

meeting the needs of asian disabled people

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This booklet looks at ways of meeting the needs of Asian disabled people. It highlights some of the difficulties many Asian disabled people experience in accessing mainstream services, and the problems they face when they do use these services as a result of poor responses to their specific cultural needs. It tackles the issue of resources for minority ethnic disability organisations and outlines the work of Asian People with Disabilities Alliance, putting forward examples of good practice in working with the Asian disabled community. Finally, the booklet addresses issues that social care agencies need to take into account when attempting to meet the needs of disabled minority ethnic people.

“It is estimated that one in four people in Britain is disabled”



The 1991 census survey revealed that the rate of disability among Asian people is 12.6 per cent, compared with an equivalent of 13.7 per cent for white people. This is widely held to be a very conservative estimate given the limited definition of disability. It is estimated that one in four people in Britain is disabled and, though research is sparse, there is evidence to suggest that the Black and Asian population suffers a high rate of strokes, multiple impairments, sickle cell anaemia and thalassaemia, lupus, diabetes and coronary heart disease.¹

Mainstream services and the needs of Asian disabled people

A number of studies have shown two main difficulties associated with the provision of mainstream services that need to be overcome if these services are to address the particular needs of Asian disabled people and indeed of other minority ethnic people who are disabled: low take-up of services and the culturally inappropriate nature of mainstream services.

Low take-up

According to Jabeer Butt and Kurshida Mirza's publication, *Social care and Black communities*, "'low" take up of services as well as ignorance of the existence of services or rejection of those that were taken up" are serious concerns when addressing the needs of Asian disabled people. Butt and Mirza perceive these problems as symptomatic of a commonly held view that 'Asian extended families look after their own', and believe they are reinforced by some Asian people's view of disability as 'a curse' or 'stigma', a reflection of attitudes that are similar to those found across society as a whole.

There is also evidence of 'multiple racism' whereby Black and Asian people are on the receiving end of racism and disablism and, if they are female, sexism. These factors, claims Scope, 'interact in different ways to shape the lives of Black disabled people.' Individual and institutional discrimination can also play a major role in preventing Black and Asian disabled people from participating in mainstream services. Policies and practices exist that prevent the needs of Black and Asian people from being met.



¹ Butt, J and Mirza, K, *Social care and Black communities*, Race Equality Unit, 1996.



'Many Asian disabled people do not have very much knowledge of benefit entitlements and some find it difficult to speak English. They have worked hard for this country but information about pensions or disability benefits is not accessible to them.'

Felix D'Souza

Black and Asian carers also find it difficult to access support. As a report by the Joseph Rowntree Foundation stated, 'It is widely recognised that minority ethnic groups experience social and material disadvantage and face barriers in their access to statutory support services. Families with a disabled child have been identified as being particularly poorly served.'¹ For example, the report showed that parents from minority ethnic communities lacked information about their child's disability and services available for their child and for themselves. Poor interpreting support and the limited availability of translated materials made it particularly difficult for these families to obtain support.

'Some organisations have been a source of psychological and emotional distress as I was not provided with interpreters as and when required. I was unable to get appropriate advice and felt I was carrying extra stress due to poor service provision.'

Mrs Mehta

Black and Asian communities therefore face a lack of information on appropriate services. Accompanied with this difficulty is the fact that service provision is frequently inappropriate, creating further barriers to Black and Asian people's take up of services.

'Many Asian families with elderly and disabled relatives are not even aware of some of the most basic support services that make life easier for them. Knowledge of support services, both in the mainstream as well as within the community, is so essential.'

Mahesh Amin

Inappropriate mainstream provision

Despite the fact that since 1990, legal duties have been placed on statutory services to take account of an individual's cultural, religious and language needs in the provision of services through the introduction of the NHS and Community Care Act 1990 and more recently the Race Relations (Amendment) Act 2000, mainstream provision frequently fails to deliver. Such services have been developed with white people in mind and do not necessarily cater for minority ethnic people.

'I experienced difficulty in communicating at other centres due to the language barrier. This situation is resolved at Asian People with Disabilities Alliance (APDA) because of our common language link.'

Rekha Mehta

There are a number of areas that mainstream providers often fail to address. These include:

- catering for Asian community languages
- offering translated information
- acknowledging and providing for religious and cultural differences
- moving away from 'mono-cultural' services
- tackling stereotypes, racism and discrimination.¹



¹ Codner, D, *Bridging the gap*, Sheffield Health Service, 2001.

This can result in feelings of isolation where, for instance, a person from a minority ethnic community is placed in a predominantly white care home. Where a person's first language is not English, or where a person does not speak any English at all, the sense of aloneness can be further exacerbated. A lack of awareness of the issues for the Asian community can also lead to an insensitivity towards certain religious or cultural practices, for example, it can mean that the specific dietary requirements of some people of certain religious backgrounds are not met.

'In mainstream provision, the cultural side is not catered for. One mainstream day centre, for example, caters for people from different cultures and their needs may be different so they don't tend to focus on culture, except in a token way.'

Pradip Shah

Asian disability organisations and the impact of inadequate funding

A number of minority ethnic organisations have been set up specifically to provide services for minority ethnic disabled people in order to close the gap left by mainstream providers. However, insecure funding for these organisations inevitably affects service provision. In addition to problems with financial support and the lack of a long-term funding base, many minority organisations also find it difficult to find affordable premises, again with a negative impact on the organisation's ability to meet the needs of service users. Therefore, the importance of adequate financial resources for the minority ethnic disability sector is key to ensuring a quality service.



What is the Asian People with Disabilities Alliance?

What is Asian People with Disabilities Alliance?

Asian People with Disabilities Alliance (APDA) was set up in 1988 by Asian people who have experience of disability and of caring for disabled people. It is an independent community organisation for Asian disabled people of all ages and disabilities and their carers and families. Recognised by local authorities in London as a service provider, **APDA** works with seven local authorities – the London boroughs of Barnet, Brent, Camden, Ealing, Harrow, Hounslow and Lambeth – to provide social care and rehabilitation and development for disabled people, including those with learning difficulties.

Its main objectives are to:

- provide needs-led and user-led culturally appropriate services
- act as a resource for Asian disabled people, their carers and families, offering peer and social support and information exchange
- provide opportunities for Asian disabled people to put forward their views about their needs in order to improve services
- to collaborate with service planners and mainstream organisations in order to raise awareness of the needs of Asian disabled people and to help them incorporate these needs into service plans.

Social care and development

APDA provides direct care to Asian disabled people at two day care centres – one based at Park Royal's Central Middlesex Hospital premises and the other at a purpose built building in Harlesden. At the Central Middlesex Hospital site, social support is offered to people of all ages with a variety of disabilities, including learning difficulties, whilst the Harlesden premises caters mainly for fragile elderly people and people who have age-related disabilities.

The services are very specifically tailored to the cultural and diverse religious sensitivities of the Asian disabled people and carers the organisation caters for and Asian cultural elements are built into every aspect of the service, incorporating dietary and language needs. A range of activities are organised including:

- Asian arts, music and drama
- Asian dance therapy
- educational visits
- talks on food hygiene and health and safety
- keep fit classes
- keyboard and computer skills development
- literacy and numeracy classes
- mobile library facilities
- respite breaks
- sewing and dressmaking
- social skills development
- yoga therapy.



Muskan dance group

APDA has formed its own dance group, involving users of the day centre. The group has been running for more than five years, putting on wheelchair dance shows, Garba, Bhangra and other traditional dance performances, as well as taking part in Asian fashion shows. Dancers and the singers and musicians that accompany them, have found the experience enriching and exciting.



Rekha Mehta

Rekha Mehta, who has polio, diabetes and arthritis and needs to use a wheelchair, is a service user as well as an **APDA** committee member. She started coming to **APDA** in the early 1990s after she heard about the service through her local Dial-a-Ride scheme. 'The place has the atmosphere of our culture. I can speak my own language and there are people here who have the same religion as I do. We share everything,' she said.

Rekha enjoys taking part in many of the activities on offer at the **APDA** day centre. 'I do the exercises, sewing, massage, reflexology and drawing. There are all kinds of activities and we talk and dance as well and play Antakshari where we sing,' claimed Rekha.

Rekha has also been on the three-year computer course organised jointly by **APDA** and the College of North West London and has now received a certificate in computing. 'We can improve our skills here in a homely atmosphere,' she added.

Apart from being a service user, Rekha likes to volunteer and contribute her time to help out at the group for people with learning disabilities.

'I enjoy the company and the way we can improve our skills here. We are all just like one big family,' she claimed.

Mobility service

APDA recently acquired a specially adapted minibus, jointly funded by Help the Aged Senior Mobility and Stage for Age, Golders Green Lions Club and the Young Sindhi Ladies' Association. The vehicle helps many frail, isolated house-bound older and disabled people each week, enabling them to live a more independent life.

Advice and information

APDA also offers its service users advice on further education courses, disability aids and equipment, benefits, mobility and independent living. It can also provide referrals to personal assistance schemes and special needs housing. Clients benefit from information that is produced in their own community language.

Volunteer support

The organisation's Asian volunteers project trains volunteers in social care work, so that they can provide additional care and support to Asian disabled people, carers and their families. Using volunteers whose background is Asian means they have some understanding of the religious, cultural, language and dietary needs of the client.





Mrs Mehta

Mrs Mehta cares for her 15 year-old daughter, Jyoti, who has various disabilities, including Down's syndrome, a hole in her heart, a severe speech impairment and damage to her lungs. She has been receiving support from **APDA** since 1994 through counselling, information and education, as well as help filling in forms and training to assist her to provide the best care for her daughter.

'ADPA meets my needs in a very efficient and a highly satisfactory manner, as I get advice that is culturally appropriate. I am able to communicate in my mother tongue without being misunderstood and misinterpreted,' claims Mrs Mehta. 'I am also able to attend religious functions like Diwali celebrations, Christmas and Navrati as well as events for carers and International Disabled Day activities.

Mrs Mehta believes that **APDA** would do well to extend its services to include provision specifically for children. She states, 'A day care facility for children like Jyoti is important. They would have the same culturally appropriate services in their mother tongue language, which would help their language development. Children with special needs could interact with one another and learn social skills in relationship building, which would enhance their personal development and self-esteem and enable them to gain some independence.'

Health awareness

Health awareness is another aspect of **APDA's** work. Through a partnership approach (see Networking on p17), the organisation runs regular culturally sensitive workshops on a range of health issues, including:

- Ayurvedic and herbal medicine
- basic HIV/AIDS awareness
- blood screening and blood pressure checks
- dental and mouth care
- diabetes
- health care for carers
- heart disease and strokes
- multiple sclerosis
- prostate cancer
- sexually transmitted infections
- women's health.





Pradip Shah

Pradip Shah has been visiting the day centre since 2000. An accident has left him with near total paralysis and with a condition called hypersensitivity, which means that he could go into spasms if he is touched or moved. He is completely wheelchair bound.

Coming to the centre means that Pradip is able to interact with other people in an environment that caters for his own culture, but which at the same time caters for different cultures within the South Asian diaspora. 'At home I'm on my own, so it's good to meet others and not feel isolated. Here there are Indians, Pakistanis and Bangladeshis, so really it's quite multicultural and **APDA** has a good support group. Although I need help with all physical issues, I'm mentally still alert and can talk,' he said. 'All of us are cocooned in our own disability. If we can't reach out we can deteriorate and our health can suffer. After my accident, I felt that I needed a boost. **APDA** gave me that boost.' But it isn't just Pradip that gains from the services of **APDA** – his wife also benefits. 'A big part of coming to **APDA** is to provide respite for my wife who is my full-time carer – she holds down a full-time job, which means she works day and night.'

Pradip works on the computer at the centre, giving him the opportunity to develop the use of his hand, which at the moment is limited, through a mouse that is supported by a special cushion and board. He is hoping for further computer adaptations that will make it easier for him to use IT. He also enjoys taking part in local forums organised by **APDA**, where he and other disabled people voice their views, and is involved in the production of the members' newsletter. He aspires to taking part in the keep fit, reflexology, yoga therapy and physiotherapy sessions as much as his disability will allow.

The health awareness sessions organised by **APDA** are also useful, according to Pradip. And a recent trip to an independent living exhibition organised by **APDA** has helped Pradip to make important decisions about having his home adapted to cater for his specific needs. 'We are in the process of adapting our house and the exhibition gave me an idea of what's available, who to contact and how to get funding,' he stated.

Finally, Pradip praised the work of **APDA**: 'This centre is superior to others. It is more flexible and the group is a cohesive one – we all work together,' he said.





In order to tap into the expertise elsewhere in the community for the benefit of its service users, **APDA** is regularly involved in networking activities. For example, it has established strong links with the NAZ project, an HIV/AIDS organisation working with the Asian community to run workshops on HIV and AIDS awareness. The group also liaises with the College of North West London which has led to courses for **APDA** users, such as computing skills, English language and communication, first aid and creative life skills. Work with Dial-a-Ride and Taxicard Users Association and the London Accessible Transport Alliance has led to assistance with accessible transport for the organisation's service users.

Healthy Living Initiative

Part of a government initiative to promote health projects at a local level, the Healthy Living Initiative provides funding to innovative responses to community health needs. In 2001, **APDA** took advantage of the initiative and set up a partnership approach with a group of other Asian organisations which included the Swaminarayan Temple, Brent Indian Association, the Asian Health Agency, the Tamil Refugee Action Group and Willesden Asian Neighbourhood Project.

The partnership has successfully bid for joint funding through the initiative to develop a shared working approach – information and expertise is exchanged between the organisations and a mutual referral system has been established. In practice this means that, for example, Willesden Asian Neighbourhood Project can offer the partnership information about services for elderly people; service users of any of the partnership organisations can access immigration advice offered by the Tamil Refugee Action Group; and the partnership groups are able to refer disabled Asian people to the services of **APDA**.

“Planning for ethnic minorities must form an integral part of mainstream provision”



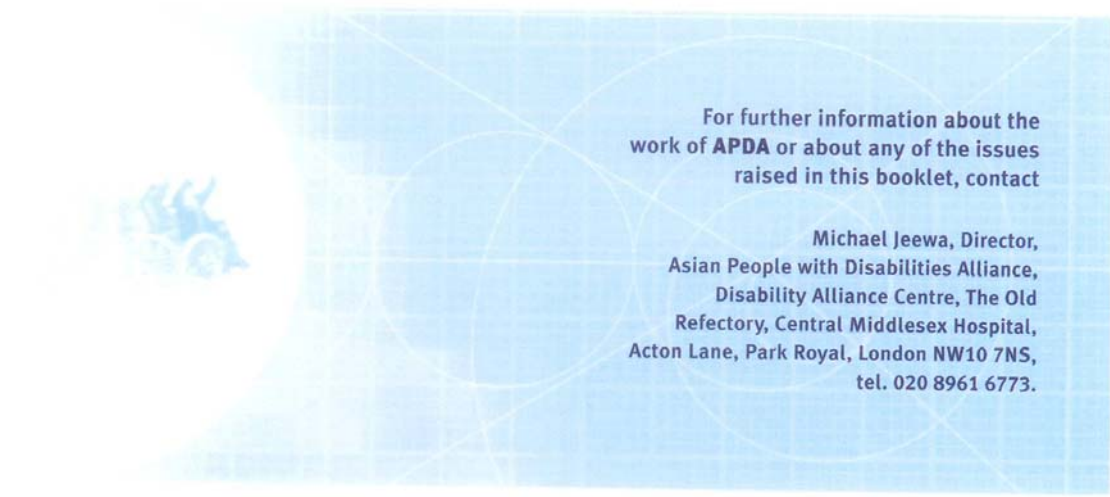
COMMUNITY ENGAGEMENT

In order to address the needs of minority ethnic disabled people, there must be a greater focus on promoting services to these communities and ensuring that the services provided take account of the specific needs of these communities. This is not optional; it is now a statutory responsibility and health and social care organisations have to address this. Organisations need to ensure that planning for ethnic minorities is an integral part of mainstream provision and that funding to carry out this work is available as a great deal of thought must go into targeting minority ethnic groups. Social care agencies and local authorities must:

- Find minority ethnic disabled people and create links with them – the use of outreach workers can help organisations to make contact with minority ethnic disabled people through tapping into informal networks in the community.
- Identify what the needs of minority ethnic disabled people are – look at what specific cultural and language needs the community has.

- Identify the needs of minority ethnic disabled children and look at providing services catering for their specific needs.
- Make sure users are involved – this means that services can more effectively meet the specific needs of users.
- Review their existing services and set priorities and targets for making improvements – an agreed action plan and timescale should be developed with specific tasks allocated to named members of staff.
- Look at ways of improving access to services by minorities – this can be done by ensuring that staff are aware of the social and cultural needs of the community by providing race equality training that covers cultural diversity and anti-racist practice; that staff have access to community language interpreters and that information is translated into relevant languages.
- Change the services they offer where necessary to make them appropriate to the needs of minority ethnic disabled people.
- Look at policy issues.
- Evaluate services – ethnic monitoring is a crucial part of evaluating services.
- Ensure sufficient statutory funding is directly available for minority ethnic disability organisations, rather than solely to mainstream organisations.





For further information about the
work of **APDA** or about any of the issues
raised in this booklet, contact

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