

Disadvantage and disability: Experiences of people from refugee backgrounds with disability living in Australia

Julie King^{a*}, Niki Edwards^b, Ignacio Correa-Velez^c, Sara Hair^d, Maureen Fordyce^e

^{a,b,c,d} *Queensland University of Technology*; ^e *AMPARO Advocacy Inc. Corresponding Author-Email: j.macknight-king@qut.edu.au*

This study of people of refugee backgrounds explored how disability is culturally constructed in the family context, including barriers and enablers to social inclusion and service uptake in Brisbane, Australia. Key themes included the lived experiences of people with disability in their country of origin; experiences of the functioning of government and non-government services; family; barriers in communication and language; transport as a barrier to access; the community of people from their country within Australia; and service gaps and needs. Participants had experienced stigma in their country of origin, and for some this continued within their community of origin. Language and lack of engagement by government and non-government services contributed to service gaps and access barriers. Family remained important. People from refugee backgrounds living in Australia experience significant and compounding barriers to service access, and have unmet needs. They have a limited voice in the current policy context, and lack knowledge and support to facilitate interactions with the current system. Further research would assist in development of a more detailed understanding of these issues.

Keywords: refugees; disability; access; inclusion; barriers; family

Introduction

Over the past 10 years 138,628 people have entered Australia via the country's refugee and humanitarian program (Department of Immigration and Border Protection, 2013). Their countries of origin vary from year to year; in 2014 20% were from Iraq, 16% from Afghanistan, 15% from Syria, 11% from Myanmar and 6% from Iran, with smaller numbers from Thailand, Pakistan, Eritrea, Nepal, DR Congo and others (.id, 2015). A year earlier, Afghanistan predominated, followed by Myanmar and Iraq (Parliamentary Library, 2015), and it is expected that Syrian refugees will predominate in the current period. This pattern mostly reflects a mix of fleeing from conflict (as in Syria, Afghanistan and Iraq) and state repression of ethnic or religious groups (as in Myanmar and Iran), although there are smaller numbers in other categories as well (e.g. journalists or political activists at risk of imprisonment). A total of 10,214 refugees settled in the State of Queensland between 2010

and 2014 (Department of Social Services, 2014).

An unknown proportion of humanitarian entrants arrives with, or develops, a disability¹ after arrival. Many people from refugee backgrounds have lived in extreme poverty, been subjected to human rights violations including torture, and experienced other hardships that contribute to an increased probability of disability. It is estimated that seven to ten percent of the world's 10.5 million refugees have some form of disability (Mirza, 2012), so the proportion of Australian refugees with disability is potentially significant, as it is among refugees in other countries of resettlement (Huang et al., 2011).

People from refugee backgrounds with disability are protected by The Convention Relating to the Status of Refugees, and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (Crock et al., 2011). Australia has ratified both Conventions. However, Australia's Migration Act 1958 (Migration Act) is exempt from the Disability Discrimination Act (DDA), and consequently applicants with disabilities are likely to be denied entry into Australia when the Health Criteria are used to assess their disability as imposing a heavy burden on the Australian community. When Australia ratified the UNCRPD on 17 July 2008, an interpretative clause was applied to Article 18 whereby the Convention does not 'impact on Australia's health requirement for non-nationals seeking to enter or remain in Australia, where these requirements are based on legitimate, objective and reasonable criteria' (para 3, United Nations Treaty Collection). Despite a number of changes following a Parliamentary Joint Standing Committee Inquiry into the Migration Treatment of Disability 2010, Australia still falls short of meeting its obligations under the UNCRPD (Stratigos, 2013).

In spite of this deliberate exclusion by the Australian Government, there are refugees with disability in Australia, including those who arrived with a disability. There is no specific information on the causes of disability, but at a general level disability in refugees could be associated with residual physical injuries consequent to torture and trauma such as epilepsy (Harris and Zwar, 2005); visual impairments and brain injury (Bradley and Tawfiq, 2006); difficulties with mobility and walking (Foundation House, 2012); and chronic pain (Prip et al., 2011). In addition, these hardships may contribute to mental health problems that may be expressed as somatic symptoms associated with disability (Rohlof et al., 2014).

There has been little crossover in terms of theory or empirical inquiry in the refugee and disability fields (Albrecht et al., 2009; Soldatic et al., 2015). A comprehensive literature review conducted by the authors found that most disability literature relevant to people from refugee backgrounds focused on mental health. Whilst mental health problems can lead to psychosocial disability, there is scant consideration in the literature of other disability types, including physical, sensory, and intellectual disability. What research has been published suggests that people from refugee backgrounds with disability are likely to simultaneously

encounter the dual disadvantages associated with being both a refugee (Colic-Peisker, 2009; Taylor, 2004) and a person with a disability (Bogenschutz, 2014; Mirza et al., 2014).

Barriers include stigma associated with race, nation or religion (Ferdinand et al., 2015), as well as their disability and refugee status. In some cases, individuals and families have experienced stigma in their home country, and this may still impact on their sense of self and acceptance in their new society. In a study of Iranian immigrants in Belgium, Albrecht et al. (2009) identified a range of factors that contribute to and maintain marginalisation. These include historical context, isolation, religion, rejection, difficulties in finding employment, and vulnerability. No similar study has been published in Australia, although there has been research regarding refugee experiences in health care. One study explored barriers to health care for newly arrived Sub-Saharan African refugees (Sheikh-Mohammed et al., 2006), and another examined health services knowledge, use and satisfaction among Afghan, Iranian and Iraqi settlers (Neale et al., 2007). This gap in Australian and international research has practical implications, suggesting that policy makers and service providers have little information about the needs of people from refugee backgrounds with disability and this has consequences for framing of service provision, and renegotiation of expectations after arrival. This dearth of information may lead to the needs of refugees with disability being overlooked entirely (Bogenschutz, 2014), potentially leading to further social exclusion and disadvantage.

It is argued that this gap in knowledge can be addressed by a gaining a more in-depth understanding of the personal experiences of refugees with disabilities and their family and carers, including barriers and enablers to inclusion in society and service uptake. Given the low visibility of the experiences of this group, research that gives voice to these experiences is long overdue (Soldatic et al., 2015).

This paper reports on a small study undertaken as a first step in building knowledge regarding the lived experience of the nexus between refugee background and disability. Through in-depth interviews this study aimed to explore how disability was socially and culturally constructed in the participants' country of origin, their experiences of service provision after arrival in Australia, the major barriers in accessing services, and gaps in service provision. After describing the method and sample, the findings are grouped under the following emergent themes: the lived experiences of people with disability in their country of origin; how government and non-government services functioned on arrival; family; barriers in communication and language; transport as a barrier to access; community of origin in Australia; and service gaps and needs.

Methodology

The research approach drew on ethnographic techniques to elicit the lived experiences of

participants, as their social and cultural constructions of disability may not align with Western understandings (Albrecht et al., 2009). The manner in which disability is ‘lived’ can be influenced by society and culture and impact on the person’s sense of identity, health-seeking behaviour, and the reaction to the person with disability by their family and community (King and King, 2011; King et al., 2014). Additionally, it is critical to understand the situation and circumstances from which people have fled; a history of torture or trauma, disadvantage, war and conflict may influence an individual’s outlook on life. For example, their formulation of, and feelings about, being interviewed could be coloured by their concern about whether it is safe to be critical of government services, or whether an added sense of security in Australia inclines them to accept what they receive, whether or not it meets their needs.

Data collection was conducted in 2014 in collaboration with an advocacy non-government organisation (NGO) located in Brisbane, Australia. The NGO advocates for and promotes the rights and interests of people from non-English speaking backgrounds with disability. Ethical clearance was obtained from the Queensland University of Technology (QUT) Human Research Ethics Committee.

In-depth interviews were conducted with 10 participants of refugee background who had a disability or who were family members and primary carers of a person of refugee background with a disability. In all cases the interviewer was introduced by a representative of the NGO whom the participants knew well. Each participant was over the age of 18 years and able to give informed consent. This method was used to gain a thick in-depth description of the lived experiences of participants and the meaning associated with their understanding of being a refugee, living with disability and accessing services (Seidman, 2013). Participants were recruited through the advocacy NGO. The primary researcher, who has extensive cross-cultural experience, conducted all interviews, which lasted between 60 and 140 minutes. Interpreters were utilized in four interviews to ensure clarity of communication between the interviewer and participant.

The interview protocol was informed by a comprehensive literature review and consultation with the advocacy NGO. Participants were asked questions exploring their personal stories of their journey to Australia; constructions of disability in their country of origin; the impact of disability on them and their families; support received from their community of origin and mainstream community in Australia; knowledge of government entitlements and services in Australia and their experiences with these; and areas where additional resources are needed. Interviews were audio-recorded with participants’ consent. Verbatim transcription was conducted by another research team member, with spot-checks undertaken by the interviewer. An iterative process allowed emerging themes to be discussed and fed back into the research. The primary researcher read the transcripts and consulted field notes taken during interviews, documenting emerging themes and insights. The transcriber and another team member then reviewed the transcripts for emerging themes. A process of open coding followed. Completed

transcripts were re-examined line by line, codes generated, and themes established. To add additional rigour, interview transcripts were thematically analysed independently by three team members. Themes that emerged were shared with the advocacy NGO in a de-identified format and cross-checked for accuracy.

Participants

Four interview participants were from a refugee background with disability and six were family members who were primary carers of people from refugee backgrounds with disability. Four family member participants were mothers of a person with disability, one was a sister, and one a brother. Participants nominated their countries of origin; however, these have been replaced with a region of origin to ensure confidentiality. Details are presented in Table 1.

Table 1. Participant Details and Region of Origin.

Region of origin	Number of interviews	Sex of those interviewed	Sex of person with disability	Person interviewed
Sub-Saharan Africa	4	4 female	3 male, 1 female	4 family carers
Southeast Asia	1	1 male	1 male	Person with disability
Middle East	4	2 male, 2 female	3 male, 1 female	2 persons with disability and 2 family carers
South Asia	1	1 male	1 male	Person with disability

Three participants self-identified as Christian, one as Buddhist, and three spoke of a god of an unspecified religion. The individuals with disability were aged 12 to 35 years. Most participants reported holding a Refugee Visa Subclass 200² (referred to by participants as the ‘two hundred’), others had come to Australia as asylum seekers and were granted Protection Visas. The participants had been living in Australia for three to twelve years. Some participants elected to have a family member sit in on the interview with them to give them more confidence.

Participants identified a range of diagnosed impairments they described as a disability, including: muscular dystrophy, severe hearing impairment, epilepsy, autism spectrum

disorder, acquired brain injury, chronic pain, mobility impairment, intellectual disability, visual impairment, and partial paralysis. One participant stated that their family member had not received a definitive diagnosis; he had been ‘diagnosed’ with epilepsy, severe autism and a war-related condition; while other participants did not specify the nature of the impairment associated with their disability.

Findings

The interviews commenced with the question: ‘*Can you tell me your story?*’ This allowed participants to discuss their lived experiences and provided a contextual background. Many provided a sequential timeline of their journey to Australia, while others provided comparisons between their country of origin and Australia. Common themes became evident within the interviews: the lived experiences of people with disability in their country of origin, their experiences of how government and non-government services functioned on arrival, family, barriers in communication and language, transport as a barrier to access, the community of people from their country of origin now living in Australia, and service gaps and needs.

The lived experiences of people with disability in their country of origin

Participants spoke about their own experiences of being a person with disability, or a family member of a person with disability, in their country of origin. Most accounts relayed a picture of stigma, discrimination, social exclusion, poor accessibility, and lack of opportunity. It is important to explore such contextual information as constructions of disability differ across cultures and can impact how disability is experienced and responded to within communities (King and King, 2011).

The language used to describe participants’ experiences in their country of origin was consistently negative. Participants from Southeast and South Asia recounted that disability occurs as a result of ‘*karma*’ (punishment for bad deeds in a previous life) for the person with disability or his/her family members; therefore they are treated poorly and stigmatised in the same manner identified by King and King (2011) in Northeast Thailand among people with disability associated with spinal cord injury:

Child’s, also the parent’s karma too. And sometimes my mother also weeps because I was also, some people also scolded in the village that you are cursed, you are idiot. Just like that, because of them, because of your sin your son is like that (Male, person with disability)

The same participants explained that because of this perception, people with disability often

feel guilt and shame. They were unable to advocate for themselves in their country of origin because of the label '*sinner*'.

Two participants from Sub-Saharan Africa stated that their communities viewed disability as the result of witchcraft or a multi-generational curse. Persons with a disability and their families would be treated with contempt and stigmatised. A number of participants said that due to this stigma, a child with disability might be hidden in the house or basement, or confined in a bedroom:

You can sit inside the house. This is your life, go read. Sit always inside the house. They say like that, and that is not a good way when you are confined within the four walls. No a good ways, yes. (Male, person with disability)

For one of the family members interviewed, feelings of shame meant they would deny the existence of their sibling. They stated that hiding persons with disability was the '*norm*' in the Middle-East:

...because the majority of people with disability, they are not able to contribute to their community, they see them as a burden. As someone who is useless, very big stigma...You have to be healthy, you have a disability you are not accepted. Not at all. (Male, person with disability)

Two participants (family carers) from the Sub-Saharan African region reported that while living in refugee camps, their children were encouraged to perform dances for others, resulting in heckling, jeering, and name calling. The children with disability and their parents were hurt by this; one child would cry and another would appear 'emotionally injured'. The participants felt they could do little about the paid dancing despite the emotional distress associated, because of their dire financial situation:

Okay, so it came to a time where I got to this place where I'm in the refugee camp and I'm very confused, because people would tell...(child) to dance so they can give money...then my chi...(child) has to dance to bring the money home, and then I will eat, and then people call...(child) the dancer, and all of that, funny names, but it injure them, you know, but...(child) will do those dances just because I had nothing, and I didn't want to go and sleep with other people on the street and make myself, to prostitute myself, so I didn't do that at all. (Female, carer of person with disability)

Bogdan (1990) has documented the parading of 'disabled' bodies for entertainment in the US before 1940 (while providing later US examples), and cites an activist as labelling it 'the pornography of disability'. Gerber (1992) and Shildrick (2001) have further explored the ways that such exhibiting of disabled bodies for either entertainment or to disgust, contributes to othering and cements a lesser status. The decline of such shows in the West is attributed by

Gerber (1992) to growing moral revulsion to their exploitative and oppressive nature. Service providers in Australia may therefore not anticipate that refugees with disability may have had experiences like this, nor understand the implications for their feelings about being seen in public and interacting with people.

For some, discrimination in their countries of origin resulted in limited opportunities to study, socialise and gain meaningful employment. After finishing year 12 of high-school, one participant was faced with the reality of the situation for people with disability within his Middle Eastern country:

Going to university, no support, nothing. And you live basically, um...day by day, you know. So you cannot, you cannot, like have a goal as, eh...as a citizen. Uhm...Yeah, ah...it's eh...it was so hard than difficult. No job, no future basically, finishing and somehow I was able to commence employment as a telephone operator. (Male, person with disability)

The accounts of the participants about their own countries show that their experiences are shaped by particular elements of their country's culture and by specific events.

How government and non-government services functioned on arrival

Government services

Interactions with Centrelink (the Australian social security agency run by the Australian Government Department of Human Services) and other government organisations tended to frame these services as impersonal and bureaucratic. Participants identified a number of issues with Centrelink: family members being told that they are carers when they wanted to work part-time; not being referred to specialist agencies; requiring a person with disability to engage in either 'earning or learning'; and not allowing participants to seek employment as quickly as they desired after settlement. For some participants, an explanation of the relevant government forms or processes was not provided:

Interviewer: Ok, and did they explain what the forms were, or help you filling them in, or give you any idea about what entitlements you could get from the government?

Interpreter: No, she said no, she just, she was told that in the form, the GP need to fill it, she have to send it by the due date (Female, carer of person with disability)

Implicit in this participant's interaction with Centrelink is the assumption that this person possessed the skills to read the relevant form or explanatory materials and write the appropriate responses. For some participants this was not the case.

The lack of communication between government services and participants was pronounced within the responses. One man waited three to four weeks for a call-back from a government organisation regarding an inappropriate residential care placement for his brother. During this time his brother was moved to another residential facility without the family being formally notified.

One participant felt that the Australian Government had been very supportive and ‘they provided all the support that they could’. This participant’s view may have been influenced by their unique set of circumstances that resulted in the Australian Government having a pivotal role in their resettlement. Reluctance to speak ill of the Australian government may also stem from traumatic experiences in the participants’ country of origin. One participant said of people from refugee backgrounds:

They lack someone comes in with the advice, because they very suspicious of the others, they have all these fear, negative fear-things, especially like government. They don’t want to see anyone from the government, they don’t want to see anything, and anything the government say...(Female, person with disability)

For some participants, the services received were better than they experienced in their country of origin, and this comparison led to lowered expectations:

We would accept things because my mum would say we don’t want to have any trouble with them. And look where he is now. Where he was they used to tie him to the window so they don’t give him any food, you know. And they torture him, they used to hit him on the head. And his teeth were like all broken. And he was tortured for years, they were giving him drugs and all these kinds of things. And look at him now, he has a room, so it is OK if they give him an extra tablet and this and this. So we accept things because we think, compared to where he was, wow. (Female, carer of person with disability)

This active physical and emotional abuse of a particular person can be contrasted with what Grech (2015: 206) calls the institutionalised ‘politics of indifference’ in Guatemala, also documented in King and King’s (2011) findings in Thailand, that emanate from central government and is reproduced down to local government level. The participants’ perceptions of government services as simultaneously better than expected and yet indifferent and bureaucratic, suggests similar patterns in their home countries.

On the other hand, some participants, while thankful for the services provided by the Australian Government, stated that more support was needed. One family member noted how the need for additional support was becoming more pronounced as her mother aged and she was no longer able to provide the care required by her son who lived with a disability. This

participant found ongoing changes in government services, funding, and the broader service system was stressful for the family and difficult to understand and follow.

Non-Government Organisations (NGOs)

All participants spoke positively about having an NGO advocacy agency help them navigate the complex Australian social services system and communicate with other government and NGO services. The advocacy agency made connections between the participants and needed services in a timely manner, would attend appointments, advocate and negotiate for their clients with third parties, and intervene in crisis situations to address issues of disadvantage:

...because like when DSQ [a State Government agency] comes in and say no to me I would hang up the phone and just go do nothing and my mum go cry, but with the advocacy service, no, because they were more specialised in this thing, and they would go and search and say no, we have contacted certain people and instead of giving us a no, why don't we go to do this and this and this (Male, carer of person with disability)

One participant had a particularly poor experience with an NGO provider. The service provider had reportedly ignored his concerns about staffing, his brother's shift to supported accommodation further away from his family, a lack of stimulation for his brother, and the organisation's application to the Queensland Civil and Administrative Tribunal for guardianship in relation to physical and chemical restraint. These issues were compounded by the reluctance of government officials to provide relevant advice and information about the legislative framework surrounding restrictive practices:

And you know, what is our situation if we said no, and do we have someone to explain it to us? And the lady on the phone was very unhelpful and she just said, oh, so what do you want me to do? Every time I say to her, ask a question she said so what do you want me to do to you? (Male, carer of person with disability)

This participant associated his association with the NGO service provider with an abusive relationship:

...they treated us so badly. I don't know because we were a bit ignorant on how the system works and they could get away with many, many things and they just wanted to do just anything they want...I think they treated us very badly. And because, we went away with it, it's like an abuse relationship. (Male, carer of person with disability)

A number of other NGOs were viewed positively by participants. The NGOs had arranged referrals for dental care, brain injury specialists, housing, hearing check-ups and interpreters for appointments. However, participants expressed a need for this type of assistance to be more readily available and more widely advertised. In many cases, it did not 'just happen', it took persistence. Compared with government agencies, where at least some participants expected indifference, NGOs were expected to be more responsive, and in many cases were.

Family

The majority of family members who participated in the research, reported feeling the stress of providing care for the person with disability. The participants spoke about negotiating with the systems around them, while attempting to ensure that their family members had a reasonable quality of life. The sister of a person with disability identified that having a family member with disability made everyone else in the family 'sick' as well, because all the care and attention had to be focused on that person.

One participant described how his brother was formally appointed an adult guardian and how he felt that the family was never consulted. He spoke about how stressful it was to understand the legislative framework associated with guardianship and having to explain this to his mother. Unhelpful explanations about guardianship resulted in him describing the process as 'going around in circles'. A lack of formal disability support services and the subsequent need to provide high levels of care to their family member was seen to have an impact on the entire family and made the settlement process more difficult:

Sometime I really look at the people who have a normal life, I really jealous of them. I see, their normal life is very sweeter than this, and maybe something is quieter than this. No more attention, everyone on the right track, they go school and come back, go work and come back, no pressure, no more thing, no more yelling. (Female, carer of person with disability)

This stress was magnified when service providers showed little or no understanding of the circumstances surrounding the families' situations in supporting their family member with a disability while trying to negotiate a foreign system:

When he leave home and never come back police at the hospital one day, I remember...they call from the hospital and the doctor was very rude, extremely rude, he just, he accusing me, how, what did you do to this boy, something, it was very, like, it broke my heart. How can he just accuse me like that? (Female, carer of person with disability)

For others, stress was associated with supporting a family member with disability within a new cultural framework:

I am worried because you know teenagers, is really hard. When I go to the school, she can go and do something bad outside, that is why I am worried...I want my daughter to stay at home, they tell me because she is 16 she is responsible for herself. But it is too hard for me because our kids are not like Australian people. (Female, carer of person with disability)

This statement implies that the Australian expectation that a 16 year old girl is responsible for herself is inconsistent with expectations in the country of origin in Sub Saharan Africa. While the statement could also be interpreted as an expression of resistance to assimilation, the participant's manner and expression conveyed a different sense, of being helpless and resigned to the conflict she was experiencing. For this mother, the security of her daughter was of utmost importance after losing another child in Australia in an accident.

In all cases where family were interviewed, a high level of distress was observed. For many the settlement process had become more difficult as they tried to negotiate a foreign social service system, while trying to adapt themselves to a new country and culture. Although most were happy with the settlement services, they clearly identified a lack of knowledge of these services in how to respond to the needs of people with disability; typically resulting in referral to other government organisations and NGOs, further complicating matters for families.

Barriers in communication and language

All participants identified language and communication as a major barrier to inclusion. A range of feelings (frustration, anger, powerlessness and despair) were expressed about trying to access services without English language skills and where interpreters were generally said to be unavailable. Some participants highlighted the frustration experienced:

Yeah, yeah. But even, as my mum doesn't have the English skill to speak, it was extremely hard. So many times she just crying, she was very upset. (Female, carer of person with disability)

To some extent, this experience overlaps with the sense of indifference conveyed by government agencies in particular, mentioned earlier. While it is arguable that maintaining a responsive translation service that covers all possible languages is impractical, participants who spoke fluent English also experienced poor communication about the services and their rights and options. Noting that there is a difference between speaking and communicating, a

participant spoke about his feelings when experiencing poor communication, saying that it was:

...really dark, and you don't know where you are going, and you don't know what to expect and what's happening (Male, carer of person with disability)

As well as understanding what is being communicated to them, participants needed to communicate their questions and needs to service providers. Some spoke about lack of speaking confidence as an issue, but others demonstrated persistence in being understood:

And every time they come in and, what poor English language, we just try to just tell them what we have problem in here. It was very extremely hard. Very very hard for us. Slowly, slowly they just, they understand. (Female, carer of person with disability)

Refugees from the same country may differ in their knowledge and background, such that their information needs can vary significantly. One participant was a well-established man from a high socio-economic background in his country of origin in the Middle East. He had been told by settlement services not to drink water from the toilet, which he regarded as an affront, given his background and education. Another participant was shown how to use the kitchen stove, bathroom and toilet, with signs that provided explanation in writing. She was, however illiterate and these signs were inappropriate as communication tools.

From social welfare and human rights perspectives, effective exchange of information is most important where it relates to the suffering and treatment of refugees with disability; however the interviews revealed examples of a failure to communicate in this area. In the case of a young man subjected to chemical restraint, little or no investigation was made regarding his mental health and history. His brother reported he had been subjected to torture, deprivation of liberty, and other abuses. This remained unknown and untreated because staff in his supported accommodation made few attempts to talk to him.

Transport as a barrier to access

Individuals who cannot access transportation are more likely to be excluded from services, as is the case for many people from refugee backgrounds (Bedford et al., 2009) and those with disability (Allen and Currie, 2007). Transportation and understanding the transportation system were identified as a barrier for participants. Comparisons were drawn between the country of origin and Australia concerning accessibility:

Yeah, because if too difficult for me, I don't know how to catch the train, how to catch the bus because in Australia here, different like [Sub-Saharan Africa]. [Sub-Saharan

Africa], yes we have bus in area to, but our kids they go to the school just walking, no bus, no car, just there, because the school is near the area (Female, carer of person with disability)

Another participant explained:

I live in [South Asia] and to go to the city is 20km from my village, and people have to carry me to the bus so that the bus doesn't disturb so many people. And all the steps, dust and they carry the wheelchair...(Male, person with disability)

Participants reported difficulties in Australia in getting children to school, visiting their family member with disability, arriving on time to medical facilities, going to respite and service centres, and getting to appointments in a timely and cost-effective manner:

...transport is quite expensive, and very hard to get. Yeah, we have to just walk until they get there, bus stop to find the bus and come back, it get three to four hours and my mum get back home...(Female, carer of person with disability)

Understanding how the transportation system worked was identified as a barrier for half of the participants. For some it became a matter of needing to sit down and study transportation routes, and for others it was a gradual process of learning by trial and error. One participant identified that his first six months living in Australia were marked by an inability to travel:

I know, but, so it took a long time to understand all the transportation. All the Translink [public transport agency services] that come. Yeah, and for the first six months, for the six months I couldn't travel here. (Male, person with disability)

Community of origin in Australia

For refugees settling in a new country, constructing social bonds with members of like-ethnic groups facilitates the sharing of cultural practices and customs, allowing for the sharing of information and reduced isolation. This can play a role in refugees feeling as though they have 'settled' (Ager and Strang, 2008: 178). Families from a refugee background with a member with disability often experience isolation (King et al., 2013: 191). A number of participants were adamant that they received very little social or emotional support from their country of origin community in Australia:

Interviewer: So have the [Middle Eastern country] community been supportive?
Participant: Never. Never. (Male, person with disability)

Participants who belonged to communities they experienced as unsupportive, also tended to

report that these communities maintained the negative views of disability prevalent in their country of origin, albeit in a less overt manner. People with disability were still seen in many communities as objects of pity, or as burdens and shameful.

However, one disabled man from South Asia who was an active participant within his country of origin community, asserted that the perceptions of his community had changed after they had settled in Australia, suggesting that after 'abit of education' they came to realise that 'disability is not sin'. This man and another participant who felt their community in Australia was supportive, were actively involved in community activities such as cultural and political events, performing arts programs, and community groups.

For some, arguably the more isolated of the participants, there was no knowledge that the community of origin existed in Australia. For one woman this meant she did not have any friends. Another two participants, from the Middle East and South Asia respectively, did not know of any country of origin community in Australia. One participant did not want to associate with his community of origin in Australia because of the stigma he faced in his country of origin. Another man from the Middle East who had spoken English fluently before leaving his country of origin said that he and his mother had made a conscious effort to integrate into the broader Australian community and develop connections to people outside of their community of origin:

...We live in Brisbane and me and my Mum just decide to really adapt to new life, new culture. Everything is like, for us, so we kind of don't have that many friends in the [Middle Eastern country] community. (Male, carer of person with disability)

For other participants, formal services provided the role of community support. One participant spoke about how her community gave little emotional support; however, her family, she said, 'don't care, because we find in here some services they were very great' (Female, carer of person with disability). Reliance on formal services was cause for concern given their limited availability and the risk of unexpected withdrawal.

For a female participant who was a parent of a child with disability, the lack of support from her community following the loss of her husband posed a barrier to her further engagement:

I used to associate with the [Sub-Saharan African country] community, but after the passing of my husband and no one came here do you know, not even to say, you know, sympathise with me, you know. And it hurts a lot, you know, yeah, to know you are part of something, and you are in need of sympathy or comfort, and none of them came around. So I don't think that is the right community for me. (Female, carer of person with disability)

Service gaps and needs

Many participants highlighted difficulties in identifying services. Participants found information by talking to strangers, other members of the community of origin in Australia, persistence in self-advocacy, through the advocacy NGO, and via interpreters. For one family this became a matter of walking through the street asking ‘everyone in sight’:

So, we didn’t know how to find a lawyer or anyone to help us for my brother, so we, my Mum one day, she took a day off and she start walking from our house and just walking and asking everyone like who could help refugees. She just kept walking and walking. And from Stone’s Corner ended up in the city [about 6km]. And then they send her back to West End [about 2km] and she was all walking, knocking on doors. Every business every door, from hairdressers to restaurants...(Male, carer of person with disability)

For a man with a visual impairment, it was a matter of years before he was able to access the technologies that he needed ‘...because I didn’t have a case manager someone to guide me, I have to rely on people asking and asking and asking. All the time’. One man with a hearing impairment was only able to gain access to hearing aids because an interpreter referred him to an advocacy NGO. Another family member stated that her brother was sent to a ‘normal school’ for study, and it was a matter of persistence in trying to communicate that he needed specialist referrals and services as he had an intellectual disability.

Participants believed they needed a ‘liaison’, someone to refer them to services, provide career advice, help find housing, provide general guidance and support, communicate with them, listen to and value their stories, and assist in ‘adapting’ on a long term and sustained basis. One participant alluded to the fact that he had been acting in this role as an informal liaison:

I guide them, I say if you walk through that way that is what you are going to face, because I’ve been here, I’ve done this, I know how things are. (Male, carer of person with disability)

All participants found the assistance of the advocacy agency to be valuable and instrumental in negotiating the complicated human service landscape, helping reduce anxiety and exclusion. There may be bias inherent in this finding because all participants were recruited through this agency, but it is worth noting that these endorsements were unsolicited.

Discussion

The findings of this research present a picture of the lived experience of people with

disability of refugee background and their family members in Australia, including barriers to services and social inclusion. While the dual barriers reported in previous research (Bogenschutz, 2014; Mirza et al., 2014) are evident, investigation of the participants' pre-refugee background cast this experience in a more favourable light. The participants predominantly reported negative experiences of disability in their countries of origin. Stigma and discrimination were common. Despite stigma and discrimination occurring to a lesser degree in Australia than in their country of origin, these experiences continued to negatively affect their relationships with their families, communities and access to services. George (2010) has critically reviewed theoretical approaches to refugee trauma, including Refugee Theory, Postcolonial Theory, Trauma Theory and Feminist Theory, and has advanced an integrated conceptual framework to assist service providers supporting refugees with trauma. One of the contributions of this framework is the recognition of the importance of the historical, social and political context in both home and host countries. However, it does not appear to take account of the interactions between contexts. In particular, traumatic events after migration are seen by George as best viewed in the historical, social and political context of the *host* country, whereas this research points to the role of *home* country experiences of stigma and government indifference in shaping the framing of their experiences in Australia.

Consistent with George's (2010) formulation, this research also highlights the diversity and particularity of refugee experience in Australia. Whilst some ethnic communities were reported to maintain their negative attitudes and behaviours towards people with disability, others had reportedly improved. This favourable change seemed to occur when a family member was very active in the community, and for small communities an engaged opinion leader can have a significant influence on its views. This suggests a possible avenue of action at community level to mobilise a more supportive environment for refugees with a disability. There were a number of barriers to the use of services, some characteristic of the services and their staff, some related to characteristics of the refugees, and some attributable to the broader environmental context. The existence of a number of influences, and their nature, are similar to those reported by Neale et al. (2007) in relation to Afghan, Iranian and Iraqi settlers without a disability; however, their impact was more significant for participants in this research. There was evidence that participants framed their expectations of service provision in terms of their home country, for example the bureaucratic indifference of government services in Australia was considered to be better than the more extreme neglect or violence experienced at home. However, there was also evidence that settlement in Australia had led to some reframing of these expectations. NGOs were expected to be more responsive and caring than government, and failure to meet this expectation was criticised. It was suggested that the capacity of NGOs to provide essential services was hampered by funding limitations. These barriers contrast with the relatively benign picture of barriers to health care for Sub-Saharan refugees without a disability presented by Sheikh-Mohammed et al. (2006), which suggests that disability creates additional barriers. Many of the comments around service delivery

suggest that more intensive case management during resettlement would be beneficial for families where a member has a disability.

Language was identified as a major barrier, with communication difficulties eliciting frustration, anger, powerlessness and despair. Many government and non-government services lack the necessary skills and flexibility in communicating with these clients, including failure to provide a credentialed or professional interpreter or translated information. Negotiation of the complexities of government services is difficult for many Australian born people, and the language difference exacerbates the problems.

At an environmental level, transport issues and complexity present challenges not experienced by refugees without disability. These barriers could be addressed, and are important: being isolated with no informal support networks makes this group vulnerable as services cannot replace what relationships bring to a person's life.

On the positive side, the research suggests that people from refugee backgrounds with disability and their families do not take a passive role. They display resourcefulness in terms of finding information, and some are active participants in their communities. It is not clear whether a factor that (ironically) contributes to this resourcefulness is the experience of indifference in their home countries. If so, the reframing of their expectations may translate into lesser tolerance of shortcomings in current services, and a need for more flexible and responsive services.

Conclusion

The lived experience of refugees with disability is an area where little research has been undertaken. This small study with a diverse group of refugees with disability and their carer family members, demonstrates that they experience compounded barriers to accessing services, and have unmet needs. Viewed through the lens of theoretical approaches to refugee trauma, their experiences can best be understood in terms of the interaction between home and host country contexts and how they frame these contexts. While the experiences of refugees with disability in Australia generally appear less negative than those experienced before arrival, they are still far from positive, and the stigma experienced in their home countries may stay with their communities after migration. At the same time, these refugees, their families and communities sometimes act as transformative agents within their communities. While the scale of this research requires cautious conclusions, there are potential benefits associated with further larger scale qualitative research into refugees with disability.

Limitations

As has been acknowledged, this research has some limitations. The participant group was small yet diverse and heterogeneous in culture, religion, ethnicity, language, age, migration and disability experience, and length of time in Australia. Thus, the findings of this study may not be generalizable to all refugees with disability. Their recruitment through an advocacy organisation means they may have experienced relatively fewer barriers and less social exclusion than those not connected to such an organisation. The interviewer was a white female Australian academic, so therefore an outsider from the dominant culture. This represents an imbalance in power, although the interviewer has extensive cross-cultural experience and had the support of an NGO that participants trusted, and the authors as a team have considerable experience in the refugees and disability settings. The findings could have been further contextualised by presenting a fuller description of the interview location and circumstances; however, it was considered that this would make it possible for participants and their families to be identified by members of their communities.

Notes

¹ In this paper we observe the WHO (2011) definition of disability as the interaction between impairments and the barriers (physical, social and attitudinal) that interfere with their participation in society both fully and equally.

² The Refugee Visa Subclass 200 visa allows people who have been subjected to persecution in their country of origin to live in Australia for an indefinite period.

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References

- Ager, A. and Strang, A. (2008). Understanding Integration: A Conceptual Framework. *Journal of Refugee Studies*, 21(2), 166-91.
- Albrecht, G., Devlieger, P. et al (2009). Living on the Margin: Disabled Iranians in Belgian Society. *Disability and Society*, 24(3), 259-71.
- Allen, J., Currie, G. (2007). *Australians with Disabilities: Transport Disadvantage and Disability*. Victoria: Monash University ePress.
- Bedford, S., van Driel, M. et al (2009). *Care of Chronic Diseases in Queensland's Culturally and Linguistically Diverse (CALD) Communities: A Qualitative Study in Primary Care*. Queensland: Ethnic Communities Council of Queensland (ECCQ) and the

- Primary Health Care Research Evaluation and Development (PHCRED) Program of Bond University. Available: http://www.eccq.com.au/wp-content/uploads/2012/02/CALD_qualitative_MVD_120909_W2003.pdf [Accessed 13 April 2015].
- Bogdan, R. (1990). *Freak Show: Presenting Human Oddities for Amusement and Profit*. Chicago: University of Chicago Press.
- Bogenschutz, M. (2014). 'We Find a Way': Challenges and Facilitators for Health Care Access Among Immigrants and Refugees with Intellectual and Developmental Disabilities. *Medical Care*, 52, 64-70.
- Bradley, L. and Tawfiq, N. (2006). The Physical and Psychological Effects of Torture in Kurds Seeking Asylum in the United Kingdom. *Clinical Knowledge*, 16(1), 41-7.
- Colic-Peisker, V. (2009). Visibility, Settlement Success and Life Satisfaction in Three Refugee Communities in Australia. *Ethnicities*, 9(2), 175-199.
- Crock, M., McCallum, R. et al (2011). Where Disability and Displacement Intersect: Asylum Seekers with Disabilities. *Discussion Paper Prepared for the Vulnerable Persons Working Group International Association of Refugee Law Judges World Conference Bled, Slovenia, 7-9 September 2011*. Available: http://www.iarlj.org/general/images/stories/BLED_conference/papers/Disability_and_Displacement-background_paper.pdf [Accessed 13 May 2015]
- Department of Immigration and Border Protection (2013). *Fact Sheet 60: Australia's Refugee and Humanitarian Programme*. Australian Government. Available at: <https://www.immi.gov.au/media/fact-sheets/60refugee.htm> [Accessed 13 April 2015].
- Department of Social Services (2014). *Settlement Monthly Reports*. Australian Government. Available at: http://webcache.googleusercontent.com/search?q=cache:qknC1KSAJVUJ:https://www.dss.gov.au/sites/default/files/documents/01_2015/state_by_migration_stream_jan_10_to_dec_14_0.docx+&cd=1&hl=en&ct=clnk&gl=au [Accessed 16 April, 2015].
- Disability Discrimination Act (Cth). (1992). Available: <https://www.legislation.gov.au/Details/C2014C00013> [Accessed May 19, 2016]
- Ferdinand A.S. and Paradies, Y. et al (2015). Mental Health Impacts of Racial Discrimination in Australian Culturally and Linguistically Diverse Communities: A Cross-sectional Survey. *BMC Public Health*, 15(1), 401-415.
- Foundation House (2012). *Promoting Refugee Health: a Guide for Doctors, Nurses and Other Health Care Providers Caring for People from Refugee Backgrounds (3rd ed.)*. Victoria: Foundation House. Available at: http://qpastt.org.au/tbcwp1/wp-content/uploads/2014/05/PRHonlineedition_July2012_000.pdf [Accessed 13 April 2015].
- George, M. (2010). A theoretical understanding of refugee trauma. *Clinical Social Work Journal*, 38(4), 379-387.
- Gerber, D.A. (1992). Volition and valorization in the analysis of the 'careers' of people exhibited in freak shows. *Disability, Handicap and Society*, 7(1), 53-69.

- Grech, S. (2015). *Disability and Poverty in the Global South: Renegotiating Development in Guatemala*. London: Palgrave Macmillan.
- Harris, M. and Zwar, N. (2005). Refugee Health. *Australian Family Physician*, 34(10), 825-829.
- Huang, C., Mehta, N. et al (2011). Region of Birth and Disability among Recent U.S. Immigrants: Evidence from the 2000 Census. *Population Research and Policy Review*, 30(3), 399-418.
- .id (2015). How many refugees does Australia take? .id the population experts. Available at: <http://blog.id.com.au/2015/population/australian-demographic-trends/how-many-refugees-does-australia-take/> [Accessed 22 May 2016].
- King, G.A., Esses, V.M. et al. (2013). Immigrant and Refugee Families Raising Children with Disabling Conditions: A Review of the International Literature on Service Access, Service Utilization and Service Care Experiences. In E. Grigorenko (ed.) *Handbook of US Immigration and Education* (pp. 179-206). New York: Springer.
- King, J.A., Brough, M. et al. (2014). Negotiating Disability and Colonisation: The Lived Experience of Indigenous Australians with a Disability. *Disability and Society*, 29(5), 738-750.
- King, J.A., King, M. (2011). The Lived Experience of Families Living with a Spinal Cord Disability in Northeast Thailand. *Third World Quarterly*, 32(8), 1475-1491.
- Migration Act (Cth) 1958. Available: <https://www.legislation.gov.au/Details/C2016C00297> [Accessed March 24 2016]
- Mirza, M. (2012). Occupational Upheaval during Resettlement and Migration: Findings of Global Ethnography with Refugees with Disabilities. *Occupation, Participation and Health* 32(1), S6-S14.
- Mirza, M., Luna, R., et al. (2014). Barriers to Healthcare Access among Refugees with Disabilities and Chronic Health Conditions Resettled in the US Midwest. *Journal of Immigrant Minority Health*, 16 (1), 733-742.
- Neale, A. and Abu-Duhou, J. (2007). Health Services: Knowledge, Use and Satisfaction of Afghan, Iranian and Iraqi Settlers in Australia. *Diversity in Health and Social Care*, 4(4), 267-276.
- Parliamentary Library (2015). Refugee resettlement to Australia: what are the facts? Available at: http://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/rp/rp1415/RefugeeResettlement#_Toc410727192 [Accessed 22 May 2016].
- Prip, K., Persson, A. et al (2010). Self-reported Activity in Tortured Refugees with Long-term Sequelae Including Pain and the Impact of Foot Pain from Falanga: A Cross Sectional Study. *Disability and Rehabilitation*, 33(7), 569-578.
- Rohloff, H., Knipscheer, J. et al. (2014). Somatization in Refugees: A Review. *Social Psychiatry and Psychiatric Epidemiology*, 49(1), 1793-1804.
- Seidman, I. (2013). *Interviewing as Qualitative Research: A Guide for Researchers in*

- Education and the Social Sciences*. New York: Teachers College Press.
- Sheikh-Mohammed, M., MacIntyre, C. et al. (2006). Barriers to Access to Health Care for Newly Resettled Sub-Saharan Refugees in Australia. *Medical Journal of Australia*, 185(11), 594-597.
- Shildrick, M. (2002). *Embodying the Monster: Encounters with the Vulnerable Self*. London: Sage.
- Soldatic, S., Somers, K. et al (2015). 'Nowhere to be Found': Disabled Refugees and Asylum Seekers within the Australian Resettlement Landscape. *Disability and the Global South*, 2(1), 501-522.
- Stratigos, A. (2013). Stairs, Not Ramps— Australia's approach to migration and disability." *Immigration Review Bulletin*, 55, 1-5.
- Taylor, J. (2004). Refugees and Social Exclusion: What the Literature Says. *Migration Action*, XXVI(2), 16-31.
- United Nations Treaty Collection (2016). Convention on the Rights of Persons with Disabilities. Available at: https://treaties.un.org/Pages/ViewDetails.aspx?src=IND&mtdsg_no=IV-15&chapter=4&lang=en#EndDec [Accessed May 19, 2016].