Health & Social Care in the community

The impact of personalisation on people from Chinese backgrounds: Qualitative accounts of social care experience

Journal:	*Health & Social Care in the Community*
Manuscript ID	HSCC-OA-15-0328.R3
Manuscript Type:	Original Article
Keywords:	Chinese, Physical Disabilities, Social Care, Personalisation, Cultural competence, Qualitative Research

Article title: The impact of personalisation on people from Chinese backgrounds: Qualitative accounts of social care experience

Abstract

The limited research that considers people from black and minority ethnic communities experiences of personalisation tends to focus on personal budgets rather than personalisation *per se.* This article provides an opportunity to hear the voices of people from Chinese backgrounds and their experiences of personalisation. The study used individual semi-structured interviews and focus groups to collect data from physically disabled people from Chinese backgrounds who lived in England, were aged between 18 and 70, and received social care. Data were analysed using an iterative and thematic approach, with early analysis informing the subsequent analytical rounds. The findings reveal that personalisation has the potential to transform the lives of people from Chinese backgrounds, especially when tailored support is available for people to understand and access personal budgets and put them to creative use. However, the impact of personalisation is barely evident because few eligible individuals access personal budgets or participate in co-production. This is related to a lack of encouragement for service users to become genuine partners in understanding, designing, commissioning and accessing a diverse range of social care services to meet their cultural and social care needs.

Keywords: *Chinese; physical disability; social care; personalisation; cultural competence; qualitative research*

What is known about this topic?

- Personalisation promotes independence by enhancing choice and control for people with social care needs.
- Personal budgets are an important element of personalisation that enable the purchase of culturally sensitive services and improve service choice.
- Underutilisation of personal budgets is evident amongst people from Chinese backgrounds

What this paper adds?

- When personal budgets are used creatively they can transform the lives of people from Chinese backgrounds with social care needs.
- Many Chinese people fail to engage in the personalisation agenda because they have limited proficiency in English and inadequate understanding of the structural idiosyncrasies of the available services.
- Chinese welfare organisations can support and empower people to actively engage with personalised adult social care.

Introduction

Personalisation, an important agenda across public services in the United Kingdom (UK), was identified as the key approach to transforming adult social care in 'Putting People First' (HM Government 2007), a concordat between UK Central Government, local government and the social care sector. One of the main aims of personalisation is the enhancement of people's choice and level of control over their social care and support services (Glasby and Littlechild, 2009, Brookes et al 2015), which helps to promote independence (Stainton and Boyce, 2004; IFF Research, 2008). Beyond the UK, discussions around choice and control are considered in terms of self-determination, which is defined by Wehmeyer (2005 p117) as the ability to '*act as the primary causal agent in one's life and make choices and decisions about the quality of one's life free from undue external influence or interference*'. This suggests that personalisation is a mechanism for achieving self-determination.

Personal budgets, which entail providing people with social care needs with the budget available to meet their needs so that they can choose how the money is spent, are one mechanism of achieving personalisation. These can be taken as a direct payment, a managed budget, or a combination of these, to enable individuals to plan and manage their own care and support (Manthorpe et al 2009; Netten et al 2009; Carr 2010; Lymbery 2013).

An inherent element of the personalisation agenda is co-production (Needham and Carr 2009). Co-production focuses on partnership between social care service users and providers; individuals become co-designers and co-producers of their services (Hunter and Ritchie 2007). According to Joyner (2012), this approach levers the knowledge, skills and expertise of those in need of support and puts service users at the heart of service planning and implementation, thereby contributing to effective public services (Needham and Carr 2009). However, there is some tension between co-production and personal budgets. For example, Slay (2012a) argues that a focus on personal budgets leads to an individualised

approach that confines the opportunity for collaboration. This merely shifts people from passive recipients of services based on formal assessment, to passive consumers, where they collaborate on support decisions but within the confines of the supporting agencies. Moreover, Slay (2012b) identified that service users are encouraged to buy services rather than actively producing their own solution, which may require input that cannot be bought, including peer support and services such as local parks and libraries. This is contrary to the purpose of the personalisation policy, which explicitly seeks to promote choice and control over care and support, and to augment community capacity (Think Local Act Personal (TLAP) 2011).

Nevertheless, the UK Government identify personal budgets as a key element of personalised social care (HM Government 2012). Furthermore, Slay (2012b) points out that as it is the only national indicator used to assess the implementation of personalisation, Local Authorities identify personal budgets as their sole means of evaluation. In England, personal budgets have only recently been put on a statutory footing (s26 Care Act 2014). However, personal budgets have become popular and uptake has been increasing for some time (Leece & Bornat 2006). According to Glasby & Littlechild (2009), uptake is largely confined to physically disabled people of working age, and other groups have been less inclined to take advantage of personal budgets. This variation in uptake is attributed to professional attitudes that stifle creativity (Slay 2012b); the favouring of personal budgets by more articulate and educated people (Lymbery 2013); and a shift in perspective that favours supporting people to understand the services available to them in order to make a choice, rather than directly assisting people to make choices (Rose 1999). This could disadvantage those who are less able to take on the additional responsibilities that may be required when using personal budgets and these are some of the people who require adult social care, such as those who are frail and marginalised (Clark et al. 2004; Carr 2014).

There is limited literature that explores the effect of personalisation on service users from minority ethnic groups. However, the expectation is that they could benefit from personal budgets since they would be empowered to purchase culturally sensitive services and improve choice in social care markets (Lewis 2005; Spandler and Vick 2005; Voice4Change 2012; Moriarty 2014). Manthorpe et al (2010 p.7.) particularly highlight the position of people from Chinese backgrounds in the UK, who they argue have been *"almost totally ignored within the literature, partly on account of their comparatively small numbers",* accounting for 0.7% of the total UK population (Office for National Statistics 2012). Nevertheless there is some evidence to suggest a poorer uptake of personal budgets by people from Black and Minority Ethnic (BME) communities (Glasby and Littlechild 2009; Moriarty 2014). The Commission for Social Care Inspection (2008) asserts that this reluctance to engage with social care services is because of previous experiences of discrimination. Similar findings from studies on the Chinese population in the UK suggest that they anticipate discriminatory practice from social and health care professionals, and this deters them from seeking help (Healthcare Commission 2009; Waller et al. 2009). The disinclination to seek assistance is also influenced by the preference of older people for traditional Chinese medicine (Li et al. 2014) and compounded by the vulnerable psychological well-being of Chinese caregivers (Zhan 2006).

Newbronner et al. (2011) question people's awareness of personal budgets, suggesting that culturally equivalent information about personal budgets is inaccessible. There is an absence of evidence on the impact of personalisation for specific minority groups and no literature that considers how Chinese communities in England have fared through the personalisation agenda. Yet we need to understand this more fully because there is a danger of focussing on the needs of more established (and researched) minority ethnic groups, such as South Asian people, at the expense of people from Chinese communities. In addition to being inequitable, this can contribute to poorer outcomes (Moriarty 2008).

Research Design

The study was of a qualitative design and aimed to examine the factors affecting the social care experiences of physically disabled people from Chinese backgrounds in England.

We followed Van Manen's (2007) phenomenology of practice perspective, which, within the scope of the relevant practice, seeks to '*explain, interpret or understand the nature of the phenomenon'* (p18). This phenomenological stance offers the opportunity to see meaning in the experiences of social care for physically disabled people from Chinese backgrounds and interpret this in terms of social care practice. The study took a descriptive approach in the initial stage, whereby participants' experiences were explored through semi-structured interviews. The later stages used an interpretive approach through which focus groups were used to facilitate interpretation.

To realise the study aim through a theoretical lens, we used the Cross et al. (1989 p3) seminal definition of cultural competence as *"a set of congruent behaviors, attitudes, and policies that come together in a system, agency or amongst professionals and enables that system, agency or those professionals to work effectively in cross-cultural situations".* Brach and Fraser (2000) believe this definition places value on informed consent, choice of providers and equity. Therefore it offers a mechanism to achieve personalisation for people from different cultural backgrounds through the enhancement of choice.

Sampling and Recruitment

We used purposive sampling to recruit people from a Chinese background with a physical impairment who had received social care from adult services in the previous six months. In

light of the known difficulties recruiting vulnerable people from Chinese backgrounds to research studies (*authors own* 2013, *authors own* 2013), we distributed Chinese and English language recruitment leaflets and posters to a wide range of relevant organisations, such as Local Authority adult social care teams, Chinese voluntary organisations and Chinese retail outlets. We supplemented this with a snowballing technique where individuals who agreed to take part in the study were asked to pass on recruitment flyers to potential participants. We invited all who took part in an interview to attend the focus groups.

Data collection

Whilst recognising the various complexities of power and positionality in cross cultural research (Merriam et al. 2010), we wanted to project an authentic and insightful understanding of our Chinese participants. Thus our research team comprised of 'insiders and outsiders' and data collection and analysis were undertaken by two bilingual Chinese researchers and one English researcher. We anticipated that this composition would strike a balance between familiarity, where Chinese researchers who had some shared identity, language, and experience with participants, asked more meaningful questions; and 'curiosity with the unfamiliar' (Merriam et al. 2010 p 411) on the part of the English researcher, thereby offering more insightful interpretation. However, we acknowledge that this is a complex issue and it would be naïve of us to overstate the claim of insider status. According to Psoinos (2015) immigrant participants' viewpoints are constructed through several social interactions within the different contexts they have encountered since migrating to the UK. Thus it is inevitable that the gender, sexual orientation, generation, migration and professional backgrounds of the research team will not entirely accord with those of participants (Kühner & Langer 2010).

We conducted in-depth semi-structured interviews in the language of choice of the participants (English, Cantonese or Mandarin) between July 2012 and February 2013. These lasted between 30 and 80 minutes and were conducted in participants' homes or Chinese community centres. Data collection continued until data saturation was reached.

To validate data and clarify our interpretations of findings (Bradbury-Jones et al. 2009), and further uncover the reasons behind people's levels of satisfaction, the interviews were followed by focus groups from February to March 2013. All interviewees were invited to take part in one of three focus group discussions (Two Cantonese (CSFG1 and CSFG2) and one English (ESFG), where we presented the key themes of the interview data and asked participants to comment and expand on the findings.

Ethical considerations

The study gained ethical approval from the Social Care Research Ethics Committee. Written consent was obtained from each participant to take part in interviews and focus groups, and for these to be audio-recorded. Confidentiality was assured and all data were anonymised.

Data Analysis

The interviews and focus groups were audio recorded, fully transcribed and anonymised. To enhance the credibility of the research, transcripts were analysed in the original language of the interview, and bilingual labelling was used through the analysis to accurately describe participants' experiences (Lincoln and Guba 1985) and retain any linguistic nuances (Maclean et al. 2004).

We read the interview transcripts to search for patterns in the data, coded them and identified initial sub-themes before agreeing on a preliminary thematic framework. Decision processes were traced and themes were scrutinised by an independent researcher by cross-

checking case charts with data reconstruction sheets to ensure correspondence, and systematically tracing interview quotations through all stages of analysis to ensure dependability.

Focus group data were analysed separately following the same analytical process. Comparisons were made between the two data sets to elicit new meanings and insights and to enhance the trustworthiness of the work. In light of this process, adjustments were made to the analytical framework. Finally, data synthesis was undertaken, where the inductive themes were considered within the context of the research aims (Sandelowski et al. 2006) to produce indicative accounts of social care based on the participants' shared experiences.

Verbatim extracts from transcripts are presented to enable judgement about our interpretations of the participants' accounts. Chinese quotes are translated into English for clarity.

Findings

Twenty-six people were interviewed and fourteen of these joined the focus groups. Table 1 gives details of the interview participants.
(Insert Table 1 here)

Using cultural competence as an interpretive lens, we report on findings relevant to the personalisation agenda in this paper. Within the indicative accounts of social care, one prominent discourse was that of personal budgets and yet, given that these are intended as technical levers to achieve personalisation (Larkin 2015), participants' accounts of personalisation *per se* were conspicuously absent from the data.

Participants revealed a diversity of experiences relating to personalisation that typified two themes, which mapped to Boyle and Springer's (2001) discourse of the conflict between traditional social services and minority values: 1. individuality, self-determination and resource accessibility and 2. minority values. These created different accents to the achievement of personalisation.

Theme 1: Individuality, self-determination and resource accessibility

The data revealed limited accessibility to personal budgets amongst participants. The majority of participants did not refer to personal budgets, and when asked directly they indicated that they were not aware of the existence and/or the detail of such a service, hence accessibility was effectively blocked:

> (I've) never heard of personal budgets (Mrs Wong)

> No one ever mentioned personal budgets to me, the Chinese community worker never told me about this. (CSFG1: Mr Lau.)

Some participants were able to describe the process of applying and using personal budgets correctly:

> A sum of money given to you and you can spend it in any way you like such as hiring a carer to look after me. (CSFG1: Hannah)

A small number of participants were aware of personal budgets, however accessibility was constrained because they felt unable to navigate what was viewed as an overly complicated system.

> I used personal budgets for a while, but it was too troublesome. Even my daughter was put off by it, although she can speak English. Nothing is perfect, we had to employ someone, and it took time to do it, organise the payroll, pay slips, their leave. There is a lot to learn. In the end, my daughter and I agreed not to use personal budgets. (Hannah)
>
> It sounds very troublesome. I don't know many people. If I have to employ someone, I don't know where to find this person. (Mr Tse)

When people accessed personal budgets they were not aware of the full extent of the services available to them and what is permissible use of personal budgets:

> I can't really remember what procedure but there is a Chinese domiciliary care service that provide for me but I can't remember how . . I only have direct debit and the money is paid into the account to pay. I receive a monthly invoice and I have to partially contribute towards it. (Cecilia)
>
> I can spend personal budgets on food and to pay the bills. (Mark)

However, many participants were unable to utilise the resources provided by personal budgets. Therefore, personalisation was unreachable, and to achieve self-determination, they resorted to personal resources, such as family and friends to meet their social care needs:

> You know I had three operations. I cannot put the socks on myself. Sometimes I feel really miserable. I need to ask my husband to help me take my shoes off. It is very stressful for him. He is getting old and he needs help as well I am not sure if I am entitled to personal budget, direct payment. (Mei Ling)

> Well I just sort of muddle along. I mean my floor never gets cleaned, my windows. I get people to come and help me you know, friends about twice a year... I just about muddle along. (Cecilia)

For some participants, maintaining their individuality meant they avoided using available services because of issues of trust or pride:

> If the government gave me money to hire someone to look after me, I will only hire my daughter.. I had negative experiences with care workers in the past... I will only trust my daughter to look after me. (Mrs Wong)

> The problem is I don't want to ask help from other people, to admit that I need help is a big step. (Ka-Lai)

Theme 2: Minority values

Cultural values had pragmatic implications that conventional social care services were not always equipped to address. The need for freshly made hot foods is a case in point:

> The most important thing is food. We Chinese, you know what I eat is simple Chinese meals. Unless you can employ a westerner who can prepare Chinese food but that is impossible. (Mr Lau)

> In the past, the Chinese luncheon club delivered Chinese meals to me. Because of the funding cut, it has stopped... (CSFG2: Mrs Ho)

Additionally, the challenge of linguistic disparity was highlighted by a number of participants:

> You know when you cannot speak the language, you cannot communicate with others. It's very troublesome. even if the social worker comes to see us, it's no good if we cannot communicate with them. (Ann)

> Language difference is the main difficulty. We cannot speak English, we cannot understand English, how do I know where and how to seek help? (CSFG2: Mr Chan)

The creative use of personal budgets helped to mitigate such problems and proved liberating to some participants who were able to purchase services that aligned with their cultural needs and preferences:

> Personal budgets allow me to hire Chinese speaking domiciliary care. it helps me

> to get someone with the cooking, cleaning, shopping. Without the budget, I will not be able to do anything I received the service as I expected and I am happy with it (Cecilia)

However, self-reliance created reluctance to seek outside help and deterred access to personal budgets:

> It's the habit of Chinese, we like being self-reliant. We seldom ask for help. We are not outspoken, so very often our family helps out as much as they can. However, apart from my daughter, I have no relatives to help me. (Alan)

> I think basically I need help for everything but naturally I say no to any outside help. My younger brother will help. I think that's a very natural response but apart from my brother, there is no one else to help me. (David)

Discussion

Our findings suggest that there is a notable information gap for people from Chinese backgrounds regarding personal budgets and thus they are not in a position to consent to or take up this service nor to access a choice of providers. This is the case for individuals who have, often through a protracted process, managed to secure some access to social care services, often through a protracted process, and suggests that those who do not receive (but may be in need of) services are even less well informed about personal budgets. This lack of information is not unique to people of Chinese origin and is experienced by other marginalised groups. For example, Newbronner et al. (2011) discovered limited knowledge about personal budgets amongst older people and people with mental health issues. Moreover, once secured, some people were struggling to manage their personal budgets. Considering that they are also grappling with language and cultural differences this is not surprising given TLAP's (2014 p.5) recent assertion that "*the personal budgets process is still too cumbersome, bureaucratic and risk averse in many areas, creating barriers that stop people accessing personal budgets and achieving the best outcomes.*"

Choice is further denied because an underlying attitude still exists amongst some professionals that people from minority ethnic groups 'look after their own' (Katbamna et al.

2004; Badger et al. 2009). This appears to be a widely held view about Chinese communities living in western societies such as North America (Tseng and Streltzer, 2004) and the UK (Chan, Cole and Bowpitt, 2007). The perception that the Chinese community is insular and self-sufficient can lead local authorities to refrain from making specific provision for Chinese people and consequently they do not always engage adequately with this group (Moriarty 2008). This is a particular concern given Zhan's (2006) findings that emphasise the vulnerable psychological well-being of Chinese carers.

Our work shows that when people from Chinese backgrounds make use of personal budgets, they are able to exercise choice and access much needed culturally equivalent services that may not be available through conventional means. This is consistent with Needham's (2011) argument that, when given autonomy, service users spend their personal budgets appropriately to meet their care needs. It supports Glasby and Littlechild's (2009) assertion that direct payments and personal budgets have expanded choice and control for service users. Participants in this study were often supported to make decisions with the help of Chinese organisations that were able to fully explain personal budgets and signpost them to individuals or organisations that could meet care requirements in accord with cultural needs. Moriarty (2014) observes the importance of such community organisations in enabling those from minority ethnic backgrounds to benefit from personal budgets. The implication for information giving here is that written material does not suffice. Rather, as corroborated by Newbronner et al. (2011) and the three national personal budgets surveys (Hatton and Waters 2011, 2013, Waters and Hatton 2014), time spent discussing personal budgets and supporting people to understand the available services in order to make a choice helps the most. This may be particularly important with people from collectivist cultures like those from Chinese backgrounds, (Hu and Palmer 2012). They will need tailored advice to ensure that they are able to reconcile the individualist premise of

personalisation with collectivism, so that valued social relationships are not jeopardised through self-determination.

Brookes et al. (2015) advocate for the funding of voluntary organisations to work directly with service users to develop their support plans. If this model is to work, appropriate organisations must exist to facilitate informed choice and for our participants, opportunities to access the support of Chinese Welfare organisations were confined to those who lived in large English cities. However, as in other countries, the Chinese population is widely dispersed (Dobbs et al 2006), and thus for the individuals who live beyond the typical geographical limits of an established Chinese community, services to meet information needs are not forthcoming. This scarcity of services might explain why none of our participants who lived in relative cultural isolation made use of a personal budget but rather resorted to '*compensatory self-organisation*' (Carr 2014 p.10), relying on unpaid input from family and friends to meet their social care needs. Such arrangements have the potential to become self-perpetuating. As evidenced by Chau & Yu (2009) and ***author's*** *own* (2010), cultural assumptions about self-reliance can lead to a reluctance to provide formal support services, in this case, culturally tailored information about personal budgets.

Personal budgets are only one means of delivering personalisation and facilitating self-determination. If equity is to be fully realised and people from Chinese backgrounds are to be empowered to plan, commission, direct and deliver services that meet their needs, they should be encouraged to engage in co-production. However, the wider concept of personalisation and the pivotal element of co-production were notably absent from our data. This is not surprising since other studies of social care highlight the limited impact of co-production, with TLAP (2014) suggesting that although the language of co-production is commonplace, the reality of a supportive infrastructure to facilitate shared decision making, is yet to catch up with the rhetoric. However, because co-production should facilitate the

provision of differentiated services and increased choice (Carr 2010; Beresford *et al.* 2011; Bovaird and Loeffler 2012), it is of particular importance for marginalised groups such as Chinese communities, for whom conventional social care services can be inaccessible or disempowering (Carr 2014).

Implications for Practice

The Care Act 2014 places a statutory duty on local authorities in England to provide comprehensive information about care and support services to ensure informed choice. Meeting this need for choice goes beyond the provision of leaflets and literature, and requires support in the process of planning and managing services (Bartlett 2009, Newbronner et al. 2011). If choice and control are to be increased, they must be combined with services tailored to meet the particular requirements of ethnically diverse groups (Care Quality Commission 2014). Netten et al. (2009) argue that co-production requires the availability of a range of options to identify and meet individuals' needs and achieve the personal outcomes that suit them best. Often, it is the marginalised communities themselves that pinpoint appropriate care solutions (Carr 2014). A collective effort towards personalisation is needed, which draws on individual, community and statutory resources and includes the traditional model of provision from local authorities and the third sector (Stevens et al. 2011; Brookes et al. 2015), as well as more innovative approaches such as specialised, peer and user-led services (Newbronner et al. 2011; Needham 2011) and the mobilisation and support of micro-providers (Manthorpe et al. 2012, Brookes et al. 2015, Carr 2014).

This discussion has global relevance since, as we argued earlier, personalisation is a mechanism for achieving self-determination; recognised internationally as a basic human right (United Nations 2013). Health and social care practitioners in different international settings will need to consider how they legitimise alternative worldviews to facilitate self-

determination. According to Ferguson (2007 p401) this will require "*the development and strengthening of collective organisation both amongst those who use services and amongst those who provide them*". Part of the solution may lie with the existing and trusted Chinese groups who are well positioned to engage in co-production in its widest sense and provide outreach services to Chinese communities that are compatible with people's cultural needs. Similar to the position in the USA, where Chinese organisations are seen to rebuild social ties, enrich community life, and enhance access to services (Zhou and Lee 2013), our participants testified to the valuable and distinctive contribution that these organisations can make. Practitioners will need to ensure they are aware of such community organisations, to meet statutory and practice obligations and consider how such agencies can contribute to meeting people's care needs. However, Carr (2014) in the UK and Zhou and Lee (2013) in the USA, caution that micro providers such as Chinese welfare organisations are vulnerable, particularly in times of austerity. Thus, commensurate with policy expectations to move to a personalisation agenda and the new legislative responsibility to shape and develop the social care market (Care Act 2014), commissioners should consider how they could support these (often) solitary organisations. This could involve mobilising groups to work collectively, and providing much needed relatively small financial support to aid stability and sustainability. However, because of their relative scarcity, the value of Chinese welfare organisations should not be overestimated, as they are only able to support people who live in high density Chinese populations. Therefore, if mainstream services are to promote equity, as Carr (2014) asserts, they cannot abdicate their responsibility for providing culturally sensitive, accessible support to particular BME groups entirely to local specialist and community organisations. However, commissioners and practitioners can benefit their organisations and the people that they serve by harnessing the expertise of these groups to understand the needs of particular BME groups such as the Chinese population, and to facilitate their engagement with mainstream services.

Limitations

The findings should be considered in light of the limitations of the study. Twenty four of the 26 respondents resided in major English cities and were mainly recruited through Chinese welfare organisations. This may have influenced their experiences and their levels of satisfaction such that they would not be transferable to people living in suburban or rural locations. Whilst we have attempted to portray a balanced report of participants' experiences, it is possible that their accounts were coloured by their perceptions of the interviewing researchers and the perceived balance of power between researcher and researched. We militated against power imbalances by using insider and outsider researchers. However, as Richards and Emslie (2000) demonstrate, the professional social worker status of the 'insider' may have influenced or inhibited participants' disclosure of their experiences. Nevertheless, the work offers some useful messages about social care for people from Chinese backgrounds with evident implications for practice.

Conclusion

Our study suggests that personalisation in adult social care has the potential to transform the lives of people from Chinese backgrounds. This is especially the case if addressed through the perspective of cultural competence whereby tailored support is available for people to be fully informed and able to access personal budgets in a way that is congruent with their cultural norms; and assert choice and self-determination by putting personal budgets to creative use. However, the impact of personalisation is barely evident because few eligible individuals are engaging with the personalisation agenda, neither in terms of understanding or accessing personal budgets, nor in participating in co-production. This is not a consequence of Chinese people's reluctance to access such initiatives. Rather, it is created by the fact that the opportunities for service users to become genuine partners in

understanding, designing, commissioning and accessing a diverse range of high quality services rarely exist (TLAP 2014). Effectively this suggests that inequity is upheld in the current social care systems (Boyle and Springer 2001). Garran & Werkmeister Rozas (2013) offer a useful perspective on cultural competence that should help to promote equity, requiring practitioners to develop flexibility in their thinking and behaviour to address the values, expectations, and preferences of specific client groups. This means that practitioners must use a variety of strategies to meet the range of needs of cultural groups that exist among clients.

Many Chinese people face the additional challenge of negotiating their social care when they have limited proficiency in English and inadequate understanding of the structural idiosyncrasies of available services. This should not preclude them from actively engaging with personalised social care. Efforts are needed to ensure that individuals are supported and empowered to make their choices known and to exert control over their care and support. Chinese welfare organisations can signpost, broker and provide such services; however, in areas where such organisations are absent, other means of securing community-based provision are needed. These will likely fall outside traditional service sector boundaries and will require support to augment the capacity of Chinese communities to assist their citizens who are in need of social care.

Fook (2002) maintains that accessing a number of perspectives and experiences from different angles is an important principle of researching experience. Thus further research is needed to consider practitioners' angles on personalisation and the promotion of choice and self-determination for people from a collectivist cultural background, such as the Chinese.

References

Authors own (2010) 'Engaging service users and carers in health and social care education: Challenges and opportunities in the Chinese community' *Social Work Education: The International Journal* 30(3): 281-298

Authors' own (2013) Role of social networks in the help-seeking experiences among Chinese suffering from severe mental illness in England: a qualitative study. *British Journal of Social Work* 43 (3): 486-503.

Authors' own (2013) *Including People with Learning Difficulties from Chinese Backgrounds: an Ethnography of Three Services*. In Norah Fry Research Centre, School for Policy Studies. Bristol: University of Bristol

Badger F, Pumphrey R, Clarke L, Clifford C, Gill P, Greenfield S, Jackson K (2009) The role of ethnicity in end-of-life care in care homes for older people in the UK: a literature review. *Diversity in Health and Care*, 6(1): 23-29.

Bartlett, J. (2009) *At your service. Navigating the future market in health and social care.* London: Demos.

Beresford, P., Fleming, J., Glynn, M., Bewley, C., Croft, S., Branfield, F. & Postle, K. (2011) *Supporting People: Towards a Person-centred Approach*, Bristol: Policy Press.

Bovaird T and Loeffler E (2012) Why public service co-production matters. In Loeffler E, Taylor-Gooby D, Bovaird T, Hine-Hughes F & Wilkes L (eds) *Making Health and Social Care Personal and Local: Moving from Mass Production to Co-Production.* Birmingham: Governance International.

Boyle, D. and Springer A. (2001) Toward a cultural competence measure for social work with specific populations . *Journal of Ethnic and Cultural Diversity in Social Work*. 9(3-4): 53-71

Brach C. & Fraser I. (2000) Can Cultural Competency Reduce Racial and Ethnic Health Disparities? A Review and Conceptual Model. *Medical Care Research and Review*, 57(1): 181-217.

Bradbury-Jones, C., Sambrook, S. and Irvine, F. (2009). The phenomenological focus group: an oxymoron? *Journal of Advanced Nursing*, 65(3): 663-671.

Brookes N., Callaghan L., Netten A. & Fox D (2015). Personalisation and innovation in a cold financial climate. *British Journal of Social Work* 45(1): 86-103

Care Quality Commission (2014) *The State of Health Care and Adult Social Care in England*. London: Care Quality Commission.

Carr, S. (2010) *Enabling Risk, Ensuring Safety: Self-Directed Support and Personal Budgets*. London: Social Care Institute for Excellence.

Carr, S. (2014) *Social Care for Marginalised Communities: Balancing Self-organisation, Micro-provision and Mainstream Support*. Policy paper 18. Birmingham: Health Services Management Centre. University of Birmingham.

Chau, R. & Yu S. (2009) 'Culturally sensitive approaches to health and social care: Uniformity and diversity in the Chinese community in the UK', *International Social Work* 52 (6): 773-784

Chan, C., Cole, B. and Bowpitt, G (2007) 'Welfare State without Dependency: The Case of the UK Chinese People'. *Social Policy and Society,* 6(4): 503-514

Clark, H., Gough, H. & Macfarlane, A. (2004) *'It pays dividends': Direct Payments and Older People*. Bristol: The Policy Press.

Cross, T. L., B. J. Bazron, K.W. Dennis, and M. R. Isaacs. (1989) *Towards a Culturally Competent System of Care: A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed*. Washington, DC: CASSP Technical Assistance Center, Georgetown University Child Development Center.

Dobbs, J., H. Green and L. Zealey. (2006). *Focus on Ethnicity and Religion*: *National Statistics Office*. Basingstoke, Palgrave Macmillan.

Ferguson, I. (2007) Increasing user choice or privatizing risk? The antinomies of personalization. *The British Journal of Social Work*, 37(3): 387-403

Fook, J. (2002). Theorising from practice: towards an inclusive approach for social work research. *Qualitative Social Work*, 1(1): 79-95.

Garran A.M. & Werkmeister Rozas L (2013) Cultural competence revisited, *Journal of Ethnic And Cultural Diversity in Social Work*, 22(2): 97-111

Glasby, J. & Littlechild, R. (2009) *Direct Payments and Personal Budgets: Putting Personalisation into Practice.* Bristol, The Policy Press 2nd edition.

Great Britain. *Community Care (Direct Payments) Act 1996. Elizabeth II.* (1996) London, The Stationery Office.

Great Britain. *Care Act 2014*. *Elizabeth II. Part 1 (2014)* London, The Stationery Office.

Hatton, C. and Waters, J. (2011) *The National Personal Budget Survey*. Lancaster, Lancaster University and in Control.

Hatton, C. and Waters, J. (2013) *The [illegible]nd POET Survey of Personal Budget Holder and Carers 2013*. Lancaster, Lancaster Unive[illegible]y and in Control.

Healthcare Commission (2009) *Report on self-reported experience of patients from black and minority ethnic groups.* London: Department of Health

HM Government. (2007). *Putting People First*. London: HM Government.

HM Government (2012) *Caring for our Future: reforming care and support*. London: HMSO.

Hu X. and Palmer S.B. (2012) Self-Determination within the Chinese Culture: Examining Cultural Values. *Review of Disability Studies: An International Journal*, 8(1): 22-33.

Hunter, S. and Ritchie, P. (2007) With, not to: models of co-production in social welfare; in Hunter S and Ritchie P (Eds)*Co-production and Personalisation in Social Care.* Research Highlights in Social work. London, Jessica Kingsley Publishers.

IFF Research (2008) *Employment Aspects and Workforce Implications of Direct Payments*. London, IFF Research. Available at http://panet.org.uk/wp-

content/uploads/2011/08/Employment-Aspects-of-Direct-PaymentsReport.pdf Accessed 14/4/16

Joyner S (2012) Co-production in social care. In Loeffler E, Taylor-Gooby D, Bovaird T, Hine-Hughes F & Wilkes L (eds) *Making Health and Social Care Personal and Local: Moving from Mass Production to Co-Production.* Birmingham, Governance International.

Katbamna, S. Ahmed, W. Bhakta, P, Baker, R. & Parker, G. (2004) 'Do they look after their own? Informal support for South Asian carers' *Health and Social Care in the Community* 12(5): 398-406

Kühner, A. & Langer, P. (2010), "Dealing with dilemmas of difference- ethical and psychological considerations of "othering" and "peer dialogues" in the research encounter", *Migration Letters*, 7(1): 69-78

Larkin M (2015) Developing the knowledge base about carers and personalisation: contributions made by an exploration of carers' perspectives on personal budgets and the carer–service user relationship *Health and Social Care in the Community* 23(1): 33-41

Leece, J., & Bornat, J. (2006). *Developments in Direct Payments*. Bristol, UK: Policy Press

Lewis, S. (2005) *Direct Payments: Answering Frequently Asked Questions*. Bristol, Social Care Institute for Excellence.

Li, S., Hatzidimitriadou, E., & Psoinos, M. (2014). "Tangled wires in the head": Older migrant Chinese's perception of mental illness in Britain. *Journal of Aging Studies*, 30: 73-86.

Lincoln, YS. & Guba, EG. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications.

Lymbery M (2013) Understanding personalisation: Implications for social work. *Journal of Social Work.* [online] available at http://jsw.sagepub.com/content/early/2013/03/01/1468017313477326. (Accessed 10/7/13)

Maclean L., Mechthild M. & Estable A. (2004) Improving accuracy of transcripts in qualitative research. *Qualitative Health Research* 14(1): 113–123.

Manthorpe, J., Stevens, M., Rapaport, J., Harris, J., Jacobs, S., Challis, D., Netten, A., Knapp, M., Wilberforce, M. and Glendinning, C., 2009. Safeguarding and system change: Early perceptions of the implications for adult protection services of the English individual budgets pilots—A qualitative study. *British Journal of Social Work*, *39*(8):1465-1480.

Manthorpe J, Moriarty J, Stevens M, Sharif N and Hussein S (2010) *Supporting Black and Minority Ethnic Older People's Mental Wellbeing: Accounts of Social Care Practice*. London, Social Care Institute for Excellence.

Manthorpe J, Moriarty J, Stevens M, and Hussein S (2012) Promoting the mental well-being of older people from black and minority ethnic communities in United Kingdom rural areas: Findings from an interview study. *Journal of Rural Studies*. 28 (4): 406–411

Merriam S.B., Johnson-Bailey J. , Lee M-Y. , Kee Y. , Ntseane G. & Muhamad M. (2010) Power and positionality: negotiating insider/outsider status within and across cultures, International *Journal of Lifelong Education*, 20(5): 405-416

Moriarty J (2008) *The Health and Social Care Experiences of Black and Minority Ethnic Older People*. London, Race Equality Foundation.

Moriarty, J. (2014) *Personalisation for people from black and minority ethnic groups. A Race Equality Foundation Briefing Paper.* London, Race Equality Foundation [online] available, http://cdn.basw.co.uk/upload/basw_111150-6.pdf (Accessed 16/08/14).

Needham C. (2011) Personalization: From Story-line to Practice. *Social Policy & Administration*. 45(1): 54–68.

Needham C. & Carr S. (2009) *Co production: an emerging evidence base for adult social care transformation*. London: Social Care Institute for Excellence.

Newbronner L, Chamberlain R, Bosanquet K, Bartlett C, Sass B, Glendinning C (2011) *Keeping personal budgets personal: learning from the experiences of older people, people with mental health problems and their carers*. London, Social Care Institute for Excellence.

Netten A, Callaghan L, Fox D and Jones K (2009) *Personalisation of Services – A Scoping Study.* PSSRU, University of Kent.

Office for National Statistics (2012) *Ethnicity and National Identity in England and Wales 2011.* ONS, London.

Psoinos, M. (2015). Researching migrants who hold nomadic identities: analysing multi-level dynamic discourses of power. *Equality, Diversity and Inclusion: An International Journal*, 34(4): 293-307.

Richards, H. and Emslie, C. (2000), "The 'doctor' or the 'girl from the University'? Considering the influence of professional roles on qualitative interviewing", *Family Practice*, 17(1): 71-75.

Rose, N. (1999). *Powers of freedom: Reframing political thought.* Cambridge, Cambridge University Press.

Sandelowski M., Trimble F., Woodard E. K. Barroso J (2006). From synthesis to script:. Transforming qualitative research findings for use in practice. *Qualitative Health Research*, 16 (10): 1350-1370

Slay J (2012a) Co-production and personalisation: two sides of the same coin or worlds apart? In Loeffler E, Taylor-Gooby D, Bovaird T, Hine-Hughes F & Wilkes L (eds) *Making Health and Social Care Personal and Local: Moving from Mass Production to Co-Production.* Birmingham, Governance International.

Slay (2012b) *Budgets and Beyond*. London, New Economics Foundation. Available at http://b.3cdn.net/nefoundation/dbde656b79d717b71e_ium6bnnew.pdf Accessed 14/4/16

Spandler, H. & Vick, N. (2005) Enabling access to direct payments: an exploration of care co-ordinators decision-making practices. *Journal of Mental Health*, 14 (2): 145-155.

Stainton, T & Boyce, S. (2004). 'I have got my life back': users' experience of direct payments.' *Disability and Society*, 19 (5): 443-454.

Stevens M. , Glendinning C., Jacobs S., Moran N., Challis D., Manthorpe J., Fernandez J-L., Jones K., Knapp M., Netten A. & Wilberforce M.(2011) Assessing the Role of Increasing Choice in English Social Care Services. *Journal of Social Policy*, 40(2): 257–274

The Commission for Social Care Inspection (2008) *Putting People First: Equality and Diversity Matters 2*. London: CSCI

Think Local Act Personal (TLAP) (2011) *Think Local Act Personal: A sector-wide commitment to moving forward with personalisation and community-based support.* London, TLAP. Available at http://www.thinklocalactpersonal.org.uk/_library/resources/personalisation/tlap/think_local_act_personal_5_4_11.pdf (Accessed 14/4/16)

Think Local Act Personal (TLAP) (2014) *Personalisation Action Plan: Key activity underway in advance of the Care Bill* London: TLAP. Available at http://www.thinklocalactpersonal.org.uk/_library/PersonalisationActionPlanFINAL.pdf (Accessed 14/4/16)

Tseng W. S. and Streltzer, J. (2004) Introduction: culture and psychiatry. In W.S. Tseng and J. Streltzer (eds), Cultural competence in clinical psychiatry (pp1-20). Washington, DC: American Psychiatric Publishing.

United Nations (2013) Press Release: Self-Determination Integral to Basic Human Rights, Fundamental Freedoms, Third Committee Told as It Concludes General Discussion. Available, http://www.un.org/press/en/2013/gashc4085.doc.htm (Accessed 08/02/16)

Van Manen (2007) Phenomenology of Practice. *Phenomenology & Practice*, 1(1): 11 – 30.

Voice 4 Change (2012) *Personalisation, the BME voluntary and community sector and social entrepreneurship* London: Voice 4 Change/School for Social Entrepreneurs

Waller J, Robb K, Stubbings S, Ramirez A, Macleod U, Austoker J, Hiom S and Wardle J.(2009) Awareness of cancer symptoms and anticipated help seeking among ethnic minority groups in England. *British Journal of Cancer* 101:S24-30.

Waters, J. & Hatton, C. (2014) Third National Personal Budget Survey. Experiences of personal budget holders and carers across adult social care and health. London: Think Local, Act Personal.

Wehmeyer, M.L. (2005) Self-determination and individuals with severe disabilities: Re-examining meanings and misinterpretations. *Research and Practice for Persons with Severe Disabilities* 30: 113–20.

Zhan, H.J. (2006). Joy and sorrow: Explaining Chinese caregivers' reward and stress. *Journal of Aging Studies*, 20(1): 27-38.

Table 1. Interview Participants

Name (pseudonym)	Age/Gender	Language used in interview	Other language spoken	Place of birth	Disability profile	Length of residence in the UK	Educational level
Mrs Wong	69/F	Cantonese	Hakka	Hong Kong	Movement impairment	40 years +	primary
Mr Tse	68/M	Cantonese	-	Hong Kong	Movement impairment	40 +	primary
Mr Lau	50/M	Cantonese	-	Hong Kong	Visual impairment	30+	secondary
Hannah	34/F	Cantonese	English	Hong Kong	Movement impairment	25+	undergraduate
Mei Ling	68/F	Cantonese	English	Malaysia	Movement impairment	40+	undergraduate
Mrs Lin	60/F	Cantonese	-	Hong Kong	Movement impairment	30+	secondary
Ann	50/F	Cantonese	English	Singapore	Movement impairment	25+	postgraduate
Peter	19/M	English	-	Mainland China	Movement impairment	15+	secondary
Mr Chan	64/M	Cantonese	-	Hong Kong	Movement impairment	35+	primary
Angela	51/F	English	-	Malaysia	Movement impairment	30+	postgraduate
Mrs Ho	64/F	Cantonese	English	Hong Kong	Movement impairment	40+	secondary
Ka-Lai	64/F	Cantonese	English	Malaysia	Movement impairment	40+	secondary
Mrs Smith	61/F	Cantonese	English	Hong Kong	Movement impairment	35+	secondary
Mr Fok	62/M	Cantonese	-	Hong Kong	Movement impairment	40+	primary
Mr Ko	65/M	English	-	Malaysia	Visual impairment	40+	postgraduate
Cecilia	35/F	English	-	UK	Movement impairment	Since birth	secondary
Betty	53/F	English	-	South Africa	Movement impairment	30+	undergraduate
Ah Fong	53/F	Cantonese	Hakka	Mainland China	Movement impairment	40+	primary
Mrs Lam	64/F	Cantonese	-	Hong Kong	Movement impairment	40+	secondary
Mr Yang	40/M	Mandarin	-	Mainland China	Movement impairment	5 years	secondary
Mrs Lee	60/F	Cantonese	English	Hong Kong	Movement impairment	35+	primary
Margaret	45/F	English	-	Malaysia	Visual impairment and movement impairment	20+	undergraduate
Alan	68/M	English	-	Malaysia	Movement impairment	40+	undergraduate
Mark	28/M	English	-	UK	Visual impairment and movement impairment	since birth	secondary
Linda	56/F	Cantonese	English	Hong Kong	Movement impairment	30+	postgraduate
David	50/M	Mandarin	-	Mainland China	Visual impairment	15+	secondary