

Healthwatch Lewisham Kaleidoscope Feedback Update

April – June 2014

Introduction

Healthwatch Lewisham was invited to participate in drop-in sessions based within the resource centre of the Kaleidoscope Children's Centre which began in January of 2014. Healthwatch Lewisham presented an initial report summarising the feedback they had gathered during their engagement activities at the drop-in sessions back in March. This is the second report submitted as requested by the Kaleidoscope User Group who will be meeting on Wednesday the 18th of June.

Healthwatch Lewisham's Mission Statement

Healthwatch Lewisham will enable people, communities and organisations in Lewisham to have a say and influence the planning, commissioning and delivery of health and social care services to improve the health and wellbeing of patients, public and service users.

Our Aims and Objectives

1. Gather views and understand the experiences of people who use services, carers and the wider community
2. Make people's views known
3. Promote and support the involvement of people in the commissioning and provision of local care services and how they are scrutinized
4. Recommend investigation or special review of services via Healthwatch England or directly to the Care Quality Commission (CQC)
5. Provide advice and information about access to services and support for making informed choices
6. Make the views and experiences of people known to Healthwatch England and providing a steer to help it carry out its role as national champion
7. Support any complaints function by signposting people to NHS Complaints Advocacy services.

Healthwatch Lewisham and Children and Young People

Healthwatch Lewisham has a clear and significant role in promoting the voice of children and young people. Healthwatch Lewisham has a legal responsibility to listen and learn from the experiences of children and young people who use health and social care services. By providing a strong voice for

all age groups in the community, Healthwatch Lewisham can fulfil its mission as the independent consumer champion.

Purpose

This report presents the findings of service user feedback collated from engagement sessions carried out at the Kaleidoscope Children's Centre in Lewisham.

The purpose of the report is to assess the data collected about patients' and carers' experiences of the services available in the centre. The report highlights good practice and good quality care, and draws attention to issues and problems that should be addressed. It will provide recommendations where possible to improve the service for service users.

The report will be presented initially at the Kaleidoscope User Group meeting on Wednesday the 18th of June. It will also be submitted to commissioners at FLaG, and shared with consortium partners, providers and interested partners.

What we did

Following on from the previous report, Healthwatch Lewisham carried out community engagement with service users and parents at Kaleidoscope from 10-12pm on the following dates:

- 28th of April
- 13th of May
- 4th of June

Partners attending on these dates were the Parent Partnership Service, Lewisham Parent and Carer Forum and Contact A Family.

On the 28th of April Healthwatch Lewisham engaged with 13 people. On the 13th of May two Healthwatch volunteers were able to engage with 24 people and on the 4th of June Healthwatch Lewisham engaged with 22 people.

Volunteers assisted in serving hot drinks in the kitchen; approaching people in the waiting area to tell them about the drop in service offered at Kaleidoscope; explaining what Healthwatch and the other organisation present do, inviting people to tell us about their experiences of health and social care services either by completing our 'personal story form' or by telling us verbally. They also provided signposting and information to local health, social care or community services.

What we found

Here are the top themes arising from the qualitative feedback gathered from speaking with service users or parents of service users, and examples of some of the comments received.

Top Themes overall for CAMHS services:

Theme	Examples	Follow Up Actions and Recommendations
<p>Access to services</p> <p>CAMHS</p>	<p>3 weeks until first appointment</p> <p>Great service - I feel I can always phone them up and get help!</p> <p>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.</p> <p>Average wait for first apt is 2 months. Too long. Threshold very high.</p> <p>Took long time for 1st home visit - took 6-8 months. Had to keep asking GP. Info has improved because she keeps asking.</p> <p>Referred to by school and took a while to get an appointment for my son.</p> <p>Took long time to access service through GP - 6 months.</p> <p>Waiting 4 months for first appointment. Also the waiting time for an initial appointment is extremely long. Our 1st appointment took 4 months, after the counselling finished - had to wait again 6 months for another initial appointment.</p> <p>The staff are always on hand, friendly and armed with information. They offer help and support at times when no other service is around. More staff to help lighten the work load. More workshops- very limited. Make sure the service more open to</p>	<p>Healthwatch to highlight issues around access to CAMHS services to providers, commissioners and those at a national level undertaking a current review of CAMHS.</p> <p>Healthwatch Lewisham to provide volunteers and partners at the drop-in with a list of useful local and national organisations supporting young people experiencing mental health issues and their parents or carers. This will assist the task of signposting parents and young people to other organisations who are in need of additional support.</p> <p>CAMHS to provide (if not currently offered) information to service users and their parents or carers about who to contact outside of appointment times if support is needed. This information could be displayed within the reception area and communicated to partners working with young people.</p> <p><i>“More coffee mornings and workshops to continue all through a child’s life because the support from each other gets us through,”</i> was a suggestion offered by a parent at the</p>

	<p>others. Promote the service.</p> <p>A little over 6 months to get 1st appointment.</p> <p>1st appointment through school and GP 3 months.</p> <p>2 weeks to first appointment.</p> <p>Took 3 months to 1st appointment.</p> <p>Difficult to consult if problem occurs. Phone CAMHS no. Can't leave message at times. CAMHS is all there is, can't go anywhere else.</p> <p>Lack of services for young people with mental health issues.</p>	<p>drop-in. Additional support that is offered either via the drop-in sessions and coffee mornings or additional activities organised by partners could be increased. Current provision could be promoted more widely to raise awareness about what's currently available, Healthwatch is happy to promote activities in their e-bulletin and on the website.</p> <p>Being able to access support outside of CAMHS services in Lewisham could be addressed if Lewisham is successful in winning the Big Lottery HeadStart funding application. This programme would provide both universal and targeted provision for young people in Lewisham between the ages of 10-14 years old to increase their emotional wellbeing and resilience. It will significantly increase the provision of support available to young people and their families should the application be successful. Healthwatch Lewisham's continues to support the development of the programme through their participation in the Steering Group. HW to undertake a questionnaire</p>
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		<p>on behalf of the HeadStart programme at the drop-in sessions with parents. Healthwatch Lewisham would welcome the support of partner organisations in this task. Lewisham will find out at the end of June whether their stage two application has been successful. Healthwatch will communicate the outcome to their members.</p>
<p>Coordination of Services CAMHS</p>	<p>Can't tell if staff are caring because never see the same person twice.</p> <p>How could the service be improved? Not to be seen by placement staff every time.</p> <p>Communication poor. Client heard nothing for 6 months after first appointment. Had to come in person to kaleidoscope to find out what had happened. Client given report today.</p> <p>No help available in the school until child gets a statement.</p>	<p>Highlight the issue of frequent staff change overs to providers through this report.</p> <p>Review system of providing parents with information at all stages of the patient pathway.</p>
<p>Quality of Treatment CAMHS</p>	<p>(name of member of staff) has helped me a lot to control my anger.</p> <p>A very efficient service particularly with CAMHS that I deal with mostly.</p> <p>I feel this - very well, can always get hold of professionals, runs very efficiently in my experience.</p>	<p>Healthwatch would like to highlight the high quality of treatment evidenced in the feedback they gathered from engagement activities.</p>

	<p>An excellent service, the staff are very supportive and go the extra mile.</p> <p>Help in a lot of ways for me and my daughter. I am not sure of how this service can be improved</p>	
Staff Attitudes	<p>It is very helpful very good and always welcoming, and very understanding.</p> <p>...the staff are very supportive and go the extra mile.</p> <p>The counsellors are friendly and easy to talk to. However the Head Counsellor could be more understanding.</p> <p>The staff are always on hand, friendly and armed with information.</p>	<p>Healthwatch would like to highlight the positive comments given about the majority of CAMHS staff in the feedback gathered from engagement activities.</p>
Access to Information CAMHS	<p>Letter, forms and appointment did not arrive until after our first appointment, so we had no information or paperwork or confirmation of process.</p> <p>Information needs to get to the service user. Follow up with service users. More information adverts etc. Service users given forms to complete at the service they use.</p>	<p>Review system of providing parents with information at all stages of the patient pathway.</p>

Analysis of themes arising:

Access to service –the trend arising from feedback of service users and their carers was that the time waiting for the initial appointment was too long. When parents and carers were able to access support outside of appointments this was greatly appreciated by parents.

Coordination of services – Healthwatch has noticed from feedback some inconsistency of continuity of care due to frequent staff change overs. This is having a negative impact on service users.

Quality of treatment and staff attitudes - the overall theme from comments were that most service users or their parents/carers felt that the quality of care was good. This is echoed in the results from the quantitative data.

Access to Information – Healthwatch received some comments that they felt there was not enough information provided before and after appointments as well as knowledge of how to access other support services.

Top Themes overall for other services:

Theme	Examples	Follow Up Actions and Recommendations
Waiting times – patient pathway Speech Therapy	<p>Long waits were noted.</p> <p>Not easy to get 1st appointment. Took four months for 1st 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. Appointments are every 3/4 months which is not often enough. Behavioural therapy not useful as child was in a group where the other children were much further behind and used little speech.</p> <p>2 months to 1st appointment.</p> <p>Got 1st appointment in 2 weeks.</p> <p>Main issue is the waiting list for speech and language therapy, as earlier intervention would be better outcome for the patient.</p> <p>Assessment went well; just amazed how long we have to wait for the actual speech therapy date (3 months wait). By not having a long waiting list (Time scale).</p>	<p>Healthwatch to highlight issue of accessing speech therapy services to providers and commissioners through this report.</p>

	The waiting time between blocks could be shorter.	
Staff attitudes	<p>Desk staff sometimes a little rude. Healthcare staff good.</p> <p>Paediatrics: Always helpful when I telephone staff and treatment is fantastic for me and xx when we need the support and help.</p> <p>Really caring. So far so good very helpful. (speech therapy)</p>	Healthwatch to continue to monitor feedback about the attitudes of reception staff. HW to communicate with provider if further issues are noted.
Quality of Treatment Physiotherapy	<p>Exceptionally good</p> <p>Excellent</p> <p>Very good service, always helpful and welcoming and understanding.</p> <p>It was quite a fast diagnosis for my grandchild and the help and information I got was good.</p> <p>I think it really helpful informative and helps my son a lot.</p>	Healthwatch would like to highlight the high quality of treatment evidenced in the feedback given about physiotherapy services provided at Kaleidoscope through this report.
Quality of Treatment Speech Therapy	Very helpful. My son has come a long way since attending speech therapy.	
Access to Service Communications and ADHD Clinic	My son was last seen in July 2013 and has not been seen since, the waiting list is ridiculous. My son desperately needs support, but I feel the system is failing us as a family. More staff required and more information needs to be provided to families.	Healthwatch to signpost service users or parent /carers to PALS in the future when they feel the service is failing them.

Analysis of themes arising:

Long waiting lists for speech therapy was the main issue that came up for speech therapy services within the Kaleidoscope Childrens' Centre.

Quality of treatment and staff attitudes were overall very positive, especially about physiotherapy.

Quantitative Results

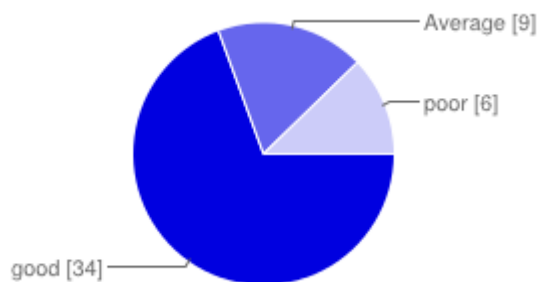
Out of the 50 personal story forms that were completed during the last three sessions at the Kaleidoscope Drop-in Healthwatch Lewisham was able to produce numerical data from the tick boxes responses given on Healthwatch Lewisham's generic feedback form.

There are the following seven areas that can be responded to by rating the service 'good' 'average' or 'poor':

1. Access to a service
2. Information and choice about your care
3. Time waiting to be seen
4. Friendly and caring staff
5. Listened to and involved in decisions about your care
6. Standard of treatment and care
7. Would you recommend this service

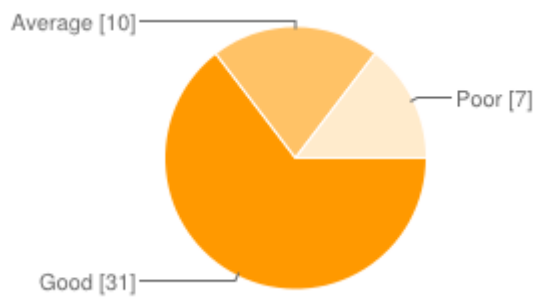
Here are the results from service user, parent and carer feedback about all services provided at the centre.

1. Access to service



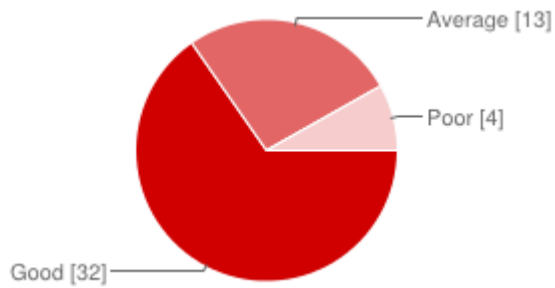
good	34	69%
Average	9	18%
poor	6	12%

2. Information and Choice about your care



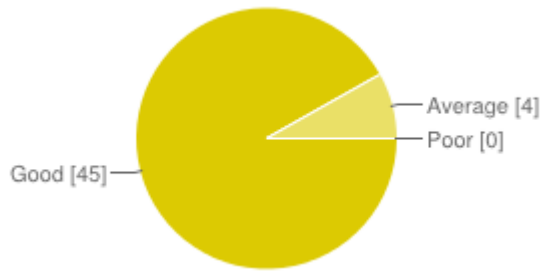
Good	31	65%
Average	10	21%
Poor	7	15%

3. Time waiting to be seen



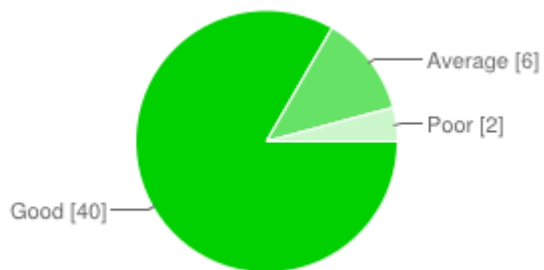
Good	32	65%
Average	13	27%
Poor	4	8%

Friendly and Caring Staff



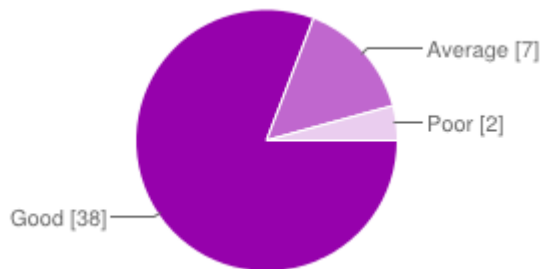
Good	45	92%
Average	4	8%
Poor	0	0%

Listened to and involved in decisions made about care



Good	40	83%
Average	6	13%
Poor	2	4%

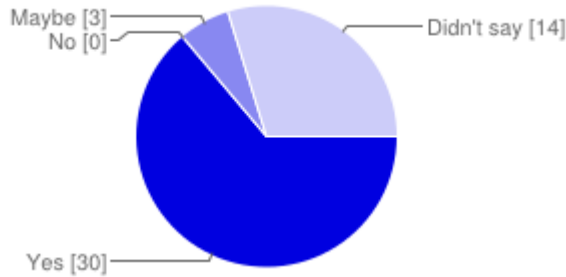
Standard of Treatment and Care



Good	38	81%
Average	7	15%

Poor 2 4%

Would you recommend this service?



Yes 30 64%

No 0 0%

Maybe 3 6%

Didn't say 14 30%

Analysis of Data

The results of the quantitative data reflect the themes arising from the qualitative comments. 'Access to Service' and 'information and choice about your care' received the largest number of 'poor' ratings showing that these are the areas that service users are least satisfied with. Alternatively friendliness of staff, quality of treatment and how involved and listened to service users felt were the areas that were rated the most highly. 92% of respondents said that staff were friendly and caring and 83% said they felt listened to and involved in decisions about their care. 81% said they received a good standard of treatment.

Analysis of CAMHS quantitative data

Looking at the feedback specifically about CAMHS shown in the four tables below, eight out of 15 people said that they thought access to the CAMHS service was good. 11 out of 16 people rated the standard of care as good. Eight out of 15 people rated the time waiting to be seen as good, and seven out of 15 people rated the information and choice about their care as good.

Access to service
Average
Average
good
good
good
good
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good
Average
good
good
poor
good
poor
poor
Average

Standard of Treatment and Care
Average
Good
Good
Good
Average
Good
Good
Good
Good
Good
Poor
Good
Good
Average
Good
Good

Time waiting to be seen
Good
Average
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Average
Average
Good
Poor
Average
Poor
Poor
Good

Information and Choice about your care
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Poor
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Poor
Average
Good

Outcomes

Raising Awareness

59 additional families know who Healthwatch Lewisham is and what services we offer as a result of the engagement undertaken at Kaleidoscope over a three session period.

Stronger Partnerships

Healthwatch Lewisham was able to continue to strengthen partnerships made with other organisations in the Consortium over the last three months.

Healthwatch is now better equipped to signpost members of the public to the partners' services having more knowledge about services provider by partner organisations. Members of the consortium are also directing more parents who would like to give feedback or complain about children's services to Healthwatch Lewisham.

Healthwatch Lewisham has since attended another coffee morning ran by the Parent Partnership Service. Lack of support for families with children with autism and the difficulties faced when visiting the GPs were key themes arising from this session. Healthwatch will be attending future meetings and promoting future events.

Healthwatch Lewisham was also invited by Contact a Family to attend a Transition Day in May. At the event parents told Healthwatch that they face challenges taking their children to the doctor with valuable suggestions that flexibility and booking preferences were given to parents with children who had a disability. Lack of joined up services between hospitals, doctors and parents was also highlighted as a problem and how this impacts on accessing medication.

These issues will be feedback to GP surgeries via the Practice Managers' Forum and communicated to commissioners.

Healthwatch has been able to feedback positive comments to their partners highlighting the important work community and voluntary organisations are doing to support families in Lewisham. One caller who requested signposting assistance to make a complaint about her doctor mentioned that Lewisham Autism Support, Contact a Family and Signal had all provided valuable support to her as a carer. *"I now know there are other parents that feel like me, that my experience isn't isolated and I'm not alone...before I went around in circles and thought that I was the problem but now I know I'm not."*

Healthwatch Lewisham will be attending an awareness event to promote services at Kaleidoscope organised by the Kaleidoscope User Group in July.

Healthwatch Lewisham Observations from drop-in sessions

Healthwatch Volunteers complete an observation form, designed by Healthwatch Lewisham, at the end of every session to record how the session went and key issues arising.

On the 28th of April one of the receptionists noted a distressed parent in the waiting room and notified the drop-in partners. The parent had a child with autism and had come seeking support at the centre feeling that she had nowhere else to go. Thanks to the drop-in session being available the Parent Partnership Service was able to listen and offer advice. This example highlights the usefulness of on hand support being available at the centre, and the importance of training reception staff to signpost young people and their parents/carers when necessary. Lack of support for parents outside of appointments was raised as a key issue at that particular session.

On the 13th of May it was noted that overall the feedback received that day had been very positive and that Healthwatch Lewisham should look into developing a more young-person friendly tool to record young people's responses.

On the 4th of June Healthwatch was pleased to see that PALS information was clearly displayed on the front reception desk. The two key issues arising from this session's feedback were around waiting times to initially access CAMHS and Speech therapy.

Feedback about Healthwatch from our partners

"I found the Healthwatch volunteers very helpful, they walk around the reception area introducing themselves to parents/carers talking to them about Healthwatch what services they offer and also how other projects/groups at the kaleidoscope Drop-in session can support parents/carers. Make cups of teas/coffees as well as talking to parents/carers while they are waiting for help/advice from the drop-in adviser and sometime keeping their children busy..." Contact a Family

"I would say Healthwatch have fitted in well within the Resource Space, working within the framework /ethos of the drop in service. HW have contributed to the running of the space, providing important information and feedback opportunities to parents / carers as well as contributing resources to the space. HW have participated in service review meetings and have provide valuable monitoring reports that have been used to feedback on the space to the wider Kaleidoscope community. HW have been a great addition to the resource Space." Kaleidoscope Drop in Service

"Healthwatch Lewisham has worked with Lewisham Parent Partnership service since meeting at the monthly drop in service that is held at Kaleidoscope Children's Centre. We have continued to work closely together and were invited to our monthly coffee morning sessions. Simone Riddle the community engagement officer met with our parents and carers who were very keen to engage with her on a wide number of issues. Having Healthwatch at our coffee morning sessions is very useful because they are a further service to our parents. Simone listens to each parent and takes on board their views and concerns and advices them accordingly. Parents have commented that they feel that their concerns have been listened to". Lewisham Parent Partnership Service, Bellingham Children's Centre

Feedback about CAMHS from CAMHS staff

One of Healthwatch Lewisham's Community Engagement Officer attended a CAMHS team meeting in April. Staff communicated to Healthwatch Lewisham that there has been an increase in young people self-harming, taking overdoses, having suicidal thoughts or experiencing mental health problems in addition to the increase in personal and public austerity. They had noted that there has been a reduction in the number of voluntary and community groups to refer young people to due to recent cuts facing a number of organisations in the borough.

On a positive note the provision of a separate paediatric unit at Lewisham A and E is seen as a significant improvement in relation to young people in crisis accessing mental health emergency services.

Staff communicated that it is not possible for the CAMHS team to respond at the point of referral i.e. to offer direct support or therapeutic interventions. During the time elapsed between point of

referral and an initial appointment there will often be deterioration in the condition of the young person which could have been avoided.

There is also an acute shortage of local hospital beds for adolescent placement with the need for a bed manager to search for out of borough beds with a common waiting list of 2 days.

They said that there is a need for CAMHS representation in schools especially at crisis points such as pre-exam times and overall more prevention work is required.

Conclusion

Overall feedback about services provided at the Kaleidoscope Children's Centre has been very positive, especially about staff attitudes and quality of treatment. This is demonstrated in the quantitative and qualitative feedback within this report. The main issues raised have been around access to services and occasionally the coordination of services, all of which have been highlighted above.

The Kaleidoscope drop-in sessions have been extremely beneficial to service users, parents/carers, voluntary sector partners and Healthwatch Lewisham. Kaleidoscope drop-in sessions provide much needed additional support to parents and carers at a time when there is a considerable strain on health and social care services, particularly mental health services in the borough. Healthwatch Lewisham is able to highlight some of the high quality of care and treatment provided at the centre, such as the positive impact good staff attitudes have on service users and their families. This report also demonstrates where services are currently unable to meet needs as well as areas in services provided that need to be improved in order to increase service user satisfaction.

The drop-in sessions continue to strengthen partnerships between voluntary sector organisations, providers and Healthwatch in Lewisham which will ultimately improve the level and standard of support offered to service users and their families in the future. Healthwatch Lewisham would like to continue to work in partnership with the consortium moving forward by participating in future drop-in sessions.

Report written by Simone Riddle, Community Engagement Officer, Healthwatch Lewisham

16th of June, 2014

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