Research Report

HEALTH AND INEQUALITY

(IT'S IMPACT ON SOUTH ASIAN WOMEN OF NARI KALLYAN SHANGHO)

BY Shingai Maramba May 2013

I would like to thank and acknowledge NKS for giving me the platform to analyse the impact that Health Inequality policy has on them. I would like to thank the Project Manager Naina Minhas and her colleagues for allowing me to participate in their group sessions. This helped to develop relations with the staff and NKS members, which facilitated my research effectively and enabled the participants to feel comfortable enough to open up and disclose personal information. Gratitude is also due to the health officials who were able answer my questions and provided me with data that was relevant to my research. Special thanks to Nargis Lalee for the support and positive encouragement that she offered me.

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Introduction

Nari Kallyan Shangho (NKS) is a health and welfare organisation working with South Asian women and their families living in Edinburgh. It provides a platform for women to come together and identify different issues relevant to them, and collectively address these. The key aim for NKS is to lessen isolation and deprivation for South Asian women as well as to promote positive health and wellbeing for women and their families. The quality of the lives of South Asian women subsequently positively impacts their families'. Through NKS, South Asian women come together and raise awareness of health and welfare issues of relevance to them. NKS hold equality, democracy and participation amongst their core values.

Having discussed different policies that may have an impact on South Asian communities, Naina expressed a need to understand the Health and Inequalities Act in Scotland. She conveyed the need to understand how policy makers meet the needs of South Asian women and how changes such as mainstreaming, will affect minority groups. This report validates research carried out previously for NKS called "Changing Cultures, Health and inequality in the South Asian".

My aim is to ascertain the facets of inequalities faced by South Asian women when accessing health care services. My methodology will include speaking to staff members, NKS users and Health officials about their views on Health Inequalities and mainstreaming. I will do this because I hope to gain clear understanding as to how mainstreaming will affect the services provided by NKS.

I will gather sources of information on health inequalities; which will assist in painting a clearer picture of the immediate impact and experiences faced by users of NKS. After having spoken to previous research groups, it is my understanding that "many standard indicators and measures fail to capture the nuanced and particular disadvantages they face. For example, in Edinburgh, the concept of "area of disadvantage" does not relate to the South Asian community which is scattered across the city". (Jones, 2012)

Research Methods

Stage 1

Analysing secondary data conducted by academics in the field of Community Education. This will include analysing data provided by the NHS.

Stage 2

The collection of data from primary source will be necessary: this will be conducted in the field as it is paramount to building a rapport with NKS users and members of staff. This will be done by spending time in their group environment at their place of work. I will also be interviewing health officials and professionals responsible for the implementation of Health Inequalities policy in healthcare.

Stage 3

The reason for interviewing NKS users is to inform them on how Health and Inequality works and what mainstreaming entails and how it will affect the service they provide. This information will be delivered over one week and subsequently followed by a week of interviewing NKS staff to try and find out their views on the particular needs and difficulties which create inequalities and their views on mainstreaming.

Main Findings

- The views of Healthcare officials on Health Inequalities and what they are doing to eradicate inequalities.
- South Asian women's views on health Inequalities, their experiences when accessing care and what they feel could be done differently.
- Funding Although health care officials would like to do more to eradicate inequalities, their
 resources are limited. The economic crisis has had a negative impact on funding, they feel
 they are not providing adequate support for minority groups, and also are not well equipped to
 train their staff adequately.
- There is a growing need to reach out to South Asian women and raise awareness about health
 care and wellbeing issues. Their population is comparatively increasing and their needs are
 required to be met.
- MEHIP (Minority Ethnic Health Inclusion Project) The part played by Translation services and their views on how to tackle inequalities and their views on mainstreaming. MEHIP is a service provided to users who face barriers when trying to access healthcare services
- There is also a language barrier affecting South Asian women when trying to access healthcare. A large number of women within the South Asian community speak very little English; some are lacking in confidence and feel uncomfortable expressing their needs. Some NKS users expressed their concern about their religious and dietary needs not being met. There are also cultural differences and a lack of knowledge for the staff members within the health care. These are just some of the obstacles affecting minorities when accessing health.

What is Health Inequality?

Health inequalities are the: "systematic differences in the health of people occupying unequal positions in society" (Graham, 2009). They are most commonly associated with socio-economic inequalities but can also result from discrimination. Health Inequality is a term that was brought about to tackle the inequalities faced by the vulnerable and minorities.

NHS Scotland is committed to understanding the needs of different communities, eliminating discrimination, reducing inequality, protecting human rights and building good relations by breaking down barriers that may be preventing people from accessing the care and services that they **need.**" (NHS Scotland Quality Healthcare Strategy, 2010)

The public sector duties on equalities included in the Equality Act (2010) place a requirement on all public bodies to consider the impact of policies and services on the needs of individuals with the 'protected characteristics' of age, disability, gender, gender reassignment, pregnancy and maternity, race, religion or belief and sexual orientation. There is also a legislative requirement that human rights are considered by public bodies and this has some crossover with equality legislation (NHS Health Scotland, 2011).

The reduction of inequalities within healthcare has been a driving force for the Scottish Government; as such they have a dedicated department within the NHS whose duty is to ensure that service is being made accessible to all and the people affected by inequalities are given a way to let their voices be heard and needs met.

Mainstreaming

Mainstreaming is about providing a service that is accessible and readily available to the general public, in contrast to having services that are designed specifically to meet the needs of a particular subgroup. When speaking to a health official, this is what he said about mainstreaming and how it was going to work;

'Mainstreaming is about trying to stop doing special activities for one group and getting mainstream services to improve their dealings with groups. For instance we run diabetes service to help people manage and cope with their diabetes, by improving their diet and lifestyle. But we've found that very few people from South Asian communities are accessing this, even though South Asian women are more prone to diabetes, than any other group. But when you have groups specifically for them they come out. Long term..., eventually, we would like to mainstream these groups as we feel it will be meeting everyone's needs and for service to be flexible. Over time we would like to mainstream...' (J Glover)

About NKS

NKS works with South Asian women and families to help them access information or services that are available to them. NKS plays a key role in researching health care changes and services; they then use this information to raise awareness amongst the women through workshops, group sessions or on a one on one basis. NKS staff member are professional, welcoming, resourceful and above all, have a great understanding of the cultural and religious needs of their service users. Their knowledge of the different languages and dialects within the South Asian communities makes them approachable and flexible. The women who come to NKS are eager to learn more, however, they lack the confidence to go out into society to find what they need. The organisation offers them a shared experience in learning, as well as a platform to support one another. The women are given a chance to build their knowledge around the skills they already possess, at a pace that suits their lifestyle or needs.

The Health Inequalities affects South Asian women on a day to day basis; this is why they have expressed a need to understand what policies means for them and how the government is tackling this disparity. The government has started to talk about introducing Mainstreaming, which raises a few concerns from organisations such as NKS. What will happen to the services they provide? How well equipped will the healthcare services be to accommodate the growing number of minorities? How will they reach those hard to reach people, and how will it accommodate those that are too vulnerable and lacking in confidence to approach mainstream services?

Interviews with the Health Officials

At this stage of my research I went out to speak to Mr J Glover, the Head of Department for Health Inequalities. The reason for the interview was for me to understand what all the above meant for South Asian women and what their future plans were. I also wanted to find out how they carry out their assessments when distributing funds to minority groups and how South Asian women fit into their spectrum. I also wanted to speak about mainstreaming so as to ascertain how they saw this being the way forward. These are the responses I received:

What does Health Inequality mean to the Health Officials?

'The different factors that make it difficult for people to access healthcare and/or to get the same outcomes from healthcare. Health inequality can be for any kind of reason, but the biggest factor is poverty'. (Glover)

'Services are usually geared to deal with an "ordinary person", (ORDINARY person would be middle class, educated, white person, not too old, not too young). Anyone else who isn't those might find it difficult to access the facilities, or they might access it, but the end result would be different. There might be language issues or cultural differences, issues to do with literacy, or wheelchair access. So his job is to educate the staff and improve services'. (J Glover)

What is being done to eradicate this inequality?

'Health boards have a legal obligation to involve people with the process of changes in services and it has a duty to involve a wide range of people, take on board a broad range of views. It will take a while for it to happen automatically, however that is the intended direction we want to go'. (J Glover)

'We have an interpreting and translation service, pushing for the staff to use it when needed. Some people don't like using them, but it may be the only way to communicate. We spend a million pounds a year; but would like to spend more. Speak to MEHIP, they work with other organisation. They educate as they translate'. (Glover)

Do you think policies to tackle inequalities are meeting the needs of South Asian women?

'No it's not meeting needs, it's a starting point. Laws are great, but how are people meeting the requirements of law? And are needs met? Equality act is a good law, very ambitious, but a lot of work has to be done before we can see the result. Every year we get a little bit better'. (J Glover)

What are you doing for the NHS staff with regards to training about dealing with minorities?

'We have over 24000 staff within the NHS, a variety in staff. And we do not have resources to teach everyone. We have electronic learning. ... There are only 3 people who teach in the area of health inequality, but there are too many people'. (J Glover)

As I was interviewing these officials it became apparent just how overwhelmed and overstretched they are, even before the mainstreaming begins. We spoke of funding, of which they said this was even more limited because of the economic climate. I wondered how they hoped to meet the differing needs of thousands of minorities if they were already struggling to train their 24000 staff members. Mr Glover however, reminded me that this was to be done over time. I decided to get in touch with MEHIP (Minority Ethnic Health Inclusion Project) to find out their views.

MEHIP (Minority Ethnic Health Inclusion Project)

MEHIP is a health inclusion service that works with the National Health Service. It provides a service to those service users who may need the help of translators when trying to access healthcare services. They offer free, confidential, advice, information and support to black, minority ethnic and refugee communities. Their link workers are of ethnic minority backgrounds who speak different languages. They are there to help ethnic minorities to access primary health care services, as well as to promote positive health and wellbeing. MEHIP also works with different organisations, as a bridge between small groups and mainstream organisations.

I interviewed the staff at MEHIP to try and establish their roles in tackling inequalities. I wanted to find out their views on mainstreaming and see if they would be able to give their opinions candidly as people from ethnic minority backgrounds and therefore culturally aware of the situations faced by these women.

During my interview I learnt that in the last ten years, BME (Black and Minorities Ethnic) have been able to influence policy and had a say in policy changes. The government has had to take their needs into consideration and listen to their views.

This is what the MEHIP team had to say;

What is Health Inequality to MEHIP?

'We have seen the growing use of interpreters and translating service within healthcare. This is positive, as it shows that the language barrier is acknowledged and something is being done about it, however the problem come when trying to get ALL the health professionals to use the translating service. They are just not using the service fully'. (MEHIP)

'At time there is breakdown in communication during consultation. There is the issue of improper use of translators. Sometimes the professionals are getting the languages mixed up, at time just getting the dialect wrong can be detrimental to the service provided... '(MEHIP)

'People just don't know how and where to access services, and finally when they do, the frontline staff are not well equipped with the knowledge or skill to deal with the non-English speaking ethnic minority. We can support people to access services, but the services also need to change, by educating their staff or raising awareness on different cultures that are around....'(MEHIP)

What does mainstreaming mean for NKS?

'We are here to support mainstreaming for ethnic minority groups. With diversity increasing, we are talking about 120 languages, to be able to reach all these people. Mainstreaming is about adjusting services, so that everyone is getting the same quality of care. We provide the link for organisation like NKS to get to mainstream services' (MEHIP)

"...it's difficult, because mainstreaming should be a group thing...because if you didn't mainstream, what you are now talking about is segregation, you are talking about second class service and that's not what any of us would want. If you are saying different groups should have specialised services, which means you are taking away patient's choice. You are limiting the quality of service they get. If someone is accessing health, they should be able to access the best specialist there is, regardless of religion, race, or culture'. (MEHIP)

The staff I spoke to was enthusiastic regarding mainstreaming. They saw this as a positive outcome for ethnic minorities. They raised very important facts about specialised services for minorities and how it may actually be seen as segregating and limiting the quality of care they receive. This is a valid observation; however, I feel a point has been missed. All is well once the users have acknowledged their needs for help. However, a person needs a starting point and follow up. What about the hard to reach people who need small minority groups to help build their confidence or provide a place for them to socialise and be a part of community? NKS provides that secure haven for these women, their shared beliefs and cultures make them easier to approach, as such should be maintained as the first point of contact. Mainstreaming will need to be able to address these concerns.

NKS Staff team

The reason why I have chosen to interview the NKS staff members is because they deliver a platform for South Asian women to come together and share ideas and concerns about health. These workers are of South Asian origin and as such know how to approach service users. They speak the same languages, have similar religious beliefs and follow similar cultures. This makes them ideal to deliver information that might otherwise be lost in translation. Having spent time with staff members at NKS I have found them to be approachable, professional and hungry to empower their fellow South Asian communities. They are passionate about their jobs and are constantly looking for ways to keep up to date with changes in policies. The service users who attend sessions at NKS are happy to have a safe place to meet. It's a private place for women, where they are free enough to discuss health issues in a group setting or on a one to one basis. They have a local GP who dedicates her time to deliver classes on certain health problems that need to be tackled. I have also since learned that some of the women who come to NKS volunteer as interpreters for those accessing Health care facilities.

These are the responses I received:

What is health inequality?

'The gaps in communication and barriers faced while accessing services are not limited to the language issues only; it goes beyond that – disempowerment, lack of information, low confidence, poor understanding of health and health issues, low literacy level among grass root women, informal advocacy and much more. People are unable to access services due to an array of constraints. That's where organisations such as NKS and MEHIP come in'. N.M

I was able to attend some health awareness group sessions within NKS which were delivered by the members of staff. They either did some research on their chosen topic or were sent out to attend a course to acquire themselves with the necessary information. Some sessions were about nutrition and wellbeing and I found the women sharing tasks and ideas within the kitchen whilst preparing food.

This meant they were learning how to prepare healthy meals. I also learnt that some women who attend sessions at NKS live in isolation, this being their only opportunity for coming out of their homes as they are wary of going out by themselves. This means that when they attend a session the staff member takes them out for a walk ensuring they are getting some form of exercise at least twice a week. They also have some instructors who come in to give exercise classes. South Asian women, because of gender and other cultural regulation are unable to go to mainstream exercise facilities. NKS provides a sanctuary for the women to exercise in private.

When asked how NKS had helped them with their health matters, these were the responses:

'Whenever you need them or they need you, you know they are there and then we are here.' – O.R. 'Because NKS is a 'women only' you can talk about things that you can't talk about anywhere else, you have the freedom to discuss. It gives women self-confidence which is the key; it is the starting point to all these other things.' – I.M.

'They encourage women to come out, to get awareness of health and to have contact with community, also an awareness of social wellbeing.' -K.N.

When asked about translation services through the NHS this is what the women said:

These quotes show the issues surrounding translating information and cultural differences.

'Most of the health talks on the NHS will be delivered by professionals in English, we have some vocabulary people can't understand, and although they do translate they are changing complex medical things into simple terms they don't understand.' -R.I.

'A lot of information that we're fed in the UK is quite straightforward and it's often bite-sized whereas trying to disseminate that same information in a more culturally sensitive way can be quite difficult... it showed that when health organisations, especially NHS, when they try to translate information it's not always the best thing for it because there's slight variations, there's topics that you can't just translate per se and give and expect people to take in because there will be cultural, other areas that you need to consider' – H.Aw.

'The gaps or barriers are not limited to the language issues; it goes beyond that – disempowerment, lack of information, low confidence, and more. People are unable to access services due to lack of communication. That's where organisations like NKS and MEHIP come in'. N.M

When asked about mainstream services:

'The word mainstreaming is highly misunderstood or misused by many. It is used by many as a way of allocation of reduced financial resources. I speak in the context of BME. Mainstreaming is not about mainstreaming people. It is about mainstreaming issues that come about in the form of gaps or barriers when accessing services. Once the issues are getting mainstreamed and gaps start to narrow, people moving on to using mainstream services will find it easier and more accessible'.
NM

'NKS gives them a platform really, a lot of the women who come from overseas particularly, who have migrated here through marriage or through other areas, they're not able to access mainstream services easily even though there's a lot of translated information flying around, but often that's not really what they need, it's more understanding what their needs are, and I think NKS has been able to fill that gap for these women and just tell them in their own language in a way that they'll understand what it is so that they know how to access these services, but also look at what their needs are and be able to bring in information, bring in experts, from different areas and give them that information in a more user friendly way.' – H.Aw.

'The word mainstreaming does not apply to community projects working in the voluntary sector, and is not introduced to get rid of ethnic minority groups that work with a social causes. These groups lay foundations to the empowerment process of marginalised communities. They help and support the process of increased social capital. Ethnic minority projects are dedicated platforms as first contacts for people to begin the process of empowerment. Through increased confidence people automatically move on to using mainstreaming services. NKS has survey reports to evidence this.'-N.M

'NKS gives emotional and moral support, and so much else. I know what has worked in my life, the path that worked for me, I try to encourage other women onto this path; coming, getting confidence, volunteering, moving onto the sessional work, maybe a job. We provide opportunities, we ensure that they can do the work, and then are able to move them forward. Many women don't have the confidence, they feel confident working within their own community, with the children, then they build the confidence, then they can move outside, to the mainstream and find jobs.' – A.K.

'NHS is not doing enough for people with different religious beliefs. They are forcing non-English speaking people to go to mainstream health agencies. The people would rather go to agencies that understand their beliefs and culture and provide non-threatening and encouraging environment. Mainstreaming will work if these organisations are around rather than cut down funding for these small agencies'. (NZ)

Analysis

It is clear to see that NKS is providing an invaluable and integral service for the South Asian communities. Through their services NKS has been successful in bridging the gap between their members and mainstream services. They play a very important role of addressing the learning needs of individuals and are in full support of lifelong learning. Lifelong learning is about improving knowledge through everyday activities and helping people to use the skills they already have to better their lives. This type of learning can be done through the community work or participation, social networking or employment related work. Some of the women using NKS speak very little English. The organisation seeks to tackle this problem by providing a platform for them to attend English lessons, meaning they are learning at their own pace and are able to interact with peers in the same situation. This opportunity to participate in education does not take away inequality issues, but has a positive impact on people's wellbeing and may in turn improve their ability to access services (Hammond, 2004; Macintyre, 2007). This is evidence that NKS actively seeks to empower women and are on a mission to assist in accessing mainstream services.

When looking at the mainstream service, "there appears to be a significant tension between the different ways in which health spending is determined. On the one hand, the Department of Health aims to spend money on reducing health inequalities without regard to whether the money might be more cost-effectively spent in other ways". (www.publications.parliament.uk, 2009) This raises questions about the other reasoning behind mainstreaming and whether the logic stems from a need to spend less on small health and wellbeing organisation and have the money spent on otherwise. It also raises questions about whether or not mainstream services are expecting to do away with groups like NKS.

There is also a great need to have lifelong learning within mainstream services. Lifelong learning is about giving the staff member's opportunities to get involved in education and training, helping them work together and learn from one another about the experiences of other cultures and languages. (www.lifelonglearningprogramme.org.uk). this can even mean getting healthcare professionals to work with organisations like NKS, where they can learn from one another.

NKS provides health education within the South Asian communities; they provide support in the form advocacy on behalf of NKS. They carry out home visits and maintain contact with families of the person they are caring for. They support cancer patients to the hospitals for chemotherapy and other appointments; they follow up on effect of medication. They find ways of explaining certain ailments or medical terms and after care to the women, in a way they understand. I feel it would be in both NKS's and the Healthcare services interest to work together to deliver a high standard of service.

• Recommendations

- NKS needs to be kept informed about changes within health care field, so that they are
 delivering the best service. On the other hand mainstreaming service needs to ensure that they
 are able to carry forward the opportunities that NKS provides. If they are unable to do this
 they may need to find an alternative.
- NKS should be encouraged to keep up the excellent work they are doing. I hope they can use
 this report to gain a better understanding about health inequalities and how health officials
 value this cause.
- I also hope NKS will be able to use this report to raise awareness of the invaluable role they
 play within the community and possibly encourage the funding bodies to take a closer look at
 what their organisation is achieving, thus positively influencing their position within
 mainstream services.
- I hope my report can be used to inspire and encourage the staff at NKS, as their roles are
 crucial for their users. It takes patience, dedication, professionalism and compassion, and
 these qualities can be difficult to balance, however NKS staff are a fine example of these
 principles.
- There is also an important message within this report; Mainstreaming is a positive way of
 acknowledging minorities and ensuring that everyone is receiving an equal level of care with
 health care services. The discrepancy lies in the lack of positive reception and understanding
 of the roles played by organisations such as NKS.

Conclusion

South Asian communities in Edinburgh are greatly affected by poverty; poor housing, unemployment and inadequate access to health care services. These are a contributing factor to the women's poor health and wellbeing. The finding through this research will hopefully provide NKS with reliable information about what is happening to tackle inequality through the Health and Inequality policy and the changes that are being introduced. This should assist in raising awareness about mainstreaming and inform service user's about the changes that will impact them and hopefully this will enable them to make informed decisions about matters affecting them.

It is clear from the interviews that everybody is fighting for the same cause; however there is no clear explanation as to where each body stands, and what the future will be for organisations like NKS.

There is a great need for all parties involved to recognise that they all have a shared interest, which is to eradicate inequalities. Marmot and Wilkinson (2009) spoke of the relationship between educational development and health. They said research had shown that poor health was caused by structural factors of inequality and poverty and the way in which these material conditions cause psychosocial stresses in early life. This is definitely the case for some South Asian women; their interaction with their social environment is very limited. Not only are some South Asian women living in poverty, but also face cultural, religious, and language barriers. Some women are restricted by the lack of social activities and the little engagement with those outside of their homes. This creates obstacles for them when they want or need to access health care. NKS is there to tackle these discrepancies and help women to gradually access mainstream services. There is a need for those providing mainstream services to understand the extent of what NKS does for these women. NKS cannot provide healthcare services, their role is to gives guidance and support, nor can mainstream service offer the services provided by NKS. These services would be hard to replace as they provide a bridge from the community to the services they require.

Instead, organisations such as NKS need to be cherished and protected by their funding bodies and encouraged to share their approaches with other such organisations. Staff members in NKS should be proud of the valuable work they are involved in. I hope this report will give them a sense of the importance of all that they do and will encourage them to continue building upon the success of the organisation. It is important for them to see all the different strands of their work and recognise the deeper, more wide-ranging and long term positive effect they are having and will continue to have in women's lives.

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