Changing Cultures

Health and inequality in the South Asian community in Edinburgh

By

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Acknowledgements are due to all the staff at NKS who made us feel welcome and who willingly worked the extra hours required. Thanks are due particularly to NKS Manager Naina Minhas who helped to organise this research, and her staff, in addition to, and in the middle of, running a busy community project. Lastly to all the women who agreed to participate in this research and share their remarkable stories.

NKS Research Report

Section 1: Background

1.1 Introduction

In common with other communities experiencing health inequalities in Scotland, the South Asian community is vulnerable to the consequences of poverty, poor housing, unemployment and inadequate access to services, including poor physical and mental health. However, 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. As a result of cultural and social practices a woman may have no personal disposable income and can experience poverty even when the family income is reasonable. Such examples would not be captured by most established instruments for monitoring inequalities.

NKS, a South Asian Women's Health Project in Edinburgh has been aware of these discrepancies for some time. At the end of 2011 the Manager of NKS, Naina Minhas and some of the Directors talked to researchers in Edinburgh and put together a research team headed up by Stephen Platt, Professor of Health Policy Research at Edinburgh University. This led to the formulation of a proposal for preliminary research to investigate the specific experiences of users of the NKS project. The findings are intended to be of value not only to NKS and contribute to a better understanding of the health and well-being of the South Asian community in Scotland, but also to explore the development of culturally sensitive indicators of health inequality and social exclusion which will be relevant to other ethnic minority communities.

Funding was sought from NHS Lothian and City of Edinburgh Council for this preliminary research. NHS Lothian provided £4000. Funding was solely for the extra NKS staff hours involved and was used to provide interview training for NKS workers; to conduct a face to face survey of current project users over a one week period; to conduct in-depth interviews with a sub-sample; translation and recording costs and data entry. NKS covered some extra costs from their reserves and the study team provided all their time without charge.

The fieldwork was carried out by those delivering services at NKS and members of the study team (Appendix 1). Dr Martin, Professor Platt and Lyn Jones had an advisory role throughout and also contributed to the development of training, the research methodology, topic guides, data analysis and this report.

<u>Stage 1</u>

A pilot study carrying out 6 interviews with NKS staff to ascertain their views on the particular needs and difficulties which create health inequality and social exclusion. Analysis of the monitoring database maintained by NKS.

<u>Stage 2</u>

A survey of users of the NKS project, conducted over a one week period. This involved interviewer training, face to face interviews, translating and recording the interviews, data entry and analysis. Qualitative interviews of a sub-sample of 15 women.

<u>Stage 3</u>

The exploration of culturally sensitive indicators, measures of health inequalities, and social exclusion in discussion with NKS staff team.

1.2 Project Description

Nari Kallyan Shangho (NKS) is a health and welfare organisation which, since 1987, has been working for South Asian women and their families (Indian, Pakistani and Bangladeshi) living in Edinburgh. The key focus of NKS is to:

- develop the social capital, health and quality of life for those families who experience health inequalities, social exclusion and deprivation
- provide a common platform for South Asian women to act together to improve the quality of their lives
- provide opportunities for the providers of health and welfare services to hear the concerns and views of South Asian women.

NKS provides the following activities:

- Health education and promotion
- Advocacy, outreach and group work
- One to one advice on issues, including housing, benefits, immigration, and racism
- Educational courses, sessions and training
- Open days/ seminars to address issues relevant to South Asian women and children
- Multicultural childcare services
- Networking and linking voluntary and statutory agencies

NKS is supported by City of Edinburgh Council, NHS Lothian, grants for specific pieces of work (such as the Heritage Lottery), and raises approximately 6% of its income through its own fundraising activities. It is a registered charity. Approximately 120 families use NKS services each week. Although services are primarily utilised by women, the childcare facility and advice service are used by men as well.

1.3 Methodology

Survey of project users

Over a one week period (6th to 13th June 2012) all the women who attended or visited NKS were invited to be interviewed about their views and experiences of the project. The interviewers were eight project workers, and one of the research team. The project staff who carried out the interviews had all received interview training which had focused on how to ask questions in a neutral fashion, to encourage elaboration of responses without leading respondents and the accurate recording of responses. The responses were translated and written up in English. Anonymity of respondents was determined through ID numbering of questionnaires and permission for the interview requested.

The interview schedule covered the following topics: basic data on each person and household; employment and income; situation before coming to NKS; and using NKS services. Most of the responses were pre-coded, but with space for additional comments to be added. The interviews were all carried out on the NKS premises, as far as possible in a quiet and private space. A total of 114 interviews (estimated to constitute 95% of those attending) was carried out over a five day period. Each interview lasted approximately 15-20 minutes. The coded interviews were then entered on to an Excel spreadsheet.

Qualitative Interviews

A sub-sample of respondents was then selected for a more in-depth exploration of these women's lives in order to identify, in greater detail, the range of issues facing them and to assess the feasibility of developing a set of culturally sensitive indicators of health inequality and social exclusion.

The qualitative sample of 15 women was selected by the external research team, without knowing the identity of any of the women. The interview sample was to focus on women who might be deemed to be "vulnerable" because of their experiences.

In the first instance, the researchers identified all those who had indicated by their answers to specific questions within the survey that they had one or more of the following characteristics:

- Experienced periods of isolation
- Experienced depression and/or anxiety
- Lived in over-crowded homes (defined as 1.5+ persons per room)
- Did not work outside the home or have access to their own money.

In all, 78 women had at least one vulnerability factor and 31 had at least two factors. The sample was selected from those who had two or more of these factors and was structured to ensure that it reflected the range of women attending NKS in relation to their country of origin, their age and the length of time they had been coming to NKS. Of the 15 women initially selected, two had moved away from Edinburgh and one declined to be interviewed. They were replaced by three further women who met the criteria for inclusion.
The composition of the final interview sample included women whose country of origin was Bangladesh (6), Pakistan (6), India (2) and one unknown. Their ages ranged from under 30yrs (3), between 30 – 49yrs (7) and over 50yrs (5). The time they had been involved with NKS varied from those who had been involved for less than 1 year (3), 1-4 years (5) and more than 5 years(7). Respondents had an average of 2.5 of the vulnerability factors.

The topic guide
The content of the topic guide was informed by the findings emerging from the survey, but also by discussions with NKS workers about their perceptions of the issues facing women involved with NKS. (Appendix 2) The guide included the following topics:

- Family and household structure
- Living in Edinburgh
- Social and family life
- Language
- Support
- Health services
- Work and caring roles
- Cultural identity

Each section had an introductory question which would give respondents an opportunity to talk about their experiences in general terms. This was then followed by a series of follow-up prompts which were intended to elicit more detailed information.

Four NKS workers attended training sessions with the external researchers in which the principles of qualitative interviewing were demonstrated. This was followed by observed practice interviews, with detailed feedback.

The interviews were conducted in English or in the respondent's native language. All interviews were tape recorded (with consent), translated if necessary into English and fully transcribed.

Data analysis
Based on a reading of the transcripts by the research team, a thematic coding frame was developed. Each interview was fully coded and summarised within that coding frame. The key points within each coding category for each respondent were then identified. A whole sample chart drew together the key points for each respondent, by thematic code. The next stage of the analysis entailed the development of higher-order descriptive categories and an exploration of the links between categories and themes which reflected the experiences of the sample.

1.4 Profile of NKS users

Three quarters (74%)[1] of the respondents in the survey had been in the UK for 10 or more years and more than two-thirds (70%) had been Edinburgh residents for 10+ years. One in six (16%) had lived in Edinburgh for five years or less. In terms of their country of origin, more than eight in 10 (84%) were from either Bangladesh or Pakistan, with the remainder coming from India (6%) and one in ten coming from other countries – three from Sudan, two from Saudi Arabia, and the remainder from Kenya, Turkey, China, Britain, Australia, and Uganda/Kenya.

Nearly three-quarters (61%) of respondents were aged under 50 years, 80% were married and the vast majority (96%) had at least one child. However, younger and older women were also represented: one in 20 (4%) were aged under 20 and one in six (17%) were aged 60+ years.

Respondents' households were equally diverse: as well as their own spouse and children, one in eight women (12%) lived with their mother-in-law and/or father-in-law, 4% lived with their own parent(s) and one in twelve (9%) had a son-in-law or daughter-in-law living in their household. One in ten (10%) had grandchildren in their household, while one in 20 (5%) lived in the same household as their brother or sister and/or cousin(s).

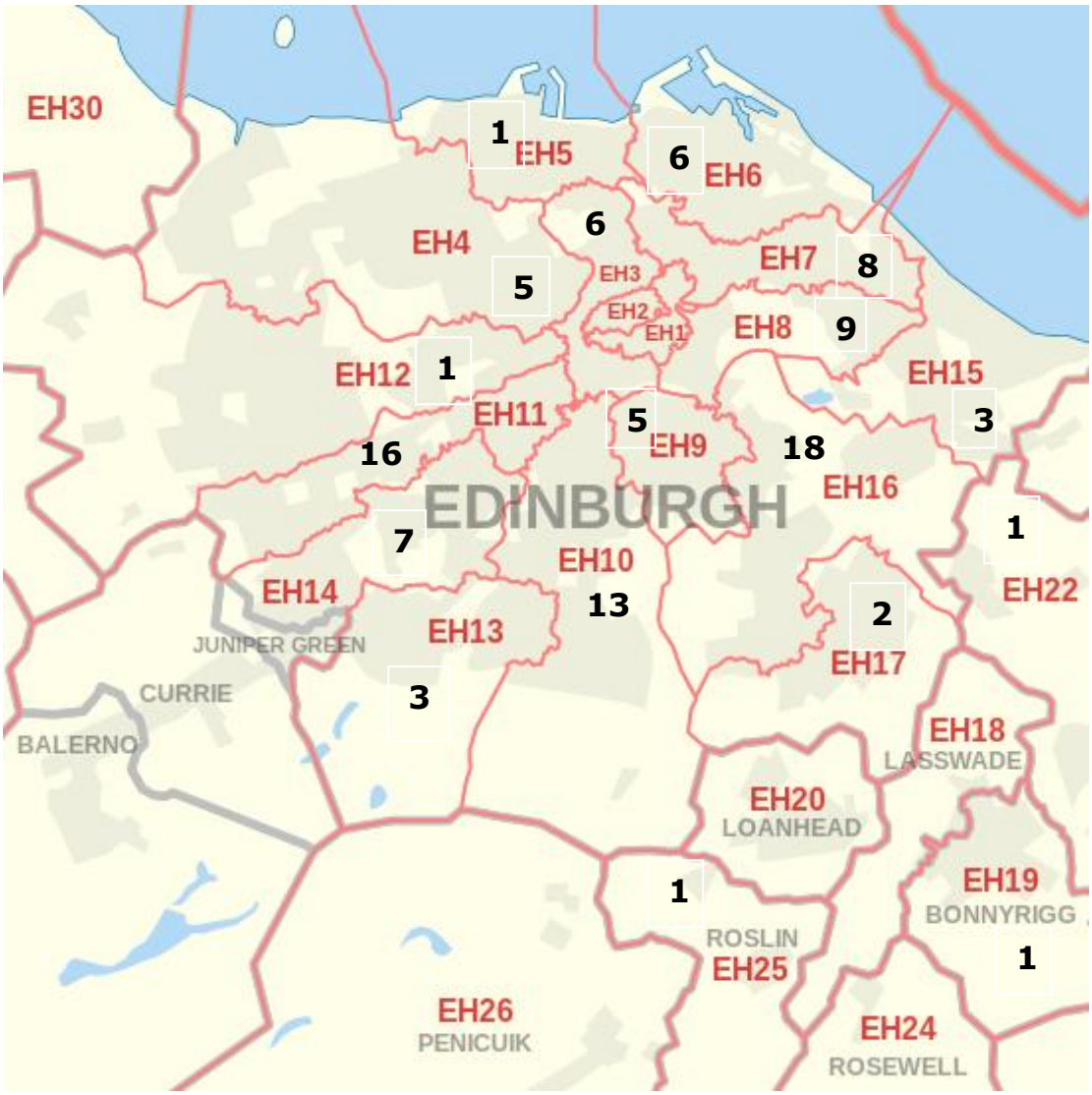
Just over two-thirds (72%) of the survey respondents were owner occupiers, while of the rest, almost one in five (19%) lived in privately rented accommodation and one in twelve (8%) lived in a property rented from the council. There were some reports of overcrowded conditions within those who were owner occupiers.

> *We have only two bed rooms. We have to manage with that. Six of us live in a two bedroom house. But we can't afford it. At least it's our own house. We manage by sleeping in the living room. My eldest daughter is a teenager. We feel that she should have separate bedroom, but we can't afford it just now*

[1] Percentages indicated in the report are drawn from the survey of 114 project users. The denominator for some variables is <114 because of missing information.

Respondents came from all areas of Edinburgh, as illustrated by the following Post code map.

Map showing Postcode distribution of respondents



Note: Three other participants came from Edinburgh postcodes not covered by this map (EH35, EH48, EH52)

Section 2: Processes leading to inequality and social exclusion

2.1 Introduction

It was possible through the survey and the qualitative data to gain an understanding of the demands faced by South Asian women - both at the different stages in their lives and, for many, in their personal journeys to move from their country of origin to Edinburgh.

> *In the beginning when I moved here, my brothers and mum and dad were back in Pakistan - I used to feel I miss them a lot and felt what am I doing here? I want to go back. Even though my sister-in-laws where with me here. Your own family is still your own family and nothing can replace them. When I had my own children that's when I started to mentally settle here and got my mind busy with them and adjusted my lifestyle accordingly.*

> *When I first came, it was weird, everything was different. I was used to open houses and open space. I felt like I was locked up in a jail here because the houses are so closed up. We use to stay in the house mostly and didn't socialise much* .

The qualitative sample illustrated how women arrived in Edinburgh for a number of different reasons. Some were born in Scotland or the UK, while others came to Edinburgh with, or to join, their husband usually following an arranged marriage. Others came to be cared for by a son or daughter already here or to address a family obligation, associated with providing care to elder family members. There were also accounts from the women we interviewed of how they came to Edinburgh to escape an abusive marriage or family.

> *I had come to Edinburgh actually to visit my son as he had moved here. I felt he wasn't looking after himself better. So I decided to move here.*

> *I had a lot of problems at home with my family …. Well my father was, I mean is very abusive.*

There were significant health and social issues affecting the women, when they first made contact with NKS. The reasons they had contact with the project included the consequences of social isolation; health problems; and for practical help and advice. One in eight (13%) said that they had had worries about housing, one in five (20%) had worries about their children, one in seven (14%) worries about money and one in five (19%) concerns about employment or education. A small number (4%) reported worries related to immigration at that time. There were also health and emotional worries for a considerable number of women: a quarter (25%) reported a concern relating to their physical health and a fifth (20%) had problems with depression and/or anxiety.

A vivid picture emerged of the different challenges women faced over time. These included: isolation and social networks, language, independence, access to services, and culture and identity.

2.2 Isolation and social networks

Two-fifths (41%) of the women in the survey felt isolated or lonely at the time they first made contact with NKS. The women in our sub-sample were not all lonely or isolated, although it was clear that especially when they first arrived in Edinburgh or the UK, it was a common experience.

> *We don't even have any relatives here. I didn't know anyone. It was hard. My husband is my cousin and I knew him from before, so I was not feeling that much out*

of place. But I couldn't speak English and couldn't go out myself. It was hard in the beginning. Someone always had to accompany me, as I couldn't speak to outsiders.

I used to feel scared , I didn't know any one at the time. Only people I knew were my in-laws and they were also new to me. I was afraid of not knowing anything about this country and people. I was afraid of not being able to settle in.

Some women mixed only with family members and with women at NKS, others had wider connections within the South Asian community and some interactions with neighbours, and there were those who had more extended social lives which included people beyond the South Asian community such as neighbours, work mates, other Scottish friends as well as their participation at NKS. In other words, although there were reports of relative isolation, it was also clear that others had developed social networks both within and outwith the South Asian community.

*I didn't know anyone when we came to Edinburgh. We rented a room from a Sikh family. We became friendly with the family and started attending prayers in , the Gurdwara [*Sikh *place of worship].*

The only place I felt confident to come was NKS. I am glad that NKS is there. It's such a relief for women who lack confidence to go to mainstream services. It's so good. At least we have somewhere to go.

Interactions with people living in their neighbourhood showed a similar pattern: there were those who had no interaction at all with neighbours or people in their locality and, indeed, talked about feeling unsafe or vulnerable within their neighbourhood; those who had friendly but casual relations with neighbours; and there were those who have social interactions with neighbours, which might include cultural exchanges with shared celebration of each others' festivals.

After moving to [X] we did feel I little threatened as we heard it was a rough area. After a few months of moving there we didn't feel any fear. We were able to be out and about till around 9pm and no one would bother us.

I know my neighbours that live around me. I chat to them when I am out.

My mother-in-law would always talk to neighbours and also give them food during Eid. Our neighbours also invite us to their houses. During Christmas, we wish them well and also exchange food. My mother-in-law is a very progressive lady. She believes in keeping good relations with people and learning about others. She keeps telling me also that I should keep good relations with neighbours.

Two, sometimes inter-related, factors affected how connected women were within both their own and the wider Scottish community. Women who had little or no English were more likely to report feelings of isolation and in many cases were also particularly dependent on their husband or wider family in order to interact at all outwith their family. For some this was to do with their health and age.

I just lie all the time. I can't sit for long. Sometimes I just lie on the chair and peel potatoes. I have a walking stick. I use that all the time. It takes a while to walk from one room to another. I am always alone at home.

I just socialise at NKS. I don't invite them home as my husband doesn't like. Coming to NKS is like breathing in open fresh air. I can be myself. I was so lonely. I had no friends. Even now I don't have any friends. My husband doesn't like me to

make friends. He thinks women gossip and get into trouble the whole family. I don't go to anyone's house and no one comes to my house.

At first I didn't have any support, my life was in the house cooking and cleaning for my in-laws. I wasn't able to go out. I used to feel so lonely all the time as I had no one to share my problems with.

2.3 Language

Although many of the women attending NKS spoke good English, this was not always the case when they first arrived in the UK and, or some, having limited English was a fact of their lives. NKS seeks to address the problem by providing access to English classes, but it was clear that those with little or no English are affected in a number of ways.

First, they may have very limited engagement outside their home: women may have restricted social activity, mixing only within their family and the South Asian community.

Second, women may struggle with everyday activities, such as going shopping, visiting a doctor, attending meetings about their children at school or accessing employment. Third, their limited English may, in turn, increase their dependence on their husband and family, including their children. While family members may be able to communicate a woman's needs, it was also suggested that the presence of other people compromised women's privacy.

Initially, I had a lot of problem. Language was huge barrier. I didn't go out of the house as I felt embarrassed that I can't speak English. I waited for my husband to come home and went out with him. He did all the talking for me.

It's very difficult, if one can't communicate. My son sometimes has to take a day off. Usually the girl from NKS helps, my son has to bear loss by taking a day off from business. It's really hard, but what to do…one has to manage.

Finally, at times, this may be a cause of distress, embarrassment and misunderstandings.

It was very hard because first we use to think what we has to say in Urdu, then translate it in our head into English and then say it, which would always be wrong because we would be so nervous and mix all the words up. Because of this we use to feel very embarrassed. But with time we started to see how to ask things.

Yes, sometimes there are diseases which I know the Urdu term to but can't say it in English.

I used to feel ignored when I first came, I felt no one gave me importance because I couldn't speak English.

For example, women gave accounts of not being able to participate fully in their children's education because they could not ask questions of teachers at parents' evenings and, as a result, were given less time with teachers. There was a sense for women that this affected their ability to fulfil their parental role.

They helped me with everything and explained everything to me. The only thing was that for parent's night I wouldn't spend much time with them like other parents. They would spend a long time asking everything thoroughly and I would just ask what I knew.

No I never, my husband used to go [to parents' evenings] every time for all our children. I once needed a reference from the head teacher of my children's school, but he refused to give it as he didn't know I was the mother of my children.

Like when the nursery arranged a trip... The nursery teacher asked me if I would like to help out, I replied yes. But I thought she was asking if my daughter would be going on the trip. The next day they phoned me up and asked me where I was, I told them I was at home. They said I agreed to go on the trip as a helper and I should have been there. I told them I was sorry and misunderstood what she said. This was very embarrassing for me. I felt really ashamed and regret not going to the English classes when I had the chance.

The women in the sample had a number of strategies to manage the situation which included: restricting verbal interactions only to their family and to people who spoke their native language; being accompanied by family (or occasionally by friend) to any activity outside the home such as going to doctor, to school meetings and events or shopping; and/or having to have an interpreter present for more formal encounters. In some cases, these steps were temporary measures as they learned English; taking active steps to learn English was, indeed, one of the ways in which women managed.

I could understand English, but couldn't speak. Once I started attending English classes, my confidence increased. I also managed to get a dinner lady's job in [secondary school]. I was speaking English by now.

I wanted to better myself and speak better English and the only way to do that is speak with English speaking people. So working in the supermarket was a start.

A number of factors either helped or hindered women to learn English. Family support to learn English was important and women talked of how their children would help them. Similarly, family support to attend classes was important, but there were accounts of husbands or members of a woman's extended family discouraging her from attending classes on the grounds that it was not necessary.

They [family] said these English classes are useless, you won't learn it from going there. I didn't get any encouragement from them to go to college or other sort of classes to learn.

A woman who may already be dependent on her husband or family might, therefore, be rendered even more so if she is not supported to learn enough English to manage simple transactions on her own.

Another factor affecting learning English was having contact with supportive professionals who gave the woman encouragement to communicate in English, even though that might inevitably require more time and patience on their part.

I used to take my sister-in-law with me but there would be situations that I couldn't say in front of her. So I started going on my own and tried to explain myself. It was hard, but there was nothing else I could do. Thankfully my doctor was very understanding and was able to understand what I was trying to say.

Local and personal factors may also be important. For example, older women reported that they found it particularly difficult to learn English and were discouraged by the sheer effort involved. Having to manage a strong Scottish accent was also described as something that made the process more difficult.

When I first started work, I could not understand the Scottish people. I kept on saying 'can you repeat that; pardon'. I found the accent to be very fast and even up until now I do not understand the slang words they use.

No I can't, I never tried to speak English I'm too old to learn.

However, access to supportive organisations such as NKS facilitated the process of learning English in significant ways: by boosting women's confidence so that they regarded learning as worthwhile and achievable; by providing taster classes where women could be with their peers; accompanying women to colleges; and providing opportunities through volunteering for women to practice the language in a supportive environment.

NKS suggested that I join English classes. I joined English classes and I am much better now. Thanks to NKS, now I can do some talking in English. I have enough confidence to say hello to my neighbours.

And after coming to NKS your confidence level goes up, you get out the house more to come to NKS and you meet other people. You observe other people and I felt that if they can pick up speaking English so why can't I? In that way it helps a lot.

2.4 Independence

Factors such as a woman's age, education, country of origin, religion, and individual personality all had a bearing on how independent women felt. For example, some women who were, by their own accounts, very dependent on their husbands or families in order to mediate their interaction with health services, shopping or schools accepted that this was their traditional role and had no wish to make changes. They might speak little or no English even though they had lived in the UK for many years, socialise only within their family and the South Asian community, need to be accompanied on any trip outside the home and have only caring roles (or be cared for) within their nuclear and extended family.

No I never go out on my own, not even in Bangladesh.

Once I leave NKS, I am back in my small world of husband and children. Not that I am not happy. I am very happy in my own world, but one does need friends too. So NKS is a perfect escape for that.

Another group of women were also, in many respects, dependent on their husband or family, but perceived this as a situation that created difficulties for themselves and others. They might have had little formal education themselves and their social activities might be limited to their community. However, they wished to learn, work or mix more widely. In some cases, women talked of being discouraged from learning English by their husband or their in-laws. Because their command of English might be poor, they were likely to need to be accompanied on all outings, but would prefer to be more independent.

I felt that by asking my sister-in-law to go everywhere I was being a burden on them. I felt that I should do things on my own and be more independent but didn't know where to start from.

They wanted me to stay home all day .They did not approve of me coming to NKS. After a long time I had to build my courage to come to NKS, but also feared what everyone is going to say when I go home.

For example and as we noted earlier, women's need to be accompanied on medical visits may compromise their desire for privacy and confidentiality. Moreover, women noted that

their restricted social position confined them largely to the home and meant that they could not work outside the home.

Finally, there was a group of women who had been heavily dependent on their husband and family but had been able, often with the support of projects such as NKS or Shakti Womens' Aid, to make significant changes to their situation. This was a group who had learnt (or were learning) to speak English. In one case, the woman sought employment so that she would have to speak English. Others were already good English speakers and may already have had educational or professional qualifications when they came to the UK. That may have given them the confidence to seek work, but also to acquire qualifications which would allow them to work in this country. This provided them with an income which not only contributed to the household finances, but also gave them a significant degree of independence. Learning to drive gave women a means to travel freely on their own, and to be more independent, although this might entail going against the wishes of their husband or family. For others, the struggle for independence was profound and required them to make drastic changes in their lives, including leaving their country of origin or previous home to escape marital or familial abuse.

2.5 Access to services and support

Several factors affected women's access to and use of a range of formal services (health, education, welfare) and informal services (such as local community projects).

First, women may not necessarily know what services are available to them, especially if the services are very different from those in their country or origin. Without the relevant social and cultural knowledge, they may not be able to access services simply because they do not know about them or appreciate how they may be of value to them.

> *I always took someone from home. I don't know, but there were never any interpreters. I didn't ask S [NKS worker]-my family didn't want any outsiders. I never went to health visitor or antenatal classes as I couldn't speak English. I missed out on so many services, because I didn't have much confidence to use these services.*

Second, the issue of the overall quality of care and how it was offered mattered to women and affected their perception of the service. In relation to health services, which all the women had used at one time or another, women who felt that they had received good clinical care and that they had been well "looked after" by staff generally felt positive about their experiences. However, if a woman's cultural needs were not met – for example, if she could not have or was not given the right food in hospital – then the experience was less positive.

> *They didn't serve halal food at the time, sometimes I would feel really hungry so my in-laws would bring me food but they couldn't always manage to bring dinner and lunch so I would be left hungry. Yes, I was admitted for gallbladder. I was in a lot of pain, staff were very attentive. But only problem I experienced was there were no interpreters and no halal food. Other than that I was happy with the service .*

> *When I had my first daughter in the hospital, the nurses didn't treat me right. Like with food, just because they knew I was a vegetarian they used to tick the lunch menu for me without even asking me. I didn't know that I had the right to ask for what I want to eat. Whatever they would give I would eat it quietly. I thought that's how it works.*

Third, a woman's ability to communicate with professionals had a marked effect on her access to and use of services. As we have already noted, women with little or no English may be disadvantaged in a number of ways, but their use of formal services is clearly constrained if communication is via a third party or if someone cannot make themselves understood or is not understood. Women were dependent on interpreters or being accompanied by their husband, a friend or a family member who acted as an interpreter, mediated the interactions and facilitated the communication of cultural and religious needs.

> *Well in the beginning of pregnancy they didn't give me any information on interpreters or agencies I can get assistance from. It was during labour when they found out I couldn't communicate with them due to my lack of English; they arranged an interpreter as my husband had to leave me and go to work.*

However, being accompanied may in turn infringe a woman's need or desire for privacy, increase their dependency and may actually inhibit learning English. Access to information and materials in the woman's native language was experienced as supportive.

Finally, it was clear that informal support from friends and family was important, but also that local community projects such as NKS had a specific role in relation to facilitating access to more formal services by – as we have already noted – giving information; building confidence; introducing and accompanying women to services; running taster sessions; and supporting the learning of English. The NKS project has developed its service over time in response to women's needs and in Section 3 we examine how these disadvantages and difficulties are addressed.

2.6 Culture and Identity

Many aspects of the respondents' cultural identity were experienced in very positive terms, but it was apparent that families' attempts to manage the transition from a rural or traditional culture to a more secular, industrialised, western society can produce tensions. It was clear that South Asian women experience difficulties in relation to:

- clashes between their own traditional and prevailing western values in the UK
- struggles to maintain their cultural identity
- challenges of managing cultural change.

These difficulties were particularly apparent in relation to the sometimes over-lapping matters of child-rearing, the cultural identity of children born in the UK, marriage and family obligation.

Clashes with western values

Inter-generational tensions were seen in women's reports of their concerns about the influence of western culture on their children. They perceived that this could impact on their future relationships with their children and with the children's grandparents. In particular, women talked about their concerns that their children would be, or were being, led astray by the alcohol culture in Scotland, what they regarded as the immodest dress of young Scottish women, exposure to sex education in schools, boyfriends and, more generally, the approach to child rearing in Scotland. These influences, in turn, were perceived to impact negatively on parent-child relationship as parents struggled to exert their authority on their children who wanted to follow similar behaviours and activities as their Scottish friends.

> *My main concern is they would get lead astray. The Bangladeshi community is led one way and the Scottish society is led another. The main concerns are that he*

doesn't get involved in drugs, alcohol, etc and stays on the right path to become a decent person.

I don't see any bad in Scottish culture, the only difference is we don't allow drinking, clubbing and don't approve of our children staying out late night.

They think I am a very strict mother - I believe I am bringing them up properly.

Since I've moved to Edinburgh, I'm finding it difficult to give my children Islamic education. I have huge respect for my religion, that's the way my parents have brought me up, my religion is my identity – my partner feels the same.

Sometimes, I wanted to and still want to go out more, but I am not allowed to because I am a girl. You know how it ist at home for Asian girls. We do have restrictions on us – all those traditional values. I feel if I had gone out more, may be I would have had more friends.

Maintaining cultural identity and values

Within the context of living within a very different society and culture, women talked about the ways in which they try to maintain their cultural identity.

There were families which endeavoured to ensure that children used their familial mother tongue and had an understanding and knowledge of their cultural and religious heritage, in the hope that this would instil a sense of continuing identification with their cultural background. Attending the NKS crèche was seen as a way of ensuring that children were exposed to their mother language outside the home. As well as participating in cultural events and celebrations, NKS – and, in particular, the crèche – was again cited as a vehicle for maintaining cultural identity.

Yes, the culture is different, but I have adapted. It is hard, but then we have to accept that we are living in a different culture. One does feel isolated as you see few people around who you can associate with, but what to do? I chose to come to this country. Now I have to accept whatever comes in my plate. No one can help with my loneliness. Neighbours are good, but they have different ways. One craves to be with people who have similar lifestyle as you have. I have to get out of the house and go to places like NKS to find people who I can associate with. It feels really at home.

Women also sought to continue to uphold or maintain specific traditional ways of living, although often with difficulty because of their clash with prevailing western values and practices. For example, some women supported their daughters who wished to wear a headscarf, even when it invited teasing or unpleasant remarks from their Scottish peers. (There were also positive examples of school teachers intervening in such a situation to ensure the young women's right to adopt their religious values and practices was protected and respected.)

My daughter is covering her head as a Muslim. She likes to cover her head. Her friends in school keep asking her why she is doing it. She tells them that it's her culture and religion. They tell her that she looks different, but my daughter doesn't mind looking different. She has chosen to cover her head. We have not insisted or forced her to do that. We do worry that when our children are older how they will react to living in two cultures. We would want our children to live according to their religion.

This was particularly the case in relation to the tradition of the arranged marriage. While for some of the women this tradition was perceived to be old-fashioned and for others had brought personal unhappiness, it was also clear that the principle of the arranged marriage was valued by other women who wanted their children (or grandchildren) to marry someone who had been selected – or, at the very least, approved – by the parents, particularly to ensure their children married a person holding a similar religious faith. The whole issue of arranged marriage was a much debated topic in the interviews and was, perhaps, one of the areas over which women perceived that there would be potential conflict with children. However, it was also an area over which women wished to find ways to maintain the tradition, while acknowledge changing opinions and values.

> *No, no one asked me. We are brought up like that. Whatever our parents did for us we believed it's for the best. I hadn't even seen him. They laughed at me that I am marrying an old man, but what could I say. I would let my mother take decisions for me. What could she do? My father died when we were young. She had to get my responsibility off her shoulders. She had to fix my wedding somewhere. Who could be better than a guy coming from a foreign land, who could offer me a better life than I had in Pakistan? I have other siblings too. My mother had to think about them too.*

Managing cultural change

For many of the women there was a need to accommodate their cultural preferences to life in Scotland. They sought to find the means to manage this adjustment so that some basic traditions and values were sustained, but in ways that were acceptable to their western-born children.

Thus, while there was still a view that arranged marriages were preferable, there was a clear perception that forced marriage was not (or was no longer) either acceptable or desirable. In some cases, women themselves felt that they had been harmed by the choices made on their behalf by their parents. Others simply felt that the times had changed and that their daughters, in particular, should have a choice in their marriage partner. This might simply mean that parents were willing for their child to decline a proposed match or that their child should be able to meet and choose a partner themselves. However, this might be tempered by a parent's continuing belief in the importance and necessity of their giving consent.

These changes were often accompanied by changes in the traditional child-parent relationship. Some women noted that they had more dialogue with their own children than had been the case with their own parents and a closer relationship. This dialogue, in turn, meant that greater freedoms than they themselves had experienced were negotiated and the limits of children's actions were extending. Some also reported that the way their parents or grandparents had favoured the boys or sons in their families, seeing girls as having lower status, had had a detrimental effect on their self esteem, their educational opportunities and their future lives.

Many women expected that they would live with their husband's parents once they were married. The relationship between women and their in-laws was often supportive but sometimes it entailed a more exploitative aspect, with women being overworked, treated poorly, not able to access health advice when in need of help, and (in one situation) experiencing physical and mental abuse. These situations are, of course, also experienced at times by white Scottish women, but the pressure not to report such behaviour or bring any shame on the family or community was at times felt to be oppressive and severely disadvantaged women.

There was evidence that women had to negotiate carefully to maintain their family support and also extend their own independence. Moving out from the extended family arrangement had pros and cons:

> *I'm happy to look after them (in-laws), I don't have a problem. It's just at times when I don't feel well myself I feel the strain.*

> *There are advantages and disadvantages. When I was living in an extended family my daughter was looked after. I was not so worried about her. But I had to do a lot of housework and look after everyone. I didn't have much say in things at home. Now when I am living alone, I have more say in what's happening at home. I can do things as I want to. When I lived with my mother-in-law, she would expect me to do all the housework before I went out. I had to do things as she expected.*

> *I like living with my in-laws, I wouldn't have it any other way. I would feel isolated if I lived on my own.*

Other tensions were described in the context of family obligations and the respect accorded to elders. For example, a husband could be supportive of his wife's desire to learn English or take driving lessons but would not want to go against his own parents' views that these activities were not acceptable. Family obligations, for example, to care for relatives and to respect elders' wishes, were accepted by many women, even though it restricted their lives.

> *My husband did understand (that I wanted to go out more) but, being the eldest son, didn't want to go against his mum and dad and do anything that would upset them. He always said because they were his elders, we have to obey them*.

Racism and discrimination

Some respondents reported experiencing racism and discrimination. It was believed, for example, that Asian girls were not always supported and encouraged at school because of a view that they would marry young and not continue to further education and a career. Assumptions were sometimes made about the care a woman wanted in hospital or the food she wished to eat without consulting her or an interpreter. There was a report of midwives treating a woman who could only speak a little English in an unpleasant fashion – laughing with each other when she was trying to give birth. A few other examples were more overt and included finding dog excrement on the doorstep, taunting by teenagers, or references to someone as a "Paki". These were not necessarily frequent occurrences and, in fact, the dominant view was that there was little overt racism or discrimination.

> *Years ago children used to come to the shop and say 'mum said go to the paki shop and get milk'…. (She laughs) I used to tell them not to talk like that as it is rude and then they would call me Mrs [S]*

> *We felt that there is less racism in Edinburgh compared to England. We are happy here. People are so helpful. When I put my washing out, they help me to get my washing in.*

However, there was a sentiment that attitudes had changed following the events of 9/11, with greater suspicion of Asians in general and Moslems in particular. Not surprisingly, even "small" incidents created insecurity and, in some instances, fear.

Section 3: NKS

The examples in the previous section illustrate the huge challenges that women and their families face in retaining their cultural identity in Scotland and the importance of culturally sensitive services that can provide a support for families as they traverse the hard terrain of adapting to, and coping with, life in a new country and a new society.

It became apparent that the factors identified could not be considered in isolation; the inter-relationship between them was the key to understanding the distinctive nature of women's disadvantage. We examined the way in which women made contact with NKS and the services provided in order to understand how these challenges were addressed.

3.1 Finding NKS

As discussed in the previous section, there were many obstacles that made it difficult for women from the South Asian community to connect with the services they need to improve their health and welfare and that of their families.

The survey concentrated on how women had found their way to NKS and covered the following: making initial contact; coming to the project on their own; language; transport;what they expected; family concerns; and first impressions.

Making initial contact

The findings suggest why these women would not easily make contact with existing mainstream services or respond to standard publicity. A few (7%) were referred by a health, education of social work professional but most of the women had originally heard about NKS via a personal contact (50% from a friend and 20% from a family member). Some (17%) were contacted directly by NKS when a worker visited them in their own home. The remainder (5%) were referred by another project or organisation or had heard about the project from a leaflet or the project's website.

Coming to the project by themselves

Fewer than one in three (28%) first attended NKS on their own, with most (69%) being accompanied by a friend or family member or by an NKS worker. While over half (55%) of those who were accompanied reported that they would/could have come on their own the first time, the remainder felt that they would not have been able to attend unaccompanied. The reasons given were as follows:

New in the country/ low confidence/ shy of mixing

> *I didn't know anyone and would have just stayed at home.*
>
> *I was new here – didn't know how anything worked, I would never have been able to come on my own – too scared.*
>
> *Because I had never been anywhere so I was too shy to come myself.*
>
> *I was too young and had many issues which affected my confidence.*

Health issues

> *It would have been two buses and a long walk to the bus stop and I couldn't manage*
>
> *I was not well mentally, was depressed and needed a lot of support.*
>
> *I have a disability.*

Language

While a minority claimed that they could speak English very well (19%) or quite well (17%) when they started coming to NKS, almost two out of three (64%) said that they had spoken either a little or no English at that time.

> *I didn't know English and didn't know anyone.*
>
> *Didn't know people, my English was poor and poor communication issues.*
>
> *I wasn't sure which language workers speak but I came to NKS because I was told workers speak Urdu*.

Coping with public transport

More than a third (36%) said that they had been worried about using public transport to get to NKS and did not understand the transport system. In a further question about any worries about coming by public transport, problems relating to health, cost, language and confidence/ knowledge of how the system worked were identified:

> *My health is poor, osteoarthritis, so I can't stand for a long time and it would take two buses*
>
> *I am not well, I had stroke and I can't travel alone. Public transport is not possible because of my health or for money reasons. I can't afford the bus ticket.*
>
> *I came to attend groups, but walked all the way. I didn't come by public transport, because not confident to use public transport. Also, I felt it was really expensive, I couldn't afford to travel by any transport, so I walked.*
>
> *I was new here, didn't know how things worked and wasn't confident to travel on public transport in case I got lost. With time I was able to fit in and start using it step at a time.*
>
> *Because I have never gone anywhere on my own. I am always accompanied.*
>
> *I had no confidence to take the bus and my husband working too busy at that time*.

Not knowing what to expect

A quarter of the women (26%) reported that they had had worries about coming to NKS for the first time. Concerns about meeting strangers and issues of confidentiality were common.

> *My daughter was disabled and I was worried if someone will ask me about my daughter and I don't want to talk about it, but no one say anything.*
>
> *I have worry that people were strange for me and I didn't know how women will react to see new person in the group.*
>
> *About what people will be like, and there were trust issues, I was vulnerable and had low self-esteem.*
>
> *I felt that I don't know these people, what will happen to confidentiality issues, no trust at that time.*
>
> *I did not have any family support behind me when I came to NKS. I was also concerned about confidentiality.*

Family concerns

One in eight (13%) recalled that their families had been concerned about them coming to a project in the community. The concerns were broadly related to their health at the time, confidentiality and control issues within the family.

> *My heart condition was very bad, had two open heart surgeries.*
>
> *Their concern is how I will travel and I am not well health wise – can't travel alone.*
>
> *I didn't tell my husband, he wouldn't have allowed me to come because I will tell everyone how I am bullied.*
>
> *Husband was not very keen that I should go anywhere on my own.*
>
> *They thought I will become more assertive and confident and retaliate.*
>
> *Because my family was not sure about confidentiality, trust was not there.*

Only a few (6%) reported that their families had continuing concerns about their involvement with the project.

First Impressions

Given the challenges involved in accessing services at all, first impressions of any service are crucially important if they are to be used effectively. The survey asked women about their first impressions of NKS. At this point in their lives, when they appeared most vulnerable, women valued most highly the practical, cultural and social support: it helped to reduce their feelings of isolation; it was culturally appropriate; and childcare was available.

Reducing isolation

> *I really liked it. Being a widow, I needed to get out and all my friends were here. It helped me get out of my suffocation of being lonely.*
>
> *It was nice meeting other women, it uplifts your spirits.*
>
> *It looked like a place where I can get help which I needed.*
>
> *I felt secure and liked it here.*
>
> *I live alone, helped me smile again.*
>
> *I felt happy, I wasn't so isolated and I knew help was at hand when required,*

Culturally appropriate

> *Met my expectation that I might find someone speaking in Bengali and make friends,*
>
> *Very quickly I felt at home. It was nice to meet Pakistani women and others, there are friends here too so I can remember things more easily. By myself I get confused.*
>
> *Very happy to see my own community people.*
>
> *Very happy they understand our religion, all staff is very kind.*
>
> *I was thrilled to see women who spoke my language and had common issues.*
>
> *Very friendly and women from my own culture and speaking my language.*

Availability of childcare

> *I liked NKS as there were women who I could identify with. I desperately needed childcare and NKS had the facility which is cultural sensitive.*

3.2 Women's experiences of NKS

NKS provide a wide range of support services and activities that have developed over many years in response to the needs and interests of women attending the project. The majority of survey respondents (72%) visited the project once a week, with 23% using the project's services and groups two or three times a week and 5% even more frequently. In relation to the range of services that women had utilised, nearly a quarter (22%) had had one-to-one "consultations" with a NKS worker or volunteer, 9% had had a home visit from a project worker or volunteer, 18% had been accompanied by someone from NKS to a doctor's appointment and about one in six (15%) had used the nursery/crèche.

Alongside these advocacy and advice services, more than three-quarters (78%) of women reported participation in regular group activities. Groups are held Monday to Friday, each offering a different experience and providing for different groups of women. Those interviewed attended on different days throughout the week. Over a third (38%) of respondents had taken part in art-related activities, and a majority had attended either health-related events or activities (80%) or outdoor activities (75%).

Learning and educational provision
As well as looking for social and practical help that they needed when they first came to the project, the women enjoyed taking part in wide range of learning and educational opportunities tailored to their own specific needs and aspirations. This was perceived as different from other community groups in which they had been involved, which concentrated more on social support.

> *When we had Leith community centre I used to go there – we got the opportunity to meet a lot of other Pakistani people. It closed down and then I started to come to the Elm Row centre more often. We used to have a party every week – I liked meeting people from the same background and we used to have a party every week. Eid party, Diwali party, one dish party, a party for everything and anything. [when attending NKS] - we have done many kinds of workshops and I picked up many skills. It wasn't like all party here every week. It was more learning and exploring new skills. Furthermore, we would share our health issues; I really liked going because of that. And we would wait every week for the day to come again so we can meet our friends again and learn things.*

Learning and educational opportunities provided included:

- Informal knowledge-based sessions on topics such as health, health services, education, the school system, the environment, benefits, housing, politics, Scottish culture
- Skills development such as cooking, sewing, arts & crafts, exercise, computers, using the library
- More formal educational courses and qualifications based programmes such as childcare SVQ's , First Aid, community work, Outdoor leaders and English

- Opportunities for volunteering and work placements in childcare, office based skills, social media, research and group work
- Visits to the countryside, Scottish towns and beaches, places of historical and social interest.

3.3 Outcomes

From the following examples, it can be seen that accessing these educational opportunities had an impact on women in their domestic and personal sphere as well as on their social and economic lives.

Increased knowledge
Health information and activities were by far the most often mentioned and very much valued by the women.

Healthy sessions – being able to get information on things which are very important was something I really liked here because my family don't know much and they can't really tell me anything.

I didn't know how important smear test was. After coming to NKS I realised and got mine done.

Diet, coming from a background where we don't eat much healthy food, this was very interesting for me.

Exercise, taking part in yoga and other classes was something different for me and gave me insight into taking care of myself and feeling good.

I have learnt most about how to handle teenage tantrums and schooling.

I have knowledge of how the Scottish education system works.

New Skills

Exercise, picking up workouts I can do in the house, cooking, new food.

Exercise, different kinds of exercise, things I can do at home too.

Cooking new food from around the world.

I've picked up skills from all areas in the kitchen, with children, and other outside people coming in and now able to study a new course.

Sewing – so I can make my own clothes and save money.

Wider impact
There was evidence that these skills were also being taken back into the home or into the wider community:

Through health session I can look after my family and myself in a better way without asking anybody

And exercise workouts, I now repeat the workouts at home too.

Health information: I can now advise my family on various health issues.

Health talks, the information given is very interesting which I can share with others.

New cooking recipes: I have picked up some new cooking recipes which I now cook for my family and friends.

Arts and crafts, comes very useful for my job.

Sewing: now I sew my own clothes and for family and friends.

Education and training
One in eight (13%) attended English classes and one in ten (10%) had attended other courses, such as childcare, first aid, computers, food hygiene, Women onto Work (WOW) and community work. Some women were helped to attend courses provided by Jewel & Esk and Telford Colleges by being shown where to go, meeting the tutors or attending taster sessions within the security of the project premises. Four in ten (40%) had accessed other forms of education or training via NKS. The NKS library was used by about one in five (23%).

Others had attended courses such as community support work, sewing, producing a cv, job interview training, health promotion, gym work, Islamic classes, outdoor leaders, Health Issues in the Community course and crèche worker training

In addition, a third (32%) had worked as a volunteer and a smaller proportion (6%) had had a work placement at NKS.

Steps to Employment
Users reported that the education and learning opportunities enabled them to engage with wider Scottish society with more confidence and independence and, for many, find a route to employment. For example:

Improved confidence and communication

I can manage to go to the GP and the children's school.
Now I can speak English and manage to speak to my GP.

Confidence, socialising and interacting with others

I was more reserved; now I open up more to people.

Getting involved in group discussions.

Employment skills

More confidence in myself – helped me look for a job and getting it.

I am learning various skills by being a volunteer – managing my work, managing people, learning to communicate.

Using computers, can now go on internet etc.

I've done child care courses and other health and safety courses.

Writing an article for NKS newsletter – I have learnt a lot.

Engagement with wider Scottish society

> *Scottish Heritage courses: learnt about local culture which helped me integrate into the society more.*
>
> *Learning about the Parliament session.*
>
> *Scottish Heritage courses about Edinburgh's history and Scottish music.*

3.4 The NKS model

While it is possible to demonstrate the successful impact of NKS on women's lives in a number of ways, the focus of this survey was not to conduct an evaluation. It was to explore the South Asian community's specific experiences of health inequality and social exclusion. These experiences are likely to be shaped by a range of social, economic and cultural factors which may be rather different – both objectively and subjectively – from those relating to other (both indigenous and migrant) communities in Scotland.

In Section 2 we presented a detailed illustration of the processes that lead to inequality and social exclusion. In this section we have explored the ways in which NKS can be seen to have helped South Asian women overcome many of the disadvantages they have experienced, not simply by addressing problems in isolation but by creating a holistic programme. Examining carefully how NKS has helped then enables us to shed light on the *nature* of those disadvantages, as will be discussed further below.

First, however, it is worth highlighting the evidence, presented in previous sections of this report, that very tangible and specific outcomes were reported by the majority of users of the project. The results from the survey show considerable and significant changes in the lives of the women attending NKS. These include: mixing with other people and making friends; increasing their knowledge; accessing services they need; making improvements to their health; feeling more confident and independent; and finding employment. In addition it is noteworthy that, as a result of their involvement with NKS, three-quarters (75%) felt that there were a range of things they could now do that they could not do before, including travelling, socialising, studying, changing diet and speaking English (see Appendix 3) .

From the data and comments reported in this study, it is clear that NKS's one-to-one outreach work and advocacy, combined with a culturally sensitive and trusted programme of activities and learning opportunities, has created a social environment in which South Asian women can improve their health and wellbeing, and flourish.

Social determinants approach

This embedding of specific kinds of support within an overall programme which is culturally attuned to its users is wholly consistent with the approach advocated by the World Health Organization (WHO) [2], which recognises the importance of the social environment in determining access to health services and influencing health-related decisions.
As the 2010 Marmot Review noted[3], a 'social determinants' approach to health inequalities highlights how it is the intersection between different domains that is critical and that

[2] *(World Health Organisation (WHO) Director-General Dr Margaret Chan, at launch of final report of the Commission on the Social Determinants of Health)*

[3] *The Marmot Review 'Fair Society, Healthy Lives' Feb 2010*

success is more likely to come from the cumulative impact of a range of complementary programmes than from any one individual programme. Programmes need to address:

- environmental, cultural, socio-economic, educational and social influences as well as access to service provision
- differences in social status – the lack of control and psychological stress that arises due to the disparity in social position ('statusanxiety') which exerts direct negative health effects.

In keeping with this view, the range of complementary activities and services provided by NKS offers a dynamic, flexible, holistic programme that enables women to find their feet in a foreign culture. It provides a secure, mutually supportive, learning community that facilitates the development of independence and improves the ability to tackle new challenges and tensions (for many, in the context of a more traditional, conservative family culture). Women's cultural and religious positions are respected throughout this process.

The service provided at the project offered women a path through these difficult life stages at a pace that is flexible for each participant. In addition to the activities and programmes, it provides a secure, culturally appropriate, social community, from which women can venture out and try new opportunities – and to which they can return. Women who have tried new courses or new challenges provide role models, inspiration and encouragement for others to follow. Advice is shared, experiences discussed, networks of friendship developed and celebrations and festivals enjoyed. It is a learning community.

The important insight provided by the NKS model is that specific aspects of disadvantage are not experienced in isolation from each other and any effective service has to adopt a holistic approach which works across these different 'life domains' and causal factors.
The following diagram illustrates some of the building blocks that are involved in the trajectory towards improved social inclusion and health. It should be noted that this is not necessarily a linear process.

Diagram 1 Key Building Blocks

Independence
'I can use public transport and go out on my own… taking driving lessons'

Employment
'Now I can speak in front of people- I run cookery classes at Leith Academy '

Childcare support
'It gives me relief as it's my stepping stone to move forward' 'I can go and study with free mind'

Improved health
'*Now I walk every morning into town. My health is better my breathing is better' 'helped me build a network and I have less depression'*

Better use of services
'I used to be uncomfortable attending appointments but now I am able to attend and discuss any problem with the GP'

Increased knowledge/education/training
'First aid and child care, community education, SVQ and voluntary work' 'Learned more about diabetes - I can control it myself now'

Improved communication and language
' before I couldn't talk to people- now I have more confidence to talk to people, I went to my daughter's school and dealt with issues of bullying'

Increased confidence
'I can now go around looking for volunteer work which I could never think of doing before'

Mixing and making friends
'*Build up more confidence, before I can't speak to the people and now I can make friends'*

Reduced isolation
'I used to feel isolated, now I feel I am part of the community'

Personal contact
'She visited me at home and told me about NKS … offered me support to attend groups'

Section 4: Discussion and Conclusion

4.1 Background

The aim of this study has been to gain an understanding of distinctive nature of the kinds of disadvantage experienced by South Asian women in Edinburgh, and thereby lead towards the development of possible indicators of such disadvantage. Before we discuss indicators in more detail, we present below some of the facts about the circumstances experienced by South Asian people in the UK generally. Most of this information comes from official figures or quite large-scale quantitative research studies.

Life circumstances for South Asian people in the UK

There has been much previous research into disadvantage experienced by people in ethnic minorities in Scotland and in the UK generally. The findings are massively consistent: people from ethnic minorities suffer substantial disadvantage in health, employment, and standard of living and many other fields, compared with the white British population. For example (and these are just a few selected figures):

Percentages of children living in households with below 60% of median household income after housing costs:

White British children	26%	
Pakistani children	57%	
Bangladeshi children	73%	*Platt 2009*[4]

Pensioners living in poverty

White British pensioners	17%	
Indian pensioners	26%	
Pakistani/Bangladeshi pensioners	49%	*DWP 2010*[5]

Research for the Equal Opportunities Commission showed that for the measures of general self-reported poor health and limiting long-term illness (LLTI), the Pakistani and Bangladeshi groups stand out as having the worst health. Census data for England & Wales and also for Scotland show high proportions of these groups reporting poor health and LLTI….. At older ages, Indian men and particularly women, also report high levels of poor health. *Allmark et al 2010*[6]

People in ethnic minority groups also have to put up with poor housing conditions. Across Scotland in 2001, Pakistani and Bangladeshi households had the highest proportion of households living below the occupancy rating standard, at 31% compared with 14% for white British households.

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[4] Platt, L. 2009. *Ethnicity and child poverty* . DWP Research Report 576. London: DWP, analysis of pooled Households Below Average Income data, 2003/04, 2004/05 and 2005/06 for GB.

[5] Department for Work and Pensions (DWP) 2010. *Households Below Average Income: An analysis of the income distribution 1994/95 - 2008/09*. London: DWP.

[6] Allmark P, Salway S, Piercy H et al, *Life and Health: An evidence review and synthesis for the Equality and Human Rights Commission's triennial review. Technical Report.*Sheffield, Equality and Human Rights Commission. 2010

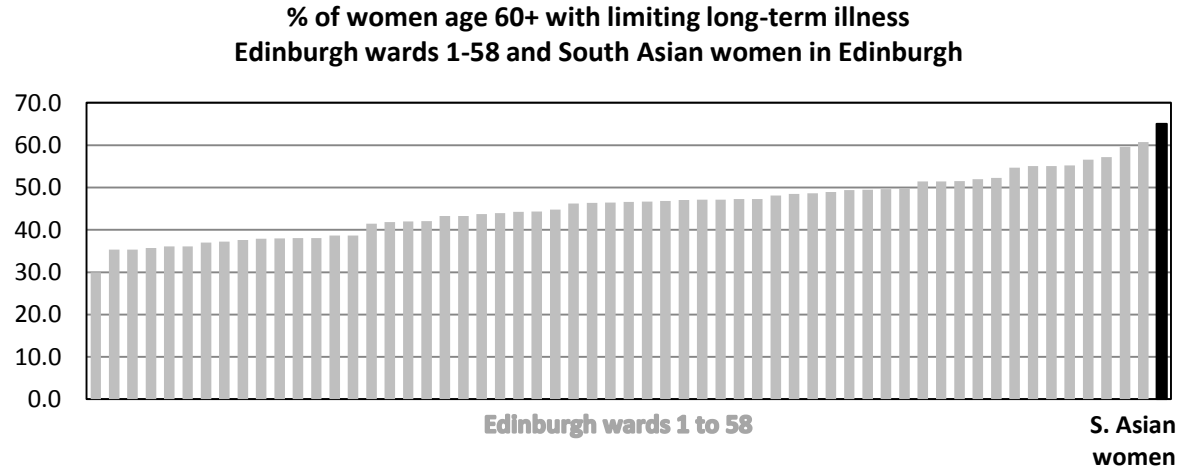
Women from ethnic minorities also suffer disadvantage in employment. A 2006 study by the Equal Opportunities Commission Scotland[7] reported that 14.2% and 14.4% of Pakistani and Bangladeshi women respectively were unemployed, compared with 5.3% of all women. Even when they do get a job, they often have to settle for something below their capabilities: a survey for the EOC in England in 2006 showed that ethnic minority women were 3 or 4 times more likely than white women to have often taken a job at a lower level than that for which they were qualified[8].

Many more such statistics could be quoted, for England, Scotland or the UK. At whatever level, the picture is completely consistent. What these figures suggest is that ethnicity itself is one of the most powerful indicators of disadvantage, along with female gender . In other words, although it would not be true to say that *all* South Asian women suffer serious disadvantage, a high proportion do – certainly a higher proportion than that of women in the population generally.

The South Asian population in Edinburgh

Is this picture on the national scale reflected locally in Edinburgh? Some statistics are available from the 2001 Census for Edinburgh, in a way that allows comparison between the figures for the South Asian community generally, and for separate wards across the city. In this way, it is possible to see how living circumstances for the South Asian community compare with those for the least and most deprived wards in Edinburgh.

For example, the 2001 Census records, for each person, whether they report having a long-standing limiting illness (LLTI) (the 2011 census results are not available at the time of writing). The figures are available for 58 standard wards in the City of Edinburgh, and separately for each ethnic group over the whole of Edinburgh, for men and for women, aged 60 and over. It emerges that South Asian women of 60 and over have a higher percentage of LLTI than any of the 58 wards. In other words, if we were to take LLTI as an indicator of need, South Asian women as a group would come out as having higher need than even the most deprived wards of Edinburgh. The chart below shows the percentages of women aged 60+ in each of the 58 Edinburgh wards and among South Asian women.



[7] Equal Opportunities Commission Scotland, 2006. *Moving on up? Visible ethnic minority women at work.* Equal Opportunities Commission, Glasgow.

[8] Botcherby S, 2006. *Moving on up? Ethnic minority women and work.* Equal Opportunities Commission, Manchester.

Further census data for Edinburgh for 2001 show that people from South Asian backgrounds were much more likely than white British people to live in overcrowded conditions.

> Percentages of people living in households with occupancy rating of -1 or less (this is the standard census definition of overcrowding):
>
> | | |
> |---|---|
> | White British people | 14% |
> | Indian people | 29% |
> | Pakistani people | 34% |
> | Bangladeshi people | 42% |
>
> *Scotland Census 2001 data, Table S244*

Lack of time and resources has prevented us from repeating this analysis with other Census variables, such as people's general level of health or employment status. On the basis of the great volume of research done elsewhere, however, a small sample of which has been presented above, it is likely that such analyses would confirm that South Asian people experience disadvantage at a level similar to the most deprived communities in the city.

4.2 Indicators and urban policy

It is particularly relevant to compare figures for the South Asian population with those for separate wards in the city because the Scottish Government, and various statutory services, frequently identify those in the greatest need in terms of the areas where they live, such as wards[9]. Social groups with poor health outcomes are often clustered in particular localities. Services, resources, regeneration initiatives and other interventions are then targeted at these geographical areas.

Probably the most widely used method of identifying areas with the greatest need is the very well-established Scottish Index of Multiple Deprivation (SIMD). This draws on data from the Department of Work and Pensions (DWP), the NHS, the Police, various Education sources, and transport sources, as well as the Census, to derive separate indices for a number of 'domains' (income, employment, crime, education, health, housing and access), and one overall index. It has been demonstrated in numerous research studies that these identify very well those geographical areas most in need of supporting services of various kinds. No such index is perfect but the SIMD has proved robust and practical. Values for all wards and other kinds of locality in Scotland are calculated and published regularly. The SIMD published in 2003 and based on the 2001 Census found that one of the Edinburgh wards (Craigmillar) was the 4th most deprived out of 1222 in Scotland.

Over recent decades the UK and Scottish Governments have used urban policy as a means of improving economic opportunities and living standards, through programmes of urban regeneration or neighbourhood economic renewal, often using indices like the SIMD to help target them. A review of these area-based initiatives concluded that there was strong evidence that the approach was worthwhile (Thomson, 2008)[10]. However, there is a major drawback: targeting areas of deprivation does not necessarily reach the majority of socio-

[9] Other smaller kinds of locality are also used. We have used wards here because the total South Asian population in Edinburgh (8149 in the 2001 census) is of a size comparable with the average population of an Edinburgh ward (7735); and the SIMD based on the 2001 census was published at the ward level.

[10] Thomson H A dose of realism for healthy urban policy: lessons from area based initiatives in the UK. *Journal of Epidemiology & Community Health* 2008; **62**: 932-936.

economically deprived people. Although defined 'areas of deprivation' contain the greatest *concentrations* of disadvantage, "At the local authority scale, most deprived people are not [living] in deprived areas and most people in deprived areas are not deprived" (Haynes & Gayle 2000)[11]. McLoone (2001)[12] estimated that, if 20% of the most deprived postcode sectors in Scotland in 1991 were targeted, only 41% of unemployed people and 34% of low income households would have been captured.

The problems are compounded when ethnic minorities are considered. This is because people from ethnic minorities, although very likely to be deprived according to most measures, are much less likely than white people to live in deprived *areas*. For example, in Edinburgh according to the 2001 Census, 16.3% of the white population lived in areas classified as "deprived"[13], but only 11.1% of the Indian and Pakistani populations. For statistical reasons, to do with the fact that the great majority of ethnic minority people in Scotland live in Glasgow, Edinburgh and a few other local authority areas, this disparity is not evident from national figures - a further reason for caution in using area-based indicators.

Thus, area-based initiatives need to be complemented by approaches which target disadvantaged individuals or households.

This, of course, is easier said than done. The great advantage of area-based measures is that much of the data is available from existing sources. How can all the other 'deprived groups', scattered in localities other than those identified as 'deprived areas', be identified?

What the above statistical comparisons show is that using ethnicity as an indicator is as likely to be at least as powerful and as precise a method of identifying a disadvantaged population as the standard area-based indices at ward level. Clearly, it only identifies one such population, one piece of the much larger jigsaw of deprivation; and, as with the area-based indices, not all the people within this population will be disadvantaged to the same extent. Nevertheless as a tool for targeting resources the indications are that it would be at least as efficient, in a general sense, as the SIMD used at ward level.

4.3 What the present research study adds to the picture

The present research study has been successful in providing insight into the many different ways in which South Asian women find themselves disadvantaged. Some of these can be expressed as single, separate difficulties in their lives, such as an inability to understand or express themselves in English, or social isolation. But what the interviews demonstrate very vividly is that these cannot be understood, still less addressed, separately. They are all embedded in and part of their overall experience of these women's lives, and in particular of their experience of transition from one country and culture to another.

A particular strength of qualitative methods is that they are able to explore, in depth, different aspects of people's lives, within which the factors to create disadvantage or advantage operate. What this research clearly shows is that each of these women's lives is a journey, geographical, linguistic, economic and above all cultural. These are not separate journeys: they are all interwoven. The geographical part of the journey has happened – they are in Scotland – but the other elements are ongoing and extend over years and even over

[11] Haynes R, Gayle S Deprivation and poor health in rural areas: inequalities hidden by averages. *Health & Place* 2000; **6**: 275-285

[12] McLoone P Targeting deprived areas within small areas in Scotland: population study. *BMJ* 2001; **323**: 374-375.

[13] Areas among those with the 20% highest SIMD scores.

generations. The journey is not an individual one; it is made jointly with their families, whose members do not all travel at the same pace or even with the same destination in mind.

These South Asian women therefore inhabit a space which is one of flux and many potential tensions. This space lies between the cultural milieu of their country of origin and that of Scotland; between that of their husbands and families here in Scotland and that of the wider indigenous Scottish community; and between that of their parents' generation, their own, and that of their children. Some women may see their ultimate destination as being an integral part of the Scottish 'host' community; others may value highly, and wish to preserve and largely live within, the traditions of their country of origin and/or their religion. Many probably would like to combine, to different extents, both aspirations. Furthermore, their ideas of their destination will almost certainly change as they grow older, have children and see them grow, as they become more accustomed to and knowledgeable about life in Scotland, and as the world around them changes. The tensions they experience will likewise alter as life goes on.

4.4 Indicators

Indicators of disadvantage for the general population are well-established and have been much used, for resource allocation and other purposes.

It is as well, at this point, to remind ourselves what indicators are. They are items of data relating to individuals or groups, which are relatively easily accessible – from existing sources, preferably, or, if not, through special surveys – which help identify and locate those who have particular needs. It is important to remember that indicators are not definitive evidence of actual disadvantage: they are pointers to where disadvantage is much more likely than for the population at large.

The stories revealed in the research show that managing the tensions created by their life journeys looms very large for these women. How well they are able to do so greatly affect all parts of their lives: their social life, their education, their prospects of employment, their ability to interact with services, their relationships with their children, and their health.

Is it possible, then, to conceive of indicators that could help identify people who are living this challenging experience?

There are some relevant features of these women's lives about which appropriate indicators might be able to provide some sort of signal. We discuss later how reliable and useful such indicators might be in practice, but first we take a brief look at some of the variables from which such indicators might be constructed, focusing on those in the Census that reflect various aspects of disadvantage . All those in the following list are included as questions in both the 2001 and the 2011 Census (except for the two noted as new in 2011), though some questions differ slightly in detail between the two Censuses:

For the household:

- the number of people in the household and the number of rooms (giving a possible indication of overcrowding)

For each person:

- their command of English (new in 2011)

- whether and for how long each week they act as a carer

- their general health

- whether they have a long-term disability or health condition, and what kind (new in 2011);

- whether their day-to-day activities have been limited because of a long-term health problem or disability (LLTI)

- which (educational) qualifications they have, from a long list of possible ones;

- when they most recently arrived to live here (if not born in the UK)

- their employment status.

- socio-economic position/occupational social class.

Census results for these items are available for each ethnic minority group for the City of Edinburgh (for 2001 at the time of writing, for 2011 towards the end of 2013). For any given ethnic minority group they cannot be broken down to ward level or any similar small locality because of small numbers. This is an important constraint, as will be discussed below.

Various other items of information are gathered by other surveys and through other means, but they are either not easily available on the basis of ethnic group, or the numbers are too small. For example, the Lothian Health and Lifestyle Survey of 2002 had fewer than 50 South Asian respondents, so little meaningful statistical information can be derived.

Apart from the Census, the three main possible sources of data on the circumstances of people in ethnic minorities would be:

(a) special surveys, covering a sufficiently large number of people in ethnic minority populations in Edinburgh

or

(b) data gathered opportunistically when someone from an ethnic minority contacts a statutory service (such as a benefits office or GP surgery)

or

(c) data from other statutory sources such as the Department for Work and Pensions, NHS morbidity and mortality statistics, and so on.

None is really practicable for the purpose of constructing indicators focusing on ethnic minority populations. Special surveys targeting particular populations like ethnic minorities are technically difficult and, for the scale and degree of reliability necessary, very expensive.

Opportunistic data, while very useful for helping to identify the services appropriate to help each individual, are far too unevenly gathered to be reliable as statistical indicators. In principle, other statutory sources could be tapped, but there are formidable administrative, practical and legal difficulties, and many such sources do not record ethnicity consistently. In the fullness of time it may well be possible to overcome these difficulties, as they have been for the area-based SIMD[14], but it is very doubtful whether this could be done for a one-off exercise in Edinburgh. This leaves Census data. This is to be regretted, since information on important aspects of people's lives, like social isolation, is absent from the Census; but there is no practicable and affordable way to gather it in any other way.

[14] Bhopal R et al, undated. *Ethnicity and health in Scotland: can we fill the information gap? A demonstration project focusing on coronary heart disease and linkage of census and health records*. University of Edinburgh. Accessed at http://www.cphs.mvm.ed.ac.uk/docs/Retrocoding%20final%20report.pdf on 7 March 2013.

Is it possible, then, to use indicators based on the Census data to help identify people who are living the kinds of challenging experience revealed in the interviews?

The answer must be: only to a limited extent. The experience of each woman's journey is multi-faceted, and the tensions it creates are multiple and contingent on her individual circumstances in complicated ways. This means that any single indicator will be a poor predictor of the difficulties a woman is facing. For example, a good command of English may be of little help to someone who is struggling with inter-generational familial conflicts over cultural norms. Conversely, someone whose family lives in few rooms might be classified as living in 'overcrowded' accommodation according to some established criterion but be relatively content with her life.

The question remains whether it might be possible to *combine* a number of census-based variables, such as those listed above, in a manner specifically derived for South Asian women, to construct a composite measure of disadvantage?

Unfortunately, the present research strongly suggests that this is unlikely to be a promising approach, for two reasons.

First, as we have argued above, the way that challenge translates into disadvantage – or not – is highly dependent on the personal and family circumstances of each woman.

Second, except for a limited range of census variables, it is not practicable to aggregate across individuals, in the way that the indices for 'areas of deprivation' do, because the South Asian population of Edinburgh is scattered widely across the city. Over the whole of Edinburgh, the 2001 Census found that 1.8% of the population was in South Asian ethnic groups; in the 58 wards, the figure ranged from 0.5% to 3.9%, with the figure in 36 wards lying between 1% and 2.6%.

It would be possible to aggregate across the whole South Asian population of Edinburgh, since data for all the relevant variables are available on this basis. This is what was done above, to show how the rate of LLTI for the all South Asian women aged 60 and over was higher than that for the general population in any of the 58 wards. The same could be done for any of the other Census variables. But at present it is unlikely that any variables derived from other sources could be aggregated in the same way.

The question must be asked, in any case, what purpose would be served by so doing.

4.5 Conclusion

Developing indicators of disadvantage is potentially a time-consuming and expensive process. It is important, therefore, to bear in mind the reasons for doing so and think about how the indicators might be used, once developed. What would be their purpose?

The present study was conceived in the context, indirectly, of resource allocation, though initially in a negative sense. There was a feeling within NKS that conventional, area-based indices of deprivation, constructed from census measures of socio-economic circumstances, did not capture the kinds of disadvantage experienced by its users. Such indices are widely used to assist resource allocation decisions within statutory services, and there was a perceived risk that, as a consequence, the needs of South Asian women might not be met. This feeling was shared with the project's funders, who agreed that it would be useful to explore whether alternative or additional indicators would be helpful to them in their resource decisions.

The research findings give a very strong and clear message in response to this, but perhaps not in the way expected. Standard indices of deprivation do not capture, or even relate to,

many of the kinds of problem that South Asian women face. Beyond that, however, what becomes very evident is that resources to help South Asian women must be those that can help them on their cultural journeys. Resources that do not recognise this will not be accessible to them. The first requisite for any resource or facility is that it must feel culturally safe and as familiar as possible, not only to the women themselves but to their families. This feeling must be maintained throughout, providing a firm foundation for everything else. Any facility that does not offer this will get few South Asian women through its doors, and those that do manage it will not be those in most need of help. Building on this foundation, women can start to learn new skills, learn more about Scottish life and the services available, become more confident and thus able to engage effectively with mainstream services.

Two main lessons emerge from the research. First, the voluminous research findings on the general economic and social disadvantage suffered by South Asian people in Scotland and the UK are borne out by the experiences gathered from the users of NKS. The most immediate and telling 'indicator' of such disadvantage is ethnicity itself. To go further than that – to try to identify particular groups within that community with special or specially great needs – faces formidable difficulties, because for all practical purposes relevant data are only available on the scale of the whole City of Edinburgh; and it is already evident that the South Asian community as a whole is one with high levels of need. This is the reason why we questioned above what purpose would be served by comparing further figures for various census variables between the Edinburgh South Asian population and that for the general population in the City's 58 wards (or other small areas). It is highly likely simply to confirm what we know already.

The second main lesson is that what matters most, in terms of meeting the needs of South Asian women, is the *kind* of resource that is offered. The holistic environment created by NKS works for these women, and their accounts provide a vivid picture of how and why it works. They are prepared to travel considerable distances across Edinburgh, despite initial unfamiliarity with transport and physical and economic difficulties, because NKS feels right to them and they feel able to develop and thrive with its help.

Consequently, statutory services need to be very careful how much they rely on indicators for their resource allocation decisions in respect of this community's needs, whether these indicators are the established ones or versions more specifically adapted to South Asian women. This is because using indicators tends to direct attention towards how much resource to allocate, or where (geographically) to allocate it, rather than towards the *kind* of resource that would be effective.

Appendix 1: Study Team

- Naina Minhas, Manager of NKS, MSc in Community Development and Health, Edinburgh University
- Jane Jones, Director of NKS. Community development and health specialist, experience in participatory research, developing health indicators and evaluations of health projects.
- Dr Claudia Martin, an experienced social researcher with relevant research and evaluation expertise and previously Research Director at the Scottish Centre for Social Research and Director of Scottish Health Feedback
- Stephen Platt, Professor of Health Policy Research, University of Edinburgh, who has extensive expertise in the evaluation of health improvement interventions and the development of health-related indicators and measures.
- Lyn Jones, formerly a Senior Lecturer in the Department of Public Health Sciences in the University of Edinburgh, then Director of Scottish Health Feedback and a Research Director in the Scottish Centre for Social Research. He has had extensive experience in the design and execution of research studies in the field of health and health services.

Interviewers

Asma Kassim, Rohina Hussain, Ruckhsana Hussain ,Ishrat Measom, Nasima Zaman, Naseem Suleman, and Rabia Ahmed who also managed most of the data entry.

Appendix 2: Key Themes from staff interviews

1. Particular vulnerability of newly arrived families
2. Cultural and family expectations
3. Poverty/low income
4. All families
   - knowledge about what services are available
   - fitting in to the host community
   - husband's casual labour or long hours – often insecure
   - not knowing about language classes and cost/location/transport difficult
   - ill health often unreported, 2/3 women suffer depression
5. Service Providers
   - service providers not understanding culture and customs
   - benefits system -poor communication.

Appendix 3: Making a difference

In response to questions asking **"What difference has NKS made to you?"** there were numerous examples of the way in which this process works and the significant changes it brings to women's lives.

Mixing with other people and making friends

I am a widow and feel isolated. Now I feel happy and enjoy life

I don't feel isolated anymore, I know help is at hand when it's required, there are people out there speaking my own language who I can turn to for help and advice

I feel alive when I attend NKS groups, I can understand English now and I feel more confident approaching people

Increasing knowledge

I have gained a lot from NKS. I can share things I learn from NKS with my family and they enjoy listening to what I have learnt. Better family bonding

More confidence and how I can get more information about my rights and disability benefits and where I can get help from after coming to NKS my life is more easier than before

I learnt a lot about services in Edinburgh by coming to NKS. I had no idea about my rights living in this country.

It's uplifting when you come out - I feel vibrant and meeting people /sharing problems

I can help others now with diabetes information.

Access to Services improved

First I was very quiet. By coming to NKS it has helped me face my fears. I used to be very uncomfortable attending appointments but now I am able to attend and discuss any problems with the GP.

I feel more confident, I can speak English, I can attend appointments to doctors, I have made more friends, I have a social life now

I am more aware of Scottish society, I know how the health services works and what help is available for South Asian women

Improvements in Health

It has helped me to build a network and I have less depression.

Good diet, feel a lot better about myself now

I'm working now - mixing with other women helped me. I have changed my cooking habits - I use less fat and fried food and I eat more fruit - didn't used to eat it at all before. Now I walk every morning into town. My health is better as a result, my breathing is better.

When you see women laughing and joking I am like a new person. I love it - the massage for my rheumatism was good .I dress up to come and look forward to it I am like a new woman. I can forget the pain for a few hours

Childcare

My child has become more responsive, more alert, more taking part in activities

I can go and study with free mind as my child is in secure hands

It give me relief as its my stepping stone to move forward

Entry to Employment

I have improved my health and gained a lot of information of what I never knew of. Also I am now able to look for work in the Childcare sector

I was a housewife, I never use to do much, now I am working part time as urdu teacher

NKS had made a huge difference to my mental health and confidence, through volunteering . I have confidence to go to other agencies and am volunteering in a mainstream agency; Dr Bell family centre

I made many new friends; I got a job through NKS- they helped with my CV few years back. I do not work now due to health reasons

Developed confidence, get further education, improve English language,got help with job

Feeling more Independent

I have more confidence in travelling and shopping

NKS has changed my life for the better, I feel more confident now and am capable of doing things I never thought I could. I gained respect from my husband which I couldn't in many years. I feel I am capable person now.

More independent - I can do things now without a carer

I can go around Edinburgh on my own without any help

The responses to the question **"What can you do now that you couldn't before coming to NKS?"** give an indication of some of the huge differences made to women's lives and their increasing sense of confidence and independence.

Confidence

I can go about doing things now -feel I have built confidence through NKS, I can now go around looking for volunteer work which I could never think of doing before

Get involved in discussions with people I don't really know

I didn't have enough confidence to do any job before and socialise with people/now I have a job and I can meet people without any hesitation

I have become more assertive my mental health is better and self esteem is good, lots of things - more confidence now, volunteering for mainstream agencies. Before I couldn't talk to people now I have more confidence to talk to people, I went to my daughter's school and dealt with issues of bullying

Independence

I am socialising more and more involved with outside world.

I can now read and write in English, use public transport

I can go shopping myself

I can use public transport and go out on my own. I have started taking driving lessons and I understand a little more English now

Talking to people more easily,I now go swimming by myself - couldn't before.

Bringing up children in a better way, job, language, confidence, travelling alone

I am self sufficient and don't rely on my family to do things for me

Employment

I am working now

A job, I now know where to go when needed

It gave me opportunity to do voluntary work in Edinbugh

I had no confidence at all before. Now I can speak in front of people and I run cooking classes at Leith Academy for adult education. I used to ask my kids to help me with computers but now I can manage it on my own