

Healthwatch Newham and Powerhouse for Women Report Health Services for Women with Learning Disabilities SUMMARY

Tae Catford, Project Coordinator, Powerhouse, April 2018

1. Introduction

The overall aim of the research project was to:

- enable Women with Learning disabilities in Newham to learn about leading healthier lifestyles;
- discuss their concerns and share their ongoing experiences and
- to produce a report on the current experiences of 3 services: GP's surgeries, blood tests and Newham Hospital.

The project was carried out with the support of Healthwatch Newham's Community Grants Programme. The group was held at Powerhouse for Women, run by Project Co-ordinator Tae Catford, with a group of up to 40 women with learning disabilities (Group Sessions and Outreach Work). The project started in October 2017 and finished in March 2018, comprising of 6 research and information sessions.

A recent report from Mencap states that "New research suggests a lack of training for health professionals could be contributing to 1,200 avoidable deaths of people with a learning disability happening every year", 15th February 2018. Newham Joint Strategic Needs Assessment 2015 estimated that 4,000 people with learning disabilities live in Newham.

It has been observed at Powerhouse that the women are often left to live with severe pain, that their complaints are not always taken seriously, that checks such as chest x-rays do not take place and that some members are not even able to make appointments with their local surgeries.

2. Background

Powerhouse for Women is a women's only charity based in Newham, East London which aims to empower women with learning disabilities, who as a group are marginalized and disadvantaged in general society. It was originally set up in 1995 as a refuge, and in 2004 it was registered with the Charity Commission and Companies House.

3. Key recommendations

Key recommendations are around further training for Health Care Staff on how best to help people with learning disabilities engage with health services such as making it easier for those without phones to book an appointment in person at the surgery; to give a better support when doing blood tests especially to those on the autistic spectrum; for surgeries to share good practice around engaging with people with learning disabilities; and for further investigation into Newham General Hospital and the service they are offering to people with learning disabilities particularly women.

4. Methodology

The research was delivered using focus groups and 1-1 interviews. The sessions and interviews consisted of the questions provided by Healthwatch Newham about the three main areas. These questions generated further discussions about participant's experiences leading

to further questions, which were recorded. Other methods used were individual surveys about experience of GP surgeries.

40 members of Powerhouse for women took part in the research, all of whom have learning disabilities, of which 10 were accompanied by support workers. The project was explained in the first week and all participants gave consent for their answers to be used anonymously. This consent was checked again at the end of the project. The participants were involved in all aspects of the research.

The diversity of the group was as follows: Age range 20-65 years. 40% of the group is of Black, Asian and minority ethnic communities.

5. Findings

GP Services and Annual Health Checks

The research project found that in general GP's surgeries were delivering a good service

- Annual health checks are offered and taken up by 75% of the women involved in the research.
- 20% of the group have check-ups but could not remember if they had had one this year and 5% have a check up only every 5 years.
- 75% of the group say that they understand what is said to them, and reported that the check-ups they were referred for, such as blood test, had taken place.
- 68% of the women say that their staff know when their annual check-up is due and make the appointment for them, 20% say that the surgery phones them and 12% receive a reminder through the post.

Most of the women are supported to make appointments or have their own mobile phones so make appointments themselves. However, one of the main issues is for the women without support workers trying to make an appointment, who do not have their own phones. They will go to the surgery to get an appointment but are told to phone at a certain time in the morning which they are not able to do, because they do not have a phone. It often takes 2-3 weeks for them to get an appointment. "To get an appointment is a nightmare; they say no we can't do anything even if she has no medication".

The general attitude and support provided by the GP's reception staff and nurses vary across surgeries, as detailed in the findings.

- 60% of the group reported that they do not have enough time to discuss their health issues with the doctor or nurse.
- 3% have a chaperone or nurse with them when they see a male doctor.

Blood Tests

All of the women have had blood tests. In general these have been well explained by the doctors, and the women understood about having to fast from 10pm the evening before the blood test. However for some of the women, especially those on the autistic spectrum, blood tests and other tests such as smear tests, were not being explained well enough and cause high anxiety, to the point of a few women avoid these altogether. "I don't like blood tests".

- 60% of the group had their flu jab for the Winter 17/18,
- 25% have not had the flu jab and
- 5% refused. ("Receptionist just said "you have to have it"; more explanation would have been useful".)

Diabetes

- 25% of the group have diabetes. They understand the information that has been given.
- 1 person out of the group has home visits.

Hospitals

The hospitals that the group had used were Newham Hospital, Gateway, Whitechapel,, Whitechapel mental health service, Whipps Cross and Royal London and gave varied feedback.

- 50% of the group have had to use A&E Newham General, for epileptic fits/other seizures/heart related episodes with mixed experiences.
- Only 1 woman in the group knew and had used the Liaison Nurse. “She was helpful, she was with me the whole time in case I had a fit” (Newham mental health unit)
- For ongoing conditions such as diabetes and asthma the care received has been good. “My asthma is stable, good medication”. 42% of the group knew about easy read. “People with a SW get a better service”(Support worker)

6. Full Recommendations and Good Practice

- To make it easier for women who do not have access to mobile phones or internet to make an appointment. Many surgeries have an online or phone booking system, yet there needs to be an alternative for those without access to equipment to make an appointment e.g. to walk into the surgery and be able book an appointment.
- To allow extra time for people with learning disabilities in the appointment, because they may take time to settle and be able to discuss their health issues.
- To provide a higher level of service through training when doing blood tests for those on the autistic spectrum to alleviate anxiety and possible avoidance of these tests. This would include allowing extra time, getting to know how someone reacts and what they need to do to make them feel more comfortable e.g. continual reassurance (this also includes smear tests)
- Liaison Nurses at hospitals should be made known, easily accessible and available to those with learning disabilities on admission to hospital.
- Standardise the service offered across surgeries in Newham to improve access.
- Further investigation into Newham General Hospital which had negative feedback in terms of their understanding and support to people with learning disabilities as compared to Gateway.

7. Acknowledgements

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