

Information Programme for South Asian Families (IPSAF)

Manchester, 28/01/2014

IPSAF

1. Background

2. Definition

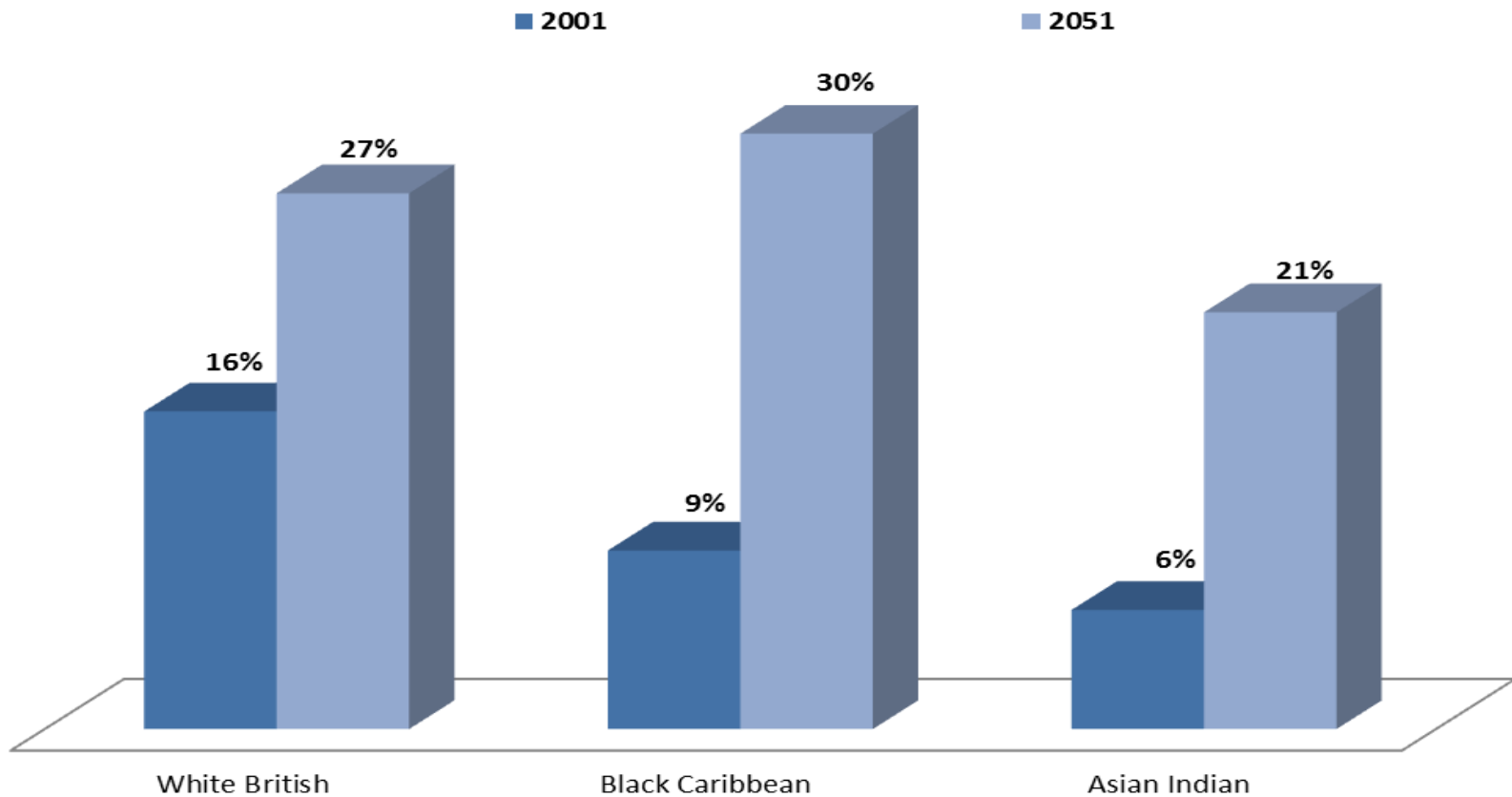
3. Progress

4. Greater Manchester experience



- There are approximately 850.000 people living with dementia in the UK. Approximately 25.000 are from a Ethnic Minority Group.
 - 'Black, Asian and Minority Ethnic Group' (BAME).
 - BAME population aged over 65 is set to sharply increase comparing to White British counterparts.
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Ethnic variation of population aged over 65



- Higher prevalence of **vascular dementia** among BAME communities.
 - Higher frequency of **early onset** among BAME communities.
 - BAME people present later to dementia services and carers experience a greater negative impact than white British counterparts.
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IPSAF

Definition

- The Information Programme for South Asian Families (IPSAF) improves the **knowledge, skills and understanding** of South Asian families of people living with dementia, by providing effective support and up to date, relevant and evidence based information
 - IPSAF comprises **four** group information and support sessions.
 - Each session covers one theme: **Understanding dementia, Legal and financial matters, Looking after others and Looking after yourself.**
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IPSAF

Definition

- IPSAF is **co-designed** with people with dementia and carers from South Asian communities across the UK.
 - IPSAF is **co-delivered** with South Asian faith and community organisations.
 - IPSAF facilitators are required to complete **Cultural Competence training**.
 - Recognizes and values South Asian community intrinsic culture, history and migrating experiences.
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- Adapt the **content, format and delivery** to a South Asian audience.
 - To develop, test and support implementation of a **collaborative service delivery model**
 - To develop a **DVD** to support delivery of the programme and information sharing within families.
 - To identify and support development of **learning resources** to increase cultural competencies and enable facilitators to deliver the programme.
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IPSAF

Progress

Alzheimer's
Society

Leading the
fight against
dementia

You  Tube



- IPSAF has enabled **increasing the reach of our services** within South Asian communities by offering a tailored service, co-designed and co-delivered with people from the community.
 - In March 2015, this evidence-based, sustainable, quality assured information programme will be ready to be locally **commissioned** and included within the Society's **Service Framework**.
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In the community

- Experience from Greater Manchester IPSAF
 - Rochdale and Oldham
 - Both in predominantly Pakistani communities
 - Needs to be based with an existing community setting with existing training provider with strong communications network and shared language(s)
 - Partnership agreement vital to acknowledge from the start who is bringing what to the event to make it a success
 - Alzheimer's Society - knowledge, training, facilitation & resources
 - Partner - communication, participants, interpretation & co-facilitation
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In the community

- The training provided by Alzheimer's Society was greatly appreciated and each participant enriched it through their contributions
 - Cultural Awareness
 - IPSAF Familiarization
 - Facilitated mutual learning and bonding between both parties and agreement on a plan of action
 - Planning involved weekly meetings to divide out the materials and ensure delivery from both parties with interpretation, an equal partnership and mutual respect
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Key learning points

- Within the South Asian Community there are many different cultures and practices – not homogenous, with some under-represented in community activism
 - Attendance can be affected by an event in community (e.g. a funeral) and so accommodations need to be made
 - Averaged 12 attendees per session with 90% staying throughout all 5 weeks
 - The sharing of appropriate food is very important and the selection of dominant language for that programme for interpretation
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Key learning points

- A wider interpretation of 'carer' was required
 - families who immigrated together in 60's and 70's became close as relatives - an 'extended family'
 - the 'aunties' are valuable community communicators
 - Cultural issues concerning duty of care to parents to be respected and explored gently in connection with self-care and sharing responsibility
 - Cultural beliefs about the origin of dementia to be explored and the physical nature of the condition established – often a real turning point
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Key learning points

- 'Future planning' requires careful discussion where religious belief has your life in the hands of Allah
 - Fair to say we learned as much from our partners to take to the next programme as they learned from us about caring for people in the community, living with dementia
 - Personal experience of the condition amongst the co-facilitators enriched the delivery process
 - One family member diagnosis was made as a direct result of co-facilitation
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Sharing the knowledge

- All sectors of the South Asian community should be offered this programme – many more required
 - Methods of sharing the programme and the knowledge through trained personnel is now required
 - Looking forward to moving the programme across Oldham to the Bengali community in Westwood, if we can secure small amount of funding
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For more information please visit:

www.alzheimers.org.uk/ipsaf

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Thank you!
