

Small Grant Projects Summary Report

Findings from Community Involvement Events on Social Care
issues

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Introduction

Background

Healthwatch Waltham Forest is the independent ‘consumer champion’ for health and social care. We were created by the Health & Social Act 2012 to represent the views of patients and the public in our local area. Whether it's improving services today or helping to shape them for tomorrow, Healthwatch Waltham Forest is all about local voices being able to influence the delivery and design of local services. Not just people who use them, but anyone who might need to in future.

The Small Grants Project

Healthwatch invited applications from voluntary organisations and community groups based in Waltham Forest who were interested in running involvement activities, such as a focus group. The purpose was to engage local organisations and support them to run projects which would help them get to know their service users better, understand their health & social care priority areas, and ensure the voices of their community can be heard. Healthwatch were looking to empower community groups to work with their service users and explore their own key topics within health and social care.

We called out specifically for Healthwatch priority areas including;

- Continence services
- Direct payments and/or personal budgets
- District nursing
- Domiciliary Care (paid carers who come into your home)
- Equipment provision and adaptations to the home
- Health visiting
- Rapid response team
- Respite care
- Social services assessment and/or review
- Stroke rehabilitation

The applications were assessed on whether they fit in with Healthwatch Waltham Forest’s aims and functions, methodology and audience reach, their intentions and what the group aimed to do with the findings. See the full scoring sheet in Appendix 1.

In November 2015 we awarded Small Grants for amounts ranging between £500 and £1,000 to 5 local community organisations. These were the East London Out project (ELOP), the Disability Resource Centre, Significant Seams, Waltham Forest Carer's Association and the African Caribbean Women's Development Centre (ACWDC). Funding was provided in two instalments; 50% at the time of award and 50% on submission of monitoring data and write up.

In March 2016 we received 4 reports, with one group unfortunately not responding. To read the full reports please contact Healthwatch Waltham Forest and we will provide them.

The findings were imported into Healthwatch Waltham Forest's database and fed into our insight on local needs and key issues, to be carried forward to our discussions with relevant providers and commissioners of local services. We also suggested further pathways in which the group itself could be more engaged in improving local health & social care for their service users. This report is a summary of the work completed by the community groups who were successful in receiving the Small Grant.

We would like to thank the community groups' staff, their volunteers, and the people who participated in the activities, for their time and commitment.

East London Out project (ELOP)

Small Grant amount: £980

ELOP provides advice, advocacy, counselling and support services for lesbian, gay, bisexual and trans (LGBT) communities in East London, with the aim to promote the mental health, wellbeing, empowerment and equality.

ELOP undertook two focus groups and did online and hard-copy surveys. They gathered “I statements” that demonstrate what LGBT people need services to do to show that they are LGBT friendly. ELOP engaged 42 people of all ages.

Key themes that came up:

- Knowledgeability: Understand unique difficulties LGBT people face and respond appropriately.
 - “An educated and professional service that takes into account my sexual and gender circumstances when they are relevant and ignores them when they are not.”
 - “Being aware of primary fears; such as rejection, anxiety, stress factors”.
- Equality: Do not treat us poorly because of our gender identities or sexual orientations
 - “Equality. I do not want health officials or health workers treating me or my partner differently because we are gay. I do not want snide remarks or raised eyebrows. I want acceptance for who I am. I do not want someone’s cultural or religious views to ‘enter my space’.”
- Anti-Assumptions: Do not assume I am cis or straight
 - “People not to make assumptions that my partner is a man.”
- Inclusive: help us access treatment and make us feel welcome
 - “Non-biased or judgemental health care. Not missing out on treatments or therapies simply because of my sexual orientation, or gender identity.”

ELOP Recommendations on LGBT inclusion:

1. Nothing without us: LGBT people need to be involved at all levels in the commissioning, design, monitoring and delivery of services as active participants in our health care.
 2. Training and changing attitudes: There is a need for all health and social care staff, including those who are not delivering clinical services, to have relevant knowledge and to raise awareness about avoiding general assumptions. In addition, stigma and discrimination need to be addressed actively.
 3. Visibility of the LGBT community in communications materials: Ensuring posters and leaflets are inclusive by using LGB&T-affirmative language and imagery to cue that LGBT people are recognised and welcome.
 4. Demographic monitoring that includes sexual orientation and gender identity is needed to ensure that a greater picture of LGBT needs is established at a service level.
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Disability Resource Centre (DRC)

Small Grant amount: £640

DRC is a user-led charity which provides supported classes and activities for disabled people, to avoid social isolation, learn new skills and take care of their own health & wellbeing. DRC ran a focus group for 15 disabled people and carers, along with a questionnaire survey for those who did not attend the event. They engaged a total of 21 people. The Focus Group discussion explored three main subject-areas: How did people find out about the equipment and adaptations that they needed or which could boost their independence? What equipment did they obtain, what was the process and how was it paid for? How satisfied were participants with the quality and usefulness of equipment they had?

Key findings:

- Many people felt that they had received very good help and support with disability equipment needs in the initial stages after acute illness or accident.

“An Occupational Therapist came out to visit me in Christmas week and I had an adjustable bed and armchair delivered before the New Year!”

- Some people had experienced problems with their home adaptations/equipment needs, however, when multiple agencies became involved in their case.
- There was widespread agreement amongst those consulted that the equipment that had been provided or prescribed by Occupational Therapists was of good quality and did the job it was supposed to do.
- Some people felt that there was a disjuncture, between the help they received in the ‘acute’ stage and for their longer term independence needs.

“When I came out of hospital 3 years ago, getting supplied with basic equipment like a commode and handrails was really fast and efficient. As time goes by, though, and you want help with ‘non-standard’ stuff to be more independent, it can be really confusing about where to turn.”
- An information leaflet presented to patients and carers in hospital could be extremely useful in helping people navigate the system in the longer term.

“Nowadays everyone tells you the information’s on the internet. It’s all ‘Look on-line. Look on-line’. What about people like me who can’t use a computer?”
- Sometimes problems could also arise between the priorities of housing providers and individual tenants’ disability needs.

“Ascham Homes updated all our properties with new kitchens and bathrooms. I have a disability but I wasn’t consulted about the flooring. I had a bad fall in September because the new bathroom floor was so slippery.”
- Were the possible implications for homeowners and public housing tenants as they aged or became disabled being considered?
- People wanted to be as independent as possible. Many people accepted that they might have to pay for some equipment and adaptations themselves, but wanted costs to be reasonable and to feel that they were spending their money wisely.

“I want trustworthy advice on what’s available and what to pay from someone impartial. Not some high-pressure salesman.”

DRC’s Recommendations for the Adaptions Service:

1. A borough-based leaflet about the adaptions service presented in hospital.

“With proper phone numbers for different types of help, not just the main Council phone number”.

2. Greater clarity over charging policies of services such as Papworth Trust.
 3. Some Focus Group participants experienced difficulties with reading, speaking on the phone or using a computer due to impaired speech, memory and/or cognitive abilities. They wanted more thought given to how people facing these barriers accessed information. Compliance with the Accessible Information Standard was due on 31st July 2016.
 4. More help with advice on equipment and adaptations in the longer term is needed, not just the acute stage when people first became ill or disabled. Having an impartial source of advice is particularly important for people who would be sourcing and paying for equipment themselves.
 5. Local demonstration events of affordable and useful independent living equipment could be really helpful.
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Significant Seams

Small Grant amount: £1,000

Significant Seams is a social enterprise which focuses on building and strengthening local community through crafting and supports people in vulnerable life moments. They provide a welcoming sewing and crafting space called the ‘Community Living Room’; bringing people together across various ethnic, faith and social divides to learn new skills and to get involved in community projects. Significant Seams utilised an existing group called Socially Supportive Stitching in which to hold the topic based discussions. This group supports people in mental health recovery and people needing social support. They engaged with 25 people.

The topics for discussion were:

- Mental Health Provision, with questions around what people think mental health problems are, when and where people would go for support, experiences of accessing support, and thoughts about what works well in current services.

“I have worked alongside MIND in Waltham Forest, and found this to be very supportive of client needs, also found a lot of involvement in regards to support and social events.”

“Sometimes there is a fear of stigma of ‘mental health’ and it can be problematic to get a GP appointment.”

- Social Prescribing, with questions around experience of social prescribing, what contributions it has on an individual's mental health and wellbeing, what types of activities should be prescribed, for what types of ill health, where to seek and expect information, and what unmet needs could be met by it.

“As a recovering stroke patient, I've experienced excellent care and support from the Stroke Unit, but after my recuperation, it seemed like there weren't many support groups and activities for stroke sufferers to do together”.

“How easy is it for men to access support, activities and groups in the borough? It seems that there isn't very much available for them in Waltham Forest.”

“Sport but also craft and social groups should be available for everyone to access and be inclusive, so there isn't any stigma involved if someone is not as well as someone else.”

- Personal Budgets, with questions around experience of receiving them, what activities could be recommended, and what concerns and advantages the budgets present.

“It's all very confusing conflicting information, I think there needs to be some nice clear concise information for people to access somewhere, so then I [as a community organisation who supports vulnerable people] could then advise you, or you could advise me further as to what assistance and advice of where I could signpost those who come to us who maybe entitled”.

- Safe, Supported & Independent, with questions around its meaning, what sort of activities/support would be a good recommendation, what concerns people have and what they like about being safe, supported and independent in Waltham Forest?

“Sometimes people who need help are also sometimes too proud (i.e. elderly and those with learning disabilities) to ask for help and don't consider themselves to be vulnerable, isolated or requiring help.”

Significant Seams also sought to better understand the benefits of their work for people, by looking at what other services people are engaging with, and the impact of participation in their regular groups. They aimed to find out why they do not receive referrals from GPs and how to best develop this route.

Recommendations:

1. Installing a coordinator who could work across the borough to help facilitate better relationships and partnerships between groups and organizations.
2. Better advertising of groups and activities for all abilities and needs, across a variety of different mediums in the borough.
3. More of a range of activities and support for those of a working adult age to support their independence, mental health and wellbeing.
4. More discounts, offers and incentives for participants of an adult working age to join up to a variety of activities, support groups and exercise opportunities, encouraging them to stay happy, healthy and independent, with the foresight that they'd alleviate pressure of the local authority health services over the duration of their adult life.
5. Regular training opportunities for the voluntary sector in Waltham Forest including first aid training, adult and paediatric care.
6. Creating a wide variety of opportunities and activities provided by a range of different local organizations, groups and providers and in particular, making more expensive but beneficial activities more accessible by being subsidized by Waltham Forest.
7. GP's practices and surgeries providing regular "wellbeing" surveys for patients, to help patients and create better continuity across the local health authority in the borough.
8. Further provision and support for those suffering with a variety of Mental Health problems, ranging from family support groups to physical activities.
9. Support groups and social groups to offer respite from those supporting someone suffering from a mental health problem.
10. There needs to be positive work done in Waltham Forest around the negative stigma and connotations of 'mental health'. This could be instrumental in the self-diagnosis of individuals suffering from a mental health problem, but also a borough wide education so that communities can better support and understand how to deal with individuals suffering from a variety of mental ill health problems.

Waltham Forest Carer's Association (WFCA)

Small Grant amount: £1,000

WFCA provide information, help, advice and support to carers, and ensure that the services of statutory and voluntary bodies meet the needs of carers.

WFCA aimed to gather detailed information with regard to experiences of the carers' assessment process and respite care in particular, in order to be better informed about carers' needs and experiences and to ensure that the charity was providing accurate information to strategic bodies, providers and other partnership agencies.

WFCA staff interviewed carers by telephone over a 6 week period in January and February 2016, using a questionnaire to instigate extensive conversations with carers about their real experiences. They spoke to a total of 42 people. They talked about topics including the Carer's Assessment, Respite services, and links the relationship and extent of support carers have with their GP.

Key issues that came up were:

- Some carers were not happy about the lengthy process of the carers assessment, and that the cared for person's condition in some cases deteriorated during this waiting time.
 - “LBWF say they want to keep people in their own homes but don't want to help them or it takes at least a year to go through.”
 - “The assessment was quite long winded and time consuming.”
- The purpose of the carer's assessment was not clear to some people.
- Many carers were impacted by service closures and the lack of alternatives. Often the support of friends and families were needed to manage.
 - “Difficult to make regular commitments due to caring role.”
 - “I wasn't told that my wife's day centre had closed!”
 - “I can manage household and tasks when he (cared for) has gone to bed.”
- Several carers reported problems and stressful experiences with accessing respite services, and this hindered them in pursuing hobbies or doing spontaneous activities.
 - “Would not apply for holiday grant again-too stressful going through process.”
- Whilst experiences varied, carers were generally unhappy that they saw different GPs, and so could not build a relationship with them.
 - “I've never been asked how I am coping.”

“GP not interested due to time constraints.”
“Doctor is there for medication purposes only.”

Recommendations:

1. Source of service provision and carer entitlement to be clearer, particularly with regard to practical support such as respite entitlement, carer assessment and home adaptations.
2. Information for carers should also be available as advice line for carers who need to be at home and do not have internet access.
3. The need for financial support for carers was evident with a high number needing to leave work and/or spend savings.
4. The need for more respite was evidenced. Specific requests were:
 - a. timely respite offer
 - b. respite following periods of cared for hospitalization
 - c. provision of day services for cared for person
 - d. clarity regarding access to holiday breaks
 - e. Information for carers to be provided on the basis of, “show me how.” One person specifically stated training needs in hoist and wheelchair use.
5. Advice/counselling to be made accessible for carers to get emotional support. 67% of all carers questioned were concerned about their emotional and mental health indicating: stress, low mood, feelings of being overwhelmed, depression, anxiety etc. as a result of being a carer.
6. A significant number of carers showed dissatisfaction with local Mental Health services. An improvement is required in the levels of care for vulnerable individuals, and development is needed in support services for people with mental health issues.
7. Increase in level of practical support (e.g. home support services.)
8. Support for carers looking for employment. Some carers struggled financially and others were unable to work due to their caring role.
9. Greater flexibility regarding service access, with the current Monday to Friday 9-5 slots resulting in limited opportunities for working carers to manage to attend events.
10. Exploring transport requirements for carers. This was raised by a significant number of carers but with limited clarity regarding gaps and needs. Some made reference to the need for a mobility scooter and/or car ownership and closer parking availability.

African Caribbean Women's Development Centre (ACWDC)

Small Grant amount: £972 (£486 has been paid to ACWDC)

ACWDC did not submit a report and Healthwatch Waltham Forest did not hear back when we tried get in contact before and after the deadline of the reports. Below is a summary of their project structure and intended outcomes based on their grant application.

ACWDC is a charitable organisation that positively addresses poverty, disadvantage and social exclusion by providing a range of learning opportunities, community services, activities, and projects. Through the Small Grants project they aimed to overcome Institutional and other social exclusion which prevent people from being engaged. ACWDC hoped to engage service users so that their views and experiences about equipment provision/adaptations to their homes can be heard. They also wanted to explore stroke rehabilitation.

The event format was an informal relaxed arts and crafts related involvement event, followed by a meal. They aimed to engage about 20 elders. This was to be complimented by individual and telephone interviews to gather the views of a further 30 people. The data was to be captured primarily by notes, with pictures.

With the findings ACWDC hoped that Health and social care providers and commissioned services would take account of people's views and experiences, so that would be a better understanding of the impact of exclusion. The findings would also enable ACWDC to review engagement and community services provision, including information sessions for services users.

There are no recommendations as we did not receive the final report.

Conclusion:

The organizations that received a small grant from Healthwatch Waltham Forest fed back that this was a good opportunity for them to further gather their service users' views, and there is interest for future collaboration. Healthwatch were happy with the level of communication throughout the process, and the insight that the reports have produced.

Healthwatch Waltham Forest have imported the full findings of each report into our database and will analyse the data alongside other comments. By carrying out research on our behalf the organisations have used their networks to diversify Healthwatch sources. We welcome organisations to share the views of their beneficiaries so we can have a greater impact when raising issues, good and bad, about local services.

We would like to thank again all those who took part for their time and commitment, and we will endeavor to use the feedback and recommendations in relevant conversations with care providers, as well as to inform our future engagement activities with the local community.

List of organizations and their contact details

If you want to know more about the organizations we worked with, please contact them:

ELOP - East London Out Project

Registered Office: 56-60 Grove Road, Walthamstow, London, E17 9BN

Website: <http://www.elop.org/>

Telephone: 020 8509 3898

Email: info@elop.org

Waltham Forest Disability Resource Centre

90 Crownfield Rd, London E15 2BG

Website: <http://wfdrc.org.uk/>

Telephone: 020 8534 1589 |

E-mail: info@wfdrc.org.uk |

Twitter: <https://twitter.com/wfdrc>

Facebook: <https://www.facebook.com/wfdrc/>

Significant Seams

131 Wood Street Walthamstow, London, E17 3LX

Telephone: 020 8521 4244

Website: <http://significantseams.org.uk/>

Facebook: <https://www.facebook.com/SignificantSeams?fref=ts>

Twitter: <https://twitter.com/sigseams>

Waltham Forest Carers Association Limited

Waltham Forest Resource Hub (Central)

1 Russell Road, Leyton, E10 7ES

Website: <http://www.walthamforestcarers.com/>

Telephone: 020 8556 0857

Email: info@walthamforestcarers.com

Twitter: @walthamwords

African Caribbean Women's Development Centre

603 High Rd Leyton, London E10 6RF

Website: <http://www.africanribwdc.org.uk/>

Telephone: 020 8556 4053

Email: info@africanribwdc.org.uk

Appendix 1: Small Grant Scoring Questions

For each application we need to consider if they meet the criteria. A minimum score is 5. A maximum score is 35.

- 5-10 will not be successful and will be referred for capacity building.
- 11- 25 may need some guidance and changes to their proposal before proceeding, including a reduced budget.
- 26-35 should be awarded and proceed with the model they have outlined.

Please score answer 1-7 with a rating of 1-5; 1= not at all, 2= partially, 3 = satisfactory, 4 = criteria fully met, 5= criteria exceeded.

Questions:

1. Do their organisations aims fit with any of our 6 functions?
2. Sufficient audience reach?
3. Does this match our aims to gather social care stories?
4. Robust and creative methods?
5. Are we happy with allocation of budget?
6. Are they making good use of the findings (other than sharing them with HWWF)?
7. Are we satisfied with their intentions? Can we build a working relationship?