

Invisible Women

Consultations with women affected by severe and multiple disadvantage

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Background

In 2015, Lankelly Chase published 'Hard Edges', a report by researchers at Heriot-Watt University which developed a profile of people experiencing severe and multiple disadvantage based on analysis of service use data (Bramley et al., 2015). The approach employed – which explored experiences of, and overlaps between, homelessness, substance misuse and offending – highlighted a population that was comprised predominantly of men. Lankelly Chase subsequently commissioned DMSS Research and Heriot-Watt University to consider whether a different conceptualisation of SMD might bring the lives of more women into view and to assess the feasibility of using this new conceptualisation to produce a profile.

The feasibility study was informed by consultations with 5 groups of women who shared their perspectives on what severe and multiple disadvantage meant to them. These consultations made clear that a whole range of disadvantaged women believed that mental ill health and experience of inter-personal violence and abuse were central features of their experience of disadvantage which needed to be considered in any attempt to define severe and multiple disadvantage. They also highlighted that disadvantages such as homelessness and substance dependence often resulted from different difficulties in men and women's lives and that the experience of both the disadvantages themselves and the response of services was often gendered. In response, Lankelly Chase commissioned the current research to develop a profile of severe and multiple disadvantage defined in terms of four 'core' areas: homelessness, substance misuse, being a victim of abuse or violence and having poor mental health plus a number of 'secondary' categories. These categories were also informed by the consultations with women and include: being an offender, being a lone parent, being a migrant (particularly when compounded by poor English skills), being a Traveller, being isolated, living in poor quality accommodation, having a physical disability, having a learning impairment, being involved in sex work, and having lost children to the care system.

Purpose of the new consultations

Analysis of quantitative data provides valuable insights into prevalence and patterns of disadvantage. However, such data requires interpretation. As part of this project we wanted

to have our interpretation informed by the perspectives of women themselves. Often data raises further questions – quantitative analysis can be effective in answering questions about ‘what’ and ‘how much’, but is less helpful in answering questions about ‘why’.

Our consultations with women affected by disadvantage therefore had three main purposes:

- To obtain their feedback on the main findings of the data analysis
- To test out and flesh out our interpretation of the data in key areas
- To explore some questions arising from the data

In the first round of consultations we talked to 5 groups of women as follows:

- A group hosted by Women’s Centre, Huddersfield attended by 21 women with 4 staff. Women had a range of involvement with the centre including being part of a young women’s group, a migrant women’s group and a group for women who had lost their children to care.
- A multi-agency group in Scotland involving 20 representatives from Up-2-Us, Argyle and Bute Rape Crisis, Quarriers, Centre for Youth and Criminal Justice, Scottish Consortium for Learning Disabilities, SAY Women, Cyrenians, Circle, Wise Women, Ivy Project, TARA, Routes Out/Base 75, Turning Point Scotland, Violence Against Women Partnership.
- Two groups held in London, one hosted by Praxis in East London attended by 16 migrant women from Africa, South/ SE Asia and Latin America. All were refugees or asylum seekers and/or women who had been trafficked – all survivors of gender-based violence. The second London group was hosted by Women’s Health and Family Services (WHFS) in Tower Hamlets and was attended by 38 women in total, composed of 13 Bengali women, 11 Somali women; 6 Vietnamese women; 8 Black African/ Caribbean and White UK women.
- A small group of four gypsy and traveller women hosted by One Voice 4 Travellers.

For this second round of consultations we held three focus group consultations with groups of women (returning to two of the above organisations) as follows:

- **Hull:** This group was hosted by the Lighthouse project and was attended by 10 women with two workers. Some of the women had been involved in Untold Stories, a collection of writing about the experience of prostitution in Hull.
- **Dewsbury:** This group was hosted by Women’s Centre and was attended by 8 women with two staff. Women had a range of involvement with the centre including being part of a group for women who had lost their children to care.
- **London:** The London group was hosted by Women’s Health and Family Services (WHFS) in Tower Hamlets and was attended by 12 women plus two workers.

The discussions were facilitated by Di McNeish and Sara Scott using a topic guide (appendix 1). We provided a brief summary of the findings of the data analysis, then asked some questions to explore the extent to which the findings resonated with women and reflected their experience, their explanations of particular patterns in the data, and what, if anything, was missing – were there crucial aspects of disadvantage that the quantitative analysis was not able to tell us.

Summary of findings

1. About homelessness

We told the groups that the data shows similar numbers of men and women experience homelessness throughout their lives, but that more men than women are single homeless and more women than men are part of homeless families.

We asked:

Is that what you would have expected, or does it surprise you?

What do you think leads women to become homeless?

Is the experience of homelessness different for women?

What effect does homelessness have? Does it lead to women being disadvantaged in other ways?

In general the groups of women we spoke to were not surprised by these findings. They pointed out that homelessness amongst women is often less visible, certainly within services:

A bit surprising that you say as many women than men are homeless cos in the hostel I was in there were about four floors of men and one for women (H)

They also suggested that street homelessness is even more of a last resort for women than for men. They will turn to family, friends and acquaintances and put up with very difficult circumstances (including abuse) to avoid becoming roofless.

I think women find it easier to find a sofa to sleep on so less likely to use services (H)

I paid for my bed with cash or drugs or sex, sometimes all three. That's exploitation really (H)

This is particularly the case where they have children: they told us that most mothers will go to any lengths to avoid becoming homeless with their children, not least because of the fear of losing them.

There was also sympathy for homeless men, especially those on the streets. For example, the Dewsbury group talked about a group of homeless men in the town who cluster together for safety after dark and position themselves near to security cameras to try to protect themselves from violence.

Asked about the factors that lead to homelessness, the groups of women mentioned

domestic violence, mental ill health and addiction

The few families I know where women have become homeless, it's to do with violence. Drink and drugs sometimes has led to the violence with the husband using drugs and later became violent to the wife (L)

Financial abuse has led to homelessness – I know a family where he has forced them to leave the home. The abuse is not always physical violence (L)

Others mentioned the impact of poverty and getting trapped into a downward spiral of debt and homelessness:

Poverty is a big part of it – if you've got no money, you can't go stay somewhere and you go to sleep on someone's settee and they want money for it you're fucked (H)

Once you're in arrears [with rent] and got in a mess it's hard to get out of. It's hard to get back on the ladder (D)

Some women talked about the links between mental health and homelessness, particularly where they were frightened in their neighbourhood:

If you've got problems with your neighbours or trouble in the neighbourhood you can feel it's easier to leave and live on the street – especially if you've mental health issues... you can live in constant fear (D)

Women talked about homelessness rarely being caused by a single thing but more likely to result from a series of

Things in life you can't cope with. Financial, losing jobs, not able to keep tenancy cos things go wrong... One thing happens, then another – it's a downward spiral (D)

Sometimes homelessness goes on longer because women are offered unsuitable places to live. One pointed out that:

If you flee to a refuge you can be deemed as intentionally homeless (D)

The group of mainly BME women we spoke to in London were clear that the experience of homelessness was different for women, because of feeling more unsafe than men and because of their ultimate responsibility for children:

Yes – because it's not safe outside for women – outside their homes. Safe home is so important to women because not safe in outside world. If don't have that, so alone, so scared (L)

It's always the women who take charge of the children – so they always have children to factor in (L)

These views were echoed by women in the other two groups. Women's different experience of homelessness was thought to be very much linked to their reliance on families and other people. Avoiding street homelessness in this way was often described in terms of being the lesser of two evils, with its own negative consequences, particularly where they were attempting to escape domestic violence:

When women face homelessness – especially if there are children – they are likely to turn to family – but family may not have room to take them in and may say they must go home (L)

It is very hard for women – if a woman leaves and takes her children and they end up in a small room and children don't like the room. Child leaves the house, child will go away from mum and back to dad or go to nan's house, or aunties, uncles. Very hard for mum when child says 'I don't like it here, let me go out. (L)

Women also talked about their experiences of hostels and refuges, with fear being a recurring theme:

Emergency accommodation is very scary (D)

Being in a refuge was really frightening – I went there cos I was being abused by my husband and it led to me being abused by lots of people (D)

One woman gave an example of being in a mixed hostel and being permanently frightened not only of residents but of staff too.

Women saw homelessness as strongly linked to other disadvantages. Indeed, for some, not having a safe, secure place to live was the key factor underlying severe and multiple disadvantage. Being homeless affects your access to benefits and other support:

If you haven't got an address, you can't get a bank account and you can't get help (H)

Homelessness reinforces substance misuse and makes it harder to get clean:

It's only the people on drugs who offer you a place to stay - it's like a catch 22...My first step to recovery was getting into a hostel, feeling secure and safe, then I could get clean then I got my own flat (H)

Homelessness can pressure women into prostitution and crime:

Once a women is homeless she might have to resort for financial reasons she might have to go down a line of work she wouldn't otherwise consider (L)

Homelessness drives women to the limit – you belong nowhere (L)

Homelessness was described as spiralling women into other issues. One woman said that for her, when she was homeless:

Any company was better than no company (H)

The fear of homelessness for many women was linked to the fear of loss of children:

If homeless, not being able to see your children – less likely to have your children returned to you (D)

2. About drug/substance dependence

We told the groups that the data shows more men than women experience substance dependence, and more men are in contact with substance dependence services

We asked:

Why do you think men are more likely to be found in services?

Is the experience of being dependent on alcohol or drugs different for women?

The women in all our groups were clear that women actively avoid services for three main reasons: shame; fear of losing children and services themselves being unhelpful and inappropriate.

Women feel embarrassed, ashamed to use services, hide their problem from families. Don't trust the services (H)

Fear of having children taken off you. If I didn't have my mum I'd have had my kids taken away. My mum looked after my kids, saw me through heroin addiction, crack addiction (H)

Everything is wrong with drug courses – they don't care. They only want to put you on methadone, then they rush you to get off it (H)

You can be clean for 5 years but you're stuck in addiction cos of the methadone (H)

For women in the Hull group, drug use was or had been strongly linked to sexual exploitation and prostitution and to histories of abuse.

The London group of BME women told us that they rarely came across women in their communities who used alcohol or illegal drugs. However, they told us that the use of prescribed medication was high:

Some women use depression drugs – lots do this.

The lives of women taking antidepressant drugs – they take it for the cultural shock of coming here – the support goes to the man leading the family not to the women–

this is caused by so many barriers, language and cultural shock and social isolation especially if they are living in a very white area. They can be so alone (L)

Antidepressants – dependence on medications – they start off thinking ‘this is going to help me’, but further down the line they are so much - 3 years later - reliant on antidepressants – and that kind of dependency is a disadvantage (L)

And several of the women in this group were very worried about their children’s exposure to drugs and alcohol:

[Translator:

She said: in here there is a lot of problems together, that we can’t manage to solve ourselves – drugs, alcohol, it would be easier for parents if these were more strictly controlled – we cannot control what is available outside – I can only control what is available at home.

Underage drinking – going on under the radar – starting to drink when aged 15, 14 even 12. I am first generation, I came 15 years before – so I am not doing these things – my children I think won’t, but maybe, but the third generation? They will?...Responsibility falls on women for the next generation (L)

3. About violence and abuse and about mental health

We explained to the groups that these two areas were introduced into our definition of SMD because they seemed particularly important in women’s lives. We told them that the data shows:

A lot more women experience extensive violence and abuse – especially as adults

A lot of people (more women than men) experience mental ill health

One in six adult women – nearly 4 million in total - has experienced poor mental health and violence and abuse (and often poverty and other issues) at some point in her life, but not homelessness or substance dependence.

We asked:

How does violence and abuse lead to other disadvantages?

Do you think other disadvantages make it more likely that women will experience violence (e.g. homelessness, mental ill-health)? How does that happen?

How does mental ill health link to SMD? [does it lead people to be more disadvantaged or do other disadvantages result in mental illness?]

The research findings about the links between poor mental health and domestic abuse had a strong resonance for women across all the groups. Women described the impact of violence and abuse on their own mental health:

When you’re struggling with domestic violence it makes you feel so small it does fuck

with your head, because it chips away at you – not just the physical but the mental... you tell yourself you've got control of it that the beating you had yesterday wasn't as bad as it was last week and it messes your head up and even if you see it as a kid it messes you for the rest of your life. My [current] husband has never hit me but if he moves too quickly I still flinch (H)

Not just violence but also mental torture. I was scared of leaving him. He got poorly and I was his full-time carer so I felt I had to stay but he was still being abusive (H)

It starts with words and they make you feel like nothing, like you don't deserve better. When you're there you don't even realise it's happening. You make excuses. You believe he'll change (H)

The shame and stigma of being subjected to domestic violence is common among women, but this was a theme very strongly reflected in the discussions of the BME women:

Women get blamed for what happens to them. One of my neighbours – her husband abused her a long time, he went to Bangladesh and got married there but he came back – maybe for money, and abused her. Her son became violent to her as well (L)

What women can and should do in such circumstances is complicated, as illustrated by this exchange between Asian women in the London group:

With the violence at home, the children are learning bad things. My personal opinion is that if someone is violent to me I shouldn't stay—it is a better life to be separated and poorer but happier

Lot of people, lot of family I see, women tolerate what's going on, sacrificing for the children, mum always must sacrifice.

I am not agreeing with this concept. This sounds like we are weak. It is our responsibility to say something – that is why the husband is taking advantage. But if we say something, if we show we will not put up with it...

Women put up with it for the children - we must sacrifice a lot – our men do not sacrifice in same way for children. Sometimes men do, but mainly women, mainly women (L)

Violence and the fear of violence outside the home was also described as having an impact and for Asian and Muslim women, life outside their home has become much more threatening in the past couple of years:

Two guys one fourteen and one fifteen a shooting in a small alley behind the house – So frightening – we just came from the chemists and didn't see too much of what happened we were too scared – police, cars, helicopter – I was very scared, too much scared.... Scared now too much guns, knife. My whole body was shaking, shaking.

We are scared because of our scarves. Sometimes very hard to go out with kids when you are wearing your scarf – someone will call you a Muslim – will put a knife to your scarf, pull your scarf off.

A Somali lady opened the door and was hit by someone with a hammer who ran away. She is in hospital.

This is a very hard time in this country for Asian ladies. The women are getting this because they are visible.

I am scared over my kids. My son is in year 9 - I am worried if he is coming home, very worried about my children.

Things have changed for everybody in the UK. People come for safety, too many people doing mix and difficult situation...But here now I don't know who is safe to trust in this country – you don't know by looking (L)

4. Poverty and peoples' circumstances

We told groups that poverty on its own is not included in the definition of SMD – but is clearly an important factor in many peoples' experience of disadvantage. However, we told them that the data shows that the more of these 4 disadvantages someone has, the greater their risk of poverty, BUT there are some people who have experienced SMD in the past who are not currently poor, and quite a few women who have experienced several disadvantages in their lives have qualifications and jobs.

We asked:

Do you find these findings surprising? How would you explain them?

The current study defines people experiencing SMD as those who have experienced 3 or 4 of the above issues in their lives.

Do you think that's right? Can someone be SMD if they have only experienced one or two of these? What difference does poverty make?

There were some interesting debates in our groups about the role of poverty in contributing to severe and multiple disadvantage. All thought it was a significant factor but there were some differences of view about how significant, as illustrated by this exchange between women in the Hull group:

It's a circle, one little problem but to solve that you got to do this thing, and to solve that you've to do this thing. Let's face it if you had a million pounds you wouldn't be homeless or drug dependent would you?

Oh, I don't agree with that. Money can make it worse. Drug addiction can affect anyone

Yes, but poverty adds a whole other layer

Money increases the choices available to you

How you think about your situation is more important than money. You're not staying in a relationship because of money. When you get in this situation it's almost like an addiction – it so hard to get out of

Some disadvantages can be overcome by cash, but there are some where it doesn't matter if you're rich or poor. If you've got money you don't need to be homeless but if you're in a violent relationship it doesn't matter if you've got money (H)

Poverty was certainly a reality in many women's lives

Being on minimum wage is just not enough. My partner works 40 hours a week but his wages are never enough... I've no certainty in my life from week to week whether I can clothe, feed or keep a roof over my kid's heads (H)

You can't provide everything for children – you have to limit it – sometimes the children take advantage of that...The children don't understand there isn't any money (L)

There were a number of women who raised concerns about the impact of the benefits system. e.g. PIP assessments. There was an example of one woman losing £400 a month through losing her PIP

It leads to mental health deteriorating more – having to prove how ill you are makes you more ill (D)

But there was a view across all the groups that money is not always the most important issue:

Money takes away that pressure but even people who are well off still have these problems

Wealth adds another layer – but I would still think someone with these problems is still disadvantaged

If a wife go to job and more money earn, and husband take a chance he beat her – family pressure still on wife. It is not fair. If women are financially and in other ways well off but beaten by their husband - they are still just as disadvantaged.

Money is not important all the time – sometimes it is but my friend – her husband mentally abused her – she left him – she doesn't have enough money now but she is

now happy! (L)

For some things money makes no difference. It has its uses but it depends on your mindset. Might lead you to be more dependent on drugs (D)

At the same time, poverty was seen as having a role in increasing disadvantage:

Being financially deprived can be a cause for a lot of these problems in men – for the violence for the drugs – that could be a basis as a source of stress. So poverty can be involved in disadvantage in another way.

This is a different way to view it – financial pressures can lead to homelessness, and homelessness can be a cause for so many other disadvantages (L)

This concept of spirals or layers of disadvantage emerged across all the groups. Women talked about one disadvantage leading to or compounding another, the difficulty of breaking out of the cycle and the lack of support in helping them to do so:

When you're facing multiple disadvantages, I couldn't get clean til I've got accommodation sorted out, I couldn't get accommodation cos I still had the addiction. You have to get things sorted in the right order. How do you get clean when you're living on the street? You're set up to fail (H)

There are many, many reasons for bad mental health. Family problem: husband, wife, his job, learning disability of family member, social problem (education of child) husband, job, everything is linked – and all these things lead to depression (L)

Pretty much all of these are connected. Which comes first depends on where you are in this cycle. It might not always result in homelessness. There are often financial difficulties in there increasing stress – or financial abuse through gambling for example. But there will always be an element of mental health as a result of all the others. Eventually there'll always be an element of mental health. (D)

5. Other things that seem linked to SMD

We told groups that the data suggest that childhood experience is important to chances of later SMD, particularly being abused/neglected by parents or being brought up in care. We also told them that:

*The more disadvantages people have the more socially isolated they seem to be.
Higher number of young women (aged 16-24) have 3 or more disadvantages in their lives
While Black women and men are more likely to have 3 or more disadvantages in their lives, this is not the case for Asian women or men*

*We asked:
Why do you think this is?*

The women in all three groups were agreed that **childhood disadvantage** had an impact.

Trauma in childhood affects your self-esteem so there is a connection between that and the choices you make later (H)

What happens in childhood does affect you in adulthood – it influences how kind a person you are in adulthood. Better childhood makes for better adulthood (L)

Some gave personal examples:

I was neglected as a child and I ran to the drugs world cos it made me feel better. When I had a child, I didn't know how to look after him. When you're a broken child you can have a broken child. (H)

When I was a teenager my mum was mentally ill and I couldn't deal with it. I kept pushing it down then turned to drugs and kept taking them until I could learn to deal with my emotions. I think kids need help when they're younger (H)

However, some women pointed out that early disadvantage is not always negative in later life:

Disadvantage can make you stronger. I was in care and I wouldn't wish it on anyone. I don't want my kids to go through it (H)

There was little surprise among the women we spoke to that disadvantage is associated with **social isolation**:

Not surprising. If you're homeless there's lots of stigma, if you're drug addicted no one wants to know you, you feel on your own if you're in a violent relationship (H)

Debt limits your access to support; mental health issues reduce motivation to go out to meet people; domestic violence isolates women (D)

With poor mental health – people talk less to each other – and this leads to social isolation and impacts too on physical health, and then you can lose your job. (L)

Women in all the groups talked about isolation being one of the impacts of domestic abuse:

The women who are leaving are more likely to be rejected by their families and in the community because they have left their husbands – even if they were abused they get seen as having taken his kids away. (L)

For many of the women in the London group, this isolation is compounded by language barriers and getting access to information:

In the Asian community women more likely to have language problems – this is still the case. Women have less knowledge – they only get information by turning to

neighbours, friends, family. If they no speak English it is very hard.

Some women talked about how isolation often made disadvantage worse:

Loneliness is a disadvantage in itself. When I was trying to get clean I was so lonely (H)

Saddest thing about being a single mum is you need to do everything - just me – I have no one to care for me – before I was living far away from London – I came to London for accommodation – but now have no support everything is just me. (L)

Asked why they thought higher proportions of **young women** experience severe and multiple disadvantage, women gave a variety of reasons including peer pressure and lack of support. It was suggested that girls are drawn to becoming 'adult' at an earlier age than boys and that this can lead to difficulties:

Girls leave home earlier and get into problems. I left home at 17 and got into a violent relationship (H)

Young women go for older men – they want to skip being a teenager. My daughter was 15, got off with a 21 year old; pregnant, he was off she was left with the baby (H)

For young mums in this situation there can be limited support, in part because:

You don't want to admit you've made a mistake, even to your own family. You're scared of social services (H)

Young mums don't want to say that they have problems in case they have their kids taken off them (H)

Women in both the Hull and Dewsbury groups were strong advocates for education and early support in schools for both boys and girls:

I bet if you went into any school they could tell you which kids have the problems so why aren't they getting help? It just makes sense (H)

Need to teach kids that they can respect themselves. It starts with yourself. Girls especially often have low self-esteem (D)

Educate young women and boys that it's not acceptable. Boys presume they can talk to women like that. Education is the key. (H)

They need to have more boundaries. Schools just exclude kids – they don't support them (D)

The women in the London group raised some issues which, whilst not unique to BME women, seemed to be particularly important to them. One was the effects on women of

living with their husband's gambling.

The main issue, well one of the big issues in our community is spending on gambling – and women is suffering. Husbands are gambling all the money. Because he is earning they are not claiming money-wise [c. not getting benefits] – they are suffering a lot [financial abuse] (L)

This group also highlighted the disadvantages faced by women caring for older or disabled family members, disadvantages which they described as worsening for women as they got older.

My son is invisible and living still at home... Disability is impacts on the family as a whole. When I go to a job – I am always thinking of him and caring responsibility – always a thought in your head

Only mother is taking the responsibility, only mother – the big responsibilities. The pressure from the family is to care for older people too. After twenty years, after caring for your child and your husband – your own mental health is affected at the end of your life, builds up pressure on the women in later life

There is a lady from my work – woman is 60, the husband is bed bound, he is 80 – she is carer all the time – can't get out get for fresh air. They don't have their family there close by.

6. Support services – what works and what doesn't

Support services can help reduce or ameliorate the effects of disadvantage, or they can make things worse. Themes emerging from the three groups of women were:

- **Lack of awareness/knowledge about services**

Women, particularly those in the London group from BME communities believed that there was a lack of knowledge about available services among women in their communities. This was compounded by language barriers. These women said they might go to the GP but wouldn't know where else to go for help.

[Asian] women don't know about anything so if you are homeless you don't know where you can go to get help – we don't know where it is safe to be – there are language difficulties (L)

Other women identified a barrier as being women's inability to view themselves as needing support. This was particularly the case for women who had lived with violence so long it had become normal to them:

When you don't get hit any more it's a bit freaky. Violence is normalised - it takes a long time and a lot of support to change those feelings (H)

- **Avoidance of services because of shame, stigma and fear**

An even bigger issue than lack of knowledge was avoidance of services. Women commonly expressed shame, stigma and fear of services:

You don't tell people you're experiencing domestic violence cos of the shame or cos you don't want to get your partner nicked. (H)

Mental health is a big 'word' in our community – so sometimes they try to be dealing with themselves – they don't know: am I depressed or not? (L)

Parents are afraid to talk to schools about their children, as afraid their children will be taken away. Social services is a big issue – there is fear of services so don't go for help (L)

Sometimes shame meant that women were avoiding telling anyone at all about their difficulties – they would not approach services because they would not want to risk exposure. Some of the Asian women we talked to felt strongly that the responsibility for avoiding shame lay firmly with them as wives and mothers:

With taboos – we feel shamed – if I tell my community they will look down on me – people are therefore hiding things. In their unconscious mind –if my family not going well – the blame's on me. (L)

- **Services being too hard to access**

If women overcome these anxieties and do seek support, they can then encounter barriers because they go to the 'wrong' agency or don't understand/meet service criteria:

Some don't get services and need help – just because they don't meet some one particular criteria (D)

I've got a child and there's nothing – I've been to the council but because I haven't been a victim of DV and I've been in arrears they say it's not their problem. If there were hostels for families perhaps there wouldn't be so much homelessness (H)

- **Negative experiences of services**

Many of the women we spoke to, particularly in the Hull and Dewsbury groups, were past or current users of services. Their most frequent criticism was the siloed approach taken by specialist services:

Mental health services and drugs services play these stupid games – like tennis with your life – they say if you didn't have a drug problem your mental health wouldn't be so bad and the drugs people say it's your mental illness. And if you try to talk to them about domestic violence they have no interest (H)

They should deal with all your issues – mental health, drugs (H)

For some women, their earlier negative experiences of services made them extremely wary of seeking help in the future. Women in the Hull group for example talked about their

experience of being labelled by services:

People like us - we're avoiding services. There's a lot of people struggling but wouldn't go for help. We're seeing the tip of the iceberg with these figures. You don't ask people cos you get judged. (H)

Conversely, women talked eloquently about the value of the support they got from their women's services. They particularly valued the non-stigmatising, open access and welcoming approach and the reciprocity of mutual support:

Having this centre has changed my life. I say it saved my life, the women who work here saw something in me that made me able to change. It made me value myself, gave me self-worth. Before, I didn't care if I died. I wanted to die. They helped me see myself as I was. Instead of saying don't be stupid they said to me OK, if that's what you want to do, how do we do that?

Before I came to women's centre I wouldn't go even to the supermarket during the day cos I was so terrified. Now I'm doing training – talking to people about adoption, going to the university. Here I know I'm not going to get judged. Elsewhere I feel I'm being watched and judged....

I like to help out as much as I can. It's too late for me and my son but it's not too late for other women.

You make so many friends here. Being here with other women around, they'll see if I'm feeling down. It's like our family. When someone new comes we welcome them.

Discussion

The women we talked to in these consultations concurred with much of the direction the analysis has so far taken. They regarded poverty as an exacerbating factor in relation to other disadvantages, but not as predictive or causal, and they described homelessness as the most feared and disastrous outcome that could stem from partner violence, substance use, debt and poor mental health. More than anything they emphasised the cumulative impact of multiple disadvantage, not as concurrent experience but as occurring across the life course; an emphasis that supports a focus on those in the 'ever SMD' group.

However, these consultations also demonstrate how people understand and talk about their lives and how this differs from the ways that these are represented in quantitative data. They speak of experiences and events, often referring to layers and spirals with disadvantages interacting with each other. They generate their own theories about causes and consequences. What they almost never do is to talk about themselves in terms of defined categories. Instead they highlight that in lived experience, severe and multiple disadvantage takes the form of patterns and pathways rather than discrete problems.

These patterns and pathways are greatly influenced by both gender and ethnicity and the intersections between these aspects of identity. It is significant that none of the BAME

women who talked to us would have 2 or more of the core disadvantages. These women were certainly multiply disadvantaged but their SMD occurred through the intersection of their (gendered) experience of migration/racism/Islamophobia with a variety of secondary disadvantages and was frequently compounded by the mental health consequences of each.

While service data and surveys focus on individuals the women we spoke to emphasised connections with those around them and often described how their experience of multiple disadvantage sprang from, or was enmeshed with, their closest relationships: for example, when a husband was a problem gambler, or they were sole carer for a disabled child.

Some of the women involved in these consultations may appear in service use data, some in general population survey samples, but many will be represented in neither. Many are invisible to services, in part because they actively avoid them. They either do not appear in population surveys at all or feature in such small numbers that no useful analysis can be undertaken. Yet nobody hearing about the lives of these women could deny that they are severely and multiply disadvantaged. The implication for any attempt to profile severe disadvantage is that the picture that emerges will inevitably be partial – showing us only those people we are already in a position to see and count: the visible part of the ‘iceberg’ of severe and multiple disadvantage. In order to glimpse the rest – the ‘invisible women’ we must dive beneath the surface and explore the lives of groups and individuals through narratives rather than numbers.