don't even bother phoning them anymore because I'm so sick of just speaking to a different person every time, and trying to explain the story, and trying to say, well she's doing this now and they're like, have you tried this, and you're like, yeah 3 years ago. And you don't have time to go over it all, the energy for it all. They don't know you so they say silly things like just pick your child up when they're trying to run out of the house."

6. Solutions

Participants were invited to suggest solutions to the issues they identified with accessing healthcare, education, employment, housing and social support in Portsmouth. Some of these were specific to the area of interest, such as addressing the issues with access to healthcare, whilst others were more generic.

6.1 Solutions: General issues

People wanted to be ***treated with respect and as individuals***, across different services in Portsmouth, and they wanted to be supported in their daily lives. Examples of this included that there be a ***better understanding of disabilities*** gained through education and training, such as disability awareness training. With regard to accessing public transport, particularly for those using wheelchairs, it was suggested that the council provide help, for example through grants, which would encourage taxi drivers to provide appropriate taxis and, between drivers, to offer availability so that there was a ***wheel-chair accessible taxi available every day***. Where children experienced learning disabilities, there was a requirement for ***groups that meet the needs of young people***, in terms of both social spaces but which also acknowledge the vulnerabilities of this group.

Involving members of the public in decision-making, and asking the views of those with relevant lived experiences, potentially through co-production, were suggested by several participants. They were not sure that those making decisions were aware of the challenges they faced in their day-to-day life and thought it key that their voices were heard.

Information needs to be provided in accessible ways. For many people, this does not include the use of online materials, for example, where individuals were physically unable to use technology or had a poor memory, or where people had low literacy levels. One suggestion was that ***local community centres could offer a combination of services***, including free calls to GP practices or benefits advisors, legal advice or education, healthcare appointments, and someone who was regularly available to signpost individuals to appropriate services:

“So if in your community you're not coping, you could go to the community centre ... And there's someone there who could signpost them to relevant services ... There's a community centre in every one of the estates”

This was supported by others, who suggested that some people could benefit from ***someone acting as their advocate*** to help people get to know more about their rights, particularly with regard to appealing decisions (for example, around benefits):

“Appealing against a decision is something that people take quite seriously and worry about but actually, you know, it shouldn't, it's their right. It's telling people their rights really. When people get very, very low, they just, kind of, accept or there's a tendency to accept it and think they can't do anything about it ... A lot of people need somebody to be an advocate for them”

Providing advice services at the same time and place as where food pantries were held was also recommended as an enabling strategy. Using venues where people could use the cafe first would enable those who lack confidence to see that those offering support are friendly and approachable.

Similarly, **having relevant information available to those accessing the Holiday Activities and Food programme** (HAF) was an enabler for parents to gain relevant information. According to participants, this is already happening in some HAF settings in Portsmouth, and is recommended as good practice.

“That’s a good way of getting information out there is having that, sort of you know, having something available for the children and some information for the parents at the same time”

For those who have children with learning difficulties or autism, it was important that those who interact with them, for example in healthcare or education, **dealt with both the child and the parents**, with a person-centred pathway which adequately meets the needs of both. Examples given included, where dental care was being provided and the child was happy to have a procedure that day, but the parent had existing work commitments and could not go ahead without planning the procedure into their lives. Similar comments were made regarding GP appointments with children who were older teenagers, or for those who care for someone with dementia. Some parents mentioned that there were forms they could complete to act as an advocate for their child, but once again this information was not easy to find. A suggestion was made that this could be a flag on the GP’s system to check with parents around the time children turn 16.

6.2 Solutions: Access to healthcare

Some people were unable to arrange **GP appointments using e-consults**, and these people considered this to be a solution to the challenges they faced in getting access to the GP.

Drop-in clinics were proposed which would enable short appointments for patients with simple concerns (for example, checking for UTIs), which participants described as being used effectively in other parts of the health services. People wanted to be able to **book non-urgent appointments in advance**. They also wanted to be able to book a **timed appointment for a call back**, rather than waiting to be called back at a time or place that might be inconvenient for them. Where people were expected to explain their healthcare needs to a care navigator or receptionist, they wished to do so in private and not in an open

setting. Participants were not aware that they could **request a face-to-face appointment** with their GP, and this needs to be communicated to them.

During appointments, **healthcare staff should encourage the patient to ask questions and to seek confirmation that the patient understands what is being said**. This included using **simple and clear** language, either in person or on the website. Whilst NHS England guidance is that GP surgery websites should have a reading age of 9-11 years old, the suggestion was made to aim for the reading age of a seven or nine year old. The Primary Care Network is encouraged to link with the Learning Disability Partnership Board to facilitate the delivery of such content, enabled by funding from the Hampshire and Isle of Wight Integrated Care Board.

Earlier intervention for those with mental health concerns, together with greater education so that these could be identified earlier, were considered key to avoiding medication and hospitalisation. This included ensuring that **information about the range of services which offered support** - whether through the NHS or charitable organisations - was made available to all, including those whose mental health issues might feel 'small' at present but which could build into a crisis. This would support those who feel that their issues are insignificant to seek help whilst these issues are still manageable. There was additionally a wish for **support for those 'in-between' primary and secondary care** - not ill enough to qualify for psychiatric care, but too ill to be treated through talking therapies. Whilst mention was made of the **Mental Health Hub**, it is clear that this was not known to many participants, and it is recommended that this is better publicised. **Additional link workers** in GP surgeries would help people to navigate where they need to go to get help.

For those with **dementia or caring for people with dementia**, there were a number of recommendations. **Wider education** across the city, including in shops and services, public transport, carers such as those employed by agencies to care for those with dementia, and for family carers is required, particularly regarding the multitude of symptoms caused by dementia. Participants thought that the focus tended to be on memory loss and did not consider, for example, violence or abuse or the person with dementia trying to leave the house inappropriately. There was a need to **provide greater levels of support and a dementia pathway**, which offers support not only for the person with dementia but to their wider family, needs to be implemented in the city. For those experiencing or caring for someone with **early onset dementia**, there was a need to provide support, as it is believed that currently there is nothing available. **Appropriate support** needed to be provided for carers, such as that offered by support groups, but in a setting where the person with

dementia was able to come along. Additionally, people need to be made aware of mechanisms of support such as the sitting service offered by the Carers Centre.

6.3 Solutions: Access to social support

A lot of social support appeared to be found through good luck and word of mouth. A suggestion was made that a **one-stop place might provide information about all services** in the area, for example through an app. More generally, it seemed that **information about the different support groups could proactively be made more widely available**, including through schools and healthcare settings. Such information could include details about what support is available to those leaving hospital and their families, specifically where family members have unexpectedly become carers through injury or ill-health.

Mental health and well-being was one area of concern, where participants were aware that support was available through a multitude of routes, but with no single mechanism for finding out what these routes were. One of the suggestions made was that people might find **support for their mental health through non-traditional routes** such as the library or local soup kitchens. Another was that the **healthy living centre**, which had provided access to healthy food, education around healthy eating, fitness classes and healthcare services, be reopened, with a market selling fruit and vegetables

There was a clear desire among participants to have mechanisms by which they could contact local MPs, other politicians and councillors, and, most importantly, **be sure that their concerns would be acted upon**. People wanted to feel listened to. For several participants, making contact with such people was a challenge itself, and they had to summon the confidence and energy to act - and to have their concerns dismissed or ignored demotivated and distressed them further.

6.4 Solutions: Access to housing

There was an identified need for **housing stock in Portsmouth to reflect the needs of the population**, in terms of disabled access, availability for those who had experienced mental health crises and for single men. Housing needed to address individual's needs and be free from mould and pest infestations.

There was a sense of housing insecurity, with people afraid they might lose their homes or have to relocate even if they or their families were vulnerable. More effort needs to be made to **address housing insecurity**.

6.5 Solutions: Access to education

Parents wished to be sure that, whichever school their child attended, they would receive the **same level of support**, particularly for those with learning disabilities, EHCP and/or autism. They also wanted **more information about next steps**, particularly at the transition from GCSEs to 16-18 provision. There is a need for educational provision locally for those children who are **academically able but which is accessible** to those who have, for example, autism.

6.6 Solutions: Access to employment

Participants wanted employers to **automatically implement support when it was requested**, for example by those with autism or disabilities. They wanted **greater training and support for employers**, including managers, around disability, to enable this.

Participants also suggested that there was a need for society, including employers, to **understand that those with disabilities faced challenges not only in the workplace, but also in getting to work**, for example, requiring a carer to get them dressed, who might be delayed.

There was a wish for employers to be **clear in their advertising about part-time or flexible working** opportunities, particularly if flexible or part-time working was not possible in that role.

6.7 Solutions: Access to health and education for children with Special Educational Needs or Disabilities (SEND)

For those yet to receive a diagnosis of neurodiversity, there needs to be quicker access to healthcare professionals and diagnosis, without judgement and recognising that parents know their children best. There also needs to be **better communication around waiting lists**:

“If you knew it was going to be eight weeks then you're like, okay, I can push through this, I can deal with this for eight weeks or whatever it is. You can see that light at the end of the tunnel ... just give you a bit of hope.”

Parents of children with special educational needs or disabilities wished for a more **joined-up approach to addressing their children's needs**, with recognition that neurodiversity and

mental health issues are often comorbid, requiring coordination between teams. Examples included CAMHS, the ND team and MHST **working together** rather than children being passed from one team to the other, leading to parents being overwhelmed. Contact with one team should prompt **multi-team working**.

There is a requirement for **healthcare support for children in crisis to be made available at the point of need, with a single point of access**. Support for children in crisis should be available **24/7**, parents made it clear that they would access this only when they had tried all of the strategies they already were aware of. For those admitted to hospital whilst in crisis, there is a need for an **appropriate space for children experiencing sensory issues**, specifically a calm, quiet space where children can feel safe and be properly assessed by an appropriately qualified professional. By **training healthcare professionals across the NHS to better understand mental health needs** and the services available, some of these issues could be addressed.

Parents also wished for a range of support for themselves, including respite care, a peer service where they could support one another, restraint training so that they could keep themselves and their child safe (for example, if their child was trying to throw themselves down stairs) and support so that they can teach their vulnerable children life skills to reduce their risk of suicide or exploitation.

7. Key Conclusions

Portsmouth residents experienced barriers when trying to access primary care, including when trying to book an appointment, trying to speak to a healthcare professional in an appropriate time and place or face-to-face, or in physically accessing their GP surgery. Many people have given up trying to seek help and either hoped that they got better, or accessed emergency services when they became seriously unwell.

As a result, local walk-in services such as Emergency Departments and Urgent Treatment Centres were becoming overwhelmed and patients were facing long waits to be seen. For those being discharged home from hospital, there is a need to take account of whether any care available at home is appropriate. Patients requiring the use of specialist equipment to support their movement either in hospital or at home need access to such equipment. There is a lack of specialist services in the local area, and some of the commissioning decisions force patients to travel further than necessary to receive care.

Mental health services were not always accessible and they were considered to be unable to offer adequate and appropriate support to many people. It was often not clear who could

refer someone for mental health support. For those who did manage to gain mental health care, this was often withdrawn. More support was deemed necessary for those with mental health concerns.

Dental care was not accessible for all, with some participants unable to join a patient list and others facing delays and cancellations. As with GP surgeries, not all dentists were practically accessible.

Whilst there were positive comments made about the community spirit in some areas of Portsmouth, local politicians were generally considered to provide little support. Support groups, community centres and similar were valued, though the city lacks accessible public transport, limiting access for some people. Support groups offer an alternative way of supporting mental health and wellbeing, as did churches and other local spaces. However, even those accessing support groups considered there to be a lack of support available in Portsmouth, with a lack of funding creating a challenge for sustainability.

To access housing, individuals needed to be able to access and use online platforms, complete forms online and send and receive emails. There is a lack of appropriate social housing in the city, and, to meet the requirements, families must comply with multiple categories of need. Individuals are not always given enough information about how they might access housing. Others' living conditions can have a significant impact on people's mental health and well-being, particularly in shared accommodation. Landlords do not always take the necessary actions to ensure privately-rented housing is kept in an appropriate state.

Education-related issues needed to be addressed using online mechanisms, creating a barrier to parents. Other barriers to education included the need for parents to not only be willing, but also able to get their children to school. For older children moving from secondary school to college, there were multiple challenges, including access to information about the local provision, the costs involved in travelling to college, and, for those with learning disabilities, issues around keeping children safe when they were only attending college for a few hours per week. This impacted on parents' ability to work, particularly as there was a gap in provision for this group outside of school settings. Financial concerns affected adults seeking to access education and parents who were working, particularly regarding the costs of holiday clubs, and of school trips.

Participants believed that there is a lack of understanding and, indeed, discrimination, among employers regarding disabilities, and that further training is required. Transport options locally did not support those trying to travel to work. Individuals with gaps on their CV, or who had been employed overseas, experienced barriers when seeking employment.

Other barriers included ongoing health issues or being a parent to young children, or children with additional needs. Despite the challenges, people did want to work in ways that were accessible for them.

For parents of children with special educational needs or disabilities, information needs to be provided regarding the support available. Services need to work more closely together, so that children were not passed from one service to another, and children with both special educational needs and mental health concerns needed to be able to access support for both elements. Staff in mainstream schools need better knowledge of autism and additional needs, and the same support should be made available in all schools across the city, including the consistent application of EHCPs and care plans.

Participants proposed a range of solutions to the issues they identified. These are incorporated into the recommendations below.

8. Key Recommendations

Key recommendations from this project include the following:

- Reliance on technology, including telephones, or the internet acts as a barrier for individuals to access healthcare, housing and education. There needs to be recognition of the digital divide and alternatives need to be made available to individuals and families. Information should be provided through a range of media, and not assume that everyone is able to access information on websites. Local community centres could offer a range of services, including provision of information, signposting, advocacy and legal advice, and access to free phones to contact healthcare providers.
- Food pantries and the Holiday Activities and Food (HAF) programme also offer opportunities to provide information, and could be expanded to provide a wider range of services.
- People in Portsmouth should be provided with more opportunities to contribute to local decisions, including a focus on their lived experiences.
- Healthcare in Portsmouth ought to be re-focused to place the individual at the centre, so that access becomes possible for all. This includes acknowledging that not all members of the public have access to or are able to use technology or the internet, and that they are not always available at specific times of the day. Patients need to be informed that they are entitled to seek a face-to-face appointment at

their GP surgery. They should be offered opportunities to book appointments in advance, and request a timed appointment for more urgent callbacks.

- Clear local pathways to be put in place for, and made visible to, those with mental health concerns, including support from local groups, healthcare and charitable organisations, so that individuals are clear how and where they can get support. Consideration should be given to how care can be provided in an ongoing manner and not stopped suddenly. The Mental Health Hub should be publicised more widely.
- Similarly, local pathways should be put in place for those with, or caring for someone with, dementia, with support for early onset dementia a clear concern.
- Dental lists to be expanded through provision of additional dental practices in Portsmouth, ensuring that patients face fewer delays and that all can access dental care.
- Information about support groups in the local area should be made more widely available, including through schools and healthcare settings.
- Individuals felt that there needed to be mechanisms to ensure that local MPs, other politicians and councillors acted upon the concerns of local people.
- More social housing is needed which is able to accommodate the needs of different families. Access to housing should not be restricted to those able to go online to apply for it, and more information about accommodation needs, in paper format, ought to be provided to those who are made homeless.
- Local authorities need to work with local landlords to ensure that living conditions for those in houses of multiple occupation and rentals through the private sector are maintained to an appropriate standard.
- Further information needs to be provided regarding educational provision for young people aged 16-18, and consideration needs to be given to provision for those with learning disabilities whose disability might not allow the same freedoms enjoyed by many young people of this age. Ensuring that schools are accessible to both children and parents will support attendance.
- Consideration should be given to how parents, particularly those earning on lower incomes, might be supported to pay for their children to attend holiday clubs and school trips.

- Employers locally should ensure that their staff training regarding disabilities is up to date, and is applied rigorously. They could consider how roles can be made more flexible, and offered on a part-time basis, to enable more people to join the workforce. Where roles were not flexible or could only be taken up on a full-time basis, this should be made clear to those considering submitting an application.
- For those awaiting a diagnosis of neurodiversity, the barriers to this need to be removed. Communication around waiting times needs to be improved.
- There is a need for joined-up services which place children with special educational needs or disabilities at the centre, where different teams work together for the benefit of the child and parents are able to gain support through a single point of access. Crisis support is required for parents 24 hours per day. A separate, appropriate space should be provided in hospital (not a children's ward) for children with special educational needs or disabilities who are in crisis, which recognises their needs, and enables assessment by an appropriately qualified professional. Parents need to be supported in order to better support their children.

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