

SELDOM HEARD PROJECTS 2016/17- FINAL REPORT

Please use this template as a guide to the main points that should be covered in your final report. You can be as creative and expressive as you like in your report and how it is presented. It is not necessary to stick to this template as long as you cover all the points below:

1. Who were the beneficiaries of your project?

were they older people; younger people; people with physical disabilities, people with learning disabilities; people with mental health conditions; LGBT; pregnant women and those who have recently given birth; of a particular race or religion; men or women; carers; socio-economically deprived communities; working population; other...? (please describe)?

We help disabled people to realise their potential, have greater choice and independence, and live happier, healthier lives. The beneficiaries of our project are disabled adults, including those with learning disabilities, physical/sensory impairments, autism and mental health needs.

2. Why do you feel your beneficiaries are 'seldom heard'?

Our membership asked us for this project and have lobbied the team for a video project through which to discuss their views and opinions. They were very keen to tell their stories as they feel they are often not listened to or directly consulted about their health and wellbeing concerns and opinions. The key objective was to give our membership an opportunity to engage in the project and communicate their views. The video has highlighted some of the challenges they face and indeed many of the reasons why they may be 'seldom heard' for instance due to communication barriers.

Unfortunately people with learning disabilities face significant health inequalities and are much more likely to be seriously overweight, with under a third of Wandsworth adults with learning disabilities being of a healthy weight. They're more likely to die younger of respiratory or cardiovascular disease, and 20 times more likely to experience epilepsy. We wanted to provide video facilities to develop a film that directly communicates our students' views about their health care and particularly where they see inequalities and ensure that the 'seldom heard' have a chance to express their views.

3. What did you do?

List your activities, locations, number of times they were held, how many people took part etc

We partnered with Healthwatch Wandsworth to run two workshops with our students to find out their views on local health services. This was publicised on our website:

<http://www.sharecommunity.org.uk/news/evaluating-health-inequalities-disabled-people>

During the first workshop at our centre in Clapham Junction, students had the opportunity to discuss their experiences on a 1-2-1 basis and record their opinions in an easy read survey. 20 students took part in this activity and it was an invaluable opportunity to understand some of the challenges students are facing when accessing health services.



The second workshop was a group session in which 30 students attended a session run by Healthwatch about the local health services available to them and when you might use them. This provided a great introduction for the next activity where students were broken into small groups to talk about their experiences of individual services. Easy read visual cards were created such as "doctors", "dentists", "waiting room" and "booking an appointment" etc so the different health services could be explored in more detail. Students really enjoyed the opportunity to hear each others experiences of using health services and a lot of insight came out of these discussions which has been summarised in this report.



To follow-up this group session, three further discussion groups were held in which 8 students came together to talk about the key points that had come out of the workshops and to discuss how this affected them, how it made them feel and how things could be improved.

We also attended a health appointment with one of our students so that we could discuss and film their experience of booking and attending an appointment. This included meeting them at home and observing how they

travelled to the appointment, located the health centre and what happened during the appointment. Their relative also attended this appointment and during the film talks about her experience of supporting her family member who has a learning disability.



These sessions and workshops highlighted the key areas of improvement that could be made to help Share students to receive a better and more accessible health service. The information gathered at these sessions has been collated both within this report and in the video created as part of this project.

4. What were the results (outcomes) of your project?

Outcome 1 - We saw an improvement in confidence in our students as they felt better able to express their views about health services. The series of workshops and discussion groups enabled the students to have the confidence to take part in the video and also improve their understanding of how to reflect and report on their experiences of health services.

Outcome 2 - This project has enabled our members to be listened to and their views shared with influential policy makers and people in positions of power.

Outcome 3 - The video is being released to our network of stakeholders including donors, beneficiaries, family, friends, care givers and the local community. They will have the opportunity to see the video and hear the views of our members. We expect to use the video often on our social media channels and external engagement.

Outcome 4 - This video offers a legacy to empower similar projects for other areas. Indeed, we are now talking to students and local services providers about other projects such as focus groups and giving feedback on the accessibility and suitability of hospital wards to those with autism.

Outcome 5 - Our students have been encouraged and motivated by this project and now have the confidence to lobby us for more similar projects.

5. How did you measure that you achieved what you set out to do?

The key objective was to give our membership an opportunity to engage in the project and communicate their views. When planning each activity we checked it against this objective to ensure it achieved what it set out to do and that the students were involved in every aspect. The focus throughout was therefore to enable our members to have an opportunity to engage in the project and communicate their views. This has been evidenced in the video.



We also thought that the project would naturally inspire an ongoing conversation within our membership about health and this has proven to be the case. Students are now regularly discussing health issues and the importance of regular health checks.

Our second objective was to provide our membership with a project they lobbied for to empower their learning and independence. We wanted our beneficiaries to build confidence and wellbeing and the therapeutic nature of communicating their views and being listened to is important. We held regular discussion groups and workshops in advance of the video to enable our students to build confidence and wellbeing. We were able to measure this through observation, as students were better able to reflect on their experiences of health services and communicate this during the groups and on the video.

6. What went well?

The discussion workshop with students went particularly well as there were lots of really interesting and insightful comments that came out of these sessions. These have been collated and shared in this report and highlights what is working really well and also what our students feel could be improved to help reduce health inequalities amongst disabled people. These sessions went well as students enjoyed being able to hear each others views, gained confidence about expressing their own and felt empowered and listened to by being given the opportunity to share their views with decision makers.



7. What could have been better?

We had hoped to attend a hospital appointment with one of our students and they were looking forward to being able to share their views in real-time. Unfortunately the hospital declined our request to film the student at the hospital and so we were unable to do this. The aim was to look at how they travelled to the appointment, what works well and any challenges they face in doing this. And then to enable them to talk about their experience, from finding the right place in the hospital, accessibility, the suitability of the waiting room and whether the health information provided to them was easy to understand. This would give a really useful insight into the full process from start to finish of making an appointment, attending and then how they carry forward any actions from the appointment that help them manage their health condition.

8. What are your plans going forward?

We are looking at ways we can help reduce the health inequalities our students face by carrying out activities such as:

- Putting together a health passport for each student that they can take to appointments
- Raising awareness of health issues through workshops and partnering with specialist organisations
- Continuing to find opportunities for our students to have a voice and input into local service design
- Working with parents and carers to raise awareness and supporting them in reducing health inequalities for those they care for

9. What benefit did your organisation or your beneficiaries get from you attending Thinking Partners, Learning Lunches, Eday and the CCG AGM?

These sessions provide a really useful insight into what is happening locally, what the priority focus areas are and how local health services are being delivered. It has also provided an opportunity for students to share their views and experiences as well as an opportunity for networking with other local providers who share a common interest in improving health services and reducing health inequalities.

It was beneficial to take part in the Eday and be able to discuss with professionals and service users within Wandsworth what improvements have been made and where changes are still required, particularly in regards to accessing local services. The first half of the day was spent with service users discussing patient experience within health services around Wandsworth. Some interesting discussion points came out such as the issue around people with learning disabilities sometimes not understanding the computer check in system at GP surgeries and needing more time with the receptionist when struggling with the system. This is an issue many of the students that access Share may face when trying to access GP appointments. It was beneficial to be able to share and discuss these elements of everyday living that can be challenging.

10. What benefit did your organisation or your beneficiaries get from taking part in the Men's Health Champion programme?

The Men's Health Champion programme was attended by one of our students; Harish and he has really enjoyed the new responsibility and sharing his learning with other students as highlighted in the case study below:

Case Study: Harish

Harish joined Share in 2001, and studies life skills and catering with us.

Harish is a happy, friendly and enthusiastic person who is always keen to help others.

Harish recently joined Share's Healthy Living Project and has become an active member of our weekly smoothie group, which aims to raise awareness about the importance of eating a variety of fruits and vegetables. Each week he helps to prepare healthy smoothies for Share students to try.

Harish is very interested in learning more about healthy living and volunteered to attend training to become a Men's Health Ambassador for Wandsworth. The training was held at Wandsworth CCG and, as part of his new role, he'll be promoting men's health issues to other students at Share and encouraging them to go for regular check-ups. He has also been working towards his goal of having regular health checks himself and recently attended a check-up at his GP surgery, which was filmed as part of Share's health inequalities video project. During the video he and his family spoke about their experience of using health services.



Following the Men's Health Ambassador training, Harish was supported to run a short session for other students to talk about his new role and let them know what he had learnt as part of his training.

"The training was good, I learnt about not smoking. I enjoyed it. It was very nice. I feel proud I'm doing health training" ...Harish, Share student

Harish is keen to take part in even more healthy living activities in 2017 and reach even more of his healthy living goals to help him 'Live Well, Feel Great'!

11. What are the health and wellbeing priorities of your beneficiaries? Do the people that your project supports have common or similar health and wellbeing issues, and what are they? Do they experience the same difficulties in accessing treatment or activities to maintain wellbeing, what are they and why?

During a group workshop, we asked Share students to express their views and discuss their experiences of using health services to establish what

works really well for them and the things they find challenging. Here are just a few of the comments we received...

'What works well for me'

- The eye test was easy and comfortable. People understood what was going on. Opticians treated people well
- Doctors at the hospital treated people well
- Receptionists at the GP were nice, and so were the doctors. People got longer appointment times
- When there's a friendly receptionist it makes you feel good
- When staff explain things to you
- It's great having local services such as local opticians, doctors and pharmacies as we don't have to travel too far
- When you walk into an appointment and they shake your hand, ask how you are and smile it makes you feel good
- I trust the doctor and they don't rush me

'What I find challenging'

- Access can be a problem for a wheelchair user, such as a lack of automatic doors and ramps
- I receive appointment reminders by letter and text but I can't read
- I am reliant on my father to deal with healthcare matters as I find it difficult to communicate through speech
- I get panicky and stressed at appointments if I'm waiting for too long and don't know what's happening around me
- It's difficult to retain information your doctor said from the GP appointment
- I tried to find the hospital but I got lost
- People who live independently or go to the GP alone can find it difficult to communicate their specific needs or understand what the doctor is saying
- Sometimes I have to sit in the waiting room a long time but I don't always know how long I'm going to have to wait
- Getting to an appointment
- Difficulty understanding equipment

12. What recommendations do you have for Wandsworth CCG for how both the planning and delivery of local health services can be improved?

The views listed above highlight some of the areas that could be improved to help reduce health inequalities. It also lists things that are working well such as having local services which are therefore easier to access such as a local GP, pharmacy and dentists etc. The logistics of trying to navigate the transport network, find the health centre and get there on time can be a barrier so having access to local services was considered a big help by the group.

When planning health services it's useful to think about the patient journey as a whole and where there may be potential barriers that contribute to health inequalities. The discussion groups were a useful tool in gaining this insight for instance we asked the students how they recognise the signs and symptoms of illness and when they would see their GP? How would they organise for that appointment to be made? How would they remember the date and time of the appointment? How would they get there and so on? This highlighted lots of potential challenges for the students, for instance

not knowing how to make an appointment, not knowing how to read the appointment reminder texts etc. By working with individuals through a focus group it enables an indicative patient journey to be mapped and highlights areas for service improvement. As highlighted in the question above this could be strategies such as providing reminders by phone call as well as text, potentially to the individual and their parent or carer. Also, looking at how a more consistent service can be provided as the patient experience was very variable, some students would get check-up reminders, others wouldn't and some hadn't been told about the annual health check and invited in for this. A recent example was a student who was referred to the podiatry service but the letter didn't arrive in the post and so he was recorded as "DNA" for his appointment as unfortunately neither he nor his carer knew it was happening. It would therefore have been useful to receive the appointment notification by phone call or text as well as the letter to ensure the information had been received.

In addition to looking at the patient journey, it could also be beneficial to work more closely with community organisations such as Share as it's the perfect environment to raise awareness among disabled adults and their carers about key information such as annual health checks, screenings and why it's important not to miss appointments. By regularly having that conversation, raising awareness and knowledge, the individual is empowered to better manage their health.

13. Please add anything else that you would like the CCG to know about your project and where possible include quotes, photos and stories about your project and its beneficiaries.

Thank you for the funding to run this project with students, it's enabled them to have a voice and think about how services could be improved to enable better access and improved health outcomes for disabled adults.

Share students have really enjoyed thinking about healthy living and learning more about health appointments. As part of our Healthy Living Project we are running a variety of very tailored activities to meet student needs, both through group workshops and one-to-one support. We are working with students to raise awareness about the importance of health checks, why they happen, how regularly, how the appointments are made and talking to them about when their last check-ups were. We hope that by raising awareness amongst the students and also the letters and information they take home with them should increase the number of health checks being done. For instance, someone might have been the GP but are they registered with the dentist? When was the last time they saw the opticians? Etc.

The activities have all been designed with a view to helping students achieve meaningful, sustainable change. This has ranged from organising community-based practical tasks, giving out home-based tasks or asking students to complete pre/post workshop activities. We will continue to build on the energy, enthusiasm and motivation students have shown to help them to set new goals and continue to work towards greater independence, health and wellbeing. Throughout the project, students have demonstrated huge enthusiasm and commitment to learning and adopting healthy living principles. When asked about the Healthy Living Project one of our students said: **"I think it's good. It's made a lot of difference to my life. The choices I make now are different - I try and get healthy things like salad. I do things I didn't do before."**...Joyce, Share student



