







## Users' views of community care for Asian disabled people

A study in the North of England collected the views of 28 Asian disabled people on what would make their lives better) and on what would make community care services better. The researcher, Ayesha Vernon of the University of Northumbria, found that:

-  **Asian disabled people and their families lacked confidence and trust in service provision. This contributed to low take-up of services.**
-  **Low take-up of services did not mean low levels of need. People reported feelings of isolation, forced dependency on family members, frustration at not being able to move about freely at home, anxiety and distress.**
-  **The people in this study lacked information about their entitlements and services, and knowledge about how to access services - even though they were all fluent in the English language or in British Sign Language.**
-  **People felt that service providers lacked cultural knowledge, and that they expected Asian disabled people to 'fit in' with existing provision.**
-  **Several people felt discriminated against on the grounds of disability and race - sometimes by service providers, sometimes by attitudes within their families and communities.**
-  **Participants identified several ways in which services could improve:**
  - consulting Asian disabled people about their needs and priorities;
  - peer support and social contact for Asian disabled people;
  - practical assistance or aids to support disabled adults in their family roles (e.g. parenting);
  - suitable housing and aids/adaptations that take account of people's preferences and religious or family obligations;
  - services that are flexible, good quality and culturally competent;
  - reducing waiting times and bureaucracy;
  - equal, transparent and non-discriminatory decision-making.

## Background

In recent years, there has been much emphasis on promoting independence and achieving positive outcomes for people using community care services. The focus of this study was to learn what Asian disabled people felt would make their lives and community care services better.

The study sought the views of Asian disabled people between 18 and 40 years of age, for whom receiving information in English (if in accessible formats, e.g. Braille) was not a problem.

## Unmet need

Low take-up of services does not mean low levels of need among Asian disabled people.

### **Isolation**

Participants described lack of social contact and feeling left out of community and religious life. This was partly about access to buildings and attitudinal discrimination. It was also about lack of sufficient hours of support for anything above basic 'personal care' needs; and lack of access to peer support from other Asian disabled people.

"My ideal thing to do would be to go and see a lot of disabled people, to talk to them." (35-year-old man)

"They've got a ramp going into the mosque, but once you are in it, to get to the floor where they pray and hold out, you have to go up two flights of stairs." (27-year-old man)

### **Lack of suitable aids and adaptations**

Several people described feeling forced into dependency on family members due to unsuitable housing.

"That's my worst problem going upstairs ... I've to do it on my bum! My sister helps me with the legs and then I lift up and go up ... Going up is hard, getting a bit harder now because, well don't forget I'm 38 now, so I'm a bit, getting old as well." (38-year-old woman)

Some people commented on the lack of cultural knowledge of service providers when assessing needs for aids/adaptations. Examples related to: housing needs for families of different generations living

together; use of space in the home arising from religious obligations; and domestic equipment (e.g. machine for making rotis) felt to be essential to improving an individual's quality of life and fulfilling family roles.

### **Lack of practical assistance with parenting and wider family roles**

Twelve participants were already or were soon to be parents. Unmet need for information on equipment and childcare strategies was a particular issue for two deaf parents who were expecting their first baby and, despite repeated requests, did not receive any information from statutory services. Several parents identified needs for practical assistance and aids to assist them in fulfilling their parenting roles, both inside and outside the family home. Support in contributing to family life was also important to other people in the study who were not parents.

### **Information and advice**

People wanted and struggled to get information so they could make informed choices. Women (in particular) who lived with their parents wanted to learn to become more self-sufficient and be informed about what options would be available to them once their parents were no longer able to support them.

## Independence and interdependence

People in the study talked about different ways of being independent. These did not always involve leaving the parental home (although this was an issue for some participants). People felt having control over decisions about money, education, work and support was very important.

"For me - to be independent... is having control over what you do." (27-year-old man)

A concept that emerged from the study was about 'interdependence' and 'mutual dependence' in the family. It was important to be able to reciprocate for help received from family members and contribute to family life.

## Consultation

Participants wanted ongoing consultation and partnership between service providers and local Asian

disabled people. On an individual level also, people wanted service providers to ask them what they needed. There was a sense that services were only geared up to provide what service providers felt were the priorities – but this was not always what was most likely to improve an individual's quality of life.

"They should ask our needs, what we need." (40-year-old woman)

### Flexible services

People wanted support to go out and join in leisure, educational, sports, cultural and religious activities. They wanted more choice and control over what services were provided, and also how, when and where they were provided.

Who provides assistance was also important. People specifically mentioned: more Asian social workers and social care staff; personal assistance from someone who shared the same religious faith; and from someone of your own age. This implies a need for flexibility with regard to the recruitment of personal assistance (e.g. through direct payments).

Direct payments offer scope for increased choice and control for people who are able and willing to use them. However, only one of the 28 disabled people had direct payments. A majority said they knew nothing about direct payments even though both local authorities were operating schemes.

### Cultural knowledge and competence

Some of the service providers interviewed felt the need for more cultural knowledge, while users of community care services noticed its absence. Some felt service providers saw cultural knowledge as irrelevant, taking the attitude that service users would have to 'fit in' to existing services.

"If I were a social services boss then I should go to university to learn about different religions, about the cultural backgrounds." (33-year-old man)

Translating ideas of 'cultural competence' into practice means ensuring that social services staff at all levels learn about different cultures as an essential part of training. It also requires that services should be delivered with respect for, and acceptance of, variations in expectations about:

- family life and family obligations;
- use of space and resources within the family home;
- religious obligations relating to the performance of self-care and domestic tasks.

Small things, such as providing Asian vegetarian or Halal food or providing somewhere for prayer, could do much to improve service users' confidence in provision. In contrast, cultural stereotypes held by workers were not useful as they sometimes stopped people from getting the services they wanted.

### Lack of confidence in services and discrimination

Perceptions of lack of cultural knowledge and competence contributed to what appeared to be widespread lack of confidence in service providers and service provision among the Asian disabled people who took part in this study. They felt services were difficult to reach and not appropriate to them.

Other factors resulting in lack of confidence in services included: negative images of social services; previous bad experiences with services; and feeling that service providers were not interested in improving their lives.

"We do want to be independent but sometimes I think they [service providers] write us off." (40-year-old woman)

Several people reported being discriminated against by service providers; they felt that their requests for support or adaptations would have been met had they been white disabled people. Whether or not this was the case, the fact that people felt discriminated against is cause for concern on the part of service providers.

A major implication of this study is that more time and sustained resources should be spent in building up the confidence and trust of Asian disabled people and their communities in service providers.

### Giving up on trying to get services

Many people in the study described giving up the fight to secure the services they needed.

"I have been and asked about [getting a ramp] and they were going to get back to me but no one has.

"It's so much hassle so I have given up trying." (38-year-old man)

Reasons included:

- not knowing what is available and how to access it (despite the fact that all the people in the study were fluent in English);
- lack of independent or peer support;
- being passed from pillar to post;
- not knowing your rights and so not challenging professional decisions;
- less incentive to battle for services that might not be worth the fight;
- local authority charging policies;
- long delays and bureaucracy.

### Providers' views on barriers to improving take-up

As part of the study, a small number of frontline workers and managers were asked their views on low take-up of services by Asian disabled people. They identified a range of difficulties in improving take-up, including:

- apparent lack of interest from communities (mainly identified by managers);
- lack of support from senior management (mainly identified by frontline staff);
- lack of sufficient and sustained funding;
- small, short-term initiatives that soon fold;
- lack of capacity among minority ethnic community groups to provide services for disabled people; and
- misplaced emphasis on translating written information into community language as the 'magic solution'.

### About the project

Twenty-eight Asian disabled people (between 18 and 40 years of age) were interviewed (individually or in focus groups) as well as a small sample of frontline workers and managers. Dr Ayesha Vernon undertook the research working with the Asian Disability Network in Bradford and the Association of Blind Asians in Leeds.

### How to get further information

The full report, **User-defined outcomes of community care for Asian disabled people** by Ayesha Vernon, is published for the Foundation by The Policy Press as part of the Social Care: Race and Ethnicity series (ISBN 1 86134 446 5, price £10.95).