

“Active Ageing and Empowerment”

The experience of establishing Dementia Cafes for Black and Minority Ethnic Communities in Leeds

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Ladder of Participation

Shelley Arnstein

- Supporting Independent Community Action
- Acting Together
- Deciding Together
- Consultation
- Information

Ladder of Empowerment

- **Information:** you tell people what is planned so that they are informed about what is happening and know what you are doing.
- **Consultation:** you are clear about what you are asking people's opinion about and why, you specify what can and cannot be changed. You offer a number of options and listen to the feedback you get. The decision is still made by the organisation, but taking account of the results of consultation alongside other factors

Ladder of Empowerment

- **Deciding together:** you encourage people and establish systems to ensure people contribute and make decisions with you about the best way forward.
- **Acting together:** you ensure there is a structure there so that not only do different groups decide together what is best, but also they form a partnership to carry it out. They are equally responsible for the outcome

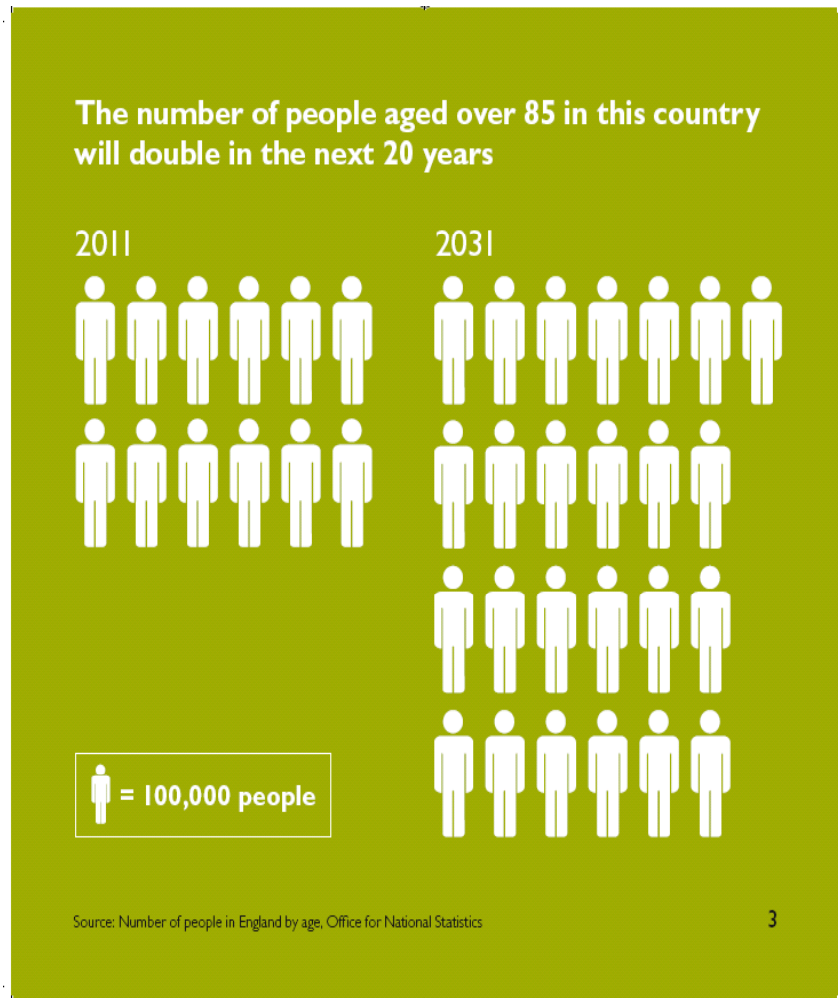
Ladder of Empowerment

- **Supporting independent community initiatives:** you support others do what they want - perhaps within a framework of grants, contracts, advice, information and support provided by the resource holder. The group themselves decide how best to deliver the outcomes and they themselves carry out the actions

What is dementia?

- A range of symptoms caused by diseases of the brain
- Memory loss
- Personality changes
- Mood swings
- Physical deterioration
- No cure, only symptomatic treatments
- Brings gradual loss of independence and control

Why is dementia important?



- Important for Black and Minority Ethnic communities because of known risk factors linked to Stroke, Diabetes and Heart Disease
- Low number of people in contact with Mental Health Services in Leeds

Barriers and considerations

- Information about dementia
- Knowledge and attitudes of Family Doctors
- Health belief systems and cultures – no word for dementia in some languages
- Stigma
- Access to services
- Capability of services to respond appropriately
- Added value of building on community capacity

“What is a dementia café?”

It’s a café - (not a ‘centre’, a clinic or a therapy room.)

- A place to go following diagnosis usually on a monthly basis
- A place where people with dementia and their carers have an opportunity to spend an enjoyable time with other people in similar situations as themselves
- Aims to promote an atmosphere that offers acceptance and recognition for the difficulties that the condition poses on those affected by it.
- Provide information and advice, and people have the chance to talk with staff as well as peers about any problems they may be having
- Encourages openness and relief from social isolation
- Encourages collaborations with local Older People’s Neighbourhood Networks and volunteers as well as professional staff
- Encourages sharing resources and good value for money

How we established cafes for Black and Minority Ethnic communities

- Linked with Black and Minority Ethnic Community Development Workers with Specialist Mental Health skills
- Co-working and building on successful strategies
- Secured funding to be able to run a café for 1 year
- Developed Listening Events at local Neighbourhood Centres
- Community languages to be used Urdu, Bengali, Punjabi then interpret back into English

“Deciding together”

hamari yaadein



**Community discussion event for
South Asian people on
memory and getting
older**

Speakers

**Share your
views**



**1pm-3.30pm
15th July 2008**

**Hamara Healthy Living Centre
Tempest Road, Beeston**

**For more info
contact Aliyah or
Aisha at Touchstone on
0113 219 2727**



What we said

- As we get older there are a number of health problems that are more likely to occur because of old age Stroke Diabetes Heart Disease
- Sometimes people develop problems with their memory and their ability to look after themselves and understand the world around them
- This might be dementia
- Dementia is more than old age
- It is a disease of the brain that can cause disability and ill health
- It is very common in older people and affects 5% of people over 65 years and 20% of people over 80 years
- It is very important that you know about this condition because there are a number of risk factors for people from South Asian communities
- It might be that you know someone who has dementia or is caring for someone with dementia right now
- It can be difficult to understand or explain to others what is happening or to get help from your doctor.
- It can be embarrassing to talk to family or friends too
- Today we are here listen to your stories and find out what is most important to you if you ever need help with this problem

- When you talk to someone you feel lighter
- Happy, not aware of dementia before today
- Easy to talk in own group
- Did not know about memory clinics
- Language barriers to be addressed
- Visits to places, building on memories, reminiscence
- How to cope and deal with it
- Audio & DVD information
- Somewhere to go to ask for specialist help
- Information on benefits
- Guidance from doctor
- Sessions to help with memory loss/therapy
- Get info on how to prevent dementia
- Transportation

“Acting Together”

Sunder Mann (Beautiful Mind) Café

Support to carers

- A place to go to help people get access to services and a diagnosis
- No Relations, difficult and don't have anyone in the family
- Information about Respite or Memory Service and Benefits
- Hard to talk in places of worship, want to talk 1 to 1 with people
- Easy to talk in own group



dignity  means... engaging with family members and carers

"We're in this together - services must involve carers"

Elvira Magrath, the Forgetfulness Club, Chapeltown

dignity 
dignity in health and social care services for older people in Leeds

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For further information on the Dignity in Care Campaign
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Leeds  
Primary Care Trust

.....“Nothing About
us Without Us”