WINNING THE BEST COMMUNITY CARE FOR LEWISHAM A people-powered inquiry



Healthwatch Lewisham The Save Lewisham Hospital Campaign







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Acknowledgements

Healthwatch and the Save Lewisham Hospital Campaign wish to warmly acknowledge all the individuals and organisations who have so generously given of their time and enthusiasm to make this work possible.

We celebrate their commitment to improving care and services in Lewisham.

31 March 2015

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WINNING THE BEST COMMUNITY CARE FOR LEWISHAM EXECUTIVE SUMMARY

This report explores community health and social care in Lewisham. The report has two views on the issues. One is the patient and service user experience captured through an extensive community engagement programme by Healthwatch Lewisham. The other is the Save Lewisham Hospital Campaign's complementary analysis of the provision of community care services and the impact of financial constraints and reductions on services, service users and staff.

Community care is an often almost invisible but vital web of support for the most vulnerable in our society receiving care outside hospital and often in our own homes. Service users may find it hard to comment on their quality of care and it can therefore be difficult to monitor the impact of any reduction or change to provision. It is easy to see a hospital and get angry when it is threatened. It is harder to see threats to a jigsaw of services to an often vulnerable and sometimes silent population. Community care is a prerequisite for safe and effective care pathways between hospital and home. With pressures to reduce hospital provision, it is even more essential to examine current community provision.

This report follows the Appreciative Inquiry that demonstrated the excellent quality of care in Lewisham. This Inquiry gives voice to service users of community care in Lewisham who may find it more difficult to comment on these services rather than those of a hospital. The Inquiry showed that, from the points of view of users, clinicians and NHS managers, the following dimensions of care were key to a good service:

- Time
- Accessibility
- Smooth Proactive Pathways
- Empowerment of the Patient
- Professionalism, Skill, Sensitivity, Listening
- Sees the Person and the Social Situation not just the Condition

It was also clear that privatisation of NHS services was a concern for Lewisham residents

This report explores the daily reality of community health and social care in Lewisham. We look at both the quality and the provision of services.

We have tried to extend work across the protected equality characteristics and focus on communities that are poorly heard.

The report draws on many sources of evidence: Healthwatch has gathered over 100 stories from service users and carers. The Campaign has spoken to NHS staff to provide a different perspective. The report also draws on previous Healthwatch reports and desktop research. Data was gathered using quantitative and qualitative methods, speaking with individuals and groups. Some evidence has been difficult to gather, some is incomplete, and some will change. We acknowledge that more engagement is needed with service users, particularly those receiving services at home. We invite our partners to support us to do this.

The Campaign emphasises that current community care provision in Lewisham needs to be seen against central government's financial and organisational pressure on health, social care and voluntary agencies. The TSA process disrupted some effectively growing services and networks, as has the re-organisation of the Health and Social Care Act.

- Although NHS funding is technically static, it is effectively falling by 5% annually nationally¹. Inflation of products and services for the NHS outstrips the national inflation rate.
- Government money to fund local authority services in Lewisham is projected to fall by 33% by 2017–18 from the level it was in 2013–14. That is from £208.1 million to £138.3 million.
- Adult social care spending nationally has suffered cuts of 26%: £3.53 billion over the last four years. The service is now under extreme pressure and facing financial crisis. If the trajectory of cuts experienced to date continues over the period to 2019/20 spending must fall by 21% in cash terms or 33% in real terms.
- There is a 5% decrease nationally in the number of people receiving social care services. As the National Audit Office concludes: "Need for care is rising while public spending is falling, and there is unmet need."
- To set a balanced budget for this year Lewisham Council has had to agree measures to save £39m. This comes on top of £93m savings already made since 2010.
 289 more staff could be threatened with redundancy out of 1,133 staff employed.

There is a commitment to improvement in community care by the SE London Strategy Programme, the Local Authority and the CCG. Both the NHS and the local authority agree that sometimes savings, when combined with imaginative redesign, do not inevitably result in a deterioration of service. Ensuring that the public are fully engaged in the development of current and future redesigns of community care while using existing patient experience evidence such as this report is imperative to winning the best possible community care for Lewisham.

¹ 4% is the figure usually quoted. There is an annual 1% tariff 'deflation' which, added together, makes a 5% average 'cost pressure' annually for most trusts

The Campaign highlights privatisation as an additional threat. Lewisham CCG has not been known for extensive privatisation, but, nationally, independent sector providers could provide 50% of NHS community services by 2020². The Campaign points out that there is no evidence that the market improves patient outcomes, while there is ample evidence that profits go out of the NHS, staff and skills are often reduced and fragmentation increased. Companies exit because profits are inadequate – and instability results.

A consistent picture emerges from the research and the stories.

Staff are increasingly stretched and are working harder and longer hours. Despite these challenges, in the majority of cases users in both social and health community care still receive a quality service delivered by caring and attentive staff who listen and involve them in decisions about their care.

Services overall, however, seem to be reducing in most sectors. Lack of access, resulting from a reduction in community care provision, poor co-ordination of services and continuity of care, confusion about where to access services and access information are themes arising in the second stage of this inquiry.

These can cause some clinicians to focus on the immediate problem rather than the bigger picture of the patient and the wider determinants of their health.

On occasion, as in findings on hospital discharge, services can be unsafe.

Time

Service users continue to tell us that time is vital to the quality of care they receive. Once patients access a particular service the majority feel that they are given enough time. However, this appears not to be the case in some areas of social care, and for patients with complex needs in general practice.

Accessibility

Access has been the number one issue raised during this inquiry, particularly access to GPs, chiropodists, practice nurses (in some areas) and diabetes support nurses, CAMHS and mental health services. It is a direct result of fewer, stretched staff. In services provided by the NHS, this is often because of recruitment problems.

Poor user access to information was a related issue.

Smooth Proactive Pathways.

The report finds that many patients have experienced difficulties in the coordination of different services, often when moving between services or being discharged from one

² <u>http://www.laingbuisson.co.uk/Portals/1/MarketReports/Documents/PrimaryCare_OOH_Bro_Web.pdf</u>

service to another. It is hard to link services if they have different management structures and reduced administrative support with too few professionals to meet the demand.

The inquiry found that Continuity of Care, a related theme issue, is also compromised by lack of access to services.

Empowerment of the Patient

Most users told us that they feel supported in sharing decisions, as much as they want to, with professionals. However, there is always room for improvement, particularly when looking at carer involvement and working with patients with learning difficulties.

Professionalism, Skill, Sensitivity, Listening.

Once users get to see a professional for a service, almost all said that they are treated well, with respect, care and commitment. This, again, is a tribute to the professionals working under pressure and still delivering high quality care.

Sees the Person and the Social Situation not just the Condition

Users reported that this aspect of good practice is not always addressed. It is central to some disciplines, such as CAMHS, where understanding the wider determinants of mental health is core. However, in other disciplines, such as district nursing, it seems that pressure encourages an almost exclusive focus on the immediate. On occasion, it appears that this can become a critical problem.

The reason for the squeeze on staff and services is clear – it is austerity.

This report supports the visions created through the Appreciative Inquiry. Service users, community leaders, health and social care staff have told us community care needs:

- Adequate investments in community care services to ensure that service users receive the highest quality of care
- Well trained and well paid staff, well supported, who have the time to offer patientcentred services with a focus on continuity of care
- A holistic approach, taking into account many aspects of the patient's life and health
- Connectedness and cooperation between services, the voluntary sector and the community
- Patients to be supported to make as many decisions about their care as they want
- Patients to have all the necessary information made available to them to support them and their wellbeing, as well as enabling them to make positive choices about their health
- Patients to be able to access services in a timely manner with choice made available wherever possible
- Healthcare as a whole we reject suggestions that boosting community healthcare opens the door to reductions in hospital care
- Smooth integrated pathways: this cannot be provided through privatisation and fragmentation
- New media to be used where appropriate.

The Save Lewisham Hospital Campaign challenges two assumptions behind current NHS thinking. It is highly unlikely that improving community care services will enable cash-releasing cuts in hospital services. There is virtually no evidence for this³. Indeed, the number of hospital beds probably needs to increase rather than contract: current bed occupancy is well over the safe threshold of 85-90%. England has fewer beds than all but one OECD country per head of population⁴.

The Campaign calls for:

- Increased government funding for community health and care services
- An end to austerity for public services
- A dissemination of this report to community groups and Lewisham residents
- Public support for rapid and permanent support for existing staff, increasing numbers and engagement

This report has been compiled by Healthwatch Lewisham and the Save Lewisham Hospital Campaign with the help of 100s of Lewisham residents and Lewisham community groups, with Carers Lewisham prominent. Some of the views are the Campaign's alone. These are made clear.

³ <u>http://www.hsj.co.uk/Journals/2014/11/18/l/q/r/HSJ141121_FRAILOLDERPEOPLE_LO-RES.pdf</u> ⁴ Ibid

WINNING THE BEST COMMUNITY CARE FOR LEWISHAM INTRODUCTION

In April 2014 Healthwatch Lewisham was invited by the Save Lewisham Hospital Campaign to join an Appreciative Inquiry to win the Best Community Care. The Campaign began this process because they were concerned that the quality of community healthcare is at risk due to budget reductions and privatisation which would result in the fragmentation and reduction of community care services.

Healthwatch Lewisham was keen to collaborate in the Appreciative Inquiry in order to identify what constitutes 'quality and excellence' in community care. By understanding what quality looks like from the patient perspective they would have a clearer vision to better represent the patient voice at a strategic level to influence commissioning of health and social care services.

The Appreciative Inquiry used a five stage participative process which included gathering stories focusing on the best of peoples' experiences, building a picture of what they want to create and working out together how to achieve the future they want. Focusing on positive stories helps to identify what is already working well in community health care and can offer a clear vision for the future.

Story collectors gathered over 100 stories from community care service users, clinicians and managers to understand the key features that make good community healthcare. We spoke to a diverse range of people including isolated older people in their homes, and young people who shared positive stories between themselves. We picked out what they thought were the 'magic ingredients' of their stories.

Over 200 people were involved in this inquiry.

An initial analysis by Story Collectors identified the following themes from the stories' magic ingredients:

- 1. Time
- 2. Accessibility
- 3. Smooth Proactive Pathways
- 4. Empowerment of the Patient
- 5. Professionalism, Skill, Sensitivity, Listening
- 6. Fear: Loss of Services and Privatisation

An inquiry event was then held at the end of June 2014 with over 40 invitees representing service users, carers, councillors, NHS staff and many representatives from the CVS (Community & Voluntary Service) sector. The themes initially identified by story collectors were endorsed by participants. In addition, a number of key messages were identified:

- Well trained and well paid staff, well supported, who have the time to offer patient centred services
- A holistic approach, taking into account many aspects of the patient's life and health.
- Connectedness and cooperation between services, the voluntary sector and the community
- The patient supported to make as many decisions about their care as they want.
- Healthcare as a whole we reject suggestions that boosting community healthcare opens the door to reductions in hospital care
- No privatisation. Smooth integrated pathways cannot be provided through privatisation and fragmentation
- If there are clinically sound and citizen-backed reasons for closing hospital services, then community services need to be in place and effective first
- Renegotiation Private Finance Initiatives where possible
- New media should be used where appropriate.

Healthwatch Lewisham and the Save Lewisham Hospital Campaign met with commissioners from Lewisham Clinical Commissioning Group and Our Healthier South East London in November 2014 who validated the themes from the Appreciative Inquiry and agreed to incorporate the findings from the Inquiry into future strategies.



What is community care?

For the purposes of this piece of work we understand community care to be any service provided outside of the hospital. This includes social care and NHS services and includes pathways in and out of hospital. Patients chose to discuss what service was most relevant or important to them rather than the story collectors dictating this.

People have told us about district nursing services, diabetes support services, general practice, dementia support services, practice nurses, 111, SELDOC, physiotherapy, re-enablement services, health visitors, IAPT, counselling, domiciliary care, walk-in centres, children's speech and language, CAMHS, chiropody, opticians, dentists, day centres and residential homes, and voluntary sector support services.

Why focus on community care?

With a total yearly investment of more than £10 billion, community services make up 10 per cent of the NHS budget yet there is currently little national data collection for community care⁵. Community care serves the most vulnerable in our society and is often the least visible. People may find it more difficult to discuss community care services compared to hospital services.

We know from the extensive community engagement undertaken by Healthwatch Lewisham that people don't always receive the excellent standards of care that were seen in the Appreciative Inquiry. Care provision isn't always joined up, there isn't always a smooth transition out of hospital and people don't always get the support they need when they need it at home.

The Save Lewisham Hospital Campaign is concerned that having secured the future for Lewisham Hospital; this puts additional budget pressure and reductions on community care services which could put patient safety and wellbeing at risk.

We know from recent and strategies like 'Our Healthier South East London' and 'Transforming London'⁶ that there is a move towards delivering an increasing amount of care in the community.

We also know from government frameworks like 'strong inclusive communities' and the establishment of Health and Wellbeing Boards, that there is a drive towards co-production between local communities, key decision makers and commissioners to develop health and wellbeing strategies at the local level.

⁵ <u>http://www</u>.hscic.gov.uk/communitycare

⁶ <u>http://www</u>.transformldn.org/

WINNING THE BEST COMMUNITY CARE FOR LEWISHAM THE SECOND STAGE OF THE INQUIRY

Aims

It was decided in October of 2014 that a second stage of the Inquiry into community care would be developed to identify the gaps between the excellent quality and good practice identified in the Appreciative Inquiry and the reality on the ground in community healthcare in Lewisham.

The inquiry wanted to identify where local services are currently providing excellent care and what this looks like, and identify which areas need to be improved and how this could be done from a patient perspective.

Additionally, the Campaign's aim is to explore whether current provision is meeting patients' need and how changes in the financial landscape is impacting on the quality of quality care for patients in Lewisham.

Having heard several examples of poor social care, Healthwatch, Carers Lewisham and other partners were keen to incorporate social care into the remit of the second stage.



Why the seldom heard?

One of the founding principles in the establishment of local Healthwatch is to maximise its reach across the diversity of the local community, with a particular focus on understanding the views and experiences of seldom heard groups⁷. This inquiry has talked with service users at food projects, libraries, university students, LGBTQ (Lesbian, Gay, Bisexual, Trans, or Questioning) service users, people with learning difficulties and people who have a long-term condition.

Why the Equalities Act?

The nine protected characteristics protected under the Equality Act of 2012 are:

- Age
- Disability
- Gender reassignment
- Marriage and Civil Partnership
- Pregnancy and maternity
- Race
- Religion and belief
- Sex
- Sexual orientation

Tackling local health inequalities is a priority for Lewisham's Health and Wellbeing Board on which Healthwatch Lewisham has a seat.

"People with certain characteristics may be more negatively affected by health inequalities than other people – even compared with others who live in the same neighbourhood. "⁸

By focusing engagement efforts with seldom heard groups and the 9 protected characteristics Healthwatch can communicate the voices and experiences of these groups to key decision and policy makers to influence their work address some of the health inequalities in the borough.

Methodology

We have used a variety of engagement methods in order to gather data. For the second stage of the inquiry we have captured both quantitative and qualitative data.

The planning team designed a spider diagram based around Solution-Focused Scaling Questions (© 2009, Coert Visser) derived from the themes identified in the Appreciative Inquiry. Using a spider diagram approach helps to create a visual image of individuals' responses, to highlight which themes scored the highest or lowest.

⁷ <u>http://www.local.gov.uk/documents/10180/11463/Delivering+effective+local+Healthwatch+-</u> +key+success+factors/0aa41576-d5f1-40e9-9b7c-fa2d9716618e

⁸ <u>www.local.gov.uk/documents/10180/11651/How+can+local+Healthwatch+tackle+health+inequalities+-</u> +a+nef+report+for/0785b95e-7ccb-4507-85eb-85bea0a003e2

We asked participants why they had given a particular area of their care the score that they did, and what would have made the experience a higher score. These probing questions help the story collector to understand what was of value to the service user, what issues resulted in making the experience less positive, and what could be improved to make the experience better.

We asked patients where possible to describe their most recent experience. Tony Quinlan who specialises in narration and storytelling suggests that this provides a more accurate account.

Community Engagement

Between December 2014 and March 2015 Healthwatch Lewisham visited 20 community groups, organisations or events to listen to their experiences of community care services.

We completed 113 interviews/questionnaires with individuals, and had 12 group discussions about community care.

Healthwatch went out to visit the following groups or places to engage with members of the public in line with our focus on seldom heard or the 9 protected characteristics groups:

Healthwatch tried to focus their engagement around the 9 protected groups of characteristics under the 2010 Equality Act.

The Diamond Club The Parent and Carer Forum **Contact A Family New Parents' Coffee Morning** The Stroke Association's Support Group Meet Me at the Albany South Lewisham Group Practice Kaleidoscope Children's Centre Whitefoot and Downham Food Project The New Cross Health Centre **Diabetes UK Support Group** 60 and Up Honor Oak and Bellingham older people's groups **Carers Lewisham Coffee Morning Maternity Services Liaison Committee Network Crofton Park Library Goldsmiths University LGBTQ Health Seminar** St Laurence Church Mother's Union Lewisham Speaking Up's Health Action Group **Retired Civil Servants meeting – Catford** The Stroke Club International Women's Day at the Green Man, Bellingham

Analysis of existing Healthwatch data

Healthwatch and the Campaign have also used evidence gathered over the past year as part of Healthwatch's wider community engagement programme to inform this inquiry:

- 'Enablement and integrated care' priority report
- Healthwatch Lewisham Discharge Inquiry
- 'Access to primary care' priority report
- 'Mental health' priority report
- Annual Event Priorities Setting workshop findings
- District nursing service user feedback reports
- Initial community care services report (November 2014)
- Lewisham Parent and Carer Forum engagement report
- New Cross Health Centre summary report
- Summary of feedback from the Physiotherapy exercise group at Lewisham hospital
- Kaleidoscope service user feedback reports
- Healthwatch "Your Voice Counts' Reference Group meetings

WINNING THE BEST COMMUNITY CARE FOR LEWISHAM USER EXPERIENCE: KEY FINDINGS BY SERVICE

GENERAL PRACTICE

48 of the 113 people we spoke to chose to share their experience of their GP service. Here is a summary of the results by theme.

Accessibility

Getting an appointment with a GP is the number one issue that patients and members of the public have raised with Healthwatch over the last year. Healthwatch has listened to a variety of experiences. While some people told us that they do not have problems accessing their GP most have said that they do experience difficulties getting an appointment, particularly getting through over the phone for same day appointments or to see their doctor of choice. Access does vary between surgeries.

Here are some examples of the comments people told us:

"I can go weeks without getting an appointment. I call 80-90 times, very stressful."

"She's had to go and wait outside doctor's door to get an appointment because she can't get through at reception."

"Never any appointments, my dad queues at 6.45am in the morning so I can get an appointment."

"If the children are ill you need an appointment on the day for school, not always easy. I can get here at 8am and there may not be any appointments left. I've had to go to A&E in many cases."

"I know some of my friends end up going to A&E because they can't get a doctor's appointment and they get panicky." Service user from Speaking Up Forum.

On these occasions, Healthwatch informed patients about the 111, SELDOC, walk-in urgent care centres, and encouraged patients to visit their local pharmacy when seeking non-urgent medical advice.

A local vicar contacted Healthwatch about the barriers some of his most vulnerable parishioners, older people and those experiencing mental health difficulties, had when trying to access doctors' appointments.

"The issue I fear is that the most vulnerable people get the worst experience because they find it more challenging to represent their own needs and concerns clearly. I don't think these stories and experiences find their way to the ears of those who need to hear. The 'system' needs to find ways of listening to first-hand experience of such people."

People who live transient lives, particularly if they are homeless, experience problems accessing certain services.



Lack of continuity of care

Not being able to get an appointment with a patient's GP of choice had an impact on their quality of care. Many felt that new or different doctors could only treat the ailment while their long-term GP understood the wider context; their medical history, social situation and how this has an impact on their health.

"They know about my whole family situation."

"If it's our specific doctor they know everything, if it's not or a new doctor not so much."

"Good when regular doctors are available because they know your situation, with increasing use of locums this is really lost."

Lack of continuity of care is a result of the difficulties in getting an appointment with patients' GP of choice. When patients were prepared to wait this usually takes between 2-3 weeks and Healthwatch heard of one case taking up to 8 weeks, which understandably had an impact on the quality of care they received.

Building a relationship with one doctor was extremely important to LGBTQ service users. They wanted to be able to choose a GP with whom they have developed a relationship of trust and who understands their medical history, background, social situation and identity. Some participants explained that they had previously had negative experiences with some doctors therefore finding a doctor you could trust was extremely important. The group felt that it was increasingly difficult to get an appointment with the GP of preference which was having a negative impact on the quality of care they received.

"I find my GP very impersonal as I never seem to see the same person twice."

Time

"Time is so important in order to listen to you, to be prepared to listen."

Healthwatch was pleased to hear that the majority of the people we spoke to felt that they had more than enough time in appointments with GPs. We heard of examples of doctors going beyond the appointed 10 minutes until the problem was addressed or examples of doctors making time in special circumstances which patients valued immensely.

"Always asks what's wrong, does the checks and speaks to you, always enough time."

Patients felt that the allocation of time varied depending on the doctor they were seeing:

"Before much better but good doctors left, now it's usually locum. 10 minutes then stop."

"My particular doctor allows me time to explain myself, others don't."

The majority of patients with low level needs felt that a 10-minute appointment was "Enough for my needs". However, many patients and families who had more complex needs felt 10 minutes (the standard GP appointment time) was inadequate to address all their health concerns.

One mother, feeling overwhelmed by the challenges, whose child has dyspraxia had visited the doctor to ask for extra support for her and her son. She was told to re-book another

appointment: 'I don't have time to deal with this, you need to book a double appointment for issues like this'. It was only when she burst into tears that she felt the doctor began to show her compassion.

Some of the families we spoke to who found it very difficult to get an appointment with the GP said they were forced to 'save up' their issues until they could get an appointment. As a result when in the appointment 10 minutes was not enough and they found it even more challenging to get a double appointment.

Having adequate time to discuss what the issues are also had an impact on the last theme 'seeing the social situation and not just the condition'.

'They could ask me what the problem is, spend more time, not just look at the ailment."

Several patients we spoke to felt that if they had spent more time asking how they were, they would get to the root of the problem.

One example of a patient who had a really positive experience with their doctor said,

"They always ask how I am doing emotionally to see how this is impacting on my health."

Professionalism, Skill, Sensitivity, Listening Caring and attentiveness

Healthwatch was pleased to hear that the majority of the people we spoke to found their doctors extremely caring and attentive, particularly when they were able to see the same doctor. Many people described having had past negative experiences with particular doctors, which resulted in them 'avoiding' certain doctors, while seeking appointments with one or two doctors with whom they had a positive relationship at the practice.

"It varies greatly depending on who you see, so now I will only see certain doctors."

"More caring now than previous years. Now I feel more than just a number."

Asking questions was something that patients felt reflected how caring and attentive staff were:

"...asked questions, encouraged to get back on track."

"My doctor knows you by name, talks to you like I were a friend, I don't feel rushed and get the time I need." Having a doctor that understands their medical history, and their wider social determinants was important to how caring and attentive patients perceived their doctors to be. Patients tended to rate higher on 'knowing the person and social situation' if they had one doctor who they were able to see when required. Patients who saw new or locum doctors gave lower scores.

Reception staff

Healthwatch has heard varied accounts of surgery reception staff. Some patients who have built up a relationship with the practice had very positive things to say about the reception staff who help them to access the services they need. Others have told us they feel 'blocked' by reception staff who they feel lack empathy or awareness about their identity or needs. Many of the older people we spoke to did not feel comfortable telling the reception staff what was the problem: "if I say I want to see a doctor they should accept that".

Feeling heard

Healthwatch was pleased to hear that the majority of people said that they did feel listened to by their doctors.

There was also a correlation between a relationship being built up with one doctor to understand their wider social context and the extent that they felt they were listened to as patients:

"It was difficult at first but once I'd explained that 5 of my children had died they understand and now listen to me."

Empowerment of the patient

The majority of the patients we spoke to felt empowered by their doctors. Having things explained properly, being kept 'informed', being allowed to ask questions, being offered a choice and leaving the ultimate decision to the patients were all conducive to helping patients feel involved and empowered.

"I was given all the information I need and explained types of the pill."

"If there's something that I don't want to do I'm not told that's the only option."

"I speak out if I want something, I ask them to do my blood pressure if they don't."

"I'm given the facts, choice left to me."

"I was informed about every aspect of the baby's care."

Seeing the person and the social situation not just the condition

Patients with more complex care needs were more likely to find this aspect of their care more important. Most people with complex needs and one named doctor felt that their doctors did understand and proactively tried to find out about their wider social context. This was less likely to be the case with new or ever changing doctors.

The majority of respondents from the LGBTQ focus group at Goldsmiths felt that health professionals did not get to know them or know their wider social situation which was very important to them. Being able to access their GP of choice improved this.

Smooth proactive pathways – communication between GP and other doctors

Healthwatch heard a number of experiences where patients had experienced difficulties around the communication between their doctors and other services. There were other examples where copies of letters, discharge information and notes had not got back to their doctors from other services like the hospital.

"I've wasted time and had to go to more appointments because the info wasn't on the system, I've had to retake tests because the results hadn't been shared, better communication would save time and resources."

"If tests are done at Lewisham Hospital my doctor can't access results. Other services send a letter or inform the doctor who will call parent if urgent but if not urgent we don't hear anything."

"I had to bring own discharge card to the doctors. A&E don't share records with doctor, 2 months ago went to A&E and the doctor still doesn't have the record of me going to A&E."

Not all GPs offer the same opportunities in referring patients to community based provision or healthy lifestyle opportunities. One community group leader we spoke to had noticed a difference in the provision offered by different GP practices to her members. Some had been referred to the Health Promotion Service and others had not. They felt it was important that all patients no matter which doctor surgery they attended had access to the same services.

Healthwatch has several comments about GPs' lack of understanding or experience in dealing with mental health issues.

"Son is unhappy about the service he has received at his surgery and requested information about a GP who was more supportive of patients with mental health issues." The importance of accessing information, and being offered and signposted to support in the community by GPs was a theme that was often raised during discussions with community groups and organisations throughout the inquiry.



NEW CROSS WALK-IN CENTRE

There were very few people that talked about the New Cross Walk-in Centre during the Inquiry. Two patients independently got in contact with Healthwatch last year to communicate their poor experiences, and stressed that they felt the quality of care received at the centre had gone down in recent years.

In both cases they had experienced long waiting times. It was felt that the centre could better communicate anticipated waiting times to patients on arrival so that they could assess the situation. This is particularly important for patients who have long term conditions like diabetes and who need to plan for their safe self-management.

Several members of the Speaking Up Action Group had very positive experiences at the Walk-in centre and felt supported and cared for.

MENTAL HEALTH

Accessibility

Access to mental health support services has been a big concern of many of the service users, groups, organisations and NHS staff we have spoken to over the last year.

Access to IAPT services (Improving Access to Psychological Therapies) has been particularly challenging for people we spoke to. At a Your Voice Counts event in June 2014, people told us that it was sometimes 'easier to self-refer' than getting a referral through the GP. They also told us many people were experiencing a 3-month wait to access IAPT.

"Very long waiting times for CBT (cognitive behaviour therapy). Needed 2 referrals before I managed to receive the service. By this point I was burnt out. Staff wrote inaccurate things in my notes such as me not being depressed."

"Access to counselling is too long – this leads to symptoms worsening and can lead to complete breakdown. More counselling services needed."

"I was told by my GP that I wouldn't be able to access IAPT counselling services if I'd already used them in the last 6 months."

One participant at an LGBTQ focus group who works closely with Trans people said that there is a national trend that transgendered people often do not access mental health support for fear that this will negatively impact on their chances of having gender reassignment treatment.

"I was referred for counselling by the surgery. I waited months for an assessment, even though Southbrook Road had already decided it would be helpful. Then I was referred for another assessment and finally was told I would need too many sessions so should go private. There should be more direct access - if your GP decides you need counselling, or any other service, you should get it. Invest more in mental health. You quote statistics about the prevalence of mental health issues. Act on this. PROVIDE SERVICES OUT OF WORKING HOURS."

There were also concerns for clients who are relapsing but do not have a Care Coordinator as they have been discharged back to the GP who may not have the experience or time to provide the necessary support. In these cases people in crisis are directed to the A&E Psychiatrist Liaison Team and this can mean a 5-6 hour wait to be seen, which can be a challenging experience for workers and clients.

"There used to be a one year wait for counselling, but now it is 2 weeks with lots of options."

Access to information

Healthwatch has frequently heard that people, including carers and young people, are not sure where to go and access support for their mental health issues. This has been echoed by

the conversations we have had with community groups, organisations and NHS staff. Knowing where services are, and ensuring GPs have time to find out and refer people to the necessary support is crucial for patients feeling supported and to ensure their problems don't escalate.

Choice

"CBT is not for everyone."

People questioned the level of choice available when it comes to treat mental health issues at the priorities workshop in December's Healthwatch annual event, and at a focus group with the LGBTQ society at Goldsmiths University of London.

One participant at the LGBTQ focus group described their experience of being referred to group therapy in Lewisham. They didn't find group therapy useful as there were so many people with so many issues different to hers, making her feel like she shouldn't be there as hers were 'less serious'. They would have preferred to be in a group with people of a similar age or with similar problems.

CBT is widely available in Lewisham but one participant reflected that there needs to be a choice of therapies available,

"CBT won't cure everything".

Feeling supported

The majority of people we spoke to who were accessing counselling or IAPT services really valued this service and the improvement in their health and wellbeing.

"Best thing that happened to me was I was given counselling. The worst was when I was an inpatient I did not get the care and attention I needed. The nurses did not have time to sit and talk to me. Kept in isolation for too long."

Healthwatch has heard many examples of patients not receiving support upon discharge or not being adequately prepared for discharge from their IAPT therapy course leaving many feeling very isolated without support. Some patients told us that they had to re-refer themselves in order to get additional support. Many people felt that 6 sessions weren't enough.

Accessing support during the referral process or outside of appointment times as well as self-help tools were things that many people told Healthwatch were needed.

"Due to the reconfiguration of day services, people have become isolated. Resulting in some people just leaving their house to go to the GP once every two months for *medication. That's the only time and the only contact with another that some people have.*" Feedback from SLAM Stakeholder event

Peer mentoring is valued as a form of support

Healthwatch heard at various public engagement events that peer support can be a powerful tool in aiding recovery. Feeling that you have someone to talk to who understands what you're going through, who can explain things and support you in a non-judgemental and non-medical way was something patients valued. It was requested by a number who were not receiving this form of support.

Smooth Proactive Pathways

Patients told us the process from finally going to get help to seeing the doctor to getting support or therapy was too long. They felt 'isolated' and on their own outside of the service and would appreciate tools, advice, self-help and crisis support.

Education

Raising awareness of mental health issues with employers, GPs and surgery staff and society as a whole was seen as important. The public health 'mental health first aid course' is seen as best practice.

CHILDREN AND ADULT MENTAL HEALTH SERVICES (CAMHS)

Access to services

Waiting times to access CAMHS has been an issue that service users, carers and members of the public have frequently raised with Healthwatch Lewisham over the last year. There is also a lack of awareness amongst young people and their families as to where and how to access additional support outside of CAMHS services. Some families at Lewisham's Parent and Carer Forum were unclear of how the referral process to CAMHS works.

Healthwatch was pleased to hear that a new triage system has been introduced which ensures that the most at risk young people can be given priority as a measure to address the long waiting times.

One of the most recent experiences gathered as part of this inquiry was a service user who had been seen three days after the referral was made by their GP:

"Two doctors have contacted me from CAMHS. I know I can phone up at any time to get help."

This service user gave very positive ratings for access and feeling supported.

However, access to CAMHS continues to be an issue for many of the people we spoke to with experience of using the service.

"Closed his original case, on waiting list for CAHMS. Couldn't contact anyone when child's behaviour deteriorating. Took a year to this 1st appointment"

DISTRICT NURSING

The impact of staff shortages including inadequate provision at the weekends, district nurses arriving late or not communicating about arrival times, lack of communication between different care givers and with carers, are themes that have been brought to Healthwatch's attention since writing a review of service user feedback in April 2014.⁹

However, Healthwatch has heard fewer issues concerning District Nursing Services in the last few months. Service users find the staff helpful, kind, supportive, friendly, and respectful. The majority said that they do feel listened to. An older people's group visited in February 2015 told Healthwatch that they were pleased to see district nurses wearing uniforms again. This helped for identification purposes. Overall the quality of nursing was considered to be good. However, many problems appear to remain.

"Different nurse every time. Didn't know who was going to come."

"They didn't turn up at all, the call centre had no knowledge of when they were going to arrive or call back."

It was noted by some interviewees in 2014 that the district nurses were the only people they saw in a day, and when they felt the nurses were 'in and out as soon as possible' without engaging with the patient it left them feeling unhappy with the experience.

One lady commented that being bed bound left her in an extremely vulnerable position and felt her overall experience of care had been humiliating.

DIABETES SUPPORT SERVICES

Healthwatch Lewisham visited members of the Diabetes Support Group to listen to their experiences after a leader had contacted Healthwatch concerned about the disparity of provision in Lewisham for patients with diabetes.

Accessibility

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n<u>http://www.healthwatchlewisham.co.uk/sites/default/files/district_nursing_review_of_service_user_feedba_ck_final_report_14_14.pdf</u>

Patients who have access to diabetes specific care generally thought that the quality of care provided was very good. They found their diabetes nurse a valued source of support and medium to access information and further support.

Some individuals we spoke to had commented seeing a 'reduction' of diabetes specialist nurses recently and felt many nurses had come up to retirement age with few new nurses replacing them.

Several people have commented about a lack of practice nurses and diabetes specialist nurses in the Downham/Bellingham area:

"There's one part-time nurse left between four surgeries, they're run off their feet. I'd called to get a dressing changed. They'd said I'd have to wait 6 weeks for a dressing change, I need it tomorrow, it's never been like this before."

Another person was currently waiting 6 weeks for her annual diabetes check.

"Told we can have a long annual check-up but hard to get an appointment."

Access to information

Members of the Diabetes Support Group said that there was a lot of fear and lack of understanding surrounding diabetes, especially for newly diagnosed patients. Although members of the Diabetes Support Group were clearly accessing support, they felt there were many more people with diabetes who were not accessing and perhaps did not know where to access support. There is only one diabetes support group in Lewisham and not everyone that we spoke to with diabetes knew about the support group, or where to access additional information about managing their condition. The group said that it was a key source of important information for its members. They also felt more could be done to inform diabetics about what they are entitled to (Healthwatch was asked to provide this information). The group who had valued a visit from the lead practice nurse in Lewisham, as well as the DESMOND programme at Lewisham Hospital.

Empowering the patient

Participants at the support group expressed that the focus had moved towards selfmanagement however there were difficulties in accessing support when it was needed.

The group weren't sure that everyone that had or was newly diagnosed with diabetes knew about the DESMOND course, and if so how they found out about local support available.

One patient who had been diagnosed out of borough had really struggled to get support in Lewisham where she now lives; Lewisham Hospital had told her that she couldn't access DESMOND because she wasn't diagnosed in the borough. (This happened three years ago.) Since accessing the course it had 'made all the difference'. Availability of DESMOND varied. Recently, one member had heard that there had been difficulties in recruiting more trainers to run the programmes which was one reason for the varied capacity.

One participant had noted a big improvement in the DESMOND course when she went recently for a top-up compared to a few years ago. She told Healthwatch that she felt the action plan was what had made the difference: patients were asked to choose one aspect of their care that they would like to work on and write actions of how they would go about doing this. This she thought helped to focus and encourage patients.

Peer support programmes, being able to access healthy living activities and the ability to access specialist support when needed were paramount to ensuring people could maintain their self-management successfully and with confidence.



COMMUNITY MATRONS

We spoke to one person who had a community matron visit her home early in 2014 after her doctor had refused a COPD check that she needed.

"The community matron from Lewisham Hospital came to my home on a Saturday, she was excellent and checked everything and was very thorough."

PRACTICE NURSES

The majority of people we spoke to about their practice nurses felt that they had more than enough time with the nurse and the majority found them very caring and attentive.

"Always enough time with the nurse." This particular patient noted the difference between time with the nurse and time with the doctor, "doctors have so many appointments to get through, the nurse takes more time to talk things through and ask questions."

"Lovely, there's no rush with the nurse, nothing's done before she talks to me."

Patients felt supported, listened to and empowered when the nurse explained the options to them, listened to their preferences and left the choice up to the patient.

"If there's something that I don't want to do I'm not told that's the only option."

Some of the patients that we spoke to in the Whitefoot Downham area noted the lack of availability of nurses in four practices:

"Still waiting for appointment, was given a 6 week wait for annual review (for diabetes check up) due to staff shortage, a locum nurse now taken on to help situation"

CHIROPODY

Accessibility

An older people's group in Catford raised the issue of accessing chiropodists. Many experienced long waiting times. The majority said that chiropodists offered an excellent service but it was hard to get an appointment or they didn't come frequently enough. Most said they come to their house every 3 months, one member had had to wait 8 months.

One respondent had used the Dalton Road foot clinic until it closed. Since then they are only able to get their feet checked with the practice nurse at the surgery. They said that the chiropodist "used to check things that the nurse doesn't check".

A participant told Healthwatch that since the foot clinic at Honor Oak Practice had closed she would need to travel to New Cross to get her feet checked. She had since put off going because a problem with her knee which meant she was reluctant to travel.

The majority of people we spoke to who had learning difficulties said that they regularly accessed chiropodists and received a good standard of care.

Having to go private

Approximately 10 people out of 35 at the group said they used chiropody. Five of those said they had to pay for the service privately because they couldn't access the service publicly. Outside of the group, two other people with diabetes said they now went privately because the chiropodist wasn't thorough enough.

CHILDREN'S SPEECH AND LANGUAGE THERAPY

From Healthwatch's engagement at the Kaleidoscope Children's Centre, families have told us that they have experienced long waiting lists to access speech and language therapy. Others have said the process of getting referral to getting support was taking too long.¹⁰

"Not easy to get first appointment. Took four months for first appointment then another 4 months till second one. Crucial time for child with speech delay. Eventually got info/tips after 9 months. Good but late."

"Very helpful. My son has come a long way since attending Kaleidoscope for speech therapy. Overall it is very good but maybe the waiting time between blocks could be shorter."

PHYSIOTHERAPY

Accessibility

Healthwatch has heard that there are long waits to get an assessment through physiotherapy at Lewisham.

One person with learning difficulties was not able to attend his usual horse riding lessons, something he really enjoyed, until he had had a physio assessment. His support worker raised the waiting time with Healthwatch.

Another person we spoke to is currently on a two month waiting list for an appointment. Her arthritic hand is already getting worse, and felt that it would be good to be given exercises to do meanwhile and advice about what she should do to look after it in the meantime along with the letter.

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http://www.healthwatchlewisham.co.uk/sites/default/files/healthwatch_lewisham_kaleidoscope_report_june .pdf

Community Physiotherapy.

"Mother was discharged from Lewisham Hospital and was told that her daily physiotherapy was to continue on discharge. No treatment received yet. A more seamless transition and discharge from hospital is needed."

"Doctors sent referral, 2 weeks to get a reply then on waiting list for 8 weeks. The patient was in a lot of pain after her surgery, 10 weeks she has to wait for physio, said the doctor said it wasn't urgent. Longer appointments and seen for physio in quicker time are needed."

"Prompt referral from GP, then full 18 week wait to see consultant. Further 10-11 week delay for required diagnostic tests, then more waiting to see doctor again to get diagnosis and treatment plan. So best part of year gone before any real practical help available. My right hand involved, impacts on MOST aspects of daily life from food preparation, laundry, driving etc, FAR TOO LONG WAIT."

"Access at GP service to physiotherapy/advice or exercise scheme. Much speedier access to diagnostic specialists - 6 week wait max for conditions which interfere with daily routine. Need more resources put into routine health care as failures here have great impact on daily life."

"Service user had a fall. Had daily physiotherapy for a week in hospital. Discharged and no follow- up physiotherapy was provided. Community Physiotherapy is different to impatient physiotherapy."

Physiotherapy for children

Parents and carers at Kaleidoscope have also told Healthwatch that they have experienced long waits after referrals to physiotherapy. Others however comment positively.

"Very good service, always helpful and welcoming and understanding."

"It was quite a fast diagnosis for my grandchild and the help and information I got was good."

Empowering the patient

When Healthwatch visited the physiotherapy exercise group last year, the group had all expressed how positive they found the 12-week course. Many wanted to continue group based exercise to help maintain motivation and encouragement but they and the leader said that transport was an issue to access other groups in the community.

Another person we spoke to is currently on a two-month waiting list for a physiotherapy appointment and felt that it would be good to be given exercises to do meanwhile and advice about what she should do to look after it in the meantime along with the letter.

At Healthwatch's annual event's 'priorities setting' workshop, one person felt that physiotherapy should be based back in the community rather than at Lewisham Hospital in order to provide patients with more joined up community care.

Maternity

Healthwatch spoke to several people, through the Appreciative Inquiry and the second stage, who expressed how useful support with breastfeeding had been. They had found breastfeeding cafes useful for support to be able to breastfeed, get advice, peer support and meet other first time mothers.

View from informed user.

The quality of midwifery in Lewisham is good. There are a reducing number of agency staff and there is good training. Home births and breastfeeding are well supported.

HEALTH VISITORS

Healthwatch has heard varied reports of health visitors: some people have had excellent experiences of health visitors while others have had less positive experiences.

One mother of a child with complex needs had moved from Sydenham to New Cross Health Centre. Her former health visitor in Sydenham had promised things but nothing happened. She had little contact with the family: "I thought that's what happens." Now the health visitor is amazing, referring her to every service possible, (her child has complex needs) and is using the services at her local children's centre, spending over an hour and half every month as well as chasing up the doctor or other services where needed.

"For first time mothers, we don't know what we were doing, we need help and information."

"I gave birth to my son in April 2011 and around 2 months later I contacted the health visiting team about feeling really unhappy and scared. I was advised to go to my nearest baby clinic which, fortunately, was being held the next day at Downham Leisure Centre. I went along with my son, feeling petrified about what was going to happen. The health visitor was amazing, she was non-judgmental as she explained that she thought I may have post-natal depression. The health visitor called my GP immediately and made an appointment on my behalf for the following day. Which resulted in me seeing the Women's health counsellor for 2 years. The HV's attitude and kindness helped to start the ball rolling in keeping me and my son both safe and happy. I have seen HVs since then and I have been thankful for the easy access and support that I've had since my son was born." A Lewisham Mother's view

SOCIAL CARE

Access to assessments

A reverend in Downham said his older parishioners had often experienced long waits for social care assessments for care packages in order to go home from hospital. Older people remained in hospital for longer than necessary while care packages are arranged. There are also delays in assessments for the housebound.

Carers have also contacted Healthwatch expressing their frustration in getting carer's assessments to ensure their needs are fully taking into consideration.

Access to services

Healthwatch has spoken to several members of the public who have seen their social care provision cut over recent months.

One participant at a Stroke Club meeting who has severe communication issues – both in receptive understanding (he prefers to see things written down) and in speech – has had his care provision stopped and is expected to pay for his care now.

Another gentleman who spoke to Healthwatch at the Greenman was complaining that he no longer had support to have the flat cleaned or get his laundry done. He told Healthwatch that he had to wait 6 weeks in order to save enough money to take his clothes to the laundrette and had to find someone to help him get them there.

The African Advocacy Foundation had also noticed that home visits to members who had long-term conditions or mobility issues were happening with less frequency and this had had an impact on the number of services that people were able to access.

Language can be a barrier to accessing social care provision and knowing how to access services.

Monitoring

One community group leader for an older people's group expressed that they felt problems seem to arise after care packages have been assigned and social workers were taken off the assigned service user. She felt that there is no one to monitor that the care package is working, and therefore it is difficult to address issues if problems do occur. This meant that if problems occurred they had to go through the entire process again to wait for a new care assessment.

Identification

Some participants at a discussion at a Your Voice Counts event told Healthwatch that domiciliary paid carers don't always carry identification or show their identification which led to safety concerns. This also causes carers, family and neighbours concern who found it difficult to identify who was going in and out of service users' homes.



Time

At a Your Voice Counts Event some people were concerned that they had witnessed domiciliary carers putting service users to bed at anti-social times in order to suit staff rather than the service user.

Healthwatch Lewisham has heard many comments that service users and their carers feel that domiciliary carer workers are always in a hurry and don't have enough time to spend with patients. Carers or service users often said that they did not blame the individual but that the time allocated to attend to service users was not long enough.

Healthwatch had heard from workers at the Stroke Association that they hear lots of lowlevel complaints about care agencies and are not sure where to direct their concerns as many are not serious enough to warrant a complaint. They have spoken to service users and carers who say staff not arriving on time or phoning them to say they have been delayed nor apologising or explaining the delay. In their opinion it is 'the basics' that make all the difference to the service user and impact on the quality of their care.

"One example was an older man who likes routine and gets up at 8am every day. The care worker didn't arrive until 9am and didn't call and this put him in a bad mood for the rest of the day."

Problems often seem to occur when the regular carer cannot come.

Patient centred

Being asked how the service user would like to be addressed, particularly for older people was important, e.g. address by first name rather than last.

Members of the Speaking Up Health Action Group expressed a desire to be directly addressed rather than health professionals speaking to their support workers.

Well-paid, well-trained staff

Participants at a Your Voice Counts event felt that low paid staff had an impact on the quality of care their loved ones were receiving.

Access to parking permits in line with community therapists would help travel and parking difficulties.

Additional Support

Many older people have told us that they value Link Line as a great support. Service users and their families know that there is someone there in the event of an emergency and this is a great comfort for them.

One Care Support is another project that offers holistic support to older people with additional needs. Members of an older people's group valued the service in helping them get the best out of aspects of their care and were concerned that this project might be reduced or stopped in the future.

SEXUAL HEALTH SERVICES

When Healthwatch Lewisham engaged with members of the LTBGQ Society at Goldsmiths University as part of this inquiry the group's 8 participants all felt that LGBTQ sexual health needs could be improved at the general practice level. Participants shared several examples of health professionals not discussing or addressing their sexual orientation, or getting advice as to where to access additional help, advice or services.

Several of the bisexual women we spoke to as part of the Goldsmiths focus group did not feel they needed to access sexual health services locally, and that further education would be needed in order to communicate the importance of doing so. They also felt that the advice being given to bisexual women is different to that being given to straight women which some participants felt was based on assumptions and judgements rather than clinical research as the risks are the same.

One young person raised the issue of accessing family planning support in different areas of the borough:

"It's not fair that I would have to pay £25 to pay for the morning after pill in a different area or borough. I live and study in different boroughs and travel between boroughs, I should be able to get the morning after pill wherever I am. This prevents young women from using the morning after pill."

The Waldron Sexual Health Clinic

Several of the participants at the LGBTQ focus group had used the Waldron sexual health clinic. One participant described having to wait a long time and suggested the chairs could be rearranged to make people waiting feel more comfortable.

Participants felt offering both a drop-in service and offering pre-booked appointments would be preferable. For the drop-in, they would like to be told how long they should expect to wait and the latest time to arrive if the drop-in gets full.

School Nurses

The LGBTQ focus group felt that school nurses are a great resource and need to be up-todate about health needs including wellbeing and sexual health needs of LGBTQ young people or young people who are exploring their identities. Having information and knowledge on hand as to where young people could go to seek future advice and support is important. This also applies to mental health services and support.

COMMUNITY ORGANISATIONS

Additional support offered by voluntary and community organisations is really valued by the people we spoke to, and can considerably improve the quality of life and care a person receives in Lewisham.

Access to information

Many people have expressed to Healthwatch that they do not know where local services are or how to access them, particularly for older people's services and for people experiencing mental health difficulties. People are at a greater disadvantage if they do not use the internet.

People at an older people's club said that they would like to see a network for carers and older people to know what services are available for them to access. They missed the information service at the library and would like to know when a new database would be ready to find out where local services are.

Healthwatch plays a key role in connecting people to local services as part of their signposting and information programme via their telephone service, and within their extensive community engagement programme.

Additional Sources of Support

Patients have expressed the need to access support outside of appointments, particularly if they are experiencing mental health difficulties.

Peer-to-peer support programmes would be valued by patients. Healthwatch has heard requests for support groups for people who have been diagnosed with diabetes, multiple sclerosis and additional support for cancer patients.

People really value the support CVS (Community & Voluntary Service) organisations provide to assist in the completion of forms to request assistance. Older people said how much they value the Lewisham Disability Coalition for assistance in completing forms to get support. Parents would also regularly attend Kaleidoscope to get similar support.

Social inclusion

People have told Healthwatch what a difference participation in community groups such as Meet Me at the Albany, The Diamond Club, Friendship Fridays has on their mental health and wellbeing. Groups can be a source of support, peer support, advice, information, events, friendship, exercise and to feel part of something.

Befriending schemes are a much valued and often oversubscribed resource to tackle social isolation.

Access

Getting referrals from GPs is imperative to ensuring isolated vulnerable people can access some of the forms of community support we have outlined here. Healthwatch has heard that some GPs are more aware of community support groups than others, for example referrals to the Health Improvement Service and the Healthy Walks programme can vary.

Transport can be a major barrier for people accessing these services. Healthwatch has heard of several examples of people with disabilities and learning disabilities not being able to access day services or activities due to a lack of transport. We have also heard that services like Dial-a-Ride are also heavily subscribed.

"Dial-a-Ride great service, over-subscribed, transport in general is an issue"

Some people told us that they need or would like people to accompany them to take them to healthy living programmes like the healthy walks.

CROSS-SERVICE ISSUES

Discharge processes

Having heard several worrying examples of unsafe discharge, Healthwatch undertook an inquiry into discharge processes last year. Although this was not a separate theme that this community care inquiry addressed, it is related to 'smooth proactive pathways'.

Healthwatch found that discharge practices can be unsafe¹¹. Findings identified the need for improvement in the following areas:

- Awareness of discharge procedures
- Inconsistency of discharge planning
- Poor communication between multi-disciplinary agencies
- Family, friends or carers not involved in the discharge process
- Long waits for those waiting to be discharged

"I was left to travel home with my belongings spilling out of plastic bags, while wearing pyjamas and with no money and/or means to travel. I was fortunate that a friendly stranger helped me out. Travel should have been provided... It should be provided for ALL vulnerable patients."

"None of the promised help such as a physio and enablement pack appeared and there was no visit to see how I was coping."

One patient from the Ladywell Unit told us that they had stayed on the unit several times over the years, and when asked about their previous discharge said:

"You never get any discharge papers, just told to leave'. Commenting further, "Maybe if you get more help when you leave you wouldn't end up coming back here".

We heard some examples during the community care inquiry where the discharge process hasn't worked as smoothly as it should:

"I had to bring my own discharge card to the doctors. A&E don't share records with doctor. 2 months ago I went to A&E and the doctor still doesn't have medical records from this visit."

Healthwatch was pleased to hear the development of a 'winter angels' short-term befriending scheme to support older people returning home from hospital although the project has received fewer referrals than expected.

¹¹ http://www.healthwatchlewisham.co.uk/sites/default/files/discharge_report_.pdf

Reablement

Healthwatch spoke to two members of the Stroke Association Support Group that felt that they had been discharged too soon from the reablement team provision which supported them when they returned home from hospital. They both agreed the service was excellent but they would have liked more than the 6 weeks of support offered. One participant said *"it just stopped with no warning"* and the other stressed that it was important to keep you motivated knowing that someone was coming to see how you were progressing with the exercises.

Access to information

During the Discharge inquiry, Healthwatch were told by residential home staff members that often there was no communication from hospitals around discharge and that the residential homes have to chase hospitals to find out when their residents are being discharged. There have been instances when their residents have been discharged without them knowing. Likewise, we have heard from family members, friends and carers that neither the hospital or care home communicates to them when their loved one or client has been discharged which often causes concern and upset.

Last year, the Healthier Community Select Committee (HCSC) heard from SLaM's patients who had been unofficially discharged from secondary care. A group of bipolar patients had been informed by their consultant or social worker that their care was being transferred to primary care. However, it had taken a long time to get a discharge appointment to inform them of the process. They stressed concerns that their condition fluctuates and often their GP does not have the time or knowledge to support them.

Carer involvement

Carer involvement is a theme that patients and family members regularly raise with Healthwatch.

Whether we spoke to parents of children with complex needs or carers of older family members, being listened to, being involved and a partner in decision making process, getting acknowledgement from professionals that they understand a patient's needs and can tell professionals about the wider social situation are things that patients and carers value and impact on their quality of experience.

We heard of a positive experience from carer's perspective whose mother is 92 and who has Alzheimer's:

"She has a visit from the Mind Memory Clinic. Had to originally go to hospital but it was really difficult to get there so they requested that they visit at home, which they did, really great. They call to find out when they should come, it's a great service and they offer to come to the house, appreciated. Always offer support, links to other services, ask how the carer is using a questionnaire, appreciated. They unfortunately have now stopped offering the home visits." "The main decisions were made by me and my husband having been informed."

"I was informed about every aspect of my baby's care"

"I'm not always told when my daughter moves from one place to another, not informed about hospital appointments."

Reduction in home visits

Healthwatch has noted reductions in home visits taking place over a number of areas in Lewisham.

African Advocacy Foundation noted the difference they had seen in their members with long-term conditions and mobility issues receiving far less home visits by social workers or support workers which left their members with limited access to support.

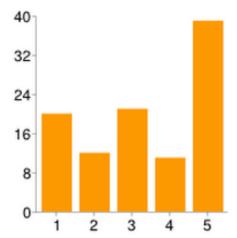
A service user of One Support Service came to a Healthwatch Sub-Committee meeting to express her concern that support for people experiencing mental health difficulties in their home is no longer available now that funding had ceased.

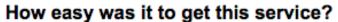
Contact-a-Family and Carers Lewisham now conduct very few home visits. Families have to attend organisations' centres or places like Kaleidoscope in order to receive support.

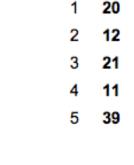
SURVEY RESULTS

Healthwatch Lewisham received 113 responses using a scaled and solution focused approach. The majority of these were gathered speaking to individuals on a one-to-one basis. A small proportion were received electronically through the online survey that was sent to Healthwatch partners, is available on our website and through the e-bulletin.

A high score means the respondent was positive about the service, a low score means the respondent felt that criterion was poorly met.

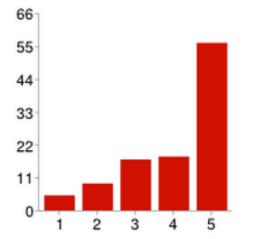






(5 is most positive, 1 is most critical)

The majority of people questioned as part of the survey, told us that they had no problems accessing the service. 20 people gave this rating the lowest score, and 12 the second to lowest score. Although the majority of people had no problems accessing the service, this area had the most number of negative responses.



To what extent do you feel you have/had enough time?

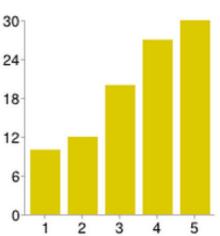
(5 is most positive, 1 is most critical)



1

5

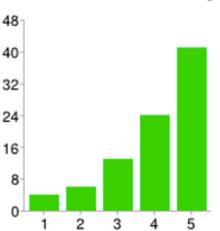
More than half the people who responded to this question said that they felt they had more than enough time using the service they were using. This supports the qualitative evidence gathered through wider group discussions.



How well do/did services work together to support you?

(5 is most positive, 1 is most critical)

Responses to the question how well services work together to support patients, looking at the co-ordination of services are very varied in comparison to some of the other questions. This suggests lack of co-ordination between services, unsmooth pathways, fragmentation of services and poor communication of services affect the quality of care from a service user's perspective.

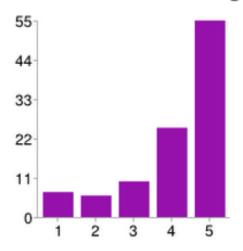


How involved are/were you about decisions made about your care

4	1
6	1
13	1
24	2
41	
	6 13 24

(5 is most positive, 1 is most critical)

The majority of people responded that they felt very involved in decisions made about their care.



How attentive and caring are/were staff?

8

5

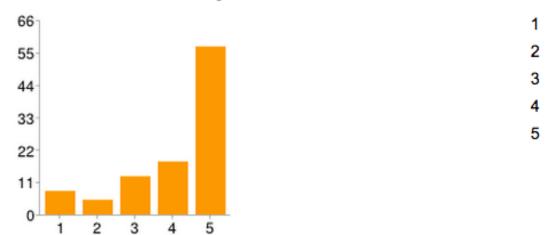
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18

57

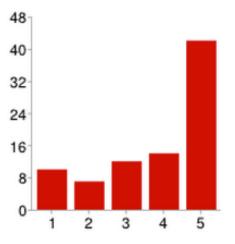
(5 is most positive, 1 is most critical)

More than half the people who responded said that staff were extremely kind and caring.



To what extent do/did you feel listened to?

(5 is most positive, 1 is most critical) More than half the respondents said that they always felt listened to.



How well do/did staff get to know your social situation?



(5 is most positive, 1 is most critical)

42 respondents felt that staff get to know them as a person and know their wider social situation.

Overall the responses to all of the questions within the spider diagram were very positive, many people gave the highest rating for all aspects of their care. Healthwatch was particularly pleased to hear that overall patients found staff extremely caring and attentive. They felt listened to, involved in decisions made about their care and had enough time while they were seeing health professionals. Responses were most varied for 'access to services' and 'how well services work together' to support patients. This suggests these areas are most in need of improvement. Feeling supported by patients and how well staff got to their wider social situation also had a variety of responses.

These responses should be analysed alongside the discussions and qualitative responses. What story collectors tended to find is that even if service users gave an excellent rating to certain areas of their care, the issues or areas they felt needed improving were drawn on when talking verbally during the probing solution-based qualitative questions.

WINNING THE BEST COMMUNITY CARE FOR LEWISHAM PROVISION OF COMMUNITY CARE IN LEWISHAM

This section of the document is primarily the responsibility of the Save Lewisham Hospital Campaign, drawing where appropriate on Healthwatch data. There were a number of examples when service users discussed issues of provision with Healthwatch, these examples are included below. It brings together stories from users, councillors, clinicians and managers, combined with desk-top research on publically available data, as well as information from Healthwatch's listening exercises, mainly over the past year.

It focuses on the provision rather than the quality of care. As service users' stories have indicated, lack of access impacts on the quality of care. This approach was stimulated by the clear early discovery that access to a wide range of services is very difficult for many users. It is designed to supplement the stories about the quality of care gathered by Healthwatch in the last few months.



It needs to be seen against a background of unprecedented financial and organisational pressure on both health and social care services. The TSA process disrupted some effectively growing services and networks, as has the re-organisation imposed by the Health

and Social Care Act and nationwide government cuts to Local Authorities and, effectively, to the NHS. As both organisations make clear, it may be possible that savings, when combined with imaginative redesign, do not inevitably result in a deterioration of service. However, with reductions in funding of 30%, even with sophisticated redesign, reductions in service will be virtually impossible to avoid.

It has been hard to find accurate up to the minute data, so details may change as decisions are made.

The council is having to find the most equitable way of making severe cuts imposed by the Government. And so far the CCG is under less, but similar pressure. There are significant gaps in our story: for instance, we have no data on care homes.

Overall, however, it seems clear that the delicate network of community care in Lewisham is rapidly being eroded. It is easy to destroy networks by reducing funding or planning a workforce based on an NHS with reduced hospital care - and without training staff for community care. The stories as a whole show very hard working staff under enormous pressure, who were still working to a high quality.

PRIVATISATION IN THE NHS NATIONALLY

Lewisham CCG has not been known for extensive privatisation, but the future for the private sector profits in the NHS seems bright. Independent sector providers could take 50% of the market for NHS community services by the end of the decade, says Laing Buisson. Total spend on community NHS services in 2012-13 was £9.75bn. 31% was paid to non-NHS providers (for-profit and not for-profit). There is a projected rise to 35% by 2018, with rise for for-profit rising from 18% to 20%. ¹²

SOCIAL CARE FUNDING – THE NATIONAL PICTURE

Adult social care spending has suffered cuts of 26 per cent: £3.53 billion over the last four years. The service is now under extreme pressure and facing financial crisis.¹³

If the trajectory of cuts experienced to date continues over the period to 2019/20 spending must fall by 21 per cent in cash terms or 33 per cent in real terms. Funding for other council services will drop by 43 per cent in cash terms by the end of the decade, from £26.6 billion in 2010/11 to £15 billion in 2019/20.

The eligibility threshold has tightened. This is one of the few levers local authorities have to manage cost and demand.

There is a 5% decrease in the number of people receiving services.

¹² http://www.laingbuisson.co.uk/Portals/1/MarketReports/Documents/PrimaryCare_OOH_Bro_Web.pdf

http://www.local.gov.uk/documents/10180/5854661/Adult+social+care+funding+2014+state+of+the+nation+report/e32866fa-d512-4e77-9961-8861d2d93238

In 2013/14 this figure was 1.27 million, down from 1.33 million in 2012/13. As the National Audit Office concludes: "Need for care is rising while public spending is falling, and there is unmet need."

The Lewisham Council picture overall

Government money to fund services is projected to fall by 33% by 2017–18 from the level it was in 2013–14.

Year	Government funding
2013–14	£208.1m
2014–15	£186.4m
2015–16	£158.8m (expected)
2016–17	£148.7m (projected)
2017–18	£138.3m (projected)

To set a balanced budget for this year the Council had to agree measures to save £39m. This comes on top of £93m savings already made since 2010. 289 more staff are at risk of redundancy out of 1,133 staff employed¹⁴. There has been an £85m funding gap over three years.

THE VOLUNTARY SECTOR IN LEWISHAM OVERALL – PROPOSED SAVINGS £1,125,000 savings are planned for 2015/16

"The level of reduction proposed is likely to lead to some organisations losing significant levels of funding. This could mean the closure of some groups and the loss of some services that are no longer deemed to be a priority." – Lewisham Council document.¹⁵

14

http://councilmeetings.lewisham.gov.uk/documents/s33720/2015%2016%20Revenue%20Budget%20Savings.pdf

¹⁵ http://councilmeetings.lewisham.gov.uk/documents/g3500/Public%20reports%20pack%2011th-Feb-2015%2018.00%20Mayor%20and%20Cabinet.pdf?T=10 p97

PROVISION BY SERVICE

YOUNG PEOPLE'S SERVICES

Local Authority youth services – proposed savings

£4.18m savings are proposed for 2015/16; £1.2m for 2016/17 and £111k for 2017/18¹⁶. This includes re-designing triage for children's' social care services and the Children Centre early intervention offer.

Youth Offending Teams

£200,000 proposed savings.

"Staff will be required to absorb the work of the deleted posts with additional cases to manage, plus additional duties. The service will have to stop the delivery of certain aspects of the service. Any cuts are likely to affect young BAME boys more than other groups of individuals."



¹⁶ Ibid p358

CHILD AND ADOLESCENT MENTAL HEALTH SERVICES - CAMHS CAMHS manager:

"A significant amount of funding was lost in 2010/11 mainly affecting management posts and delivery of CAMHS in community and GP settings. This community provision is no longer possible which is quite a reduction in accessibility, Funding has been protected since that time. "

Impact on services

- Conduct disorders are no longer seen unless accompanied by other mental illness.
- Long waiting times generally which can lead to deterioration in the condition of the young person which could have been avoided.
- Very difficult to get a psychiatric opinion for a diagnosis of autism. A long waiting list. Some of the work appears to be outside NICE Guidelines.
- Interagency Forum has been stopped.
- A shortage of beds for adolescent placement (by definition an emergency in mental health) with a common waiting time of 2 days.
- Parent Partnership Service says there is a lack of support for families with children with autism

Impact on staff

- Problems getting stationery and materials.
- Limitation on training leads to problems recruiting which in turn leads to stress on staff.
- More is going to the third sector which is shrinking.
- There are too few psychologists
- There are too few skilled nurses.

Users tell us that the health needs of carers is often not considered.¹⁷

Staff comments:

Staff told Healthwatch Lewisham in April 2014 that they had seen an increase in young people self-harming, taking overdoses, having suicidal thoughts or experiencing mental health problems. This was exacerbated by difficulties in accessing CAMHS services. They had also noticed a reduction in the number of voluntary and community groups to which to refer young people. Lack of alternative options of support for children and young people continues to be an issue raised with Healthwatch Lewisham in 2015.

On a positive note the provision of a separate paediatric unit at Lewisham A&E is seen as a longstanding valuable service for young people in crisis. Lewisham was successful in winning a Big Lottery Funding bid in 2014 called HeadStart Lewisham to support the emotional wellbeing and improve the resilience of young people between the ages of 10-14 years old.

¹⁷http://www.healthwatchlewisham.co.uk/sites/default/files/lewisham_parent_and_carer_forum_workshop_ report.pdf

Users' comments

"First appointment took 3 months 10 years ago. Son was taken off service and re referred June 2013. Heard nothing called in twice. Went back to GP for a 2nd referral letter. Has taken nearly a year to get appointment. Much worse than it used to be."

"The staff are always on hand, friendly and armed with information. They offer help and support at times when no other service is around."

"An excellent service, the staff are very supportive and go the extra mile."

SPEECH THERAPY FOR CHILDREN

"Not easy to get first appointment. Took four months for first appointment then another 4 months till second one. Crucial time for child with speech delay. Eventually got info/tips after 9 months. Good but late"¹⁸

SERVICES FOR CHILDREN WITH COMPLEX NEEDS

Manager:

"We had good progress in planning until we were disrupted by the TSA process."

"We need sophisticated community services to keep children out of hospital. These are on the whole insufficient, so kids stay in hospital longer than they need to. We do have an effective community nurse at A&E deflecting children back home, but there are too few community supports to make that very useful. There are too few people to smooth the pathways. "

"Community Based Care is not happening adequately fast enough."

"Multiagency Planning Meetings are targeted now for children with educational needs. They are essential for children with many kinds of disabilities."

Another professional's view of social care provision for children:

The increase in the number of children on Child protection plans and the complexity of cases being referred to social care has resulted in a reduction in preventative work both in Lewisham and nationally. Social workers spend a lot of their time in court and responding to crisis. We have highly skilled social workers in Lewisham, but their workload has increased and Lewisham Children's Social Care receive almost 100 child protection referrals a day. Budget cuts have reduced support staff which increases the workload of social workers.

¹⁸ <u>http://www.healthwatchlewisham.co.uk/sites/default/files/healthwatch_lewisham_kaleidoscope_report_june.pdf</u>

Social work admin support has been cut in all the social work teams which increases the workload for social workers.

EARLY INTERVENTION SERVICE

This supports professionals in their management of children's safeguarding issues. The EIS (Early Intervention Service) will be shutting soon. At the same time, Children's Centres will be shrinking and funds reducing. There are concerns that organisations such as Children's Centres, which will be expected to take on this sensitive and essential work, will be unable to do it – or do it well enough.

"I don't know how we're going to explain that they don't any more qualify for a service."

Another professional's view of social care provision for children:

"There is now almost no preventative work. Social workers spend a lot of their time in court. We have highly skilled social workers in Lewisham, but they are poorly supported. Social work admin support has been cut from 4 people to 2."

"It can't get any worse. 90% of referrals to SWs are turned down." Manager/clinician

HEALTH VISITING

GP view on health visiting provision:

"There seem to be no more long-term stable health visitors. It seems to us that only one visit to new baby is being offered. There seems to be no more preventative work – only safeguarding."

"The monthly meeting between the practice team and the health visitor at surgery is very good."

Other professional's view:

A Health Visitor's view:

"There seems to be a shortage of people, the organisation seems reliant on agency staff. Health visitors offer more than the basics in Lewisham, but there have huge caseloads, doing safeguarding most of the time. They are encouraged to do a bit of preventive work with targeted families. There is no reduction in funding, but huge problems in recruiting. Where are the 30000 Health Visitors? People are working harder and harder with longer hours. They must be doing a day extra every week. This is the new normal. The car park is full at 0800. " "The work is very interesting and rewarding but over the last 5 years the needs of families have become more complex and the cuts to local support services have resulted in an increased workload for Health Visitors. Lewisham offers more than the minimum service required by NHS England and is a good place to work but the national shortage of Health Visitors has impacted on the borough and health visiting teams work many extra hours and work under pressure to meet targets."

A Community Nurse's view:

"Parents want good evidence-based advice to support them in bringing up healthy children. Parenting in the 21st century is challenging and Health Visitors are well placed to offer effective interventions. There is a shortage of qualified Health Visitors nationally and a reliance on agency staff which is more expensive for the NHS and does not offer parents continuity of care."

FAMILY NURSE PARTNERSHIP

This is a specialized service supporting the most troubled families and their children. It has been implemented successfully in Lewisham and the team have expanded. The service cannot be offered to all teenage parents as many more nurses would be needed.

Community care for under 5's will be commissioned by Public Health in Local Authorities from October 2015. This will put the Health Visiting Service and the Family Nurse Partnership service at risk of being put out to tender and being run by non NHS organisations. In a few areas in England where local authorities have funded Family Nurse posts they have made cuts to these posts

ADULT MENTAL HEALTH

Proposed local authority savings to Mental Health provision £250,000¹⁹

There are examples of reductions in service in both NHS and local authority services.

One Support Group, funded by One Housing Group, has been cut. They offered highly practical support for 60-70 people. A number of COS services have been cut for instance Time Out services.

A treatment programme at the Cassel Centre can now last only a maximum of 1 year.

Moderate mental health problems still seem to fall between IAPT and the Community Mental Health teams. Some people with such problems seem to be refused help by both services.

¹⁹ Decision 11022015 1800 Mayor and Cabinet

On a positive note.

Things are better as Lewisham now has a MIND group locally.

There used to be a one year wait for counselling, now it is two weeks with many options.

The local authority has been able to open a new Dementia Centre at Ladywell using capital monies.



PRIMARY CARE DISTRICT NURSING Clinician with close experience of District Nursing (DN) service

"People go home and there is no District Nurse there. This can be serious. Surgical drains don't get drained. No District Nurse available over weekend if discharged on Friday. Anonymous referrals do not get dealt with – it is better if you know someone and can discuss with them."

"There are problems with equipment such as incontinence pads for which there can be weeks of delay. Hospital beds seem to be easily available. Toilet frames can be hard to obtain." (Medequip is a private firm) "Coordination of care is fairly good."

"There is rarely a wider, holistic view of the patient's situation. The District Nurses on the whole do the task at hand because they are stressed and stretched. They dress the ulcer, but don't deal with the immobility."

"There are not enough District Nurses. They are hard to recruit. Funding is available."

Banding.

This respondent felt that many posts are actually too low a Band. Band 6/7 are qualified District Nurses. But most are Band 6 over last few years. And now are often Band 5. This is a way of saving money, but it may lead to poorer care.

"The District Nurses say there is not enough staff. There is poor morale and lots of informal complaints"

A respondent told us that District Nurses often don't schedule visits so the patient may not be in which is a waste of time.

GP view of services:

"Good District Nurses are leaving, often to the private sector. There are more agency nurses. They are now often paid by task, so it is less holistic now. As a result, there have been 2 serious incidents as a result of leg ulcers not having been spotted or acted upon.

There is too little continuity."

COMMUNITY MATRONS

GP and local clinician:

"There has been a reduction in the numbers of Community Matrons from 10 to 3. It appears as though none are being replaced."

GENERAL PRACTICE

The GP view of General Practice:

- There is lots of pressure to improve access, so we see more minor illnesses. This may result in poorer follow-up of long-term conditions.
- 4 practices across Lambeth, Southwark and Lewisham have gone bankrupt. £60K was stripped from one practice's staff funding.
- 4 GP partners in Southwark and Lambeth have decided to become salaried rather than stay as partners. This is to avoid the stress of partnership.
- Good managers and GPs are under huge pressure and stress.
- Training is being squeezed.

SEXUAL HEALTH SERVICES

Proposed local authority savings to sexual health services £321,600²⁰

Lewisham offers comprehensive sexual and reproductive health clinics in 4 centres around the borough with 2 centres - Waldron and Hawstead Rd - being the main sites with extended opening hours. The clinic opening hours have been cut in recent years due to budget constraints.

Sexual Health Clinician's view:

"We offer high quality care but we often have to turn patients away due to clinics being too busy and patients often have to wait 2 hours or more to be seen. We need more clinics with longer opening hours."

Service user Female aged 22 years:

"I often have to wait 2 hours to be seen and it is difficult getting to the clinic in time after work as it shuts at 7pm. It used to be open until 8pm and that was much better for me and many of my friends. The Nurses and Doctors are very helpful and give good care but I wish the waiting times were shorter."

Sexual and reproductive health services have been commissioned by public health since 2014 (Lewisham LA) and have been affected by the austerity cuts.

SELDOC

English language can be a problem. Clinicians don't have information about the patient, so patients may end up too quickly in A&E. There is a significant wait for visits. They don't have Coordinate My Care, an online resource that enables OOH clinicians to see the palliative care needs for a patient.

LOCAL AUTHORITY SERVICES FOR OLDER PEOPLE – PROPOSED SAVINGS Reassessment of Adult Care Packages: proposed savings £2,680,000²¹ (15/16: £2.480, 000: 16/17: £200,000) There will be more charging for Adult Social Care Services to save £275,000

Local clinician

"Care packages do happen, but can take a long time to set up. The quality of care agencies vary a lot – some are very good, Carewatch for instance. But some are very

²⁰ <u>http://councilmeetings.lewisham.gov.uk/documents/g3500/Public%20reports%20pack%2011th-Feb-2015%2018.00%20Mayor%20and%20Cabinet.pdf?T=10</u> p185

²¹ <u>http://councilmeetings.lewisham.gov.uk/documents/g3500/Public%20reports%20pack%2011th-Feb-</u> 2015%2018.00%20Mayor%20and%20Cabinet.pdf?T=10 Appendix 1A

rushed with a poor relationship with patients. No paid travelling time. Staff English seems good enough."

Feedback provided to Healthwatch supports the view that the quality of care varies.

Some community based packages of care are ending or being reduced where needs can be met in different and more cost effective ways.

PUBLIC HEALTH – PROPOSED SAVINGS

There are two sets of savings suggestions for Public Health.

Public Health programme review with £1,500,000 savings and a Public Health programme review (II) with £1,154,000 savings²². A further disinvestment of £1.15m was also identified, although it was acknowledged that this was likely to have some negative impact

The programmes where savings are proposed include the following:

- Dental Public Health
- Health Inequalities
- Mental Health (adults and children)
- Health Protection
- Maternal and Child Health
- NHS Health Checks
- Obesity/Physical Activity
- Sexual Health
- Smoking and Tobacco Control
- Training and Education.

Public Health says that the proposed disinvestments in current public health initiatives were prioritised for disinvestment on the basis that these initiatives would result in the least loss of public health benefit per pound spent when compared across all current public health investments.

"...it is acknowledged that a full and comprehensive assessment of the implications of this re-allocation of funds cannot be undertaken until other local authority areas for investment have been identified."

The CCG commented

"Given the importance of health improvement and prevention ... we are concerned that money is being taken away from the current public health budget priorities without a comprehensive assessment of the implications on health outcomes and inequalities."

²² <u>http://councilmeetings.lewisham.gov.uk/documents/g3500/Public%20reports%20pack%2011th-Feb-2015%2018.00%20Mayor%20and%20Cabinet.pdf?T=10</u> p171

LEARNING DISABILITY – PROPOSED SAVINGS £1.450m savings for 2015/16 (an additional £50k will be considered)²³

The savings proposals included a proposal to consult on changes to the Council's adult social care charging policy to achieve a saving of £275k and an additional saving of £50k in relation to charges for LD clients using supported living services. The impact of the proposals would be as follows:

Proposal 1 There will be a reduction in the level of 1:1 support for some individuals. However, there may also be an increase in the number and type of shared activities that people will have an opportunity to participate in.

Proposal 2 (i) Some families may be concerned about the transfer of care management and funding responsibility to another authority/ CCG (ii) Some families may be concerned that extra care housing services may not fully meet the needs of their family member.

Proposal 3 Service users directly affected will potentially experience a reduction in the amount of disposable income that people have available to spend.

Service users and their families have expressed their concern as to how reductions in provision will impact on their health and wellbeing.

HOUSING – PROPOSED CUTS £1,349,000 will be delivered in 2015/16 and a further £1,174,000 in 2016/17²⁴

A professional's view:

"In real crisis. Housing benefits don't cover rents, so families move to other boroughs."

Housing-related support activities

The reduction in funding will lead to a significant reduction in capacity across a range of services. This will mean that individual service users will no longer receive a service in their own homes and some will need to be decanted from accommodation based services. This removal of service will be targeted but ultimately the threshold for services will have to rise.²⁵

²³ 2015-16 Appendices 2-20 for Savings Report – Appendix 3a. A2

²⁴ <u>http://councilmeetings.lewisham.gov.uk/documents/g3500/Public%20reports%20pack%2011th-Feb-2015%2018.00%20Mayor%20and%20Cabinet.pdf?T=10</u> p224

²⁵ ibid

Risks of the savings

- Any losses to the floating support service will carry increased risk of more households becoming homeless
- Loss of hostel bed spaces will inevitably lead to pressure elsewhere within council resources.
- Further reductions in funding may impact on staff quality and morale to such an extent that service users are put at risk
- The loss of buildings currently used as hostel accommodation is in itself a significant one.
- Numbers of people living on the streets in Lewisham will rise significantly
- Anti-social behaviour on the streets in Lewisham may rise significantly
- Remaining services become financially unsustainable for providers and they withdraw from provision.

APPENDIX 1 COMMUNITY CARE – THE VISION

Part of the success of the Appreciative Inquiry Vision Day was empowering participants to collectively create a vision for the future of community care services according to how they would like to see it, incorporating the 'magic ingredients' from the 100 stories gathered from the Appreciative Inquiry.

The four sketches developed by the 60 participants maintained a similar vision:

Excellent community health care is delivered by well-trained and well-paid staff who are well supported and have the time to offer patient-centred services. It is holistic, taking into account many aspects of the patient's life and health. Central to successful delivery is cooperation between services, the voluntary sector and the community. Common to all the stories was staff having the time to deliver excellent care. Time enabled them to listen to and understand the patient and their needs, create a smooth pathway between services and empower the patient to manage their own health. There was an emphasis on the need to integrate health and social care in order to offer barrier-free care to those who need it.

At the Healthwatch Your Voice Counts event in July 2014 focusing on community care services, using the findings of the Appreciative Inquiry and 'Our Healthier South East London Strategy' participants broke off into groups to develop this vision for certain services to consider what they would want the future of health services to look like in 3-5 years' time.

Here is a summary of what people told us at the event and incorporating people's recommendations given during this inquiry:

MATERNITY SERVICES

- Lewisham will have fully baby-friendly-initiated accreditation from Unicef in order to increase breastfeeding rates
- Want women to make informed decisions based on evidence and research i.e. breastfeeding versus bottle
- Women feel comfortable to breastfeed in public: places are breastfeeding friendly
- Women will no longer have difficulties breastfeeding once leaving hospital, there will be peer and volunteer breastfeeding support which is funded
- There will be a reduction in the number of labour inductions and C-sections. Continuity reduces inductions. Need more staff and the same midwife throughout
- There will be more midwives (many currently leave after a few years due to stress, midwife led unit is unit)
- Midwives will work in partnership with GPs
- Midwives have more training

PRIMARY CARE

Communication

- There will be accurate and up-to-date information from patient to service providers and between service providers – there could be a personal profile kept and managed by the patient – e.g. a paper document they can take to appointments with the relevant information
- Patients do not have to chase up referrals or records between services
- GPs should have accurate and up-to-date information about all the community services available that allows for good signposting
- Clarity about diversity languages, culture etc.
- good use of social media/technology when needed
- Inter-provider clarity important same message to/from all

Access

- Phone call answered in 3-5 minutes
- Same day or next day appointments will be available
- Everyone attending their booked appointments (no DNAs)
- It will be attractive to be a Lewisham GP (& therefore able to provide more appointments)
- More funding to support primary care staff
- Saturday surgeries available
- Answering phone calls early in the mornings to make on the day of appointment (no more queuing outside the surgery before 8am)
- Effective telephone triage to signpost of make appointment
- Opportunity for phone or Skype consultations (online chat lines)
- People will have continuity of care: being able to get an appointment with the doctor or health professional of choice, especially for long term conditions, families with complex needs and people experiencing mental health issues.

OTHER

Improved education for all age groups

- Preventative public health education
- How to help yourself
- Improved 111 service (triage)
- Services offered in locations that people feel safe in (e.g. drop in centre at New Cross is less daunting and there are private areas to wait if needed)
- Everyone registered with a dentist or optician should be offered services that are free at the point of care (like GP)
- Free prescriptions for everyone
- People need to be aware of the knowledge, ability and usefulness of pharmacy services. Should be the first point of call for minor conditions
- Patient groups have lots of links and information

Mental health at the GP level

- Doctors will be more aware of mental health difficulties, how to deal with them and when to direct people and refer people to. Referral processes will be smooth
- Friendly, people-based system with doctors seeing people face to face and listening well (less time on the phone): smooth, efficient process as a result the essential thing is getting better quickly.

SOCIAL CARE

Access to information

- Better information leading to greater awareness of support groups; part of that is accessibility: difficult to find groups online and if not using internet, even more difficult
- Greater focus and support for cardiac support group: currently purely voluntary and therefore difficult to publicise
- Better understanding of what social care is about and how they can access it; removal of barriers to getting involved
- Move away from only internet access to give better access to information
- Telephone calls are returned in a timely manner
- Service users and their families will know how to contact to complain if they are not happy with the care they are receiving. Complaints will be dealt with quickly.

Patient centered care

- Social care looking at people as individuals: movement away from emphasis on health and hospitals
- Staff ask service users how they would like to be addressed and spend time getting to know the patient
- Service users have a named care worker who attends the majority of appointments wherever possible

Access

- Greater access to social care dealing with language barrier by branching out with social care groups in different local communities
- Volunteers working with care groups to overcome language barriers, rather than first placing the blame

Care assessments for service users and their carers will happen in a timely manner

Continuity of care

- Improved delivery services; currently issues, e.g. cancelling appointments or deliveries etc, possible solutions maybe one person assigned to deal with each patient, rather than lots of different people
- Adequate processes in place to deal with staff absences and annual leave
- Service users and their families will still have a named social worker to contact after care packages have been implemented in the event that problems occur.

Time

- Domiciliary workers arrive at the agreed times, or communicate in advance is there is a delay in arriving
- Service users and staff will be given adequate time to carry out all the tasks as required in the service user's care plan with care.

MENTAL HEALTH SERVICES: VISION FOR THE FUTURE

Building on the points discussed at Healthwatch's July 2014 Your Voice Counts event, Healthwatch took this vision to service users at Mental Health Connection Day and the SLaM Stakeholder's Event. This is what local people told us they would like to see out of future mental health services in the future:

Awareness

- People will be able to spot signs and symptoms because there will be an increased awareness of what mental health is and knowledge of how to spot the signs that someone is developing mental health problems
- There will be no stigmatisation of mental health due to the increased awareness of the issues
- Isolation will be tackled as it is accepted that isolation can lead to depression therefore work will be done to prevent social isolation
- People will not be scared to admit they may need help and will not be scared that they will be judged
- Parents will be assured and feel more confident in knowing what to do in regards to the mental wellbeing of their children
- There will be regular feedback provided and promoted about mental health services
- There will be tool kits provided for professionals
- People will be able to access to own records and information online
- Lewisham will be a Dementia Friendly Community to raise awareness of the condition and to provide support within community settings such as shopping centres, supermarkets, public places, libraries and any other community venues.

Information

- Patients will be aware of all the services that are available to support them. This could be a one-stop shop which offers 24/7 support (for example advice and guidance) when needed or a phone line with access 24/7
- Drop-in centre providing information but not necessarily professional led. There would be speakers, leaflets and peer support on offer
- Patients will be empowered by having access to the information needed to make informed decisions about their own care. For example medication, they will understand the side effects of the medication and how to deal with them, this will have been fully explained by a staff.

Continuing Support

- There will be more support especially for young people and older people. There will be constant support throughout the patient pathway; while waiting for the referrals, during and after treatment. Support will also be tailored to the changing needs of the individual as it will be understood that patients' needs change through the pathway
- Support will be integrated partnering organisations will work together to ensure there is a smooth patient pathway
- The transition between CAMHS and adult services will be smooth and joined up
- There will be adequate support for new mums after birth so that post-natal depression is identified and then addressed
- Support will be timely, appropriate and relevant as it is acknowledged that different groups have different needs
- Patients are aware of the support available through the community and voluntary sector that can offer additional support
- More services where people can meet and support each other in an active way not just drop ins
- Local occupational therapy centres that do cooking, gardening, exercise, clothes washing, ironing etc. Also teaching DIY skills
- Dedicated services for LGBTQ community
- Mental health and wellbeing centre where people can access a range of activities and advice and support
- One place to go and access help if in crisis not hospital

Referrals

- Referrals will be speedy with support offered while waiting for the appointment for example people know who to contact or how to access support if they are in crisis
- Easier and quicker access back into step-up or step down (self-referral)
- Proactive approach at GP level (before Crisis).

Prevention

- Prevention we need to educate the younger generations to prevent the onset of mental health problems. Interventions and prevention need to be stabilised by providing sustainable support that is ongoing rather than dependent on funding cycles
- There will be more community initiatives to reduce social isolation.

Carers

- It will be acknowledged that carers, both adults and young people are affected by the illness and therefore are offered adequate support as well
- There will be consultations arranged between carers and commissioners facilitated by Carers Lewisham

- The public will have a greater understanding about what it means to be a carer
- There will be more young carers identified and offered help
- Carers will provide workshops, forums etc. for others in need of support
- There will be more funding available for support groups
- There will be better access to talking therapies for carers, and peer mentoring programme
- One port of call 24 hr telephone service for Carers in need
- Increase capacity of Lewisham Carers
- By 2019 services will be localised so that patients and their families don't have to travel far and they and professionals have extensive knowledge of local support available in the area.

The workplace

- A focus on recruitment and training will need to happen now in order for this to happen in five years' time
- Nurses' training will be more holistic so that they are able to treat the patient as a whole and not just the mental health illness
- Encourage relaxation, wellbeing, provide support to workers. After work and during work
- There will be an openness about admitting problems
- No stigmatisation
- Make counselling available
- Provide open group work discussions
- Prevention, wellbeing and mindfulness techniques.

Collaboration Partnerships cooperation

- The CVS will play in important role in supporting the patient so their condition does not worsen, offering employment and financial support for example
- Patients are aware of the support available through the community and voluntary sector that can offer additional support.

Young people

- Mental health and wellbeing will be taught in the classroom
- There will be more discussions and more openness in a variety of settings
- Mental health will not be a taboo subject
- There will be a variety of places for young people to go to talk about their feelings
- Speaking to professionals but not in a professional setting
- Online directory enabling young people to choose appropriate services based on their need from crisis to less critical support

- More publicity and information available in surgeries pharmacies, service providers, libraries, churches, job centre, schools, markets
- There will be more peer mentoring training
- There will be a focus on identifying more young carers. This is preventative work. Work with GPs, schools, colleges and hospitals to identify and refer young carers to projects
- Counselling services that are accessible and free to access
- School nurses are key but need to be well trained especially in terms of knowing what services are available and preventative and public health programmes like sexual health. Need to work closely with CAMHS
- Ex-service users to communicate their experiences good practice, peer-led
- Engage with parents via schools, after school, parents evenings, workshops organised like the (Healthwatch) Reference Group but don't call it mental health, wellbeing or other language should be used
- There will be enough beds in Lewisham for young people in crisis when needed
- Need for out of school activities and work with families and community groups holistic approach to increasing wellbeing of the child.

Discharge best practices

When the discharge process is coordinated, involving the patient, their families and local support networks, when discharge is timely and consistent and provides the service user with all relevant information to their condition and to their discharge, the process of discharge can be an extremely positive one.

Providing service users and carers with adequate information in order to prepare for discharge and the recovery process, giving adequate time for staff and carers put discharge plans in place before patients are discharged from hospital, discharging patients at sensible times during the day with the transport of transport available if necessary, and ensuring patients have the information, skills and support needed in order to manage one's care upon discharge are the magic ingredients in a successful discharge process.

A list of recommendations is provided in the Healthwatch Lewisham's full report into discharge services.

APPENDIX 2 OVERALL THEMES

Access to information

"Kaleidoscope contacted me within three days and the information was shared with my GP"

When patients, service users and their families or carers could access and find information, they felt empowered, confident and included in the care giving process.

We heard several examples of patients and health professionals not being able to find and access medical information during the transfer from one service to another.

"Info mislaid, continually having to explain all over again what's happened."

Lack of access to information is a trend that we saw across services in this inquiry that had a negative impact on the quality of care a patient received. Problems occur when patients have limited access to information. People have told us that they often do not know where services are or how to access them, how to get assessments and where to go to find support to complete assessments or forms. Many patients are also unsure of their rights and entitlements as service users of health and social care.

Knowing where older people, people experiencing mental health difficulties, and for those who have a long term condition can access information and support were the three areas that are most in need of improvement.

Access to services

Access to GP appointments is the number one issue Healthwatch has heard when engaging with members of the public during this inquiry, and over the last year. The majority of people experience a high quality of care when they get to see a doctor but find it increasingly difficult to access one.

Access to podiatrists, particularly for patients who have diabetes and need to see a specialist for their regular feet check has become increasingly difficult. Older people who need a home visit are also struggling to access the service or know where to go to find alternatives. Many people have chosen to go privately because they cannot access public clinics.

Access to diabetes specialist nurses varies depending on where people live in the borough, and which surgery they attend. It appears that there is currently a shortage of practice nurses in the Whitefoot/Downham area.

There is a high demand for counselling and talking therapies in Lewisham. Generally, people seem aware as to the availability of IAPT but are experiencing difficulties getting a referral to the services as well as long waits after being referred.

Access to CAMHS continues to be an issue for many young people. Although there is a new triage system to see the most severe, many others have to wait a long time and other no longer meet the criteria and do not necessarily know where to access support outside of CAMHS.

People have told us that they are experiencing long waits for physiotherapy for adults, as well as similar waits for children for physiotherapy and speech and language therapy at the Kaleidoscope children's centre.

Access to care assessments and carers assessments can take a long time with service users or families having the 'chase' professionals in order to speed the process up.

Continuity of care

Poor access to GP services has lead to a lack of continuity of care for many patients who have to choose between long waits to see their GP of choice or see another doctor. People have told us it has a negative impact on their quality of care of they cannot build up a relationship with one doctor, or cannot see their doctor of choice which in turn has an impact on the extent to which they can see and treat 'the whole person and not just the condition'.

Time

When patients do access a particular service the majority have told us that they do have enough time while they are within the service. The two areas that stand out are social care, with many people feeling they or a family member need more time with a domiciliary care worker, and patients with complex needs at the doctor, who require a double appointment, which can be hard to get. People who are experiencing mental health issues often feel the do not have enough time to discuss their issues in the 10 minute appointment provided.

Patients have also told us that they often have to save up issues because getting an appointment with a doctor is difficult which leads to a lack of time to address all these issues in the appointment.

Joined up services – smooth practice pathways

We have found many examples in a variety of services where patients have experienced difficulties in the coordination of different services. This can often arise upon discharge or moving from one service to another.

Caring and attentive staff

Healthwatch was pleased to note that the majority of people spoken to felt that staff were very caring, attentive and listened to them. Having time to listen to the patient's needs and concerns as well as asking questions about the wider context which has an impact on their health were all given as examples of why patients felt that staff were caring and attentive.

Choice

Choice was an important element in the quality of community care. The importance of getting an appointment with a GP of choice was the most quoted example however being given a choice of support for mental health difficulties, for treatments and medication were all important. Having adequate information in order to make these decisions was also important.

Patient empowerment

Most patients felt involved in decisions made about their care, empowered to make decisions with enough information in order to do this. The patients we spoke to with learning difficulties would like health professionals to address them directly and not their carers, this helped them to feel more independent and empowered as service users. There were some examples where patients were not prepared for discharge from a community care service, or did not have the tools to continue to self-manage outside of appointments, or seek support while waiting for appointments.