

Lewisham Parent and Carer Forum

Healthwatch Lewisham Engagement about Community Care

January 21, 2015

Introduction

Healthwatch is made up of 152 local Healthwatch organisations that were established throughout England in April 2013, under the provisions of the Health and Social Care Act 2012. The dual role of local Healthwatch is to champion the rights of users of health and social care services and to hold the system to account for how well it engages with the public.

The remit of local Healthwatch is to be an independent health and social care watchdog to be the voice of local people and ensure that health and social care services are safe, effective and designed to meet the needs of patients, social care users and carers.

Local Healthwatch gives children, young people and adults in each borough a stronger voice to influence and challenge how health and social care services are purchased, provided and reviewed within the borough.

The Parent and Carer Forum

Lewisham Parent and Carer's Forum (LPCF) are a registered charity (Charitable Independent Organisation). We are a group of parent carers who have a child or young person with a disability or additional need, living in the Borough of Lewisham. Apart from the Parent Participation Officer, the Board of Trustees and all other members are volunteers who give their time freely.

The aim of the Parent Forum is to try and get the best services for our children, working with the local authority, health and social care.

The important thing about a parent forum is that our aim is not just to think about our own children but ALL of the children living in our area, as collectively we have a stronger voice.

There are 152 parent and carers forums across the country, 33 of them in London, totalling more than 55,000 parents and carers across the country collaborating to try to improve the services for their children - such is the commitment of parents.

Lewisham Parent and Carer's Aims and Objectives

- To be the strategic consultative body contributing to the development of policies and practice within Lewisham representing families of children with special and additional needs, providing a liaison point for Statutory and Voluntary Agencies within Lewisham

- To consult with and inform our membership with a view to ensuring that all children in Lewisham with special and additional needs have the best possible outcomes. These outcomes may be updated from time to time in the light of changes to Government policy
- To raise awareness of issues faced by disabled children and young people and their families
 - To share experience, knowledge and skills
 - To promote independence, empowerment and initiative in our members
- To inform the local authority of occasions when our experience of practice does not match current policy
 - To expect a 'can do' approach from Service providers
 - To positively change and enhance the lives of disabled children young people and their families
 - To enable and ensure parent carer's participation in the development of excellent services for disabled children young people and their families.

Background

Contact A Family produced a [briefing document](#) advising on how Parent and Carer Forums can work together.

Healthwatch Lewisham has been working closely with the Parent and Carer Forum as part of a consortium of CVS organisations who provide support, advice and signposting and information at the Kaleidoscope Children's centre in Catford since January, 2014. Healthwatch produced two [reports](#) collating the feedback from families who use the children centre in 2014.

Having been invited to present at a previous Forum meeting in 2014, Healthwatch was invited to come along to the forum in January 2015 for a more in-depth discussion with parents with a particular focus on community care services.

Healthwatch will use this information as part of an inquiry into community care services being undertaken with the Save Lewisham Hospital Campaign, Carers Lewisham and Lewisham Disability Coalition. Healthwatch will also use this information along with other evidence gathered from other engagement activities with families who have children with complex needs to produce a report, including recommendations and best practice for local providers, commissioners and health professionals.

Objectives for Healthwatch engagement

- Members to understand the role of local Healthwatch and how Healthwatch and the Parent and Carer Forum can work together
- Understand families' experiences using health and social care services for children with complex needs
- Understand which services in the community members value, which services are working well, which are not working well, how they can be improved
- Develop a set of recommendations based on the issues identified to improve patient and carer experience using local services
- Identify if there are any gaps in service provision across the borough
- Feed information gathered from the discussion into the community care inquiry to identify the reality on the ground in Lewisham in community care services
- Ensure families whose children have complex needs have a voice in the planning, delivery and monitoring of local services.

What we did

After explaining the role and responsibilities of Healthwatch, we introduced the discussion which was to consider the following in relation to community care:

- Issues and problems
- Possible solutions
- What Healthwatch can do

There were 21 members of the Parent and Carer Forum present who took part in the discussion.

Key issues	Possible Solutions	What can Healthwatch do?
<p>GP practices GPs and reception need to understand families' needs who have children with learning disabilities</p> <p>Not having enough time with GPs</p> <p>Waiting times for appointments are too long</p> <p>Access to GP services</p> <p>poor transfer of information</p> <p>111 - poor referrals</p> <p>Communication with children using with alternative means of communication needs improving. What adjustment is there for deaf people?</p> <p>Hospital 16 + staying overnight without a parent at hospital</p> <p>Last minute appointment cancellations</p> <p>Communication problems with paediatricians</p> <p>Social care</p>	<p>Parents to flag up with doctor's surgery that the patient has a disability or learning disability</p> <p>Letting people know who's coming</p> <p>Letting people know how much time they will have to wait</p> <p>Language or interpreters needed at different services, engagement directly with service user through visual aids</p> <p>Look at current communication systems to</p>	<p>Look into the issues</p> <p>The importance of change</p> <p>Set up YP's Forum for Health issues</p> <p>What is Healthwatch doing? What's the CCG doing?</p> <p>Campaign for clinically qualified call centre staff for 111</p> <p>Find out or develop a phone</p>

<p>Need more one-to-one hours allocated by social services</p> <p>Social services (lack of help) not returning calls</p> <p>CAMHS CAMHS referrals, who does them? Being sent to different professionals to refer, take into account parents and home experience</p> <p>Long waiting times for outcome of referrals</p> <p>Parents working full time just to get the referral done</p> <p>Nobody's listening to parents and home experience</p> <p>Safety - environment House on the hill - no cameras, unsafe</p> <p>Transition to adult services poor - no kaleidoscope equivalent</p> <p>General No consistency</p> <p>Involving parents in decisions when children are too young to make their own decisions</p> <p>All services - no consideration of health needs of carers and result of impact of caring</p>	<p>improve communication channels</p> <p>Duty to phone back and discuss by social services</p> <p>Could CAMHS consider changing their name - stigma with mental health</p> <p>Preparation for transition - key workers to pull services together</p> <p>Consistency, same place, same person,</p> <p>Better communication of health offer</p> <p>An organisation should listen to all family members' views to understand the reality, different person's views should be valued differently. Younger child's views should be heard but not relied upon to make a responsible decision.</p>	<p>call policy for social services</p> <p>Look into 16+ staying in hospital with parent</p>
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Actions for Healthwatch to take forward

- Share this report with parents of the Lewisham Parent and Carer Forum via the Parent and Carer Forum newsletter
- Healthwatch will collate the findings from all the engagement undertaken over the previous year with families who have children with complex needs. We will analyse the findings and produce a report to highlight the key issues and themes that have arisen from the information collected. This will include recommendations from parents and Healthwatch to improve their experiences of service users and their families. Healthwatch will look to include a 'good practice and recommendations' document to share with local providers, health professionals and commissioners
- Feed information gathered into the community care inquiry
- Feed the experiences about the 111 service back to the 111 stakeholder meetings
- Healthwatch will be working with the Lewisham Young Mayor's Team and the Lewisham Disability Coalition to organise a youth forum to discuss the needs of young people who have a disability in Lewisham. This will be part of a campaign to raise awareness with young people in Lewisham about disability and how this impacts on young people's lives
- Ask CAMHS for information about their referral and triage process to communicate back to parents and send to the Healthwatch wider network via the Healthwatch e-bulletin
- Provide information about
- Ask for clarification from children's social care in regards to dealing with communication and phone calls with parents
- Continue to communicate with the Parent and Carer Forum about the work Healthwatch is undertaking and what outcomes happen as a result of the Parent and Carer Forum involvement.

Simone Riddle

Community Engagement Officer

Healthwatch Lewisham

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