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RESEARCH ARTICLE

Cultural case workers in child disability services: an evidence-based model of cultural responsiveness for refugee families

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The medical/disabled category for quota refugees selected for resettlement in New Zealand allows entry to those who have either a medical condition that can be treated or helped in New Zealand or a disability that requires support. Children from refugee and other culturally and linguistically diverse backgrounds with impairments comprise an increasing proportion of the caseloads of Auckland region child health and disability services. For people from refugee backgrounds, the New Zealand disability system can be complex, difficult to understand and hard to navigate. Disability therapeutic, rehabilitative and support services are often non-existent in countries of origin. The interventions offered in western countries such as physiotherapy, occupational therapy and speech language therapy may be unknown and therefore poorly understood by refugee clients and families. This article presents the findings of an evaluation of the establishment of cultural caseworker positions in the Waitemata District Health Board Child Development Service.

Keywords: refugee children; cultural caseworkers; disability; New Zealand

Introduction

From 1987 onwards, the New Zealand Government established an annual quota of 750 refugees, including the specific selection of those in the medical/disabled category (UNHCR 2002). The profile of refugees in need of resettlement since the 1980s has been increasingly characterised by new and diverse nationalities and by complex health and disability and social issues requiring specialised attention and treatment. Refugees resettled from this time have come mainly from: the countries of the Horn of Africa, Somalia, Eritrea, Ethiopia and the Sudan; the Middle East and West Asia, Afghanistan and Iran; as well as Burma, Sri Lanka, Bhutan and Colombia (Ministry of Health 2012).

Since the early 1990s, there has been a significant increase in the numbers, dependency and

diversity of refugees entering New Zealand health services. This article highlights the role of district health board child development services in the integration into the New Zealand health system of refugee families with children with impairments. The development of cultural caseworker (CCW) roles in a child development service has been shown to improve understanding and acceptance of care and outcomes for refugee children and their families (Waitemata District Health Board Child Women and Family Services 2011).

Refugees with disabilities: a special case for integration

Approximately 1200 refugees are resettled in New Zealand every year (NZIS 2004). Added to the

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annual quota of 750 refugees, are asylum seekers and family sponsored migrants who join family members settled in New Zealand. Unlike quota refugees, who are provided on arrival with health screening and orientation to New Zealand health, education and social services, asylum seekers and family reunion members receive little support and face additional barriers in accessing disability services and supports. Although these are small numbers, refugee groups represent cumulatively significant high health and social needs populations, particularly in the Auckland region. Refugee groups demonstrate a unique set of health and psychosocial needs as a result of both pre- and post-migration experiences. New Zealand studies indicate that refugees experience a relatively high rate of both physical and mental health problems on arrival (Ministry of Health 2012). Poor physical and mental health in refugee groups reflects the population health patterns of countries of origin, the refugee experience of trauma, flight and deprivation, the conditions in refugee camps and little or no previous access to healthcare (Ministry of Health 2012). Post-migration experiences—of unemployment, discrimination and a lack of family and social support-act as significant long-term barriers to social and economic integration (Marlowe 2013). Refugees with disabilities, and their families, require specialised support and culturally competent services to access and navigate health and disability services (Waitemata District Health Board Child Women and Family Services 2011).

Background

In 2006, the Auckland Regional Settlement Strategy Refugee and Migrant Health Action Plan identified improving access to child disability services and supports for refugee and migrant children as a health action area (Department of Labour 2010). New Zealand studies had shown that accessing disability services and supports was an issue for these populations (Ripple Trust 2003; Tse et al. 2006). In 2007, the Auckland Regional Settlement Strategy Health Steering Group, comprising representatives of the three Auckland region district health boards, undertook a needs analysis for children and

young people with disabilities from refugee and other culturally and linguistically diverse (CALD) backgrounds (Mortensen 2007). These are groups coded by Statistics New Zealand at Level 2 as Asian NFD, Southeast Asian, Chinese, Indian, Other Asian, Middle Eastern, Latin American/Hispanic, African (or cultural group of African origin) and Other (Ministry of Health 2009).

The report found that clients from refugee and new migrant backgrounds comprised between 20% and 25% of the caseloads of child development services in the Auckland region. Families from refugee and other non-English speaking backgrounds presented with high and complex needs, and had intensive needs for disability services and support on arrival. The findings of the needs analysis indicated that, from the available information, there appeared to be disparities between CALD groups and the total population in: the uptake of needs assessments; access to support services after assessment; and access to equipment and technology. The findings suggested that refugee and new migrant children with disabilities may not have been receiving the same quality of care as the total population (Mortensen 2007).

The cultural case worker model

The use of CCWs is a new development in the provision of mainstream health and disability services to refugee families in New Zealand. The roles of CCWs (also termed 'cultural brokers'), now well established in healthcare delivery in comparable immigrant societies (Jackson-Carroll et al. 1998; Carlson & van Kooten Prasad 2001; Harris 2004; Bronheim et al. 2006; Abrahamsson et al. 2009; Jones & Thomas 2009), informed the development of the New Zealand model.

Definitions of cultural brokering have evolved over time. One definition states that cultural brokering is the act of bridging, linking, or mediating between groups or persons of different cultural backgrounds for the purpose of reducing conflict or producing change (Jezewski 1990). Models of cultural brokerage have been shown to enhance the ability of health and disability services to provide appropriate care to CALD populations (Jezewski &

Sotnik 2005). In particular, the CCW role benefits vulnerable groups such as refugees who under utilise services and are frequently overlooked within mainstream health services (National Center for Cultural Competence 2004). Within a healthcare setting, the benefits to patients have been reported as: improved access to services; recognition by communities that healthcare providers are committed to delivering services in a culturally competent manner; increased motivation to seek healthcare earlier; improved ability to effectively communicate healthcare needs; and communicating the benefits of the service to others in the community (National Center for Cultural Competence 2004).

CCWs can bridge the gap between services and the communities they serve. They need not be members of a particular cultural group or community. However, they must have a history and experience with cultural groups for which they serve as a broker, including: the trust and respect of the community; a knowledge of the values, beliefs and health practices of cultural groups; an understanding of traditional wellness and healing networks within diverse communities; and experience navigating healthcare delivery and social support systems within communities (National Center for Cultural Competence 2004).

A cultural brokerage model in a child development service

Child development services are one of the services offered by district health boards in New Zealand (Ministry of Health 2010). They are multidisciplinary allied health services that work with families, children and young people to determine how best to encourage the development of children with disabilities or developmental delays. The services include: specialist assessments for children; organising intervention and management services; and working with other agencies to ensure that children get integrated support. The focus is on early intervention to achieve the best long-term results for children with impairments. Child development services are community-based and are delivered in the home and other community settings.

In 2009, the Waitemata District Health Board (WDHB) Child Women and Family Services, funded by the Northern Region DHB Support Agency Auckland Regional Settlement Strategy Refugee and Migrant Health Action Plan, established two CCW positions within its child development service, and put in place the resources and framework to support these roles (Waitemata District Health Board Child Women and Family Services 2011). The aim of the CCW service was to provide child health and disability services that were accessible and culturally appropriate for children and families from refugee and other CALD migrant backgrounds. Service users were identified as children and young people from CALD backgrounds with disability or development concerns, and who were engaged with specific WDHB child health services. An evaluation of the CCW model was commissioned in 2010 to better understand progress in implementing the model, the impacts on families and to inform further development of the service.

Methodology

There have been no previous studies of the roles of CALD cultural caseworkers in child health and disability services in New Zealand. The formative evaluation was conducted a year after the introduction of the new service. The study sought to assess the impact of the CCW roles in improving care for refugee and other CALD families, and to inform managers and decision-makers about progress in establishing the CCW service and to provide recommendations for future planning. Formative evaluation is defined by Stetler et al. (2006, p. 51) as:

[A] rigorous assessment process designed to identify potential and actual influences on the progress and effectiveness of implementation efforts. Formative evaluation enables researchers to explicitly study the complexity of implementation projects and suggests ways to answer questions about context, adaptations, and response to change.

Qualitative methods were used in order to 'illuminate the people behind the numbers and put faces on the statistics to deepen understanding' (Patton 2003, p. 2) of the refugee and migrant service users. Understanding 'participant's stories is useful to the

extent that those stories illuminate the processes and outcomes of the program for those who must make decisions about the program' (Patton 2003, p. 2). This article describes the impact of the service on refugee children and their families.

Ethical approval for the study was obtained from the Health and Disability Northern X Ethics Committee. Potential interviewees were invited to participate in the study. All participants gave informed consent. Pseudonyms were used to protect the identity of case study participants and the names of countries of origin were replaced with the names of stars in the solar system.

The evaluation employed a mixed-methods approach involving three datasets: a document review; interviews with stakeholders and key informants; and case studies. The purpose of the document review was to learn about the history, philosophy, goals and intended outcomes of the service. The information gathered in the interviews added to the data obtained from the documentation review, provided in-depth knowledge on the genesis and aims of the service, delivery on contracted services and the outcomes for families and services.

Potential key informants were identified by the research team in consultation with an advisory group. Interviewees included: service funders; management and staff; and representatives of collaborating teams and services accessing the service. Consumer representation was sought from families using the CCW service and from representatives of refugee and migrant communities. Following this process, a member of the research team contacted potential interviewees and invited them to participate in the research. A series of face-to-face, semi-structured interviews were then conducted with stakeholders and key informants.

The case studies included families who had accessed the service. Participation was anonymous and families were assured that they would not be identifiable in the final report. A combination of observational work and interviews with the families and the CCWs was employed to gather information. The researcher observed the interactions between the CCWs and/or families with the child health teams, multidisciplinary meetings, Strengthening Family conferences, parent focus groups and parent sem-

inars. Informed consent was obtained from the case study families prior to the researcher being present at each interaction and verbal permission from other key workers was sought before these interactions began (Waitemata District Health Board Child Women and Family Services 2011).

In-depth qualitative interviews were conducted with each of the participating families in their homes. Semi-structured interview guides were developed to explore topics such as: what life was like before coming to New Zealand; what life was like when the family arrived in New Zealand; when and what it was like when the family found out their child needed to use the child development service; and what difference having the CCW made to them. The study team developed a set of protocols to guide the conduct of researchers and interpreters during the interviews with refugee and migrant families.

Interviews with key informants and family members were audio recorded and transcribed with the participants' permission. A general inductive approach was used for analysis of the data (Thomas 2006). This enabled the researchers to: first, condense raw textual data into a summary format; second, to establish clear links between the evaluation objectives and the summary findings derived from the raw data; and, third, to develop a framework of the underlying structure of the processes that are evident in the raw data (Thomas 2006). Data was then coded with the aid of computer-assisted data analysis software QSR NVivo version 8.0.

Results

The sample

A total of 25 interviews were conducted with stakeholders and key informants over a six month period (Waitemata District Health Board Child Women and Family Services 2011). Key informants comprised: CCWs and management; WDHB child health workers, team leaders and supervisors; non-governmental organisation (NGO) providers; staff from government agencies; and community representatives. Stakeholders comprised service funders, management and staff, and representatives of

collaborating teams and services accessing the service. Consumer representation included the refugee and migrant families using the service, plus representatives of the communities targeted by the service. Five case studies were conducted, two with refugee families and three with migrant families. Where possible, case study interviews were conducted with both parents and the child/children present and, on one occasion, a grandparent was present.

Benefits for CALD families

The key benefits for families can be grouped under four broad headings: improved access to health and other services; reduced isolation; increased knowledge; and an improved living situation.

Improved access to health and other services

As a result of engaging with the service, CALD families' access to health and other services had improved. As well as better access to child disability and support services, this included access to government services such as Housing New Zealand, Work and Income, Ministry of Education (MOE) Special Education services and Immigration New Zealand services as well as health-related services such as hearing, dental, optometry, psychology and mental health services. One service provider gave the following example:

Luke was referred to a doctor after displaying behavioural problems at school. The normal process would have been for the paediatrician to make a referral to a psychologist which would have taken at least two weeks. Instead the paediatrician made a referral to the CCW. The CCW then immediately contacted the MOE Refugee coordinator to see what information he held on the school and the child. No records were found and the MOE coordinator made contact with the school within the same week, and a plan was put in place to help the child with his learning. While the CCW worked to sort out the needs of the family, a range of other tests were being carried out on the child to check his teeth, ears, eyes and to assess his learning and behavioural problems. As a result, Luke has received one-on-one time with a teacher at school, he has been provided with glasses, and all his other health checks have been carried out promptly. Both Luke and his mother are happy and report that he is progressing well ... (Waitemata

District Health Board Child Women and Family Services 2011, p. 30)

Reduced isolation

The study found that refugee and migrant parents interviewed commonly felt isolated. Not only were language and cultural differences a factor; they were often separated from extended family and community support networks and, additionally, many withdrew from their communities due to a sense of shame about their child's disability (Waitemata District Health Board Child Women and Family Services 2011). The study found that families had begun to participate in support groups started by the CCWs. An allied health worker gave an example of a CCW setting up a network of mothers from the same language group. She said:

I've got another [ethnicity removed] family whose mum also wants to meet another mum with a [ethnicity removed] child and this child's also got autism and he's going to need fencing and housing modifications to ensure his safety so that will be another child I'll be referring through to [CCW]. He has contacted these mums and he has set up a support group for these mums to meet together and to discuss their children, and the mums have been really chuffed about that because having someone who can speak their own language, who's got a child with a similar disability, and they can share ideas, because there's nothing like having a child with a similar disability to share ideas with-what works, what doesn't work. [P13] (Waitemata District Health Board Child Women and Family Services 2011, p. 30)

Increased knowledge

Key informants spoke about the importance of educating CALD families about health and social service entitlements in New Zealand, given that similar services in home countries are likely to be organised very differently, or may not exist at all. Both families and key informants noted that families' knowledge in these areas had improved significantly. One mother said:

[The CCW] give me understanding how they look after Abraham, people come they help you, but to like watch, but for Abraham day and night there is a respite care, he gives me all things but particularly understanding, understanding. [Eva] (Waitemata District Health Board Child Women and Family Services 2011, p. 31)

Improved living situation

Research findings suggest that connecting with a CCW had brought about an improvement in some families' living situation. This was a result of assistance with accessing better accommodation, financial improvements due to help with securing benefit payments, and facilitating access to furniture and food parcels: One mother interviewed stated that:

[H]e helped me with Income Support. He offered to come with me and did that. He offered to ask on my behalf the Housing New Zealand informed me what ideas and for the time being its rejection, I'm not eligible for the Housing New Zealand houses. He asked me if I'm intending to move out then I'll need furniture so the easy way is to look for second-hand furniture. He helped with that, he brought the furniture from other people who are going overseas so that I can put it on one side in the garage whenever I move out. He's still helping me to find a house for rental. So I'm very, very grateful. He made all the difference. [Rachael] (Waitemata District Health Board Child Women and Family Services 2011, p. 32)

Benefits for services

Key informants reported that the main benefits for services were: improved cultural knowledge and understanding; improved relationship between health services and families; and the streamlining of processes for families.

Improved cultural knowledge and understanding

Practitioners in child development teams reported that engaging with the CCW increased their cultural understanding of the families they worked with. Service providers were better informed about their family's ethnic, cultural, religious and refugee or migrant backgrounds. For example, one practitioner describes the following experience:

I had a shared client with [a CCW] and had a lot of discussion around, it was a [ethnicity removed] family and I believed I knew about their background but I really didn't. I just knew at the surface and [the CCW] said where did they come from, how did they get there, and I was like, I didn't know, I didn't ask them, and he said well if they were this then it means this, and it gave a big understanding to why they might be more difficult to engage in what our European

image of how a child should be eating or behaving within the household. [P1a] (Waitemata District Health Board Child Women and Family Services 2011, p. 23)

With increased knowledge of cultural issues, practitioners reported that they were able to provide a more culturally appropriate service and felt more confident in working with their clients. Building culturally competent practice across the team had been an additional benefit, as services were not entirely dependent on the CCWs for this knowledge:

The benefits are that we have a demonstration model of what benefits there are to be gained from having cultural caseworkers, that we understand more what the needs of families are and how this service could provide those, that we build capacity in CDS (child disability service) and hopefully in the wider child health services to meet needs. (Waitemata District Health Board Child Women and Family Services 2011, p. 33)

Service providers noted that the service had a commitment to all staff undertaking CALD cultural competency training (Waitemata District Health Board Asian Health Support Services 2011) and that this training had improved understanding of the cultural backgrounds of the families they worked with and of the services of the cultural caseworker.

Improved relationship between health services and families

The CCWs were reported to have played a key role in liaising between families and other agencies, particularly where there had been areas of conflict or difficulties in resolving problems. In these cases, CCWs had acted as mediators and, as a result, relationships between services and families had improved. Practitioners gave a number of examples. In one case, communication between a therapist and a family had become fraught when trying to resolve an issue around the modification of their housing to accommodate their disabled child. With the CCW's involvement, the therapist gained a better understanding of the family's background and relations had subsequently improved:

I could see a bit better their side and also it just stopped me from taking it personally. As a therapist, at the end of it, honestly, I want to make people happy. I want to give a good service ... but I wasn't getting there with that family and it was very frustrating because I had done lots of things and lots of work and still not getting there, and it just helped me to sit down and perhaps the family are in a mourning process and perhaps that family are not thinking totally straight for that specific family. [P14] (Waitemata District Health Board Child Women and Family Services 2011, p. 34)

In another example, a family had declined an interpreter and the health provider was having difficulty communicating with a family about the equipment needed for their child. However, the CCW (who spoke the same language as the family) was accepted because he was part of the health team. The CCW subsequently organised the equipment for the child. As a result, relations between the family and the service improved significantly.

Streamlining of processes

A number of practitioners who had made referrals to a CCW spoke about the difference this had made in terms of streamlining processes. CCWs had resolved issues between services and families by setting up meetings, liaising with other providers, and collecting information from family members and other stakeholders. For example, a therapist stated:

[A] lot of the contact I had with the family was through [the CCW]. He would set up the meetings, he would set up the trial of the equipment for me, which was absolutely fantastic, so I just had to work with the supplier to work with the equipment, work with AccessAble for the funding authority, and then facilitate it all, so he played an incredibly pivotal role in settling that for them. [P13] (Waitemata District Health Board Child Women and Family Services 2011, p. 35)

Discussion

This is the first study in New Zealand to explore the role of CALD CCWs in child development services. There is a paucity of New Zealand studies on the responsiveness of disability services and supports to refugee and migrants, and those that have been conducted focused on the needs of adult

populations. However, adults must negotiate the health and disability systems on behalf of children, so it is of note that these studies report that respondents had difficulty in understanding the disability system, in obtaining information about services and in accessing those services (Ripple Trust 2003; Tse et al. 2006; Changemakers Refugee Forum 2012).

The study makes a contribution to our knowledge about the experiences of refugee families with children with disabilities in New Zealand. Engagement with refugee families around the support needs of their child may be intensive in the initial stages and also over the longer term. The CALD CCW model informs future planning and development of child development services in regions of refugee resettlement in New Zealand.

While the qualitative findings of this study prevent generalisations, it appears that families from refugee backgrounds are far less likely than other groups to understand and navigate disability services and supports. The findings are relevant for other health and disability services with client groups from ethnically diverse backgrounds.

The complexity of health and disability service delivery was confusing and overwhelming for families. This was compounded by the stress of adjusting to life in New Zealand, and of receiving a disability diagnosis for their child. These findings were reinforced by the findings of CALD parent feedback groups conducted during the study period by the WDHB Child Health Service to obtain parent feedback about WDHB child disability services (S. Doe, WDHB, pers. comm. 24 September 2012). As well, prior to the development of the CCW service, child health services had a poor understanding of cultural and familial dynamics in operation in refugee and migrant families.

The international literature on the role of cultural brokers confirms the value of the CCW model in child health and disability services (Bronheim et al. 2006; Jackson-Carroll et al. 2008; Jones & Thomas 2009). Importantly, CCWs are knowledgeable about cultural and religious beliefs about disability within CALD communities, and they understand the healthcare system (Harris 2004; Jezewski & Sotnik 2005; Hasnain et al. 2008). They have been shown

to be change agents as they model and mentor behavioural change which can improve practitioner behaviours and attitudes so that organisations can build the capacity to respond to the new and emerging communities served (National Center for Cultural Competence 2004).

The study of the WDHB CALD CCW model in the child development service has identified the range of activities the CCWs provide to services and families including: relationship building and establishment of trust; education and information sharing; advocacy; the linking of families to other services; and the provision of practical support, for example assistance with housing, schooling and benefits (Waitemata District Health Board Child Women and Family Service 2011). The importance of relationship building is highlighted as a cornerstone for all work with refugee and migrant families. The CCW role also provides: language and cultural support; liaison between services and families; and cultural education. On occasion, CCWs have taken on a coordination role, particularly where there has been a breakdown in relations between families and health services.

The study found that the key benefits for families as a result of engaging with the CCW service were: improved access to health and other services; reduced isolation; increased knowledge about a range of issues such as the New Zealand health and social system, financial and other entitlements, and child-specific health issues; and an improved living situation due to assistance with accommodation or benefit payments, and access to furniture or food parcels. CALD parent feedback groups conducted in 2012 by the WDHB Child Health Service confirmed that the families continued to experience these benefits from the CCW roles:

None of the [refugee] families who gave feedback in the 2012 feedback groups reported being lost or confused. Instead they spoke of how helpful the CALD caseworkers were at explaining how the system worked and what to expect, and helping them to identify what do so next and to manage appointments. [Refugee] families also expressed appreciation that the CALD caseworkers did not just focus on the disabled child, but considered the needs of other members of the family and the family as a whole. Lack of concern

for the wider family was a theme in the feedback in 2010. Families reported that the CALD caseworkers had also helped to resolve complaints and assisted them with getting to appointments. (S. Doe, WDHB, pers. comm. 24 September 2012).

The key benefits for services included: increased knowledge and understanding of families' ethnic, cultural, religious and refugee or migrant background; an improved relationship with families resulting in better engagement and outcomes for the service and the family; and a streamlining of processes for all involved.

The findings of the CALD CCW service study inform future planning to enable child disability services and supports to improve their care for refugee and other ethnically diverse clients and their families. Child development services can strengthen the cultural appropriateness of the services they provide through the inclusion of CCWs and an organisational commitment to culturally competent practice for the refugee and migrant families in their care.

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