

Chinese Voices of Social Care: Satisfaction with social care for physical disabilities among people from Chinese backgrounds

KEY POINTS FROM THE RESEARCH

- People from Chinese backgrounds highlighted the importance of social care that values the individual and respects cultural diversity. Their satisfaction with services seemed particularly shaped by experiences of accessing services, the attitudes displayed by care workers, the cultural and linguistic sensitivity of services, and the ease of access to information about services.
- Participants reported that most care providers do not speak Chinese and do not offer Chinese written materials. This seemed to have a profound effect on satisfaction.
- Poor understanding of social care terminology could lead to a situation where some people from Chinese backgrounds failed to take up social care services and became self-reliant or resigned to having no support. Sometimes this was to the detriment of their well-being, where, in the words of one participant, they were required to 'muddle along', which sometimes led to a crisis.
- Respondents generally did not have high expectations of social care services and some did not know what services to expect. For some, these limited expectations resulted in high levels of satisfaction if a service was offered but for others it meant disengagement from services.

The aim of this study was to understand how to improve social care services for physically disabled people from Chinese backgrounds in England. It explored people's experiences of social care and examined how cultural nuances shaped their expectations.

People from Chinese backgrounds and who received social care services for their physical disabilities were asked about their experiences and perceptions of social care. The project began with individual semi-structured interviews; the initial findings from these were taken back to focus groups to validate and clarify interpretation of participants' experiences.

The final stage of the study involved a 'world cafe' where stakeholders including service users, carers, and representatives from the Chinese communities, social care commissioners and practitioners were invited to think together and innovate corroboratively to open up new visions and solutions.

- Some participants described the complicated processes they had followed when accessing social care support and in some cases people had reached a desperate situation such as hospital admission before receiving input. Chinese welfare organisations often played an important part in facilitating access to services and also helped people through signposting, brokering, where they negotiated services for the individual, or by offering culturally sensitive social care services. The Chinese welfare organisations that were mentioned received some of their funding from the local council but also relied on donations and fund raising.

The study represents independent research funded by the National Institute for Health Research (NIHR) School for Social Care Research (SSCR). The views expressed are those of the authors and not necessarily those of the NIHR, SSCR, Department of Health, or NHS.

NHS
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BACKGROUND

People from black and minority ethnic (BME) groups in England have lower levels of satisfaction with adult social care services; they have less contact with services, experience prejudice and suffer from a lack of information about services. However, there is limited research on physically disabled people; and most BME research focuses on the experiences of people of larger minority groups such as those from Indian, Pakistani and Bangladeshi backgrounds (Amin 2002, Bowes and Sim 2006). There is some evidence that organisations have found it difficult to meet the needs of people from BME groups but no research has focused on the needs of people with physical impairments who are from Chinese backgrounds.

FINDINGS

Access to social care services

Participants said that they struggled to access social care services when they first needed support because they did not know what services were available. This is disappointing because several had medical conditions that would have necessitated contact with NHS services, where the availability of social care should have been raised. The situation is similar for other minority groups, particularly those in less well established groups.

As a result, many participants described having no support from social care services for a prolonged period until their conditions deteriorated to the extent that some required hospital treatment. For these, it was during their stay in hospital that support services were organised so that they could return to live in the community:

It seems the only way you would get help would be if you were hospitalised and then you would have the service I think I need to get myself into the system! (Focus group participant)

Consistent with others' findings (Aspinall 2007), language differences created a major barrier in accessing and using social care services:

The reason that I don't know how to access services is because I don't know English. I don't

know how to ask for the information I need. (Focus group participant)

Use of personal budgets

Most participants were unable to tell if their care was paid via personal budgets. They had either never heard about personal budgets or misunderstood what they were. A number of the participants who had heard of personal budgets did not make an application for direct payments because they could not find someone to work for them:

I want the service but, to find someone to look after me is a big problem. (Linda)

Only four participants had used personal budgets (as direct payments) and two discontinued their use. One indicated that despite his eligibility to receive publically funded care, he preferred to forgo the benefit and come to a private and less intrusive arrangement. However, one participant who was pleased with her personal budget said:

Personal budget allows me to hire Chinese domiciliary care (workers) ... it helps me with cooking, cleaning, shopping, so without the budget I wouldn't be able to do anything. There was nothing bad; everything is good about personal budget. (Cecilia)

Expectations and level of satisfaction

Respondents generally did not have high expectations of social care services and some did not know what services to expect.

I didn't know what service was available, I just knew that I could try but I didn't know what exactly I should be asking for. (Mr Lau)

For some, these limited expectations resulted in high levels of satisfaction once services had been put in place. However, not all participants had positive experiences with the services they received. Some were very dissatisfied with care homes, because they lacked stimulation or culturally sensitive care. Other respondents were not always happy with the attitude of social care workers:

I just felt they [social care workers] were treating me like you know, you're just another one of these hopeless cases ... And there was a different person every time so I never got any sense of continuity ... they didn't seem very caring. (Ah Fong)

It is clear that respondents prefer Chinese specific social care services, where there is a shared linguistic and cultural background. However, they acknowledge that this is not always possible in which case, like other people from BME backgrounds, they appreciate services that value the individual and respect cultural diversity.

Coping strategies – self-reliance and muddling through

Many participants used personal resources such as family and friends because social care services could not adequately meet their needs:

Well I just sort of muddle along...I get people to come and help me you know, friends about twice a year... I just about muddle along. (Cecilia)

Seeking help from Chinese welfare organisations

Participants emphasised the crucial role that Chinese welfare organisations played in supporting them to access services and throughout the whole process of using social care:

There are people from the Chinese Association, they really help me. I am fortunate to have them to help me. Otherwise, it's a big headache. (Focus group participant)

Apart from bridging service gaps because of language differences and culturally sensitive services, Chinese welfare organisations also served to signpost people to other mainstream service providers:

I come here [Chinese welfare organisation] and find something, they can help you otherwise they will give you an address to go to. You know that helps. (Focus group participant)

CONCLUSION

People from Chinese backgrounds need to have information about services in their own language that is easily understood and uses familiar terminology that crosses cultural boundaries.

Expectations of social care services are low among people from Chinese backgrounds and

ABOUT THE STUDY

Twenty-six people from Chinese backgrounds with physical disabilities (15 women and 11 men) were interviewed. Fourteen of these those interviewed also took part in focus groups.

Participants' ages ranged from 18 to 70 years; 20 of them were 50 or older. Twenty-three participants lived in their own homes and two lived in residential care. Most had mobility impairment as a result of long-term illness such as stroke and cancer. Five of them had visual impairment. All except two of the participants were born outside the UK. One person was waiting for a social care assessment, whilst most others received domiciliary care and/or attended a day centre.

All participants' names have been changed.

To obtain further information, please visit the project website www.staffs.ac.uk/research/cpsi/CVSC.jsp or email Professor Fiona Irvine (f.e.irvine@bham.ac.uk).

therefore they do not always access the services that may benefit their well-being.

Access to services would be easier if the right information got to the people who needed it; and if the market met people's cultural needs. This might be facilitated by helping people use the services that are already provided by Chinese Welfare organisations.

There may be a case for calculating what funds are needed for resourcing of these organisations to enable them to continue and expand their role in signposting, brokering and providing culturally appropriate social care services and in supporting other social care providers to develop cultural sensitivity.

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