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Issue 1

QUALITATIVE RESEARCH REPORT HEALTH & WELLBEING SUPPORT

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EXECUTIVE SUMMARY

- Based on the experiences shared in this research, Newham residents deeply need and desire the type of engagement the Health and Wellbeing Support roles promise to provide. However, these roles have low awareness and can be difficult for both residents and providers to navigate, which may limit their potential impact.

- In fact, the ethos of personalised care is the basic expectation residents have for all care, from any professional, in any service. This aspiration contrasts to the reality of non-personalised, non-care that residents tend to experience, and which can have a significantly negative effect on their health and wellbeing.

- This can create a feeling of being stuck between a rock and hard place, knowing that one needs help, and also knowing that every encounter with the systems providing that help may further damage your wellbeing. The feeling of helplessness may be further amplified by tension between the desire to be independent and self-reliant yet needing to be seen in state of extreme crisis to qualify for services.

- Due to sustained experiences of trauma and mistrust, a significant number of the residents in this study had crafted roles as advocates for themselves, their loved ones, and other people in their communities.

- Given this context, the Health and Wellbeing Support roles sit in an interesting space between and across boundaries in the NHS, local authority, and VCS. This creates tension in balancing the needs of the individual versus the system, the ideals of unconditional care vs self-reliance, and the act of signposting versus servicing. These tensions don't necessarily need to be resolved, in many cases they are intrinsic to the roles, but stakeholders should be aware of them and negotiate them with care when attempting to improve services.

- There are many instances in which these roles are “plastering over cracks” or dealing with fundamental failures or limitations within other parts of the system. Strategic choices and constraints far outside the purview of these roles determine the balance of attention and resource directed towards prevention vs cure, acute vs chronic need, navigation vs delivery, understanding vs action. However, this situational reality does impact on the relationship between health and wellbeing support roles and the residents they serve.

- Specifically, all roles expressed significant issues getting adequate support from adult social care and housing. They understand the extreme pressure on these services and the high bar for eligibility this creates, but also experience frustration in leaving patients and residents in unhealthy or potentially dangerous situations over long periods of time. However, these roles tend to share a strong “there is always a way” mentality, a reluctance to consider a situation hopeless or unsolvable, and a creative and flexible mindset in approaching them.

- From the interviews, it seems unclear whether Health and Wellbeing Support is seen as universal service, or a special resource for a limited population. Certainly, all of the residents interviewed could have benefited from support from the roles. All human beings require care at some point in our lives that is simply beyond the resources of the individual or household. All human beings are capable of and find meaning in providing care for the people around us. The complication is that this is a constantly shifting landscape, and people need what they need, at the moment they need it, and are both novices and experts in their needs and the resources available to them, at the same time.

- This implies that the need for Health and Wellbeing Support and the task of communication and awareness around this type of support is continuous and ever evolving. In particular, residents need very clear description of the support they can receive from health and wellbeing support roles, at multiple touchpoints, in the context of their daily lives and access of other services, and ideally a simple, centralised self-referral system that doesn’t require them to choose between 6+ roles in order to ask for help.

INTRODUCTION

ABOUT THIS DOCUMENT

This report documents descriptive analysis and anonymised data from a series of 1:1 interviews and group discussions conducted during August - September 2022, on behalf of Newham Public Health.

This qualitative research is one strand of data collection and analysis, exploring experiences of health and wellbeing support, personalised care, and social prescribing within the London Borough of Newham, provided across NHS and council organisations.

Therefore, **this report is intended a working resource** for further analysis and reporting, providing narrative description of the experiences related to the researcher, as well as patterns and reflections that cut across the data.

The overall objectives of the study this report contributes to are to better understand:

- the current offering,
- experiences of service users, individual providers, and other stakeholders
- areas where improvements could be made.

For more information on the overall objectives and context and deliverables for this project, please contact Ysabella.Hawkings@newham.gov.uk.

METHOD AND SAMPLE

This qualitative research consisted of:

- Twenty-three 1:1 interviews
- Three focus group discussions
- Attendance at two existing stakeholder meetings

People were invited to participate by Newham Public Health, and self-scheduled via a Calendly link. Participants had the choice of meeting in person, via Zoom or Teams. One in-home interview was requested and completed; the rest were conducted online.

Residents were eligible for reward and recognition compensation of £11.05, via bank transfer or shopping vouchers. The researcher helped participants complete and submit the forms.

All discussions were conducted under the GDPR data policy of the researcher (available upon request from julie@juliejenson.com), and participants were assured that their personally identifying information would be kept confidential and their input anonymised this report.

Participants were informed that the researcher is an independent contractor without any visibility into, or ability to impact, their own service provision or employment.

1:1 Interviews

Each interview lasted 60 minutes, and included a discussion of the individual's situation, their emotional experience of accessing or providing services, a more detailed examination of the journey of receiving or providing support, their mental models and understanding of the services and roles being explored, and a discussion of the impact of social determinants on health and wellbeing.

A series of emotional response cards calibrated to the Geneva Emotional Wheel were used with many participants to help expose more unconscious thoughts and feelings. Screen sharing was used whenever possible to work together in structured workbooks for discussion and reflection. Discussion guides and workbooks are included in the Annex.

The discussion guide was used flexibly, in order to ensure that each discussion worked to understand the person's own subjective experience, in their own terms, to the largest extent possible. This means that not all participants provided homogenous data.

Across the 23 interviews, participants included

- 11 residents
- 10 health and wellbeing support workers
    - 1 community connector
    - 2 community neighbourhood link workers
    - 2 care navigators
    - 3 care coordinators
    - 1 health and wellbeing coach
    - 1 social prescribing link worker
- 2 other NHS or council staff
    - 1 hospital doctor
    - 1 support worker

Focus Groups

Each staff focus group lasted 90 minutes, and each resident focus group lasted 2 hours. The discussions were structured as a joint "workshop" experience, focused on constructing a shared view of the system in which health and wellbeing support is provided and areas for improvement.

Participants were invited to sign up for a 1:1 interview if they wanted to discuss their personal experiences and issues in more detail. In total, 1 staff member and 3 residents chose to participate in both activities.

Across the focus groups, participants included

- 6 residents
- 3 health and wellbeing support workers
    - 1 community connector
    - 2 community neighbourhood link workers
- 3 staff members of voluntary and community service organisations

All focus groups took place online. An in-person residents' group was offered, but did not take place, as participants cancelled due to health issues or other commitments.

Attendance at Existing Meetings

The researcher attending two existing meetings: The Newham Autism and Support Group and the Personalised Care Forum.

At the Autism Support Group, formal interviews and activities were not conducted, but the researcher observed the group dynamics, listened to stories related to health and wellbeing support, and invited people to take part in a 1:1 interview. 4 residents and carers followed up.

At the Personalised Care Forum, a few questions were asked to clarify or validate key themes in this report, prior to finalisation.

Resident Profiles

Of the 14 residents and carers who participated across interviews and focus groups.

- 3 were men, 11 were women
- 1: 20-29, 4: 30-39, 2: 40-49, 4: 50-59, 3: 60+
- 2 White British, 1 White Other, 2 Black African, 2 Black Caribbean, 1 Asian Bangladeshi, 3 Asian Indian, 1 Asian Pakistani, 1 Asian Other, 1 Mixed White and Black African
- 3 diagnosed with autism, 2 carers with children awaiting diagnosis
- 3 with physical disabilities which impact their mobility and require care
- 3 with mental health issues that significantly impact daily life
- 4 with substantial caring responsibilities for family members

DISCLAIMERS AND LIMITATIONS

Participation in this study was limited to people public health can reach via channels such as the Council co-production team, Council communications and resident newsletters, and professional networks.

All interviews were conducted in English, by a white woman with an American accent.

The original research plan included 6 observations with health and wellbeing support workers in the context of their daily practice. Nobody volunteered for an observation. This would be useful data in further exploration, and if possible, the barriers to participation should be identified and negotiated in future studies. For example: issues of consent, confidentiality, time required, and power dynamic of employer relations.

The sample did not include any GPs or adult care social workers. As the health and wellbeing support roles act as a buffer for these elements of the system, this is a crucial element for further exploration.

Quotes have been edited for brevity, clarity and to remove filler words.

THEMES AND FINDINGS

MENTAL MODELS AND UNDERSTANDING OF HEALTH AND WELLBEING SUPPORT

A substantial amount of time with each participant was spent understanding how they understand health and wellbeing support. Which parts of the health and wellbeing support are visible to them? How do they see it? What do they assume about it? What myths and misconceptions arise? What do the core concepts being discussed actually mean to people?

Summary of this section:

- People don’t separate the idea of clinical and non-clinical health and wellbeing support and would like to be treated as a “whole person” across all of their mental and physical health needs.
- In reality, people actually function within “health and wellbeing units,” such as a family or household, where issues for one person significantly impact on the others.
- Personalised care is a powerful concept that people aspire to across all of their services. The term itself is well understood by professionals, but residents often confuse it with other types of service, particularly those provided by adult social care.
- The names of the individual Health and Wellbeing Support roles are easy to confuse and provide very little insight into their specialist positions or differences between them. There is universal confusion amongst residents, other stakeholders, and people working within the roles themselves.
- The roles share many key values and a common approach, while holding different expertise. These overlaps and boundaries could be better articulated in order to increase collaboration and reduce overwhelm.

Health and Wellbeing Support

As a descriptive term, “Health and Wellbeing” has many different meanings for different people, which may not adequately represent the type of support these roles provide.

Many residents specifically defined this as their physical and mental health and safety and the statutory care that should be provided by NHS clinicians or the council. In interviews, they would very much want to discuss the issues they encountered working with GPs, hospitals, mental health services and social workers. Particularly, the conversation would gravitate towards difficulty getting appointments, delays in diagnosis, and failures of staff to deal adequately and professionally with their own needs and those of their loved ones.

Almost every resident described the need to become an advocate, fighting at every interaction to ensure the professionals had correct information, did what they had said they would do, and didn't make mistakes in prescription or service delivery. This became an extreme burden, both on time and emotions, which created its own negative spiral of mental and physical ill health.

> *I'm an expert. By experience in the condition. I'm 54 now, but I know for 52 years that I've been struggling. So why is it that when we're turning around and telling them, this is an issue, this is constantly happening, it doesn't get changed. We're giving you that insight, we're that this is happening, and they're still not taking any notice of it. I don't trust. I have no trust. That's a constant road that we're constantly going down on. Yeah. And it's not as easy as going through a maze. We would be going round and round in that maze for weeks and months and years at a time. It's not a straight line.*

There was an extreme tension between knowing that one needed care, and also knowing that every encounter within the systems providing that care further damaged their own health and wellbeing. And a tension between the desire to be independent and self-reliant yet needing to be seen in state of extreme crisis to qualify for services.

> *[From a VCS] We know that with communities that we work with, that if they experience a poor service or discrimination, then then they feel that that is reflective of the healthcare system as a whole. And so people may self-prescribe and source things themselves, and not want to have involvement with healthcare professionals because of some of the issues that have experienced. So that might be things like institutional racism, maybe transphobia. A good example of that, there was a report that came out around the belief that black women don't experience pain as much as white women. And therefore, they're less likely to be given an epidural. And as a result of that, black women are more likely to suffer complications during pregnancy, because they may not seek out maternity services. I think there's a lot of factors that then mean certain communities or people might not even actually be seeking out those services anymore. And then becomes a self-fulfilling prophecy and complicates the issue.*

For people working within the roles, they largely defined themselves as providing non-clinical and non-statutory care – so in some ways the opposite of what residents wanted to discuss in the research. Instead, they saw their roles as preventing people from needing that more expensive, long-term, specialist care. Or as one provider described it, "keeping people in the front garden rather than coming in the door."

At the other extreme, health and wellbeing was associated with the cultural codes of "wellness" and things like gyms, leisure centres, spas, mindfulness, holistic healing and healthy eating. Things that are both a luxury in the context of survival mode, but also essential self-care to keep functioning in states of extreme stress, and that can be out of reach financially for most of the residents we spoke to. In some cases, the roles touch on these aspects quite explicitly (i.e., health and wellbeing coaches) or more tangentially (for example, a link worker helping a resident find a walking group). In other cases, these fall far outside the council services, for example working with naturopaths or Chinese medicine providers to fill gaps in care from the NHS.

> *[From a VCS] For some of our clients, it's sometimes holistic therapies. It's not necessarily sort of traditional health care services. I think it's something that gives people their own say, an element of respite. I think actually, these are really valid healthcare service that sustain people living well.*

There isn't a clear, existing alternative term to "health and wellbeing support." Perhaps a more accurate term would be "whole person health." This reflects residents' strong desires to be seen as a person, rather than a series of problems, and also the interconnected reality of physical, mental, financial, and social wellbeing that these roles attempt to navigate and that people intrinsically understand about their own health.

A further build on this would be "whole household health," acknowledging that a family unit is only as well as the sickest link, and that the individuals' needs are often overlapping (i.e., shared housing), causal (i.e., shared genetics and lifestyle), and inter-dependent (i.e., domestic violence, stress from caring for a sick child, intergenerational trauma). Many residents expressed a desire for practitioners to support the domestic ecosystem together, rather than as individuals.

Personalised Care

Within the health and wellbeing roles, "personalised care" is a well-understood and shared concept, largely defined as care which is centred around the patient or resident's own needs, desires, goals and capabilities.

All of the health and wellbeing providers in this study understand themselves to be providing personalised care. Some of them also describe themselves as working in the "social model" as opposed to the "medical model." More colloquially, they might describe themselves as working outside "target-driven" and "tick-box" models vs other parts of the NHS and social care systems.

For residents and others outside the role, the term is less well defined and often confused with other concepts. In particular, for residents with more significant needs, it is confused with "personal care" within the adult social care setting, for example help with bathing or a personal care assistant who helps manage activities of daily life. Or a personal care budget they manage to fulfil these needs.

However, all participants in the study **desire the concept** of personalised care, as defined by the health and wellbeing support roles.

In fact, this is the basic expectation and aspiration of all care, from any professional, in any service, in contrast to the reality and disappointment of the non-personalised, non-care that they tend to experience.

> *I get offered the things I don't need and don't get offered what I do. and then they say I refuse the service and make it look like I'm the bad person. I want the freedom to choose. I want someone in my corner, a champion, an advocate. I want my family to be safe, living in a comfortable, clean accommodation and get the service that we rightfully deserve to help me and my children's physical and mental health to get better.*

> *They speak about patient-centred care, but there isn't any, in any way, you cannot ask for anything. When they offer you this, when they accept your application [for adult social care], you need to go through a sort of assessment. But the report is a copy and paste of other people's reports. It's not tailored. It's just their assumptions and biases about what certain people are like. It said my in-laws spend all day in front of the TV. We don't even have a TV.*

> *I think that what would benefit me, what would kind of make me feel better, is sometimes being given what I wanted, instead of others saying, Oh, this is what you need.*

The Roles – for Residents

For the most part, residents had no spontaneous knowledge or recognition of the six health and wellbeing support roles, by name. Several had experience using a social prescriber. None of the participants had direct experience that they could recall of a community connector, community neighbourhood link worker, care navigator or care coordinator. One may have had experience of a health and wellbeing coach, but the description sounded more like a personal trainer based at a leisure centre within a standardised 12-week group programme.

There was a lot of confusion about the relationship of names like "care navigator" or "care coordinator" and that of the social worker. And also, the sense that they are their own care coordinator. That navigating support and services becomes an extra job they take on in order to ensure their needs, or those of their loved ones, are met appropriately.

> *"Navigator? Would that be the same as a social worker? Community Connector? The social worker helped devise my care package, and in that there was an element of me being able to get out into the community. Coordinator? No, unless I put myself in that role."*

Residents who had access to and “clicked” with a social prescriber found it a very useful experience, although limited in terms of time and scope.

> *She listened well, made sure I was ok, explained the situation and provided follow ups, and many useful links, felt like my family aunt. Consoling, and provided what to do in simple order instructions. Understood my disabilities, was gentle and kind. I will miss her. And I hope for the best for her future. And she took a lot off my shoulders. And she was quick too. She got things done. She was limited to what she could help with and had limited time to give, but she tried to help me as much as she possibly could.*

The Roles – In Their Own Words

People working the roles had a clear understanding of their own scope and the parts of the system they directly connect into on a day-to-day basis. They are able to articulate their position in relation to the system as well as to the patient or resident, and the boundaries of where their support begins and ends.

This clarity is explicitly acknowledged to be essential in managing caseloads successfully, but also managing one’s own mental and emotional health within a stressful and demanding context. In cases where roles weren’t clear at the beginning of the job (for example, because the role was new or they were new to the role), establishing these boundaries was the first and most important task to be effective.

Across all of the roles, there is a clear focus on working within the patient or resident’s own situation, goals and empowering them to manage their own care over time. There is also an element of extended time, being able to take 30 or 60 minutes with a person instead the 8 minutes a GP might have. And the universal value of just listening and allowing people to vent, while still encouraging a bias in their behaviour from words to action.

A Community Connector:

> *And so, with my job as a community connector, we've been seconded by the National Health Service, the NHS, under the Mental Health Department, so we work under the community integrated mental health service. We’ve got the clinical side, and then we've got the non-clinical side, which is us, who are in the community. I come in to help create community spaces, to find activities for people to do in the community and trying to empower people really to take ownership of their health and, and also make people realise that, in most cases, the solutions are with them, instead of running to the doctors or heavily relying on medication or just focusing really on medical practices to help them. We encourage them to seek support from each other, create support groups with each other, and, find help from themselves. But we work hand in hand with the clinical side as well. And it's a very new role in Newham. We're still making baby steps, we're still changing. It's*

> *a job that requires a lot of change, a lot of flexibility. Thinking outside the box, that's one thing I'm grateful for.*

A Social Prescriber:

> *I was the first social prescriber within my PCN. They were moving towards the idea of personalised care and having different roles, but it hadn't been established yet. So, I could do research in other boroughs and shape the job a bit. I say that I work in a doctor's surgery, but the main idea of the role is supporting patients with non-medical needs and focusing on improving their health and wellbeing and empowering them to take control of their wellbeing. For example, you're filling out forms or finding out their financial entitlement, seeing what support they can get or housing. Or if they were isolated, what community groups they can get involved with. These are some of the reasons why patients come see me, and I support them.*

A Care Navigator:

> *I work with people who have got long term conditions. So people who are at risk of being admitted to hospital. We try to prevent unplanned hospital admissions. So, I'm the central point of contact for those people who have been identified as people who might need or benefit from the services. And those include the carers and their families. And we signpost patients to different health services that will benefit them and enhance the quality of quality of life. We provide information, we advocate for them, support them in any way. The aim is to improve health outcomes and promote self-management where possible.*

A Care Coordinator:

> *If you see my office here, it looks like a detective job, to be honest. I have a wall full of hundreds of pieces of information to gather a directory, how to direct people. As a care coordinator, my role will be to monitor and coordinate patient's treatment plans. And educate them about the condition they have. Maybe also connect them with the right services and service providers evaluate their progress. Monitor, coordinate, educate, connect, and evaluate. If I don't know something, I say, I will do some research, Mr. Smith, and let me set up follow up with you in two weeks' time. Let's see what they find. It's also being a rock for these people. They are so stressed, for whatever reason, that being there for them is giving the space to talk. To tell you what matters to them. Sometimes I'm the first person who ever asked him, 'How are you today?' And yeah, I love to do this.*

A Health and Wellbeing Coach:

> *Health coaching is something very new. It's not new but now it's been officially created as a role. Coaching is about having, meaningful and*

> *deep conversations with our patients and understanding what they want. It's not the same as counselling or therapy. Coaching is about understanding where they're at, tackling their limiting beliefs, looking at their mindset, meeting them there. It's different from me as a nutritionist saying to them 'eat this eat that' -- everybody knows what needs to be done. It's all on the net, there are programmes run by the councils, the surgeries, the community centres every month. But we see the same patients coming back again and again. So, what will make a sustainable change? It's about sitting with a person for half an hour to an hour, eliciting their story, what are the wider determinants of health? Where are the health inequalities getting to them? If someone's got homelessness, or unemployment, or mental health issues, and I sit there and write them a diet, and I say, 'Oh, do you know you need to eat X, Y, and Zed or exercise five times a week, 30 minutes?' It's good advice. And they might do it may not do it. But because of all the other factors, they don't do it. We refer to them as referral fails, people drop out. And then it's a huge loss, you know, to the NHS, to the local authorities. So how do we help make a sustainable change? And NHS England believes that it's through coaching, and through social prescribing.*

A Community Neighbourhood Link Worker:

> *It's developed very organically in reaction to resident's needs. And now as a team, the community neighbourhood link workers focus primarily on reducing loneliness and isolation and reducing the impact that disability and being isolated and not having connections has on health and wellbeing. It's totally from a person's perspective, really, and what their goals are, what they want to achieve, however small or large those things are, and what's blocking them. How do we remove those barriers. But also, to ensure that they keep control of things, that it's at their pace, and that they they're enabled, rather than it's all done for them, so that they can learn and adapt and evolve.*

The Other Roles – for People working in the Roles

Unsurprisingly, managers within the roles had a better "birds eye" view of how things connect together and, also expressed a desire for more clarity amongst them.

Amongst people working in the roles, there tended to be a lot of confusion between care navigators and care coordinators, and a sense that they were probably the same, just working out of different contexts.

Social prescribers were relatively well recognised by other roles, with a sense that they were well established (had been around for a while), well positioned (known to be working out of GPs) and well bounded (will work with people for a limited period of time on one or two things). They also have a more distinctive name vs the other roles.

Community neighbourhood link workers were well known to some other roles, as a key collaborator within a geographic area in partnership with local GP practices. They seem to be better understood and known as a person ("I work with Jane a lot, she's great and knows everything going on") rather than as a role. They would sometimes be "misnamed" as community connectors.

Community connectors has limited recognition. For those that are familiar, they are most distinguished by their expertise in mental health. For those who hadn't encountered them yet, they existed in a blur with all the other generic "c" words.

Health and wellbeing coaches were perceived to be a bit "what it says on the tin" and assumed to mostly work on diet and exercise issues. The full scope of the coaching ethos and practice they bring (versus "just" being a nutritionist or personal trainer) wasn't appreciated or articulated by anyone outside of the role. They are known to be new and not widely available.

Across all the roles, people perceived that they were a bit muddled and confused, and that they all do very similar work in slightly different contexts.

However, the specialisation across roles is crucial and valued– for example, it's useful to have some people positioned with the GP practice, some in the libraries, some in the hospitals, and able to "work" that part of the system more proficiently and share that expertise with other roles when appropriate.

> *I think that it's very good a lot of things overlap with our roles. It doesn't matter, there is a need for both. There is a need for people to be out there in the community as neighbourhood link workers. And within the surgery, we have so much need, that we don't need to put it all in one basket. It's good too, because like I said earlier, people you find in surgeries you may not find in community, they are always going to the doctor. People who are in the community may not have been to the doctor for five years, but they're happy to talk to a link worker.*

In particular, it seems important to maintain a network of intersecting expertise in:

- specific geographic regions and neighbourhoods
- specific contexts of work and position within system
- specific areas of practice and knowledge
- specific individual patients

However, it's problematic when residents are engaging with too many similar support roles at the same time, when referrals go to the wrong place, or when people working in the roles don't know of an individual or service that would be useful to collaborate with or provide help their patient/resident needs.

Although fully renaming the roles probably isn't practical or useful within systems where they have started to establish some knowledge and credibility, it would be good to get more specificity into the names and drop some of the blurry words where possible. For example, "Mental Health Community Connector" or "Complex Care

Coordinator" add a bit more clarity while keeping the vocabulary that has been established and institutionalised.

It may also be useful to designate for individual patients or residents, the role and practitioner who is acting as the central contact or key advocate at a particular point in time. So that if other referrals come in, they can be cross-referenced and coordinated, and so that if referrals out to the other roles are made, they can be tracked and followed up on. A hub-and-spoke type of system, where only one person is the lead on health and wellbeing support at any one time.

The Roles – for other staff

VCS staff have some sense that these roles refer into their services. But they don't refer back to them or understand them well enough to work with them in close collaboration.

> *I asked my team last week. We get some referrals from link workers for our services, but the team didn't recognise the other titles and I am not sure they would be able to remember them.*

They also had some familiarity with social prescribing as a key concept and felt the name was the most distinctive.

> *I feel like the only the one that stands out for me more is social prescribing, because I sort of understand that as more of a five ways to wellbeing, so kind of like physical exercise, mental health and other ways of engaging people in activities that might reduce things like social isolation and poor health outcomes. I get the premise of them.*

But there was also some residual sense that social prescribing had been mis-sold to the sector in the early days, as something that would be paid for to generate income.

> *I think it's quite interesting to see how the concept of social prescribing has changed. I think originally, some members of the voluntary sector were under the apprehension or possibly misapprehension that social prescribing services would be paid for. And that doesn't seem to be on the table now... It would be nice if some money came with the person when they were referred. I think, the original model, or at least at one point, the idea was that there'll be a pot of money that would come with the person, but obviously, within Newham that doesn't work. And, you know, I understand what budgets are tight, but...*

And that they would like to understand more about the training and scope of the roles and how they intersect with other clinical and statutory professionals.

> *My team felt that the referrals they received from community neighbourhood link workers were good quality referrals and that that the referrals were generally accepted. I think there's a little bit of frustration about the bureaucracy, of needing to understand all these roles. And we work with social workers and mental health, so we would quite like to know what professional qualifications of any of these*

> *people have. I know, some do have. But you know, what actually, is their role? What are the boundaries of their role? When do they hand over to other members, professional members of the health services at whatever level? And what does success look like for them?*

> *Who's holding the personalised care plan is more the question. Who's the hub of that plan, and who are the spokes are the pieces that that move into it?*

The number of interviews with other staff within the NHS and council was extremely small and should be interpreted with caution. However, the theme of blurry confusion across roles continued to play out. In some cases, staff had quite firm sense that they understood a particular role, but the actual description they provided was for a different role, or a historic use of the term, rather than the current scope and usage.

> *All those roles, in my opinion, both personal and professional, they all overlap. When I was seconded to work in the primary care network, I found it very confusing at times, because I would sit down and say, so what are you supposed to do? And then what am I supposed to do? Because we don't want to overlap. But not only that, we don't want to overload the residents as well. Because if we as professionals get confused, then what are the residents going to do? It's about overlapping and confusion.*

> *To me, as someone that has had mental health challenges for like, 10 years, I would be fine with accessing a Mental Health Connector, not a community connector. I think sometimes we've got to name it for what it is. So we know it's something that's for us.*

ACCESS, COLLABORATION AND DISCHARGE

With each role, the researcher dived deeper into the experience of working with individual patients and residents, from referral to conclusion.

Summary of this section:

- The roles are largely reliant on the clinicians and other professionals around them for appropriate referrals. Although some of the services have a self-referral option, direct access is rare.
- Many clinicians are hesitant to open difficult conversations with patients, knowing they don't have the time or knowledge to resolve them. This can limit referrals of people in need of Health and Wellbeing Support because the need is never expressed.
- The different roles appear to have different levels of autonomy over how long they spend with patients over what period of time. There may need to be a clearer and seamless escalation path defined for residents who have more complex needs than a specific role is allowed to provide.
- People in the roles tend to feel well-supported in their work and feel they know where to turn for help.
- People in the roles tend to feel confident that they leave their patients in a better place than they started, and easily see the impact that they make.
- Referrals and resolution of adult social care and housing issues prove to be a consistent source of frustration.

The point of entry is probably the biggest differentiator between the roles: where their referrals come from defines their orientation towards the system and the type of patient or resident they are working with.

Most of the roles are satisfied with the number and quality of referrals they get. However, there is a sense that clinicians have low awareness of the roles, as well as an aversion to asking the questions that reveal a need, for fear of opening a "can of worms" during limited consultation time. There is a sense that the roles are new, and still settling in, but that momentum is building, and that this way of working is a strategic priority of the NHS in order to manage capacity moving forward.

Once engaged, the process across roles looks more similar: a period of assessment, expectation setting, and goal definition; a period of determining what services are available to help, and more intensive hand holding and coaching to help people engage with those services; followed by a gentle weaning of support towards independence and individual resilience.

However, there are differences in the length and type of support provided. Some roles express more autonomy over how long the engagement should last and what success looks like. A degree of "we will do what it takes and help until the goals are met – I'm their advocate and hold their case until I'm satisfied it's not needed." Others have a more set engagement window, and a clear ethos of "I'll do what I can while I can, and then I have move onto the next person, so everyone gets their turn."

Of the roles, the care navigators and community connectors described the highest levels of autonomy and involvement in the idea of treatment and the complexity of the cases they take on. The care coordinators and health and wellness coaches appeared more in the middle. While the social prescribers and community neighbourhood link workers seemed to have most limited scope. *Please note,* this is the researcher's interpretation of the language and sense of power and authority people expressed within a limited data set, not necessarily the objective reality of a job description or skill set.

For those working within the NHS, the MDT appears to act as an important point of coordination and collaboration. Many people working in the roles also spoke about the significant role of their line manager in allocating cases, managing workload, and ensuring their time is spent in the right way.

When people working in the roles are unsure of where to go or find the help needed, they rely on their managers, peer support and trusted allies in the network.

There is a strong "there is always a way" mentality across roles and a reluctance to consider a situation hopeless or unsolvable.

> *And obviously the NHS is doing its best. And you know, there's a huge cost involved. And with the threshold so high, people are not eligible for lots of things. So, if we can help them by being really creative, and using our charities, like AgeUK. And often they have the support network around them, but they just can't see it. So you ask prompting questions like, but how would you do this? Or who's around you? Or what do you mean you don't have anyone around? Oh, yes, there's a neighbour who says hello. I am a person who doesn't believe in giving up. And I just think that as a clinician, if you can just be a bit creative, you can always find the solution. So if they're not eligible, they don't meet the threshold. You can use the charities, volunteers, there's so much out there. And I think, to be fair, we're in a great country. And there's lots of resources and there's lots of support and help. And I think within the ethnic communities, people don't know about the resources. They don't know about befrienders, they don't know about the charities, people often think Age UK is just the elderly, where it's for anybody above 18. If you're not eligible for carers, then there's volunteers. You have to be very vigilant and know what's going on. You have to be very aware of the community as well. And I think that often this middle path is non-existent. It's a grey area. Yeah, that's where I feel like that's where we are lucky. Because as a care coordinator, you can kind rescue someone, you can find a way you can be creative. I'm trying to build my own little folder of all the different resources in Newham. I'm trying to use mosques, the temples, the churches that the volunteers, the army, wherever we can get help. So even if people are*

> *not eligible and they don't meet threshold, they can still get referred on. They get help.*

All roles expressed significant issues getting adequate support from adult social care and housing. They understand the extreme pressure on these services and the high bar for eligibility this creates. They actively work with their patients and residents to set appropriate expectations for the support they may be able to receive and explore other options. However, they are often left with significant issues that impact health and wellbeing that can't be resolved within their time working with the person.

> *If you refer the patient to adult social care, the waiting list takes months and months and months sometimes they are on the waiting list for ever, waiting for a social worker to be allocated.*

> *I do find when I do send patients off, they get referral, they have an assessment, I find there's a lot of confusion when that assessment takes place. I'm not sure how that is explained. But I think residents that maybe English is not their first language, it gets really confusing for them. So, they just said don't want it because they feel like they're going to have to pay for it. Because I've had a few that have called back and they'll say, Okay, I've seen you've had your assessment, how did it go? And they just say, No, I didn't want it because they told me I had to pay. I've had a few of those incidents, I made sure I fully explain what is going to be expected when you get the assessment, you may be eligible, you might not be eligible, if you are eligible, there's going be a financial compartment and you might have to pay. It's making them aware that they don't do cooking, they don't do cleaning, only you have to self-fund that going down the route of like maybe disability benefits if you're entitled to just kind of making sure that they're aware, sometimes it has worked, but sometimes it's still a bit confused. I'm not sure how some of the social workers are explaining things to them is sometimes it can be very confusing, and all the assessments are quite long as well. It's quite a long assessment that they have. We do find this quite a bit of confusion, a lot of time on the assessment takes place.*

> *We get a high level of referrals for housing. And some patients, it's affecting their mental wellbeing, but they are managing as best they can, and we can work with them on other things. But then you get those patients where the housing is really, really detrimental. And these patients can be very difficult, because we're very limited on what we can do in the housing area. And we get so many housing referrals. So*

yes, it's quite difficult, where they can't even engage in any other activity. It's literally just housing, and just kind of trying to manage expectations, let them know that housing is a long-term goal, and what we can and what we can't do, it can be very, very difficult.

It's a nightmare. Because the thresholds are so high. And social workers are so stressed out that you can't even get hold of a social worker, it's like, because obviously, they have a lot of people on their caseload. With my assessments, now, I know, the first thing I should do is message the social worker, so that even if it takes them 10 days, I start by contacting them on the first day, because you might not get a response until the 10th day. And then there's this thing about, oh, you're not eligible, the thresholds are too high. And then there's the housing crisis, okay, we have a housing crisis in England. But you know, for God's sake, there's patients that need supported housing, and you're not looking at the whole situation. And, you know, I've got patients who are 90 years old, you can't expect them to stay on their own like that. But they just kind of sometimes I feel like they just go with their threshold and their criteria and their tick box system. These are human beings, it's not about a tick box system, you need to look beyond that. And I think like, a lot of things are messing up with social work, because it's just everybody's so scared about their accountability, that sometimes you're missing the point, you're missing the point that some people do need to have that support. And some people, okay, they can manage at home, but there are some patients that really are housebound, and they're not coping, and I sometimes go home worrying about them thinking, wow, how do they how do they manage…

RELATIONSHIP MODELS

Across the relationship between residents and the different professionals they encounter, some themes emerge.

Summary of this section:

- The term “advocate” is used by both residents and Health and Wellbeing Support roles to describe themselves. This highlights a consistent need for people to have their interests represented and championed while navigating NHS and council services.
- Personalised care isn’t just about the patient or resident. It is delivered in the relationship between two individual people, and that element of human empathy and trust is difficult to transfer to systems or organisations.
- In the course of advocating for themselves or loved ones, residents are often required to challenge the knowledge and behaviours of the professionals they interact with. This can create a sense of being labelled as a troublemaker and a concern that professionals are sharing damaging or incorrect information between themselves in order to protect each other. Health and Wellbeing Support roles may have an opportunity to bring people into shared ownership and decision making over their data.

Advocacy, agency and changing things for better

Some of the roles explicitly use the word “advocate” when describing their work. When probed, they generally mean acting as the voice of the resident or patient in situations where they are not present or don’t have access.

> *We've been able to help with lots of things and obviously, with the doctor really busy, there's been a few blips, or I don't know if it's, I wouldn't say mistakes, but a few things that haven't been quite right, which we have been able to point out because we have access to EMIS in Rio, we can look at the patient's history. And we have the time to really look at the history before we make the initial phone call. So I probably pointed out a lot of things about the patients that people have been quite surprised about. Patients can often get boxed into a certain category. And that's not the case. I feel as someone who advocates for the patients, I have to try to be really confident and be really certain. In the MDT meetings I have been like the voice of the patients, which was a bit challenging to begin with, but I think we're really slowly getting there. There's lots of work to be done.*

Residents also use the word advocate, in terms of describing the work they need to do to manage their own care or that of their loved ones. However, in this instance, it means being the only one who has their own best interests at heart and who can be trusted.

Due to these repeated experiences of trauma and mistrust, a significant number of the residents in this study had crafted roles for themselves as advocates for other people in their communities.

This is partly an effect of the self-selected nature of participation – these were people already engaged and eager to make change. However, it also reveals a skill set and mindset that can emerge out of lived experience – people want to make sure their problems don't happen to other people and that their voices can make a difference. This includes a mastery of the institutional language and the creation of community and voluntary roles that help fill the gaps and give a sense of meaning and purpose to their lives. Many of these people still need significant care and support themselves, but that doesn't mean they aren't also able to provide care and support to others.

> *Well, I've also cared for people in the past. I also run a voluntary group. When I worked, I had private medical insurance. I never saw what it was like to have to go into the NHS to get treatment. When I did, I was flabbergasted I was just in shock. I had many doors shut in my face, because I carry myself well, they will say you haven't got a mental health illness. If you can be a manager or you can run a company, how can you have a mental health illness? Oh, the discrimination and stigma around it is disgusting. And still in the very services that it's not meant to be in. So, I have been trying to change things for a very, very long time. But once again, I feel I still feel we're not listened to, we're not believed. And that's one thing from my childhood, I can't deal with is being told that I'm a liar. And they may not use those words. But when you still have, in my opinion, when you still got the same member of staff having the same attitude, or you still got the same service doing the same thing. In my opinion, there's a saying the real definition of insanity is doing the same thing over and over again and expecting a different result. Now, this is what they keep doing. They're doing the same stuff over and over and there's nothing changing.*

Interestingly, a number of people within the health and wellbeing roles reported a similar connection to their own personal and professional journey.

> *I'm living proof that you can change your life and learn how manage your condition. Then I thought, I would like to help people do the same. I came across a job for social prescribers and care coordinators. And I was like, wow, what is this? So now I know I'm helping the right people because they are looking for help. My help is not going wasted. Before I was helping, helping, and no one was listening. Now people say I want to lose weight, or I have struggled with this. So I say, okay, let's explore this. Let's see where we can start. My professional journey came from my personal growth and personal changes.*

> *Coming from a background where I once myself was quite vulnerable. And I needed it, I needed support, and I got the support, and I, you know, managed to get my degree and get to where I am now. So I feel like these people made a huge difference in my life. And if we can make a difference in somebody else's life just by advocating them, because there is this still this stiff, upper lip snooty, do you know, medical model, it's very different from the social care model.*

Trust and personalisation

By listening to people who work in these roles, it quickly became clear that although personalised care is always defined as “patient-centric” – actually it is characterised by two people being in relationship. The system doesn’t provide personalised care. An individual does. And the care they can provide is informed by their own experience, context, and health.

> *At the end of the day, I have to give love to myself because all day, providing, providing, providing, and giving lots of support. I have to look after myself, to give myself compassion, to give myself love. It's both ways to breathe if that makes sense. I'm giving to the patients, but it's very important to keep healthy distance, and keep the boundaries and but at the same time, it's unconditional love. I see you as you, not as a million health conditions. I see you as a human being. And that's my role.*

This human empathy and the acceptance of people as they are, is where much of success in these roles lies. It just takes one person listening to you and understanding your needs to break through years of neglect and frustration. But trust is hard-earned, easily broken, and difficult to transfer from one human relationship to other people, organisations, or systems.

Trust emerged as a particularly potent issue for the autistic people in the study. They have had a number of experiences where people don’t turn out to be how they presented, have attempted to exploit them, or where they present a danger of responding angrily or with emotions the person finds difficult to handle.

> *Hold on a minute. Are people who they say they are, or are they someone else? That's why exactly why I want to do things that are safe, like the friendship groups that are in confined places. If meet people outside, it could be dangerous. If you're in a place where there's people with autism or Asperger's or disabilities, you feel a lot safer, because you think, oh, yeah, okay, this is organised, this has a time to end. So you know that you can leave.*

> *My observation of my feeling while I've interacted with NHS members is that it feels like they have a job role that's in the back of their mind, the rules and guidelines. I have one friend who helps me and he helps me more. There's no rules and no guidelines. He just wants to help me and that's what I find is missing from the staff members that I've seen, whether it's the GP, social prescriber, the art therapist. I feel like they're not giving normal empathy. That's what I'm looking for. I feel like their giving a bare minimum base, no extra.*

Self-worth, compliance, troublemakers, and shared data

While a Health and Wellbeing Support role may be helpful and trusted within the scope of the engagement, it doesn't eliminate the hyper-vigilance required outside of that scope. And ultimately, residents see that any person employed by the NHS or the council is responsible to their own interests, that of their peers, that of the organisation, and those of the "greatest" good alongside any responsibility they have to the patient or resident.

There appears to be significant gap in the degree to which residents are active, informed, and empowered participants in their own care and decision making around that care on a continuous, long-term, and predictable basis.

> *[From a VCS] I feel like sometimes, when we talk about a service user, it can feel that just because they may that sort of experience or challenges or have one element of support need, that means that they're incapable of deciding their care. It becomes like this very weird power dynamic, because I'm giving you an element of care, that I will sort of steer you in a direction. And there are people with high support needs, but any way that we can give people the skills and confidence to have their say, or an opinion in the care that they receive, or to say actually, this isn't working for me...*
>
> *But you know, generally speaking, not always, of course, but generally, people want what's best for them and what's best for their families. So, our responsibility is to present with options that they may not be aware of, and then allow them to, to kind of run with that.*

In a world where some individuals and households will have life-long, complex and progressive needs, they would benefit from a more permanent point of contact who can advocate for and with them. Perhaps historically this was the GP or the social worker, and that is the place where people are expecting to be "held" and looked after in a trusted way, but that trust is broken.

Data, and shared data appears to be both a problem and a potential opportunity in the landscape of personalised care. People are aware that professionals control the narrative in the system, and that narrative can be wrong, incomplete, or used to protect the interests of the professional. There is often a suspicion that notes are used to label the resident as non-compliant or a troublemaker.

Conversely, the Health and Wellbeing Support roles find the data, and their access to data across services invaluable in planning for their assessments, documenting their plans, and finding and following up with the right people. They see opportunity for the data to be more widely shared, across more organisation boundaries, in order to help people receive consistent, informed and personalised service.

> *If somebody could create something the police, the school, the hospitals, the GP practices can have like one kind of connector, where the person doesn't have to repeat the story or the situation and everybody kind of knows, okay, this is Mrs. Morris. She's been in hospital, this is her background, she's got a history of strokes. We don't have to have all the details about the person because of confidentiality, but I think maybe safeguarding should be at the forefront of everything. I've attended a meeting where professionals have had a conflict about this issue of safeguarding. Where clinicians say no, this person needs to be discharged. And I've seen a doctor freak out and say no, there's a safeguarding issue here. There is a conflict of interest, there is still this working in silo practices and big gaps in things. I don't know if it's because the workload and the stress… Sometimes if you're in a field where you know, medicine is the best answer you think, well, why can't this person just have the medicine and then just try and get on with life? Sometimes they don't think that it's not easy for someone, for example, some of the patients are really depressed, and they struggle to even get up in the morning and do the basic things. And I'm not going to write somebody off because of that. I'm going to look at the deeper issues.*

Given this context, it seems that Health and Wellbeing Support roles could provide a vital service in helping residents establish the correct narrative in the record, have access to it in a more transparent and accountable way, and facilitate their more direct participation in conversation and decision making as an equal and empowered partner.

USAGE SCENARIOS

Across the conversations with residents and support roles, certain archetypical scenarios of engagement and use emerged. These aren't intended to be comprehensive personas or service journeys, but they do attempt to pull apart a typology of experiences, rather than a generic blend.

Summary of this section:

- When the right people get referred to the right Health and Wellbeing Support role, things appear to work in a fairly straightforward and satisfying manner for both the resident and professional. *Note*: this study had limited visibility into the actual experience of residents working with these roles, and so this observation is largely driven from the professional's perspective.
- Prior to engaging with the Health and Wellbeing Support role, people may have attempted to self-ration their care, fallen through the safety net, or bounced off it in repeated, unsuccessful engagements.
- People who have never had significant need to engage with health and social services in their lives often find it difficult to establish what services they are entitled to or to feel justified in asking for help. This can lead to suffering that may be unnecessary.
- Many people have been consistently abandoned, abused, or mistreated in both personal and professional lives from an early age. Triggering these feelings, or existing in survival mode, can create behaviours which may appear counterproductive or irrational from the outside.

Straightforward

This the ideal scenario. Someone is struggling or has a problem, they get picked up in a referral, the health and wellbeing support worker helps them feel listened to, sets some goals, and they get unstuck. The impact is visible to both parties, and they both leave the relationship feeling satisfied.

Self-rationing and too proud to ask for help

People both outside and inside the roles observe a significant portion of the population who avoids engaging with services because they either believe there is no capacity, their need isn't high enough, or they are ashamed to ask for and accept help. This is compounded by clinicians who avoid asking about their needs, in order to keep within time and comfort zones.

> *Lots of people are at home, they don't go anywhere, and they are left alone, so we are trying to get the patients who are not included in society. We're looking for the ones who are vulnerable, frail, sad. We want to support them in a healthy way, not like other people who could abuse them. So, it's important for us to be kind and sensitive and really listen because you are stuck and you don't know how to move. And you think it's the end of the world, but it's not.*

> *I think people are self-rationing in that people now, unfortunately, have an assumption that everything's going to be difficult. You know, there was a time when if people had an issue, not necessarily a medical thing, they'd go to their GP surgery. Where now people, I've heard it a number of times from older people, that the GPs are bloody useless. You know, obviously, I don't believe that, because I know they do great work, but things the system is just seems to be slightly creaking. And, you know, for people, they're not even attempting it. Now, whether they attempt it and their successful or not, we don't know. Because they're just not. The assumption is, the system is creaking and it won't work for us.*

The Health and Wellbeing Support roles provide a vital service in helping people understand their needs and entitlements and ask for help from people who can respond. This resource could be better advertised and communicated to people who may be avoiding or withdrawn from services. In some cases, the roles (for example, care coordinators in the frailty project) reach out to people proactively, and this has often been greatly effective in finding the people who do (and do not) need help.

In fact, many residents express proactivity as a critical element of care. A person or organisation whose job it is to care for them, should be anticipating their needs, reaching out proactively, and encouraging them to engage. (Rather than being chased or begged to provide care.)

Downward spiralling through the spaces in the safety net

Then, there are the people who know they need help, but can't seem to find a place to engage to get that help. They may be people who haven't needed help in the past, or who don't fit the typical "profile" of a service user. For example, professionals who work in related caregiving fields, private homeowners, or recently retired individuals. But life or crisis intervenes, and they are left spiralling in space, unable to "get caught." Often, they are attempting to get help for family members (parents, young children, or adult children) who are more vulnerable than they are.

Often, by the time they do find help, they feel the situation has deteriorated and they need even more support. It's like falling through space, and occasionally catching a ledge for support, but then falling again with an additional injury.

> *[A woman struggling to find help for her in-laws]. Both of us, me, and my husband, we are struggling with our mental health, we don't have a private space because this flat became a family house. I don't know what to do. And yes, it's having an impact on my work and on my life. I don't know what is right or wrong. I would like to know from someone that knows the system better than me. What is right and wrong? What*

> *should we get, that we're not getting and why we're not getting it? And why are there so many professional roles you mentioned, the Community Connector, the Social Prescriber - why is it difficult to access them?*

> *[a mother with an adult son who lives with her and is suffering from a series of mental health issues] Oh, that would have been useful for my son, we didn't know any of this stuff. And I just felt like, you know, well, if some if a service is available, then it needs to be advertised. Because if you don't know what you can ask for, then you're not going to ask for it. And it's not going to be used. And my son has suffered from anxiety forever, really. And it's only just this year when we ended up A&E twice, when he's 34, the doctors said straightaway, he's autistic. And I felt, you know, disappointed, obviously, that nobody had thought about this before. So we've, we've been getting some support. And he's also developed an eating disorder, which is got a lot worse at the moment. But the actual autism assessment, the waiting list is 18 months. So we're talking November next year, which is quite a long way away. When he went to the day hospital they said, there's various things that he can do, group things. But when he was there, he wasn't well enough to access them. And as soon as he left there, then he didn't know how to access them. There was nobody, nobody told him what was available. As far as we were concerned, there was nothing available. So he has a private psychotherapist, that at the moment, he's just talking to him once a fortnight, but originally, he actually got him onto the bus on the bike and all the like kind of one to one stuff. Which was really good. And then obviously that all fell apart with the COVID and locked down. So, he hasn't been back on the bus. Which is one of the things that would be good if somebody could actually get out and, you know, accompany him on a few bus rides and given that confidence back again. That's the kind of thing and he seems each time he has a kind of crisis. He seems to get back to a lower bar. So, he's accessing the community less and less each time he's unwell.*

These people may not appear to Health and Wellbeing Support roles as the vulnerable individuals they are prioritised to help. They may be judged as too educated, too well supported, or too capable to qualify.

This is probably an instance where a robust self-referral service would give people a first entry into the system in partnership with a Health and Wellbeing Support role.

Bouncing off the safety net

Conversely, you have the people who have engaged a lot in services, often repeatedly, and seem to bounce from one service to another or appear to become dependent on care. They may be taking up a disproportionate amount of professional's time, without making progress.

> *Some people here are really institutionalised. And they say to me, I'm not going anywhere. I'm staying here until I die. And I'm just like, you got to think of the future as well. I want to move out. I don't even know where, but I want to move in the future. But as long as you don't lose that desire of moving, that desire to live on your own and have your wife and kids or something like that. That's the future.*

These appear to be the classic case that Health and Wellbeing Support Roles are designed to engage with, in order to relieve burdens on other parts of the system. However, people are largely reliant on another professional to recognise this need, know that the roles are available, and make an appropriate referral.

This appears to be opportunity for increased education, awareness and incentives for both clinical and statutory workers to connect people with Health and Wellbeing Support. This also appears to be an opportunity for clinicians and social workers to be trained in and provide more personalised care, themselves.

Crisis, survival, abandonment and "the angel"

Across all of these scenarios, the resident or their household and family may be living in an extending period of survival mode or in a regressed state of behaviours due to unresolved PTSD triggered in daily life or in relationship to services.

Some people are aware of this and attempt to manage their environment to reduce the risks to their own health. Others are unaware of the root cause of self-destructive behaviours and need help to see the patterns and address them.

In many cases, residents will describe the one person who sees them, accepts them, and attempts to get them what they need (which may not be what the rules and regulations allow) as an angel who literally saves their life. If the apparent angel lets them down, the cycle continues and intensifies.

Health and Wellbeing Support Roles appear to be very aware of this dynamic and trained to deal with it.

> *But when I went to visit her, I had a lot of empathy for her and I sat down with her and, you know, I just let her speak and then… what was what was happening with her PTSD, which she hadn't sorted out. So, she kept jumping back into her early years. And it was something that nobody had identified. How can she move forward? And then that, because she hadn't sorted it out, she was just depressed eating chocolate cakes bingeing, not eating food, smoking, like a chimney*

> *drinking alcohol. And feels like people, professionals judge her like for being an alcoholic or, or smoking and you know, just being someone who really doesn't care about their health. But it's, it's beyond that. There's a root cause problem that's making her do this. So even though she was like 50, something, I could still see that little, little 15-year-old girl, that's just really suffering.*

The roles also understand themselves and transitory and temporary angels, rather than a permanent solution. They spend a lot of time and effort setting expectations and boundaries with clients, and then gradually weaning them off their support and able to manage their care more independently.

This does leave a gap, however, for individuals who have life-long needs or progressive conditions. They may be unable to self-manage, it appears that the clinical or statutory services are rarely apple to provide the personalised care that they need over the long-term.

> *[From a VCS] And it might be that there's eight sessions, but actually, for some clients that might become a lifeline that needs to be sustained. I've definitely worked for other organisations where they might be kind of like, what, why? Why are you holding on to clients. And I think once they build a rapport and trust with you, they then often call on you for more and more and more support. And then the expectation is sometimes too high because they have maybe a dependency on you or think more highly of you. But that can be a really positive thing. Particularly if they felt like let down by other services. But I think it also comes with its consequences, where you have your limitations about what you're commissioned to do, or what you're funded to do.*

OPPORTUNITIES FOR IMPROVEMENT

A number of issues, gaps and opportunities have been highlighted throughout this report, both at a micro and macro level. As a working resource for other analysis and integrated reporting, it does not attempt to provide strategic recommendations, but rather raw material to feed those recommendation. However, certain themes emerged across the data that appears important to highlight.

Summary of this section:

- Staff in the Health and Wellbeing Support roles appear to be well trained, managed and supported in their work. They have highlighted some gaps in clinical supervision and have a strong need to protect their time and have resources for strategic development, planning and networking.
- There are some gaps in resources and services available for common issues seen in Newham. Researching, identifying, coordinating, and filling those gaps is an important, ongoing task that should be "baked in" somewhere into the Health and Wellbeing Support system.
- Conversations with both residents and professionals highlighted some important nuances that should be reflected in social determinants of health and wellbeing.
- The Health and Wellbeing Support roles are seen as new and emergent, with significant support but a lot of work still to be done. This is an exciting time to make change, but also creates a certain fragility, of elements within a complex system being "messed about with" before they have time to mature.

Staff support and strategic development

People providing health and wellbeing support need to have their own health and wellbeing supported in order to function properly. Some described their own line management acting like coaches themselves, in order to help develop and sustain staff in complex and challenging conditions.

Generally, people felt well supported, well trained, and like they knew where to go for support that they needed. A few highlighted challenges getting clinical supervision for their cases. Others, noted that the clinical environment struggled to understand how their time was spent, and the need to protect long appointments and non-appointment time in the diary.

> *It can be difficult trying to find the balance, because I always try to book no more than maybe eight patients a day. And then the rest of it is like community services, meetings, and other areas of the role. But I do find that sometimes that can be an issue with the GP, because they sometimes think we should have fully booked clinics, and we have to remind them that we are seeing different types of patients. That's not the aim of the role, to just be having back-to-back conversations,*

> *difficult conversations. We need spaces and time protected time for admin, looking for services, and even just networking, finding out what else is not what else is out there. Seeing how we can raise the issues of like gaps, and helping the healthcare services out there, it's not just about just seeing the patients and numbers, so I think that is also something that does come up a bit every now and again. We've reminded them that this is how the ROI is. I don't feel like they fully understand because I know they're very much target-driven and they do get the role, but there is a bit of a bit of miscommunication there.*

Gap identification

Other gaps identified across access and referrals included:

- Access to affordable and safe domestic help for tasks like cleaning.
- Getting men to engage in health and wellbeing services. Wives and mothers will often attempt engage with the system on their behalf. This can be particularly challenging with households may struggle with abusive behaviours but need or want to stay together.
- Language support. Many people with limited English receive almost no meaningful information or support from the clinicians and services they engage with.
- Form filling in general. But especially for housebound patients with digital access problems. Autistic adults often struggle with forms and would benefit from consistent access to support services.
- Support groups for younger populations (i.e., young Bengali women limited English, and with children, who are isolated and alone, young adults struggling with mental health issues).
- Sensory appropriate activities and environments for people with autism.
- Help for older parents of vulnerable adult children to plan for life when they are no longer around or are unable to care for them because of their own health issues. This becomes a serious source of chronic stress and mental ill health, but there don't appear to be specific resources to help. Especially in a system driven by acute, short-term needs.

Social Determinants of Health

Across all interviews, with both residents and professionals, housing will be highlighted as the most important and challenging social determinant of health. Issues ranged from housing that actively contributed to making people sick, to small fixes around the home that could drastically improve mobility and wellbeing, but which never got done. Without safe, clean, and comfortable housing, it's difficult for people to feel safe and secure, emerge from survival mode, and engage in other activities to improve their health and wellbeing. Even for people who owned their own homes, housing emerged again and again, as a concern, and limitation, and contributor to wellbeing.

Other considerations added or expanded to the determinants included:

- mobility and transportation

- digital inclusion and access to information
- bereavement and grief
- availability of child and elder care
- ability to find romantic and life partners
- a sense of being visible, included and proactively cared for
- access to affordable and healthy food
- addiction and trauma
- sensory and environmental factors

Shared directories of resources

All of the roles rely on extensive knowledge of other resources and services available for residents and patients. Many of them speak of creating a directory or library, and mention that significant time is required to network and stay informed about what's available. There may be ways in which its easier to share resources and eliminate administrative burden across roles. However, care should be taken not to remove the specialist knowledge that people build up in a particular domain or geographic area.

Service versus signposting

There can be a tension in Health and Wellbeing services being seen a redirection of resources away from service provision. A perception that in general, people know what they need, and don't need signposting to the service, but for the service to exist.

> *[From a VCS] I think our customer group of people with early stages of dementia has been terribly badly impacted, through the cessation of face-to-face services during COVID, and a lot of those have not fully reopened. I believe there are waiting lists or services don't exist, or people have got out of the habit of going places. And I think I'm talking particularly about services that reduce social isolation. Those carers will say they want more of those services, rather than an enhanced link worker team, or whatever. The want more day opportunities, and want respite, and to give our family member some cognitive stimulation and independence.*

From residents, this could be expressed as feeling like "a hot potato" handed around from person to person, but never actually getting the service that would make a difference.

Bedding in and making change

Although some of the roles have been around for 5-10 years, and other are much newer, all still were described as somewhat emergent. Community Neighbourhood Link Workers appeared to be the most embedded, with Social Prescribers the next most established.

Although professionals in the roles tend to have a positive, growth-oriented mindset and are eager to improve the system and the lives of their clients, they did express some wariness in getting “improved” or reorganised while still getting “stuck in” and understood.

Clearly, they are parts of complex and dynamic systems, who have been designed around and within and because of the limitations and constraints in those systems, rather than on a blank sheet of paper. This may mean that some aspects of the roles are optimised for the environments they are positioned in, rather than the external gaze.

Efforts made to make the roles more visible, accessible and navigable to residents and other professionals should take care not to disrupt the ties with the clinical or statutory environment they are positioned within.

From the outside, there is a sense that although things aren’t fully realised, there is an important aspiration and movement in the right direction.

> *[From a VCS discussion] I think we are groping towards something. They're not quite there yet. And I'm talking about largely in terms of how we've engaged with these roles...*
>
> *And sometimes we try and reinvent the wheels and always hear about, like, what innovative new projects can we come up with? And sometimes actually, it's the simplest things that can be really effective and can be easily scaled., I think definitely the base model of understanding the person as a whole, and other things that might be going on for them, and how those needs can be addressed is absolutely the right one,*
>
> *I think actually having a person that supports that linkage, and holds different organisations more to account, to communicate better with one another. I think also, we all use so many different systems and stuff. You go to a new service, and you're having to explain your life story for the first 10 minutes, but you've only got a 15-minute appointment, like every single time for a lot of people. Like with our marginalised communities, having to come out every single time that you access a service. Like, I'm a gay man. So, I think there's like a lot of shared learning that still feels like it needs to happen.*
>
> *I think the model is there, but it feels like it's not clear in the titles. And I don't think they're necessarily clearly enough distinguishable from one another.*

ANNEX

HEALTH AND WELLBEING SUPPORT ROLES

Title	Acronym	Location / Based in	Summary	Employed by	Funded by
Social Prescribing Link Workers	SPLWs	GP practices	Connects people to services, community support and advice to improve their health and wellbeing. Give people time and focus on what matters to the person.	Primary Care	NHS
Health & Wellbeing Coaches	HWbCs	GP practices	Use specialist coaching and behaviour change methods to enable people to be **active participants** in physical and mental health.	Primary Care	NHS
Care Coordinators	CCs	GP practices	Work as part of multidisciplinary team to provide proactive support to people living with complex needs requiring multiple care services.	Primary Care	NHS
Community Neighbourhood Link Workers	CNLWs	Libraries	Provides a 6 week personalised and targeted service designed to prevent loneliness and isolation by reconnecting into the community, and delay or reduce the need for more intensive, long-term health and social care support.	Council	Adult Social Care
Health and Social Care Navigators	HSCNs	East Ham Care Center (EHCC) - ELFT sites	The HSCNs support people who have complex health care needs by working closely with the GP, local authority and other stakeholder colleagues. They can be a central point of access for patients and their relatives / informal carers when they need advice and/or sign-posting and do home visits if needed.	ELFT	NHS (ELFT)
Community Connectors	CCs (ELFT)	VCSE & ELFT Sites	Provides 1:1 or group support as part of the 6x Community Integrated Mental Health Service (CIMHS) to provide support for residents with a Serious Mental Illness and/or Complex Mental health needs.	VCSE	NHS (ELFT)

DISCUSSION GUIDES AND PARTICPANT WORKBOOKS

insert Links to documents

QUOTES BY THEME

On being your own expert and care coordinator:

> *I'm an expert. By experience in the condition. I'm 54 now, but I know for 52 years that I've been struggling. So why is it that when we're turning around and telling them, this is an issue, this is constantly happening, it doesn't get changed. We're giving you that insight, we're that this is happening, and they're still not taking any notice of it. I don't trust. I have no trust. That's a constant load that we're constantly going down on. Yeah. And it's not as easy as going through a maze. We would be going round and round in that maze for weeks and months and years at a time. It's not a straight line.*

> *"Navigator? Would that be the same as a social worker? Community Connector? The social worker helped devise my care package, and in that there was an element of me being able to get out into the community. Coordinator? No, unless I put myself in that role."*

On the ramifications of poor service, discrimination, and stigma:

> *[From a VCS] We know that with communities that we work with, that if they experience a poor service or discrimination, then then they feel that that is reflective of the healthcare system as a whole. And so people may self-prescribe and source things themselves, and not want to have involvement with healthcare professionals because of some of the issues that have experienced. So that might be things like institutional racism, maybe transphobia. A good example of that, there was a report that came out around the belief that black women don't experience pain as much as white women. And therefore, they're less likely to be given an epidural. And as a result of that, black women are more likely to suffer complications during pregnancy, because they may not seek out maternity services. I think there's a lot of factors that then mean certain communities or people might not even actually be seeking out those services anymore. And then becomes a self-fulfilling prophecy and complicates the issue.*

> *Well, I've also cared for people in the past. I also run a voluntary group. When I worked, I had private medical insurance. I never saw what it was like to have to go into the NHS to get treatment. When I did, I was*

> *flabbergasted I was just in shock. I had many doors shut in my face, because I carry myself well, they will say you haven't got a mental health illness. If you can be a manager or you can run a company, how can you have a mental health illness? Oh, the discrimination and stigma around it is disgusting. And still in the very services that it's not meant to be in. So, I have been trying to change things for a very, very long time. But once again, I feel I still feel we're not listened to, we're not believed. And that's one thing from my childhood, I can't deal with is being told that I'm a liar. And they may not use those words. But when you still have, in my opinion, when you still got the same member of staff having the same attitude, or you still got the same service doing the same thing. In my opinion, there's a saying the real definition of insanity is doing the same thing over and over again and expecting a different result. Now, this is what they keep doing. They're doing the same stuff over and over and there's nothing changing.*

> *I think people are self-rationing in that people now, unfortunately, have an assumption that everything's going to be difficult. You know, there was a time when if people had an issue, not necessarily a medical thing, they'd go to their GP surgery. Where now people, I've heard it a number of times from older people, that the GPs are bloody useless. You know, obviously, I don't believe that, because I know they do great work, but things the system is just seems to be slightly creaking. And, you know, for people, they're not even attempting it. Now, whether they attempt it and their successful or not, we don't know. Because they're just not. The assumption is, the system is creaking and it won't work for us.*

On the value of non-traditional therapies:

> *[From a VCS] For some of our clients, it's sometimes holistic therapies. It's not necessarily sort of traditional health care services. I think it's something that gives people their own say, an element of respite. I think actually, these are really valid healthcare service that sustain people living well.*

On not getting offered what you need:

> *I get offered the things I don't need and don't get offered what I do. and then they say I refuse the service and make it look like I'm the bad person. I want the freedom to choose. I want someone in my corner, a*

champion, an advocate. I want my family to be safe, living in a comfortable, clean accommodation and get the service that we rightfully deserve to help me and my children's physical and mental health to get better.

They speak about patient-centred care, but there isn't any, in any way, you cannot ask for anything. When they offer you this, when they accept your application [for adult social care], you need to go through a sort of assessment. But the report is a copy and paste of other people's reports. It's not tailored. It's just their assumptions and biases about what certain people are like. It said my in-laws spend all day in front of the TV. We don't even have a TV.

I think that what would benefit me, what would kind of make me feel better, is sometimes being given what I wanted, instead of others saying, Oh, this is what you need.

[From a VCS] I feel like sometimes, when we talk about a service user, it can feel that just because they may that sort of experience or challenges or have one element of support need, that means that they're incapable of deciding their care. It becomes like this very weird power dynamic, because I'm giving you an element of care, that I will sort of steer you in a direction. And there are people with high support needs, but any way that we can give people the skills and confidence to have their say, or an opinion in the care that they receive, or to say actually, this isn't working for me…

But you know, generally speaking, not always, of course, but generally, people want what's best for them and what's best for their families. So, our responsibility is to present with options that they may not be aware of, and then allow them to, to kind of run with that.

[From a VCS] I think our customer group of people with early stages of dementia has been terribly badly impacted, through the cessation of face-to-face services during COVID, and a lot of those have not fully reopened. I believe there are waiting lists or services don't exist, or

> *people have got out of the habit of going places. And I think I'm talking particularly about services that reduce social isolation. Those carers will say they want more of those services, rather than an enhanced link worker team, or whatever. The want more day opportunities, and want respite, and to give our family member some cognitive stimulation and independence.*

On the relationship with a social prescriber:

> *She listened well, made sure I was ok, explained the situation and provided follow ups, and many useful links, felt like my family aunt. Consoling, and provided what to do in simple order instructions. Understood my disabilities, was gentle and kind. I will miss her. And I hope for the best for her future. And she took a lot off my shoulders. And she was quick too. She got things done. She was limited to what she could help with and had limited time to give, but she tried to help me as much as she possibly could.*

On the benefits of overlap between roles:

> *I think that it's very good a lot of things overlap with our roles. It doesn't matter, there is a need for both. There is a need for people to be out there in the community as neighbourhood link workers. And within the surgery, we have so much need, that we don't need to put it all in one basket. It's good too, because like I said earlier, people you find in surgeries you may not find in community, they are always going to the doctor. People who are in the community may not have been to the doctor for five years, but they're happy to talk to a link worker.*

On the confusion between roles:

> *I asked my team last week. We get some referrals from link workers for our services, but the team didn't recognise the other titles and I am not sure they would be able to remember them.*

> *My team felt that the referrals they received from community neighbourhood link workers were good quality referrals and that that the referrals were generally accepted. I think there's a little bit of frustration about the bureaucracy, of needing to understand all these roles. And we work with social workers and mental health, so we would quite like to know what professional qualifications of any of these*

> *people have. I know, some do have. But you know, what actually, is their role? What are the boundaries of their role? When do they hand over to other members, professional members of the health services at whatever level? And what does success look like for them?*

> *Who's holding the personalised care plan is more the question. Who's the hub of that plan, and who are the spokes are the pieces that that move into it?*

> *All those roles, in my opinion, both personal and professional, they all overlap. When I was seconded to work in the primary care network, I found it very confusing at times, because I would sit down and say, so what are you supposed to do? And then what am I supposed to do? Because we don't want to overlap. But not only that, we don't want to overload the residents as well. Because if we as professionals get confused, then what are the residents going to do? It's about overlapping and confusion.*

> *To me, as someone that has had mental health challenges for like, 10 years, I would be fine with accessing a Mental Health Connector, not a community connector. I think sometimes we've got to name it for what it is. So we know it's something that's for us.*

On challenges with referrals to other services:

> *If you refer the patient to adult social care, the waiting list takes months and months and months sometimes they are on the waiting list for ever, waiting for a social worker to be allocated.*

> *I do find when I do send patients off, they get referral, they have an assessment, I find there's a lot of confusion when that assessment takes place. I'm not sure how that is explained. But I think residents that maybe English is not their first language, it gets really confusing for them. So, they just said don't want it because they feel like they're going to have to pay for it. Because I've had a few that have called back*

and they'll say, Okay, I've seen you've had your assessment, how did it go? And they just say, No, I didn't want it because they told me I had to pay. I've had a few of those incidents, I made sure I fully explain what is going to be expected when you get the assessment, you may be eligible, you might not be eligible, if you are eligible, there's going be a financial compartment and you might have to pay. It's making them aware that they don't do cooking, they don't do cleaning, only you have to self-fund that going down the route of like maybe disability benefits if you're entitled to just kind of making sure that they're aware, sometimes it has worked, but sometimes it's still a bit confused. I'm not sure how some of the social workers are explaining things to them is sometimes it can be very confusing, and all the assessments are quite long as well. It's quite a long assessment that they have. We do find this quite a bit of confusion, a lot of time on the assessment takes place.

We get a high level of referrals for housing. And some patients, it's affecting their mental wellbeing, but they are managing as best they can, and we can work with them on other things. But then you get those patients where the housing is really, really detrimental. And these patients can be very difficult, because we're very limited on what we can do in the housing area. And we get so many housing referrals. So yes, it's quite difficult, where they can't even engage in any other activity. It's literally just housing, and just kind of trying to manage expectations, let them know that housing is a long-term goal, and what we can and what we can't do, it can be very, very difficult.

It's a nightmare. Because the thresholds are so high. And social workers are so stressed out that you can't even get hold of a social worker, it's like, because obviously, they have a lot of people on their caseload. With my assessments, now, I know, the first thing I should do is message the social worker, so that even if it takes them 10 days, I start by contacting them on the first day, because you might not get a response until the 10th day. And then there's this thing about, oh, you're not eligible, the thresholds are too high. And then there's the housing crisis, okay, we have a housing crisis in England. But you know, for God's sake, there's patients that need supported housing, and you're not looking at the whole situation. And, you know, I've got patients who are 90 years old, you can't expect them to stay on their own like that. But they just kind of sometimes I feel like they just go with their threshold and their criteria and their tick box system. These are human

> *beings, it's not about a tick box system, you need to look beyond that. And I think like, a lot of things are messing up with social work, because it's just everybody's so scared about their accountability, that sometimes you're missing the point, you're missing the point that some people do need to have that support. And some people, okay, they can manage at home, but there are some patients that really are housebound, and they're not coping, and I sometimes go home worrying about them thinking, wow, how do they how do they manage…*

On the desire to support and advocate for others:

> *I'm living proof that you can change your life and learn how manage your condition. Then I thought, I would like to help people do the same. I came across a job for social prescribers and care coordinators. And I was like, wow, what is this? So now I know I'm helping the right people because they are looking for help. My help is not going wasted. Before I was helping, helping, and no one was listening. Now people say I want to lose weight, or I have struggled with this. So I say, okay, let's explore this. Let's see where we can start. My professional journey came from my personal growth and personal changes.*

> *Coming from a background where I once myself was quite vulnerable. And I needed it, I needed support, and I got the support, and I, you know, managed to get my degree and get to where I am now. So I feel like these people made a huge difference in my life. And if we can make a difference in somebody else's life just by advocating them, because there is this still this stiff, upper lip snooty, do you know, medical model, it's very different from the social care model.*

> *Lots of people are at home, they don't go anywhere, and they are left alone, so we are trying to get the patients who are not included in society. We're looking for the ones who are vulnerable, frail, sad. We want to support them in a healthy way, not like other people who could abuse them. So, it's important for us to be kind and sensitive and really listen because you are stuck and you don't know how to move. And you think it's the end of the world, but it's not.*

> *But when I went to visit her, I had a lot of empathy for her and I sat down with her and, you know, I just let her speak and then… what was what was happening with her PTSD, which she hadn't sorted out. So, she kept jumping back into her early years. And it was something that nobody had identified. How can she move forward? And then that, because she hadn't sorted it out, she was just depressed eating chocolate cakes bingeing, not eating food, smoking, like a chimney drinking alcohol. And feels like people, professionals judge her like for being an alcoholic or, or smoking and you know, just being someone who really doesn't care about their health. But it's, it's beyond that. There's a root cause problem that's making her do this. So even though she was like 50, something, I could still see that little, little 15-year-old girl, that's just really suffering.*

On healthy boundaries:

> *At the end of the day, I have to give love to myself because all day, providing, providing, providing, and giving lots of support. I have to look after myself, to give myself compassion, to give myself love. It's both ways to breathe if that makes sense. I'm giving to the patients, but it's very important to keep healthy distance, and keep the boundaries and but at the same time, it's unconditional love. I see you as you, not as a million health conditions. I see you as a human being. And that's my role.*

On trust:

> *Hold on a minute. Are people who they say they are, or are they someone else? That's why exactly why I want to do things that are safe, like the friendship groups that are in confined places. If meet people outside, it could be dangerous. If you're in a place where there's people with autism or Asperger's or disabilities, you feel a lot safer, because you think, oh, yeah, okay, this is organised, this has a time to end. So you know that you can leave.*

> *My observation of my feeling while I've interacted with NHS members is that it feels like they have a job role that's in the back of their mind, the rules and guidelines. I have one friend who helps me and he helps me more. There's no rules and no guidelines. He just wants to help me and that's what I find is missing from the staff members that I've seen, whether it's the GP, social prescriber, the art therapist. I feel like*

> *they're not giving normal empathy. That's what I'm looking for. I feel like their giving a bare minimum base, no extra.*

On shared data and shared learning

> *If somebody could create something the police, the school, the hospitals, the GP practices can have like one kind of connector, where the person doesn't have to repeat the story or the situation and everybody kind of knows, okay, this is Mrs. Morris. She's been in hospital, this is her background, she's got a history of strokes. We don't have to have all the details about the person because of confidentiality, but I think maybe safeguarding should be at the forefront of everything. I've attended a meeting where professionals have had a conflict about this issue of safeguarding. Where clinicians say no, this person needs to be discharged. And I've seen a doctor freak out and say no, there's a safeguarding issue here. There is a conflict of interest, there is still this working in silo practices and big gaps in things. I don't know if it's because the workload and the stress… Sometimes if you're in a field where you know, medicine is the best answer you think, well, why can't this person just have the medicine and then just try and get on with life? Sometimes they don't think that it's not easy for someone, for example, some of the patients are really depressed, and they struggle to even get up in the morning and do the basic things. And I'm not going to write somebody off because of that. I'm going to look at the deeper issues.*

> *[From a VCS discussion] I think we are groping towards something. They're not quite there yet. And I'm talking about largely in terms of how we've engaged with these roles…*
>
> *And sometimes we try and reinvent the wheels and always hear about, like, what innovative new projects can we come up with? And sometimes actually, it's the simplest things that can be really effective and can be easily scaled., I think definitely the base model of understanding the person as a whole, and other things that might be going on for them, and how those needs can be addressed is absolutely the right one,*
>
> *I think actually having a person that supports that linkage, and holds different organisations more to account, to communicate better with one another. I think also, we all use so many different systems and stuff. You go to a new service, and you're having to explain your life story for the first 10 minutes, but you've only got a 15-minute appointment, like*

> *every single time for a lot of people. Like with our marginalised communities, having to come out every single time that you access a service. Like, I'm a gay man. So, I think there's like a lot of shared learning that still feels like it needs to happen.*
>
> *I think the model is there, but it feels like it's not clear in the titles. And I don't think they're necessarily clearly enough distinguishable from one another.*

On not knowing what services are available or entitled to:

> *[A woman struggling to find help for her in-laws]. Both of us, me, and my husband, we are struggling with our mental health, we don't have a private space because this flat became a family house. I don't know what to do. And yes, it's having an impact on my work and on my life. I don't know what is right or wrong. I would like to know from someone that knows the system better than me. What is right and wrong? What should we get, that we're not getting and why we're not getting it? And why are there so many professional roles you mentioned, the Community Connector, the Social Prescriber - why is it difficult to access them?*

> *[a mother with an adult son who lives with her and is suffering from a series of mental health issues] Oh, that would have been useful for my son, we didn't know any of this stuff. And I just felt like, you know, well, if some if a service is available, then it needs to be advertised. Because if you don't know what you can ask for, then you're not going to ask for it. And it's not going to be used. And my son has suffered from anxiety forever, really. And it's only just this year when we ended up A&E twice, when he's 34, the doctors said straightaway, he's autistic. And I felt, you know, disappointed, obviously, that nobody had thought about this before. So we've, we've been getting some support. And he's also developed an eating disorder, which is got a lot worse at the moment. But the actual autism assessment, the waiting list is 18 months. So we're talking November next year, which is quite a long way away. When he went to the day hospital they said, there's various things that he can do, group things. But when he was there, he wasn't well enough to access them. And as soon as he left there, then he didn't know how to access them. There was nobody, nobody told him what was available. As far as we were concerned, there was nothing available. So he has a private psychotherapist, that at the moment, he's just talking to him once a fortnight, but originally, he actually got him onto the bus on the*

> *bike and all the like kind of one to one stuff. Which was really good. And then obviously that all fell apart with the COVID and locked down. So, he hasn't been back on the bus. Which is one of the things that would be good if somebody could actually get out and, you know, accompany him on a few bus rides and given that confidence back again. That's the kind of thing and he seems each time he has a kind of crisis. He seems to get back to a lower bar. So, he's accessing the community less and less each time he's unwell.*

On the desire for independence:

> *Some people here are really institutionalised. And they say to me, I'm not going anywhere. I'm staying here until I die. And I'm just like, you got to think of the future as well. I want to move out. I don't even know where, but I want to move in the future. But as long as you don't lose that desire of moving, that desire to live on your own and have your wife and kids or something like that. That's the future.*

On the need for long-term support:

> *[From a VCS] And it might be that there's eight sessions, but actually, for some clients that might become a lifeline that needs to be sustained. I've definitely worked for other organisations where they might be kind of like, what, why? Why are you holding on to clients. And I think once they build a rapport and trust with you, they then often call on you for more and more and more support. And then the expectation is sometimes too high because they have maybe a dependency on you or think more highly of you. But that can be a really positive thing. Particularly if they felt like let down by other services. But I think it also comes with its consequences, where you have your limitations about what you're commissioned to do, or what you're funded to do.*

On the need for protected time:

> *It can be difficult trying to find the balance, because I always try to book no more than maybe eight patients a day. And then the rest of it is like community services, meetings, and other areas of the role. But I do find that sometimes that can be an issue with the GP, because they sometimes think we should have fully booked clinics, and we have to remind them that we are seeing different types of patients. That's not the aim of the role, to just be having back-to-back conversations, difficult conversations. We need spaces and time protected time for admin, looking for services, and even just networking, finding out what*

else is not what else is out there. Seeing how we can raise the issues of like gaps, and helping the healthcare services out there, it's not just about just seeing the patients and numbers, so I think that is also something that does come up a bit every now and again. We've reminded them that this is how the ROI is. I don't feel like they fully understand because I know they're very much target-driven and they do get the role, but there is a bit of a bit of miscommunication there.