



**Evaluation of Waitemata District Health Board Child Disability  
Service Project for Culturally and Linguistically Diverse Families**

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## **ABBREVIATIONS**

ADHB	Auckland District Health Board
ARSS	Auckland Regional Settlement Strategy
CALD	Culturally and linguistically diverse
CCW	Cultural caseworker
CDS	Child Development Service
CRRC	Clinical Research and Resource Centre
CWFS	Child, Women and Family Services
DHB	District Health Board
GP	General Practitioner
HNZ	Housing New Zealand
KI	Key informant
MOH	Ministry of Health
MOE	Ministry of Education
MSD	Ministry of Social Development
NASC	Needs Assessment Service Co-ordination
NDSA	Northern District Health Board Support Agency Ltd
NGO	Non-government organisation
OT	Occupational therapist
PLM	Programme Logic Model
ST	Speech therapist
TL	Team Leader
WATIS	Waitemata Auckland Translation and Interpreting Services
WDHB	Waitemata District Health Board
WINZ	Work and Income New Zealand

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## **EXECUTIVE SUMMARY**

The purpose of this formative evaluation was to investigate the Waitemata District Health Board (WDHB) Child Disability Service Project for Culturally and Linguistically Diverse Families ('the Project'). The Project was established in 2009, and the evaluation sought to provide decision makers with a better understanding of its progress, including impacts to date for families and communities accessing the Project.

The Project was born from the Ministry of Health (MOH) funded Auckland Regional Settlement Strategy (ARSS) Health Action Plan. The ARSS plan aims to improve access and equity for culturally and linguistically diverse (CALD) families using health and disability services. This is, in part, a response to the changes in Auckland's demographic landscape which shows an increasing ethnic diversity following changes to the Immigration Act and to refugee selection policy. Of note, Asian peoples comprise 19% of the local population (Statistics New Zealand, 2009), and the region has the highest number (and proportion) of migrants and refugees who come to New Zealand (Auckland Sustainable Cities Programme, 2006). Previous research and consultation processes have identified that refugee and migrant communities face significant barriers to accessing New Zealand health and disability services (Asian Public Health Project Team, 2003; Lawrence & Kearns, 2005; Mortensen, 2007).

The WDHB Child, Women and Family Services (CWFS) used funding provided for the implementation of the ARSS Health Action Plan to establish two cultural caseworker (CCW) positions within its service (the Project) and to put in place the resources and framework that would support these two positions. Cultural caseworkers, also known as cultural brokers (Jezewski & Sotnik, 2001; National Center for Cultural Competence, 2004) mediate between groups or persons of different cultural backgrounds to effect change that will ultimately lead to better health outcomes for CALD families. The aim of the Project is to provide a service that is accessible and culturally appropriate for the care of children and families from refugee and CALD migrant backgrounds, delivered via the CCW model. Service users were identified as children and young people from refugee and CALD migrant backgrounds with disability or development concerns, and who were engaged with specific WDHB health services.

### **The evaluation**

As a means of informing future delivery of the Project, a formative evaluation was undertaken to help project decision makers better understand: the Project; how it impacts on families and communities; and, what works/does not work, for whom and why. More specifically, the evaluation sought to qualitatively evaluate the Project's progress in: establishing the service and internal and external networks; provision of advice and support to Child Health team members; provision of cultural support services to children and their families; and, building cultural competence of the Child Health teams.

A 'taskforce' (or advisory group) was established for the research to ensure the evaluators worked in an effective and inclusive manner with the Project team, and to enable expert guidance for the overall research process. The evaluation employed a mixed-method approach involving three stages of data collection including: document review, face-to-face semi-structured interviews with 25 key informants (KIs), and case studies (involving five

families who had accessed the project). A programme logic model (PLM) was also developed, which provided Project stakeholders with an overview of the Project's planned activities and intended results.

### **Key findings**

The evaluation gathered information on the experiences and needs of CALD families who have relocated to New Zealand, with a child with specific health needs. It has identified differences in migrant and refugee families in terms of their needs, and the resources they are likely to have available to them when arriving in New Zealand – and highlighted the importance of services adjusting to these. Children and adults from refugee families may enter New Zealand with pre-existing mental health issues due to the trauma they have experienced, compounded by adjusting to life in a new country. For both migrant and refugee families, there is a need for health and disability support services to consider the cultural and familial dynamics in operation within CALD families.

Findings from the research highlight the frustration and difficulties experienced by CALD families in accessing health services and disability support, either for themselves, or their child/ren. This was due to a lack of knowledge amongst families of what was available and the processes for accessing health services, as well as a result of health services being provided in an ad hoc fashion without clear communication. Of note, there was evidence that the delivery of health services was not necessarily a co-ordinated process and sometimes proved confusing and overwhelming for families. This was compounded by the possible stress and anxiety for parents adjusting to life in New Zealand, and the challenge of navigating unfamiliar health and social systems. Importantly, this means that CALD families may come to the Project with high needs, and be looking for the CCW to mediate in somewhat tense relationships with other service providers.

Key tasks for the CCWs were defined as project work, networking and clinical work. In seeking to better understand the workings of the Project, the evaluation investigated the different ways in which the CCWs are supported to perform their roles. Support structures in place at the time of the research were: clinical and line management; project management; external cultural supervision; clinical supervision and, peer support/supervision. Most of these were delivered via weekly or fortnightly meetings. The research highlighted the importance of support mechanisms being in place for CCWs, due to the demands of the role, and to ensure that they do not become overloaded.

The evaluation identified a range of activities being delivered to families by the Project, 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 (e.g. assistance with accessing accommodation). Of note, the importance of relationship building was highlighted as a cornerstone for all work with CALD families. For health services who have engaged with the Project, the CCWs have been active in providing the following: language and cultural support; liaison between services and families; and, cultural education. They have also taken on a co-ordination role at times, particularly in circumstances of conflict or where there has been a breakdown in relations between families and other (health) services.

The research explored possible barriers for CALD families accessing the Project (although it should be noted that the research did not involve CALD families who had not used the service). Key potential barriers identified included: not meeting the referral criteria or difficulties in navigating the health system; health professionals acting as gatekeepers between the Project and families; and, an unwillingness to engage with the Project due to stigma associated with disability.

The barriers for services engaging with the Project included: a lack of familiarity with the Project staff (with health workers reluctant to refer families until forming a relationship with the CCWs); a lack of knowledge of project offerings (some potential service users were unsure about the services provided by the Project); and, uncertainty over the appropriate time for making a referral to the Project (which was generally assumed to be when families were in a crisis situation).

The key benefits for families as a result of engaging with the Project were: improved access to health and other services; reduced isolation (due to families being linked up with other services or organisations where they could be supported); 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). The key benefits for services included: increased knowledge and understanding of families' ethnic, cultural, religious or migrant/refugee 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 those involved.

The research identified that, amongst key Project stakeholders, the age, gender, religious background, or ethnicity of the CCW are less important than attributes such as knowledge of the New Zealand health and other social systems, empathy, compassion, and a sense of understanding and respect for CALD families.

The Project strengths were mostly linked to the skills and expertise of the staff who were viewed as: having a good understanding of, and ability to relate to, CALD families and the issues they face; effective advocates; effective at engaging families; and, having well established community networks. The accessibility of the service, in terms of its location within CDS, was also viewed as a strength as it facilitated team working and informal networking between the CCWs and health staff.

The Project faces a number of challenges, many of which could be expected from an intervention of this type at an early development stage. These include a need to clarify and communicate the features and limitations of the CCW role to ensure that expectations are managed and to protect staff, and the longer term sustainability of the service (and its potential transition from a project to an integrated programme). A number of staff-specific challenges were identified including the uniqueness of the CCW role and its potential clash with the mainstream DHB culture, the need to manage staff workloads to ensure that the CCWs do not become overloaded, and staff recruitment and retention.

In taking the project forward, it is recommended that the following key issues are considered:

- The staff and their associated skills and experience are a clear asset for the Project, in particular their ability to engage with families, and their wide community networks.

These qualities also bring a level of responsibility for the CCWs, and the fact that they are part of the community in which they are working needs to be explicitly acknowledged, particularly in relation to the potential ‘blurring of boundaries’ between the two.

- The research has identified the tension of working holistically within a medical model. Of note, the unique qualities of the CCW role needs to be acknowledged, including that it may not fit a typical template of other family advocate or health service roles within the DHB. This includes recognition that what might not be seen as a defined aspect of the position is in fact a key part of the relationship building aspect required. Whilst there are indications that some role clarity is required – to reduce the risk of staff ‘burnout’, and to manage the expectations of both families and other stakeholders – it will be important to ensure that the role does not become too bound by restrictions.
- Other issues to be considered with regard to staff safety/protection include the provision of accessible and appropriate (cultural) supervision, as well as time off from the role.
- Currently, where appropriate, CCWs are able to act as key workers (i.e. co-ordinate all visits to a family, and act as a first point of contact for the family). There was some (limited) evidence of this identified in the evaluation, and findings from the research suggest that this may be beneficial in certain circumstances. Of note, the case study data have further reinforced the stress and anxiety experienced by CALD families when attempting to navigate not only a new country, but also often complex and disjointed health and other services – and the benefits of a CCW in facilitating this process. It also highlights the advantages of early involvement of the CCW, rather than waiting until problems or issues develop.
- The issue of job sizing (i.e. the relative time and resources allocated to each aspect of the role) is important. This includes decisions around whether the Project works in-depth with a smaller number of families, or provides lower level services for a larger client group. This is a consideration both in terms of the cost of the Project relative to numbers of families ‘served’, as well as ensuring that the CCWs do not become overloaded. It is worth bearing in mind that project work will likely reduce over time as a pool of resources is developed.
- The restructure and management changes earlier in the project resulted in some additional responsibility for the team leaders (TLs) of the CCWs, although not to the extent that was first anticipated. Working across services may continue to present some challenges in relation to the management of the CCWs, in particular who has ultimate responsibility for their supervision and management, and their accountability for the work they are doing within their individual cases.
- The research highlighted that the Project is not fully embedded within the WDHB structure, with some health staff unable to envisage benefits of engaging with the CCW. Potential strategies for addressing this include:
  - staff who have previously worked with CCWs will play a key role in communicating the benefits of the Project to other potential service users;

- further communication of what the CCWs do (e.g. via on-going presentations) would be beneficial in generating additional referrals from potential service users (e.g. allied health staff);
- there is a need to communicate with potential service users about appropriate time points for making a referral;
- given that the CCWs are in the unique position of working across multiple Child Health services, a stakeholder group of representatives from the various services within WDHB could be a good support mechanism for the Project staff. Such a group could assist with facilitating communication about the CCW roles, identify pertinent issues, and help to improve buy-in from other areas (particularly at upper management levels).

# 1. INTRODUCTION

This document reports findings from a formative evaluation of the Waitemata District Health Board (WDHB) Child Disability Service Project for Culturally and Linguistically Diverse (CALD) Families ('the Project'). The Project was established in 2009, and the evaluation sought to provide decision makers with a better understanding of its progress to date, including impacts for families and services accessing the Project.

## Background

The ethnic demography of the Auckland region has changed significantly since the early 1990s, with increasing cultural and linguistic diversity in the local population (Auckland Sustainable Cities Programme, 2006). The Auckland District Health Board (ADHB) estimates that more than 40,000 peoples from refugee backgrounds are resident in the Auckland area (Auckland District Health Board, 2002), with around two thirds of the approximately 1,550 refugees resettled in New Zealand every year (New Zealand Immigration Service, 2004) residing in the region. In addition, two thirds of Asian peoples in New Zealand live in the city (Auckland District Health Board, 2002; Auckland Sustainable Cities Programme, 2006), and currently comprise 19% of the local population (Statistics New Zealand, 2009).

Previous research and consultation processes have identified that refugee and migrant communities face significant barriers to accessing New Zealand health and disability services (Asian Public Health Project Team, 2003; Lawrence & Kearns, 2005; Mortensen, 2007). This includes an inability to communicate, as well as difficulties due to health practitioners' limited cultural understanding of clients (Asian Public Health Project Team, 2003). Health staff may have little understanding of the impact of the refugees' experience, or of migrant settlement issues on families' ability to cope or to navigate the New Zealand health system. These, and other issues, can result in CALD families receiving less than optimal care (Mortensen, 2009). Indeed, the Asian Public Health Project Report (2003) highlighted the under-utilisation of health and disability services, due to language and communication barriers, cultural barriers and different conceptualisations of health and disability (Asian Public Health Project Team, 2003). Such issues may be compounded by the breakdown of traditional family support systems for disabled family members, as a result of the migration experience. It has been reported elsewhere that families from minority ethnic communities with a disabled family member may be doubly disadvantaged due to racial discrimination and the provision of care which is culturally inappropriate (O'Hara, 2003).

## Auckland Regional Settlement Strategy

The *Auckland Regional Settlement Strategy* (ARSS) was recognised by Cabinet as requiring a whole-of-Government approach to improving settlement outcomes for refugees and migrants. Improving health and disability outcomes for these populations is a key target in the strategy. Goal four (*Enhance Physical and Mental*

*Health Outcomes*’) states that ‘health care services should ensure that they are accessible and responsive to the health needs of migrants and refugees, and do not create health inequalities’, and includes development of culturally responsive child disability services (Auckland Sustainable Cities Programme, 2006).

The ARSS Migrant Health Action Plan is a region-wide approach to improving the health of refugee and migrant populations in the Auckland region led by Waitemata, Auckland and Counties Manukau District Health Boards. The over-arching ARSS health strategy aims to improve the responsiveness of health and disability services to CALD families by providing interpreting services, cultural competence training and improving access to child disability services, as well as conducting research and evaluation studies to inform service planners and funders. A scoping study undertaken in 2007 (comprised of a needs analysis, literature review and consultation process) identified a range of action points around health and disability service provision for refugee and migrant communities. In 2008, the MOH provided funding for the implementation of the ARSS Health Action Plan. Two goals for the funding are:

- to build the capacity and capability of health and disability services through the availability of interpreting services, cultural competency training and where appropriate developing roles to improve access for refugee and migrant groups
- to increase access to child disability and rehabilitation services for groups from refugee and migrant backgrounds.

The WDHB Child, Women and Family Services (CWFS) used the allocated funding primarily to establish two Cultural Caseworker (CCW) positions within its service and to put in place the resources and framework that would support these two positions (e.g. the translation of service information).

## **The cultural caseworker model**

Cultural caseworkers, also known as cultural brokers, diversity consultants, ethnic community workers and cultural experts (Jezewski & Sotnik, 2001; National Center for Cultural Competence, 2004) are a relatively new development in the provision of mainstream health and disability services to CALD families in New Zealand – although the concept of cultural brokering has gained momentum internationally in disability services over the past ten years (Mortensen, 2009). Jezewski and Sotnik (2001) define cultural brokering as the act of bridging, linking or mediating between groups or persons of different cultural backgrounds to effect change. Such initiatives have been shown to enhance the ability of organisations to provide health care services to CALD populations, particularly those who are vulnerable and may be being overlooked within mainstream health services (National Center for Cultural Competence, 2004). Within a health setting, the benefits to patients have been reported as: improved access to services, with subsequent improved health outcomes and reduction in health inequalities; recognition of health providers’ commitment to delivering services in a culturally competent manner; increased motivation to seek healthcare earlier; improved ability to effectively communicate

health care needs; and, given the potential for communicating the benefits to others, may result in positive health impacts for the wider community (National Center for Cultural Competence, 2004).

## **The evaluation**

As a means of informing the future delivery of the Project, developing knowledge, and directing policy development in this area, an evaluation was commissioned in 2010. As noted previously, whilst there were two aspects to the work that were developed by the CWFS, the evaluation focussed specifically on the CCW positions and overall cultural caseworker model.

The broad aims of the evaluation were to help Project decision makers:

- better understand the Project
- better understand how the Project impacts on families and communities
- better understand what works, what doesn't work, for whom and why.

More specifically, the evaluation sought to qualitatively evaluate the Project's progress in:

- establishing the service
- establishing internal and external networks
- provision of advice and support to Child Health team members
- provision of cultural support services to children and their families
- building cultural competence of the Child Health teams.

## **Report outline**

The remainder of the report presents the main evaluation findings and is divided into the following sections:

- *Section Two* contains a description of the research methodology, including an outline of the evaluation approach adopted, research processes, and the data collection and analysis methods undertaken.
- *Section Three* presents the evaluation results. This includes a description of the Project, key activities undertaken to date, barriers in accessing the Project, impacts for families and health services, and challenges facing the Project. A presentation of each of the case studies is also provided.
- *Section Four* contains a discussion of the findings and includes a summary and review of the key learning from the evaluation.

## **2. RESEARCH METHODOLOGY**

A formative approach was undertaken for the evaluation. Formative evaluations seek to improve or strengthen a specific programme or intervention, and typically examine aspects of a programme such as structures and processes, project delivery and personnel (Patton, 2002). In examining the strengths and weaknesses of a particular intervention they provide context specific findings (Patton, 2002). The short time period of this evaluation (and the stage of development of the Project) did not allow for the identification of any medium or long term outcomes for CALD families and health services accessing the Project. However, it was able to identify short term and immediate impacts such as developments in service delivery; satisfaction with services; and, perceptions of impacts and positive changes in the wellbeing of CALD families.

The evaluation was designed to enable the research team to work closely in collaboration with the Project staff and its beneficiaries throughout the evaluation. This was primarily achieved by combining the research and evaluation expertise of Clinical Research and Resource Centre (CRRC) staff with the skills, knowledge and perspectives of those involved with the project. In doing so, it was intended that information gained from the evaluation would be both rigorous and reliable and be used effectively to address problems, as well as build on strengths and opportunities. The study received ethical approval from the Health and Disability Northern X Ethics Committee (reference: NTX/10/03/020).

### **Evaluation Taskforce**

An evaluation 'taskforce' (or advisory group) was established for the evaluation to ensure the evaluators worked in an effective and inclusive manner with the Project team – and to enable expert guidance for the overall research process. This group comprised of a mix of Project stakeholders including: the Project funders, Project staff, CALD family representatives, CALD community leaders, representatives from other Government and non-government organisations (NGO), and the evaluation researchers. The purpose of this group was twofold: a) to discuss and help plan the evaluation and, b) to provide on-going input into the evaluation process via a series of face to face meetings throughout the research process (see below). Taskforce members outside of WDHB were reimbursed for their travel expenses, and offered a gift voucher in recognition of their contribution to the evaluation.

#### ***a) Evaluation planning***

The first function of the taskforce was to identify key objectives against which the evaluation could assess the Project's progress. Existing Project documentation informed this discussion. The research team also sought the multiple perspectives of the taskforce members to ensure that those who knew the project best were actively involved in driving and defining the evaluation's purpose, its questions and the methods it employed.

### ***b) Provide on-going input into the evaluation process***

A second function of the taskforce was to collaborate with the research team in order to:

- Provide direction in identifying documentation for review
- Assist with identifying evaluation participants (key informants)
- Advise on how best to engage with evaluation participants
- Provide expertise on the analysis of preliminary research findings
- Ensure the evaluation remained focussed on and useful to the needs of Project providers and beneficiaries.

The taskforce met four times throughout the evaluation period; outside of these times open communication was maintained with different members.

### **Data collection**

The evaluation employed a mixed-method approach involving three stages of data collection. This allowed data from different sources to be compared and contrasted to strengthen the validity of findings, and to build a fuller picture of what was happening in the Project. The three data collection methods – document review, interviews with Project stakeholders, and case studies – are outlined below.

#### ***Documentation review***

The research team undertook a review of pertinent documentation related to the Project. The purpose of this review was to contextualise the Project, and allowed the research team to learn about its history, philosophy, goals and intended outcomes

The Service Level Agreement (SLA) between the Child Women and Family Service and the Waitemata DHB Planning and Funding Team, the CCW job description, and the referral guideline document comprised the key documentation reviewed. Drawing on these documents, the evaluation sought to describe the following: expectations of the role and responsibilities of CCWs; expectations of Project focus and reach; expectations of Project impacts; and, resources available to the Project. This information was synthesised and fed into the programme logic model developed as part of the research.

#### ***Semi-structured qualitative interviews with key informants***

A series of face-to-face, semi-structured interviews were conducted with stakeholders, or key informants, linked to the Project. Potential KIs were identified by the research team, in consultation with the taskforce. These comprised individuals in a range of roles, including Project funders, management and staff, and representatives of collaborating teams and services accessing the Project. Consumer representation was also sought from CALD families currently using the Project's services, and representatives of migrant and refugee communities targeted by the

Project. Following this process, a member of the research team contacted potential interviewees and invited them to participate in the research.

Under the guidance of the taskforce, the research team developed a question guide which outlined topics for discussion during interviews. The questions were tailored depending on the background and role of the research participant, and covered a range of topics that were selected to meet the information interests of a range of audiences. They included: background to the Project and its development (Project staff); awareness of the Project (non-Project staff); Project activities; strengths and weaknesses of the CCW model; barriers for families and services accessing the Project; what difference the Project and work of the CCWs is making (for services and CALD families); and, suggestions for improving the Project. The semi-structured interview approach allowed interviews to be more conversational in style, and for more in-depth, comprehensive information to be elicited. The information gathered by these interviews added to the data obtained from the documentation review to provide a more rounded picture of how the Project was established and its overall aims, as well as progress made to date in terms of Project delivery and outcomes for families and services.

A total of 25 KI interviews were conducted. Participants came from a range of backgrounds and had varying degrees of knowledge about the Project. Some were invited to participate because of their knowledge of working with refugee and migrant communities and others had worked closely with the CCWs. The KIs interviewed comprised: Project staff and management, WDHB Child Health workers and TIs and supervisors, NGO providers, staff from government agencies, and community representatives.

Interviews were conducted between May and October 2010, and were between 30 minutes and two hours in duration. All were held at the workplace of interviewees. Interpreting and/or translation support was offered, but not required by participants in this phase of the research. Where appropriate, participants were offered a gift voucher in recognition of their contribution to the evaluation.

### ***Case studies: observations and interviews***

As a means of 'bringing to life' the Project, a case study method was employed. Case studies can provide detailed information about a small number of 'events' and are useful for exploring the complex issues and influences affecting particular people in specific situations (Patton, 2002). The evaluation conducted five case studies, with each centred on the experiences of a different family using the services of a cultural caseworker.

The cultural caseworker identified families who had been accessing the project and invited them to participate in the evaluation. A pre-interview meeting was organised by the CCW for the researcher to meet the families on an informal basis. The researcher explained the purpose of the study, discussed what questions would be asked, confidentiality matters, the voluntary nature of participation, informed consent and whether they would like an interpreter. Where the families were willing to participate a suitable time was made to conduct the interview. Participation in the

study was anonymous and families who took part were assured that they would not be identifiable in the final report. Each participating family was offered a gift voucher in recognition of their contribution to the research.

A combination of observational work and interviews with the families and the CCWs was employed to gather information in the case studies:

- the observations aimed to explore how the Project is experienced in 'real life' for those involved, and took the form of the researcher taking field notes during interactions between the cultural caseworkers and the families. Observations were made of the cultural caseworkers and/or families interacting with the Child Health teams, multi-disciplinary meetings, Strengthening Family conferences, parent focus groups and parent seminars, and were conducted throughout the evaluation. 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.
- in-depth qualitative interviews were also conducted with each of the participating families. Semi-structured interview guides were developed in collaboration with the taskforce and used to explore the experiences of each family. The interviews explored topics such as: what life was like before coming to New Zealand; what life was like when they arrived in New Zealand; when and what it was like when they found out their child needed to use child health services; and, what difference having the CCW made. Interviews were between 42 and 103 minutes in duration and took place at the home of the families.

Under the guidance of the taskforce, the research team developed a set of protocols to guide the conduct of researchers (and interpreters) during the interviews with CALD families. This included, for example, protocols around meeting the families and appropriate behaviour when conducting interviews.

A total of five case studies were conducted. This included three with migrant families and two with refugee families; all but one of the families<sup>1</sup> were engaged with a CCW at the time of the research. Where possible, case study interviews were conducted with both parents and the child/ren present (this occurred for two case study interviews). None of the children were interviewed separately - either because of their young age or due to their disability. One interview was conducted separately with each parent, and at different time points, and another took place with a parent and a grandparent present.

## **Data analysis**

Information gathered during the documentation review was synthesised to present a narrative describing the Project's history, aims and objectives. All interviews with KIs and family members were audio recorded and transcribed. Transcriptions were

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<sup>1</sup> One family had recently been discharged from the health service they had previously been engaged with.

read and re-read by the research team to gain an understanding of the issues relative to key themes.

Analysis of the data was informed mainly by the general inductive approach (Thomas, 2006). A coding frame was developed via an iterative process of coding sections of transcript and free form text according to thematic similarities, review and discussion by the researchers and re-coding. Data were then coded with the aid of computer-assisted data analysis software (QSR NVivo version 8.0).

As a part of the analysis process, information gathered during the KI interviews and the case study observations and interviews were collated and presented to the taskforce in a preliminary form, to enable members to discuss and contextualise the findings. The taskforce were also consulted to ensure that the themes identified were an accurate and reasonable reflection of participants' experiences, and to check whether any further interpretations could be derived using their particular expertise.

Verbatim interview extracts are presented throughout the report in italics, with participant sources coded for anonymity (e.g. participant one is represented as P1). Pseudonyms have been used to protect the identity of case study participants and the names of countries (outside of New Zealand) have been replaced with the names of stars in the solar system.

### **3. RESULTS**

This section of the report presents the key findings from the evaluation. This includes a description of the Project, key activities undertaken to date, barriers in accessing the Project, impacts for families and health services, and challenges facing the Project. A presentation of each of the case studies is also provided.

#### **Description of the Project**

In providing a context for the evaluation, and as a way of documenting the Project's aims and intended activities, this section provides a description of the Project. The following is based on information provided during the KI interviews and a review of the Project documentation.

##### ***a) Aims and service delivery of the Project***

The aim of the Project is to provide a service that is accessible and culturally appropriate for the care of children and families from refugee and CALD migrant backgrounds. More specifically, the Project seeks to ensure that:

- culturally and linguistically appropriate support and information is provided to the child and young person's family;
- services offered are appropriately linked with other services that the child/family may be accessing;
- services are family centred and provided in a suitable setting in a cost-effective manner.

Service users were identified as children and young people from refugee and CALD migrant backgrounds who had a disability or developmental concerns and were users of WDHB-provided Child Development services, Out of Home Respite services or Child Rehabilitation services. As the CCWs became more comfortable in the role, and the referral process was working well, the referral criteria were extended to include referrals from Home Care for Kids and paediatrics (see Appendix A for a more detailed list of the criteria). It was intended that entry to the CCW service would be via a number of routes, with the primary source of referrals from WDHB Child Health Service<sup>2</sup> teams.

##### ***b) Description of the cultural caseworker roles***

The CCW model was identified as an appropriate means of meeting the aims and requirements of the project. The CCW positions which were developed were based on a thorough literature review that highlighted what similar CCW models looked

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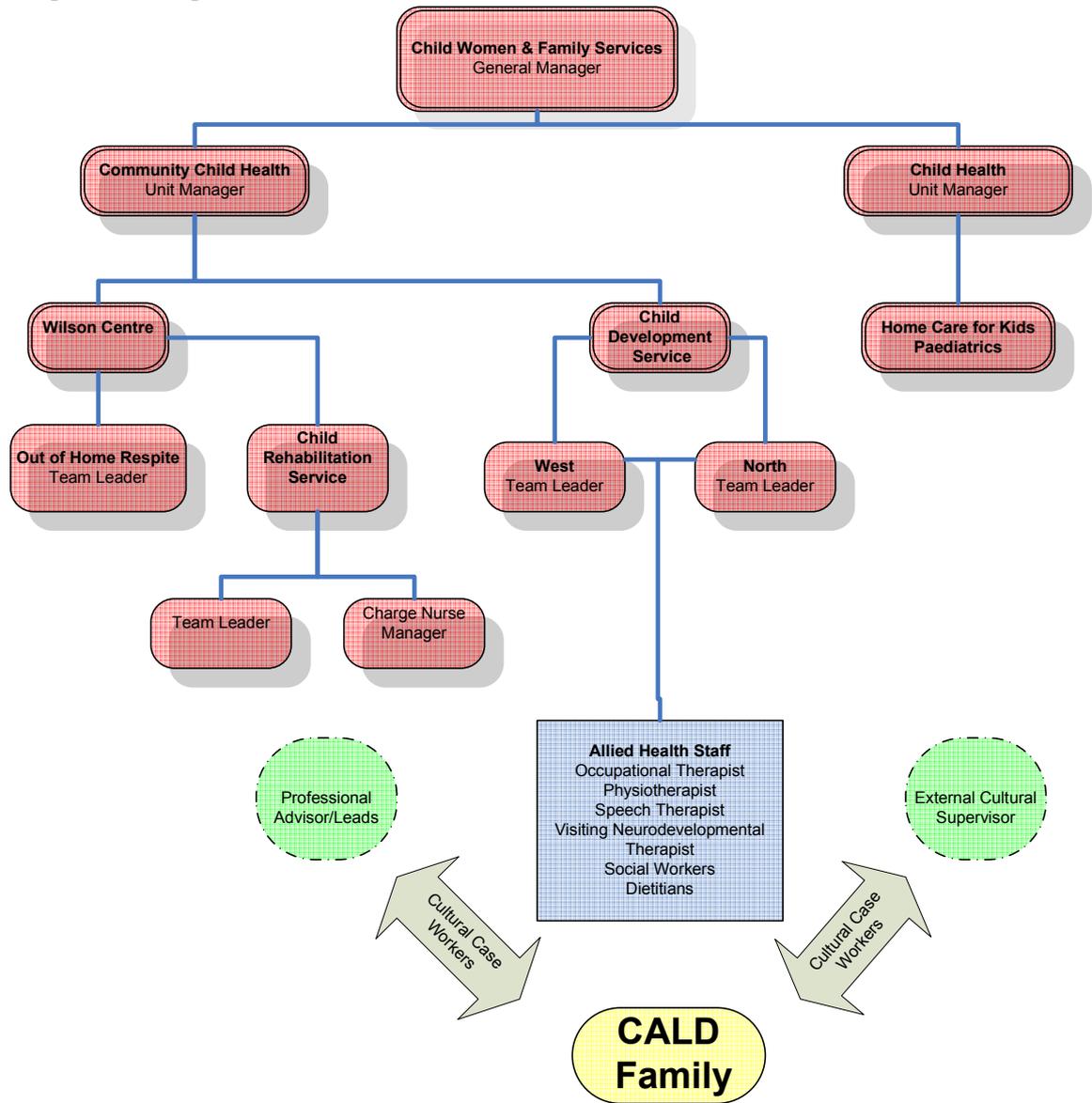
<sup>2</sup> Generally, CALD families may be using Child Health Services within Waitemata DHB after attendance at a hospital Emergency Department, via a GP referral to an outpatient clinic or other services, or by referral from Taikura Trust or other health providers e.g. Plunket.

like in Sweden, the USA, and Australia (Mortensen, 2009). More specifically, the role of the CCW within the Project was established to:

- Provide community and hospital/centre based cultural support services to children and families from CALD backgrounds. These include: engagement with children and families in order to support them to meet their own needs; educating parents about the New Zealand health system and New Zealand perspectives of disability; and, advocacy as needed to ensure the allocation of support services for children from CALD background. It may involve acting as a key case worker when appropriate.
- Provide advice and support as needed to assist Child Health team members in the delivery of culturally appropriate services to children and families from CALD backgrounds. In addition, as a member of the multidisciplinary teams, CCWs will work collaboratively and contribute to case reviews and discussions.
- Assist teams with eliciting consumer feedback and supporting complaints resolution.
- Provide information on cross-cultural resources and training, services available to CALD children and families; NASC system and other methods for accessing resources for disabled people; refugee and migrant settlement in the district and the cultures, religions and languages of the groups settled.

Key tasks were defined as project work (e.g. keeping abreast of developments in the area of working with CALD families); networking (e.g. establishing linkages within the community); and, clinical work (e.g. providing advice and support to Child Health team members). Waitemata DHB's catchment has two distinct North and West Child Development Services (CDS) teams, which are allied health multidisciplinary teams that carry out largely community-based intervention and assessments. It was intended that the CCW positions would be located within the CDS North and West teams, working alongside the allied health teams in CDS and with the social workers in Out of Home Respite and Rehabilitation services, to liaise with CALD families and services. The diagram on the following page displays the positioning of the Project within this structure.

**Diagram 1: Organisational Chart**



### ***c) A description of intended activities - programme logic model***

A systematic approach to the implementation of cultural brokering projects is necessary to ensure their long term sustainability (National Center for Cultural Competence, 2004). In keeping with this, and as a part of the participatory approach adopted in the study, a programme logic model (PLM) was developed for the overall CALD Project and the CCW model.

A PLM is a systematic and visual way to present and share understanding of the relationships among the resources required to operate a programme, the planned activities, and the desired changes or results that the programme aims to achieve – and is a ‘living’ document that can evolve as the evaluation progresses (WK Kellogg Foundation, 2004). Programme logic models can enable a more effective evaluation by ensuring that: the evaluation focuses on the most important aspects of the project, as identified and agreed by project stakeholders; evaluation questions remain relevant to the identified focus area(s); and, indicators of success are determined by project stakeholders and appropriate data collection methods are designed accordingly. The purpose of the PLMs was twofold:

- *As a Project tool:* In linking the various Project activities together in a manner that indicated the process of the Project’s implementation, it was intended that this would provide Project stakeholders with the ‘big picture’ of how the activities and processes pull together into a cohesive whole to achieve desired outcomes.
- *As an evaluation tool:* The PLM acted as a backdrop for the evaluation and a framework against which the Project’s progress could be documented and benchmarked as part of the research process. In particular, this included: which activities had been completed?; where did the Project face barriers?; how successfully were activities completed?; and, what additional activities and processes were discovered along the way that were critical to the Project’s success?

The PLMs that were developed (WK Kellogg Foundation, 2004) are structured with five key components, as follows:

- *Resources:* also referred to as inputs, these include the range of resources (e.g. human, community, financial) available to undertake the work.
- *Programme activities:* are a description of what the project or programme intends to do with the resources available – and include the tools, events, actions that are a planned part of the programme implementation.
- *Outputs:* are the direct products of the activities undertaken (i.e. evidence of the service delivery).
- *Outcomes:* also described as benefits, these are the specific changes that occur amongst a programme’s participants (e.g. they may be a shift in behaviour, and/or increase in skills and knowledge). They may be defined as short-term outcomes (i.e. within 1-2 years) or longer term outcomes (e.g. within 4-6 years).

- *Impact*: these are the (intended or unintended) changes that occur as a result of programme activities within 7-10 years. They may take place within organisations, communities or systems.

The initial development of the PLMs was jointly undertaken by the Project Leader and the researchers, with additional input provided by members of the evaluation taskforce. A range of documents were also reviewed as part of this process, including: the Project's Service Level Agreement; the CCW job descriptions; and, the Project's stated referral criteria. The PLMs developed are presented on the following pages. When read from left to right, they provide a chronological overview of the Project's development, from planning through to intended results.

Diagram 2: Programme Logic Model Child Disability Services Project for CALD Families

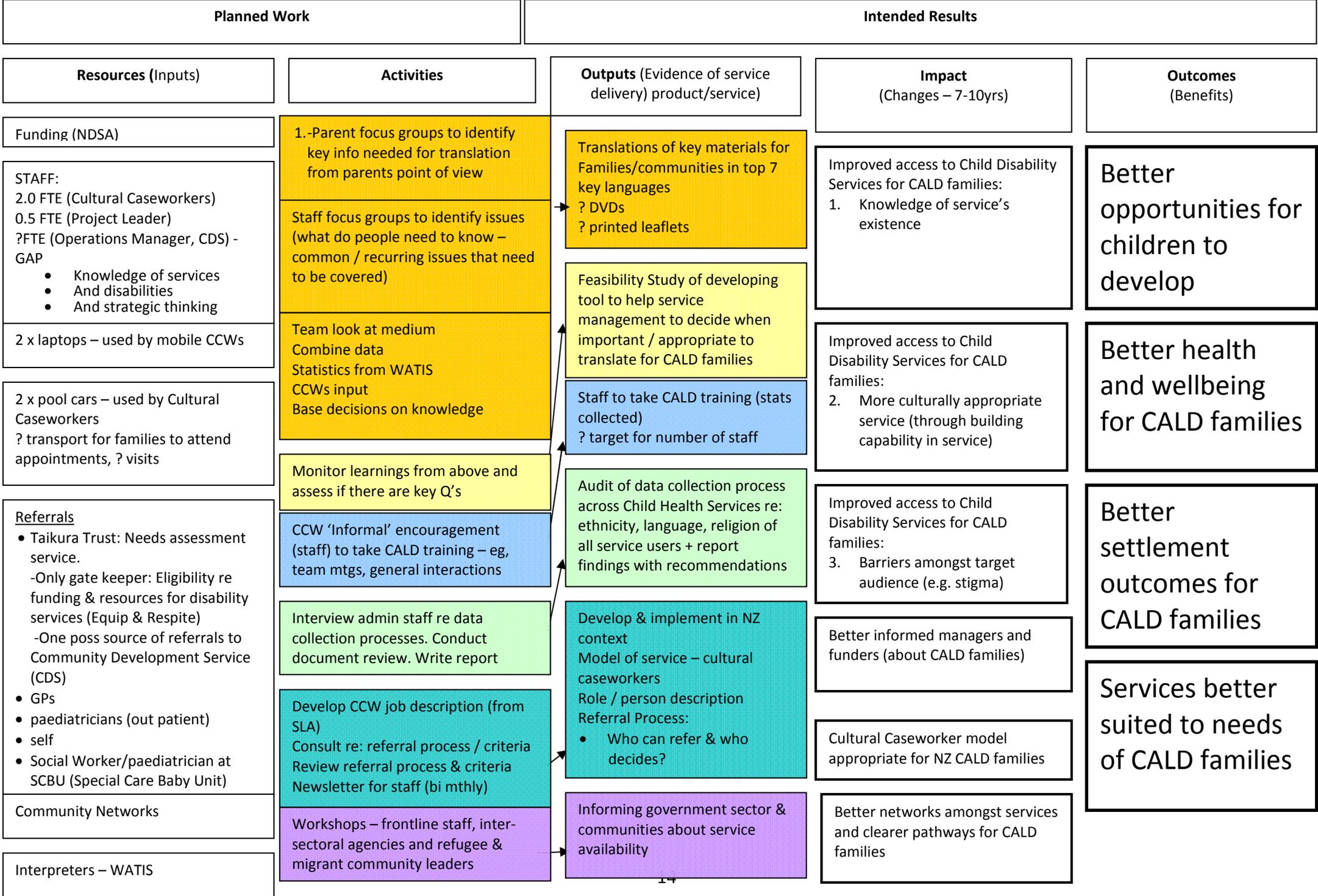
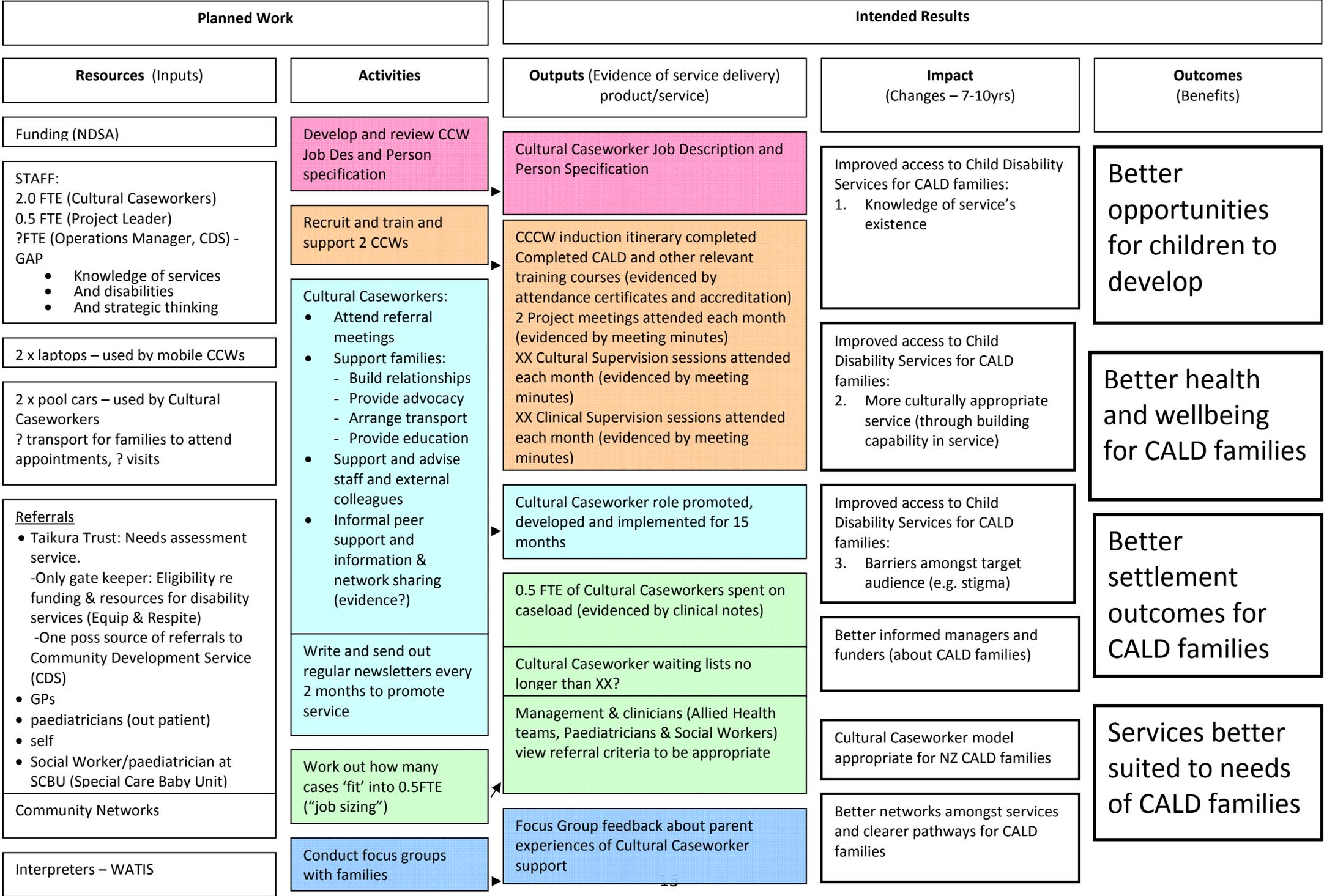


Diagram 3: Programme Logic Model Cultural Caseworker Model of Service



### **Support mechanisms in place for the CCWs**

In seeking to better understand the workings of the Project, the research investigated the different ways in which the CCWs are supported to perform their roles. Table 1 contains a breakdown of the current support structures that were in place, as reported by a number of KIs. As can be observed, a range of different support options were identified, with each fulfilling a particular function.

**Table 1: Current cultural caseworker supports**

	<b>Description of the activity</b>
CDS clinical and line management	<p><i>Weekly meetings:</i> The purpose of regular weekly meetings is to provide regular contact times for the CCW and TLs to discuss any issues relating to their casework or other tasks.</p> <p><i>Open door policy:</i> The TLs reported that they are available and have an open door policy in place for all staff members.</p> <p><i>WDHB policies and protocols:</i> One TL asserted that staff safety protocols are in place to protect the team members. An example of this is the TLs need to know how to contact staff at all times and that the in/out board functions to collect this information.</p>
Project management	<p><i>Bi-weekly project meeting:</i> It was reported that the purpose of this meeting is twofold. Firstly, to focus and progress work being done on translating documents, and facilitating parent focus groups and seminars that support the health services and the CCWs in working with the CALD families. Secondly, the meeting enables other matters related to the project to be discussed and assess what is/is not working well and potential changes required.</p>
External cultural supervision	<p><i>Monthly meetings:</i> KIs reported that cultural supervisors were identified and chosen by the CCWs for their particular skills and ability to meet the needs of the CCW. The purpose of cultural supervision was reported as being able to provide the CCW with cultural support from a person who is knowledgeable, experienced and has an appropriate cultural understanding. Evaluation findings suggest that external cultural supervision was in place for one CCW before the data collection period ended (and that this was reportedly working well) whereas it had not been established for the other CCW (although it was being accessed unofficially via a well-networked individual working in the sector)<sup>3</sup>.</p>
Clinical supervision	<p><i>Fortnightly and monthly meetings:</i> It was reported that formal professional supervision meetings enable the CCWs to discuss the following types of issues: how they are coping in situations, barriers to their work, practical issues, and other issues they want to discuss. The frequency of meetings differs between the CCWs given that one is a qualified social worker (meets on a monthly basis) and, at the time of the</p>

<sup>3</sup> The research did not establish why on-going external supervision had not been put into place on a more permanent basis for this CCW, although one Taskforce member highlighted that there was a shortage of appropriate individuals available to fill this role.

	<p>research, the other was in the process of studying (and thus supervision meetings were held fortnightly).</p> <p><i>Informal discussions:</i> It was reported that the CCWs took regular opportunities to discuss issues, and keep the supervisor updated on recent developments and intended actions with regard to particular cases.</p>
Peer support/supervision	<p><i>CDS team meetings and meetings by discipline:</i> KIs reported that weekly team meetings and formal meetings for the health professionals (e.g. social workers, occupational therapists, physiotherapists, speech therapists, visiting neurodevelopmental therapists) provide an opportunity for peer support/supervision by discussing cases.</p>

### *Issues relating to support and supervision for the CCWs*

Six months into the project, a restructure took place within WDH Child Health Services that saw the line management of the CCWs change. Before the restructure the CCWs received both clinical and day-to-day or line management from the operations manager; after the restructure this changed to the CDS team leaders (see previous organisational diagram).

On the whole, the day-to-day functions and tasks of the CCW role did not alter. It was believed by one KI that the change would be an improvement, as the CCWs would report to the team leaders (TLs) in the same line structure as the CDS teams. It was, however, recognised that the overall management structure was a different concept for the TLs to contend with – with the structure described by one KI as a “*matrix management*” framework where the CCWs do not report solely to the TLs, but to respective managers or members of the different services they are working within, as well as the project leader. Moreover, whilst the TLs had an awareness of the Project and had some (limited) involvement in the development of the initiative, they were largely unfamiliar with the Project. Therefore, it was reported that following the restructure the TLs needed time to learn more about the background of the Project, the CCW roles and what managing these staff would entail. One TL interviewed soon after taking over this new role reported that:

*I kind of felt a little bit at sea and also his role within the team, although it's an Allied Health team it's very different as well, so it was a new person, a new position, and then a new fit into the team as well. [P1]*

Additional interviews conducted with the TLs four months after the restructure identified a shift in perspective in relation to concerns raised around management of the CCWs when working in other Child Health Services. An example of this change was reported by one TL who had come to understand that it was not necessary to know what the CCWs were doing at all times:

*It's a bit like the dietician, I wouldn't have a clue what they're doing and whether it's good practice, poor practice, evidence-based practice or a bit of quackery. I just wouldn't. So we do I suppose rely a lot on the fact that there's internal supervisors..... The supervision model ensures that there's some accountability to the organisation, too, as well as the professional and the children. [P1b]*

Of note, concerns around an unmanageable increase in their workloads did not eventuate. One TL did, however, feel under pressure to facilitate some of the additional project work (e.g. organising the parent seminars) but realised later that this could be performed by the project leader.

## **How CCWs are supporting families – a description of key activities undertaken**

In seeking to better understand the Project, the research explored how the CCWs have been supporting families to date, in terms of the specific activities undertaken. This information was gathered via interviews with CCWs and other KIs, as well as during the case study work. Whilst some KIs were able to share personal examples of working with the CCW and detailed narratives of the different types of support provided, others spoke from a more observational stance. It is important to note that KIs spoke about both the level and nature of support provided by CCWs as being fluid, in that a family's needs may fluctuate over time. One KI highlighted that, in particular, support needs may be more intense at initial engagement:

*Families at the beginning or at different stages of the child's life require different intensities of input so it might be at the very beginning it's very intensive because there's lots of things to get organized and then over a period of time the intensity reduces as the family are connected with the right people and then the cultural case workers will drop back to more of a monitoring role. [P9]*

The main types of support identified in the research can be grouped under the following broad headings: building relationships and trust; education and information sharing; advocacy; linking families to other services; and, practical support. A description of each of these is presented below.

### ***Building relationships and trust***

- Examples of the CCWs building relationships and trust with CALD families were identified in the research. This involved taking time to get to know the families they worked with, finding out about their backgrounds, and gaining an understanding of their needs.
- The research identified that much of this took place in more informal ways, particularly during initial interactions with the family (e.g. via casual conversations about a range of issues).
- Both CCWs and other KIs who worked alongside the project highlighted the importance of this facet of the CCW role – particularly in terms of it being the basis from which all other work could develop. It was also viewed as having a key role to play in engaging with families – and in facilitating families' access to other health services.
- Relationship building with CALD families was evident within some of the other activities reported below (e.g. a key part of the CCW's advocacy role involved establishing a relationship with family members).

*“You can’t just go in there and say I’m here to do business. It’s cup of tea, how’s the family, how’s the family back home, then you’ll hear the story, I’m not well, somebody’s died.... So traditionally, what would be an hour’s worth of meetings, of working with our communities, would probably be three, four hours, but I tell you those three, four hours, the trust building, the relationship building, and the information the worker will get out of them that maybe the GP is not able to get out of them”. [P24]*

*The most important thing is trust. The first time I approach the family I offer my trust and ask them to trust. For that ground creates more understanding and gives me a chance to tell them this a, b, c, I can do. This d, e, f, I will ask someone has to do for us. [P7]*

### **Education and information sharing**

- The research identified a range of areas where CCWs are providing education and information on ‘life in New Zealand’ for CALD families, including topics such as:
  - health systems
  - the education system
  - views of disability
  - how communities operate.
- This was generally undertaken as a part of casework with families, and via informal discussions. There were some examples identified where CCWs were providing information and education as part of organised meetings with other service providers (see below).
- Whilst parents appear to be the main focus of such activities, KIs highlighted instances where wider family members (e.g. siblings, grandparents) were also targeted.
- Examples of more formal education included facilitating families’ attendance at a Disability Expo, which allowed the CCW to share *“this is the NZ [health] service and how it works”*, and at the parent seminars.

*Time to explain him that how New Zealand neighborhood watch works, how police New Zealand have something called Community Policing Liaison Officers, I told him everything in New Zealand based on the community and you are part of the community so you need to share your neighbors the difficulty that you are having to get a support. [P 7]*

*They can provide a culturally specific service, they can bring them to the right place and provide information relevant to their particular disability, that can assist them. [P20]*

## **Advocacy**

- KIs reported advocacy-type activities being undertaken by CCWs, whereby they acted as the 'voice' for their clients.
- This often arose in situations where the relationship between a service and the family had broken down or reached a crisis point; sometimes due to a misunderstanding or because of language barriers and/or a lack of communication.
- KIs reported that CCWs took on such a role within family meetings, multi-disciplinary meetings with a range of agencies, as well as between the family and individual health workers.
- The advocacy role was reported as being somewhat fluid in that the CCWs were seen to be variously representing the family unit, the parents, or the disabled child in different circumstances.

*He also met with the staff of the preschool that the child was going to and gave them a really good understanding of how the client, the family might be perceiving things differently and he was very proactive at bringing together a family meeting [P1a]*

## **Linking families to other services**

- Examples of the project staff linking families to other services were provided in the research.
- This included setting up meetings with other service providers (e.g. UMMA Trust) and providing CALD families with links to agencies that could provide further assistance (e.g. respite care).

*He [CCW] brought a family from, I can't remember where they were from... but they had a special needs child and they wanted more information about the resources available for their child once he starts school, so he brought them to meet with me. [P21]*

## **Practical support**

- It was reported that the CCW role is a "hands-on" job, with some activities undertaken by the project staff of a more practical nature.
- Some examples provided in the research included CCWs transporting families to meetings, helping them access appropriate housing and furniture, and providing assistance with WINZ applications.
- In some cases, it extended to "doing lawns, helping people with their immigration issues or with the children's education issues".

*She said he 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 it's rejection, she's not eligible for the Housing New Zealand houses. He even asked her if she's intending to move out, then she will need furniture so the easy way is to look for second-hand furniture. He helped her with that, he brought her himself the furniture from other people who are going overseas. [CS3].*

## **How CCWs are supporting services– a description of key activities undertaken**

The research also explored how the CCWs have been supporting services to date, in terms of the specific activities undertaken. This information was gathered via interviews with CCWs and other KIs. The key types of support identified in the research can be grouped under the following broad headings: language and cultural support; liaison between services and families; coordination; and, cultural education. A description of each of these, along with examples from the research, is presented below.

### ***Language and cultural support***

- A key project activity reported by KIs was the delivery of language and cultural support. This entailed CCWs translating on behalf of services, as well as interpreting the needs and requests of CALD families.
- The service provided by CCWs was differentiated from that provided by generic interpreters, given their level of understanding of the families and their culture (via previous relationship building).

*[CCW] jumped and he said look, I can see that the father, he thinks that it's only going to be him that's going to get graffiti so that everybody in the meeting said no, no, it's not just you, it's everybody, but an interpreter wouldn't have easily done that. So it just makes communication perhaps easier. [P14]*

*[CCW] started at our service and I said to him I was having difficulties with this family ... I know the child needed the equipment but they were reluctant to get an interpreter in and I was really battling to establish exactly what their needs were, what they wanted...he [CCW] went in and he spoke to the family, being able to speak their language, being in the position of a cultural support worker with our service rather than being an interpreter from another service, the family were more open to him, more open to working with him and speaking about their concerns with him. [P13]*

### ***Liaison between services and families***

- The research identified examples of the CCWs acting in a liaison capacity between CALD families and different service providers. This mostly occurred when problems or issues had arisen – often related to a lack of cultural understanding or communication issues.
- It generally entailed the CCW working with both the family and the service to identify what the issue was, and working to bring about a resolution between the two parties.
- In some cases, where the service provider was unsure how to proceed, the CCW was able to explain the perspective or position of the family.

*[CCW] was a very good broker getting Taikura on board to look at options and he's built a relationship with Laura Fergusson and visited sites with the father and got a good outcome for dad. [P1b]*

*[CCW] said he had a contact at the Ministry of Ed Special Ed and I think [both CCWs] and the whole family went with them at Ministry of Ed and they had like a little family's meeting. [P12]*

### ***Co-ordination***

- It was highlighted that, in some cases, CCWs had taken on a co-ordination role, and were streamlining processes for all those involved.
- This involved bringing together all stakeholders involved with working with a family, as well as carrying out some of the organisational tasks (e.g. setting up meetings, sending out information, etc.)

*When the CCW became involved he was able to act as a bridge and fill the gaps between all the agencies...in pulling everything together and making sure that people understood the rationale behind some of the decisions of ... the parents and child's point of view but also from the agencies' point of view [P9]*

*It takes a lot of extra co-ordination when you've got external services involved because you're ringing numerous people trying to get hold of lots of different people and relaying the same information but in a slightly different way depending on who the audience is, and when you don't have somebody who's taking overall responsibility for that, information gets missed and it's really messy, and so the cultural case worker not only took on the cultural aspect of that case but also the key worker as well, so it was a combination of the two that worked incredibly well. [P9]*

## **Cultural education**

- It was reported that CCWs have been educating services with regard to a range of issues affecting CALD families. Key issues identified in the research included:
  - cultural perceptions of disability;
  - cultural and religious issues (e.g. family structures within different ethnic groups);
  - the challenges facing migrant and refugee communities (including background on ‘life before New Zealand’);
  - appropriate ways of working with families (e.g. protocols when undertaking home visits).
- This was generally undertaken as issues arose, via one-on-one discussions between services and the CCWs.
- It was also reported that the CCW model has provided the opportunity to educate health staff in a more formal way by organising “speakers from a few different agencies” to speak about what they can do with, and for, CALD families.

*I had a shared client with [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 [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]*

## **Barriers for CALD families in accessing the service**

As a way of better understanding how the Project was working, and for whom, the research explored potential barriers for CALD families accessing the service. It should be noted that it was beyond the scope of the evaluation to involve CALD families who had not used the CCW service. This includes, for example, families who had declined a referral to the project, had difficulty accessing the Project, or who were unaware that the service existed. Thus, it is not known what the barriers for these types of families might be in relation to engaging with the CCWs. Interviews with key informants, however, explored perceptions of what might make it difficult for families to access the CCW model. Some of these were based on experience, and other were put forward as potential barriers given the nature of the client group that the Project seeks to work with.

Key barriers identified included:

- KIs spoke about the referrals process acting as a barrier for some families. In particular, it was noted that families needed to be engaged with CDS before

they could access the CCWs, which may be a source of frustration for family members who find out about the cultural case workers within their community and expect to be able to access them directly. Moreover, it was highlighted that negotiating the referrals process requires families to have a certain level of knowledge of New Zealand's health system (e.g. being able to navigate their way around different agencies and/or knowing what service options are available).

- Findings suggest that some health workers were acting as gatekeepers in terms of facilitating (or not) CALD families' access to the service. For example, one KI reported that they found it difficult to establish an individual's eligibility for referral, due to feeling uncomfortable asking people about their ethnic or cultural background (and, therefore, possibly resulting in a family not being referred). In other cases, health workers were using their own judgement regarding an appropriate time to make a referral (e.g. in circumstance where there were no perceived problems, families may not be given the opportunity to access additional support via the CCWs).
- Stigma or a sense of shame associated with disability was put forward as a possible reason for families not connecting up with the Project. Findings from the research suggest that much of the stigma associated with disability amongst CALD families originates from their home country, where perceptions of disability may differ significantly from New Zealand (e.g. that having a child with a disability is punishment for a parent's 'bad' behaviour). Particularly given the small size of migrant and refugee communities within New Zealand, it was highlighted that this may mean that some families are reluctant to access the Project, due to a fear of others finding out about their situation. One research participant highlighted that some families may not even be comfortable disclosing their child's disability to a health service provider, due to the shame that they feel. Another KI indicated that, similar to the family violence sector, CALD families may not feel that it is acceptable to ask for help, because of a belief that they are somehow responsible for their child's disability.
- One KI highlighted that some families might be reluctant to invite the CCWs into their home if there were other issues present that they wished to keep hidden (e.g. care and protection issues).
- Another interviewee suggested that some families may prefer to wait until their residency is confirmed before engaging with a service, due to not wanting *"to leave some kind of bad history or record on their document"*.
- One CCW also suggested that, given the background of refugee families, they may be wary of engaging with any *"government agencies"*, including health services, due to their perception of the power and authority that these institutions hold.

## **Barriers for services in accessing the Project**

In developing an understanding of the workings of the project, interviews with KIs also explored what the barriers were for services with regard to engaging with the CDS Project. The key obstacles identified in the research included a lack of familiarity with Project staff, a lack of knowledge of Project offerings, perceived inappropriate timing for CCW involvement, as well as a small number of other barriers. Each is discussed in turn below.

### ***a) Lack of familiarity with Project staff***

As highlighted earlier, KI participants varied in terms of the level of interaction they had had with the Project and the CCWs. Consequently, a lack of familiarity with the Project staff was raised as an issue by some KIs. These individuals spoke about the fact that they had had little to do with the CCWs, and therefore lacked knowledge of their skills and track record. One KI noted that this could act as a barrier, particularly given the importance of trust within such a relationship:

*I think it's around the trust thing. We had to know we could trust [CCW] and I suspect now [name of other CCW] has got to prove himself. [P1a]*

Given the above, some KIs indicated that they were reluctant to refer families to the service until they either formed a relationship with the workers, or they knew more about them. As evident in the following extract, one of the KI participants indicated that they would need to be certain that there were clear advantages for the family, before making a referral:

*I think for me, it would be because our families meet so many people I would need to know it was beneficial and not just thrusting another person at them for no reason, and because I don't always know, because I don't know these people so well, because they're not members of my team, I don't know their skills, so that would make me hesitant, too. [P2]*

It was highlighted by some KIs that this was not an unexpected issue given the relative infancy of the Project, and was something that would be resolved over time once potential service users engaged more with the Project:

*Once they start to see, that's what I've found, some staff are really engaging with him [CCW] a lot and other staff are not really and it's just that once they see the benefit of him being involved with brokering things and just being a bit more of an informant for the families then those therapists are just like, wow, now I've got this one, now I've got this one. Some people haven't really gone there yet. [P1b]*

In addition, there was evidence that this issue had abated somewhat further into the Project's development (i.e. spoken about less during KI interviews conducted later in the evaluation). At this time, there was evidence that some potential service users had greater familiarity with the CCWs. For example, one team had identified "champions" who had utilised the services of the CCWs, and were communicating the positive benefits of involving the CCW at an early stage of engagement with CALD clients, and the project itself.

### **b) Lack of knowledge of Project offerings**

Whilst a number of KIs had a broad understanding of the aims of the project, and some of the activities being undertaken, they were unsure of the extent – or specific nature – of the project offerings. Findings from the research suggest that this had impacted on the level of uptake of services amongst some potential service users:

*I was thinking that now [CCW] has started that he could perhaps go along to a meeting of the [health professionals] and just introduce himself because [name of other CCW] did some really good work with one [health professional's] client but that's all, that's the only referral he's had..... I guess they're in the same boat that we were in the beginning, not knowing how to use them, so even if he could talk about the work that he'd done with that particular [health professional's] client as a case study and so they could see how that might be working for them. [P1a]*

In addition, it appears to have contributed to some service providers limiting the number of families they referred to the project:

*I guess I don't know if we are using them to their full potential because we're certainly only using them with two families at the moment and I don't think perhaps I've actually met with them enough to work out where they could be useful with other families because obviously I see other families. [P2]*

One KI who held a management position within a health service highlighted that they had a key role to play with regard to both families and potential service users accessing the project: *I think if people like me in my position don't have enough information about how you can use it, it's not going to get used, because we pay a pivotal role in reaching families. I think that's my own fault".*

### **c) Perceived inappropriate timing for CCW involvement**

The CCW model was set up for referrals to be made from a range of services including CDS, Out of Home Respite and Child Rehabilitation; later, these criteria were extended to Home Care for Kids and Paediatric Services. KIs added that referrals can be made from other services (e.g. Plunket) or directly from CALD families. Where the family is not currently engaged with WDHB Child Health Services they may need to first be assessed by Taikura Trust<sup>4</sup> before engaging with the health services and/or utilising the services of the CCW. Generally however, referrals are made to the CCW, based on the judgment of the key worker involved in the family's case.

Discussions with KIs revealed a perception that involvement with the Project was most appropriate when families were facing particular problems – or found themselves in a crisis situation, particularly when circumstances were such that an impasse had been reached between family members and their health worker. Thus, some KIs were not referring families who did not meet these criteria – e.g. 'new'

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<sup>4</sup> Taikura Trust is Auckland's (Mercer to Wellsford) single facilitator of disability support services.

families they had recently begun working with and/or where there was no evidence of specific problems or challenges:

*If it's not, everything's going flowingly, the family seems to be accessing lots of things in the community, settling in, and they don't see the need to have a cultural case worker. I mean I will make sure they have the information about what's out there. No, I don't think I will push it. [P14]*

One KI spoke about the importance of timing in relation to engaging the CCWs. As they explain in the interview segment below, there were particular stages of the process when families were coming to terms with their child's disability that may mean CCW involvement is not appropriate:

*A lot of the time, and I don't know again with our families, it's very early stages for our families and a lot of them are still grieving so they're perhaps still in that denial stage or even the anger or whatever but particularly the denial, so it may be that yes, the cultural case workers need to come back in a month or so when they perhaps are a bit further along the line. [P3]*

Whilst one KI reported that they generally only referred families who they had 'problems' with, they also acknowledged that they could see the CCWs playing a role earlier in the process – and highlighted that a lack of knowledge of when an appropriate time to refer was impacting on the level and timing of their referrals:

*It's quite a new concept and I think at this point in time it's only families we're running into problems with that we are using them as a resource, using them to support, but I think there certainly is a place if they were on board earlier, I think that might still develop with time. Even just for us to know which families we should be referring to them or not. I don't think we should be waiting to run into a problem before they're supported. I think there is a place for them to be supported before but I'm not too sure we know as allied health staff when to refer to them. [P12]*

#### **d) Other barriers for services**

There were several other less common issues that were raised by KIs as potential barriers to accessing the CALD Project. These included:

- *workload issues*: it was highlighted that staff were sometimes “too busy” to consider making a referral; moreover, one KI reported that they were reluctant to “overload” the CCWs and had therefore refrained from referring some families.
- *the ethnicity of the CCWs*: one KI described how the ethnicity of the CCWs was a consideration when making referrals to the service, and that they limited referrals to families that were of the same ethnicity as the CCW
- *lack of families that fulfil referral criteria*: one KI reported that they worked with few CALD families.
- *lack of processes to make referrals*: one participant recognised that “we haven't got a process” for linking up families with a CCW, and that initial engagement with a family new to the service might provide a good opportunity to ask family if they would like to meet the CCW.

## Characteristics of a CCW

Key informants and case study families were asked to share the characteristics they looked for in a CCW, in particular whether the age, gender, culture, ethnicity or religious background of the CCW was important. The following outlines the feedback that was provided during interviews.

- The *age* of the CCW was generally not viewed as important, although a couple of participants believed an older or mature person might have more experience and wisdom, and as a consequence be more acceptable for families.
- Some participants did not think the *gender* of the CCW would be an issue for families. However, others felt that there were pros and cons for having either a male or female CCW, depending on the cultural or religious background of the families. For example, it was believed that males would be more acceptable to those from patriarchal societies.
- When asked if the *religious* background of the CCW was important in being able to work with CALD families, rather than adhering to a particular religion, participants reported that it was more important for the CCW to be respectful and have an understanding for the religious beliefs and background of the families they worked with.
- Participants generally felt that, whilst there were advantages in matching the *ethnicity* of CCWs with the families they worked with (e.g. concordant language skills), it was not a realistic expectation given the diversity of ethnic groups residing in Auckland. Instead, participants reported that having someone who understood the diversity between, and within, different ethnic groups was more important.
- One participant reported that were advantages in having a CCW who had come thorough the New Zealand education system, whilst others asserted that this may not be necessary if the person had a good knowledge of New Zealand's health sector.
- Overall, participants reported that the most important attributes for a CCW were: friendliness; team player skills; honesty; openness; warmth; good listening skills; knowledge of disability issues; knowledge of the services available in the health sector, local community and other government agencies or NGOs; an understanding of the stigma that may impede families from seeking help for their children; and, an understanding of the difference between migrant and refugee families.

## **Project impacts**

A key aim of the evaluation was to gain a better understanding of how the Project impacts on families and communities, including what works/does not work, and for whom. This section outlines the main findings in this area, including the reported benefits for CALD families and services, and the perceived strengths of the Project.

### ***a) Benefits for CALD families***

The perceived benefits for families in engaging with the CCW model were explored in interviews with KIs, including the CCWs. It should be noted that the benefits for families discussed below are drawn from the interviews with KIs (who were in a range of different roles, but many of whom worked directly with CALD families) as well as the case study data.

Key informants reported that engaging with the CCWs and the Project had resulted in a range of benefits for families. These often related to the resolution of problems that had developed prior to the CCW's involvement – and which the CCWs played a key role in addressing. As noted by one KI, *“from what I've been hearing there have been some quite remarkable stories of changes in families for better outcomes for their children which is fantastic”*.

The key benefits identified 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 Project, it was reported that CALD families' access to health and other services had improved. This included access to government services such as Housing New Zealand (HNZ), Work and Income New Zealand (WINZ), Ministry of Education (MOE) Special Education services and Immigration, as well as health-related services such as hearing, dental, optometry, psychology and psychiatry and Child Disability Services. Findings from the research suggest that this was achieved via educating families in terms of what was available, as well as organising meetings with different providers to facilitate information sharing:

*He's played a pivotal role with the medical profession in getting the dietician seeing to him, because the parents have concerns about his feeding, he was doing a lot of vomiting and losing weight, losing condition. A lot of seizure activity, and the parents felt that the medical profession, the doctors and nurses were not hearing what they were saying. [P13]*

A KI who worked in the disability sector spoke about a child they were working with and their attempts to get them into a different school. As a result of the work undertaken by the CCW – and their connections within educational networks – they reported that progress was being made in relation to securing a place for the child at the school. Other examples identified that as a result of improved access to health services, families had secured the correct equipment for their child.

One of the CCWs spoke about the sense of isolation that many migrant families experienced when coming to New Zealand, with communication a key contributing

factor. As presented below, he claimed that engaging with the Project enabled families to more comfortably access health and other providers:

*Migrant communities are generally isolated from the mainstream service because of lack of information and language barriers and sometimes they feel intimidated to contact English speakers and so through me they feel more comfortable to access to service. [P8]*

*An example from the research:* Luke was referred to a doctor after displaying behavioural problems at school. The normal process would have seen the paediatrician making 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 co-ordinator 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 at school.

### *Reduced isolation*

As highlighted previously, a key issue raised in the research was the sense of isolation commonly experienced by CALD families. This was not only linked to the fact that they were in a new country, often far away from social and family networks, but was also a result of the (sometimes self-imposed) withdrawal from the community due to a sense of shame about their child's disability.

The research identified that some families had experienced reduced isolation due to their engagement with the Project. An allied health worker who participated in the research provided an example of how engaging a CCW had resulted in one family she worked with linking up with other people in their community. She reported that her initial request to the CCW had resulted in a network of mothers being established, who had found the additional support from others in a similar situation very beneficial:

*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]*

It was also reported that one of the CCWs had linked up a family with another cultural social worker who had provided coping strategies for the mother to help reduce her isolation, and in one case study it was identified that the parents had

been encouraged to meet other families to help develop their own social and language skills.

*An example from the research:* John has been living in New Zealand for eight years but has had little time to investigate what is available for his family because he is always working at one of his two jobs. His wife is home-bound looking after the children, and because she speaks only a little English and cannot drive she is heavily reliant on her husband. The CCW has linked up John to a local organisation where he has been introduced to the centre's co-ordinator, who spoke to him about what they offer (e.g. playgroups, and a women's support group). The coordinator has provided him with a couple of food parcels (containing rice and flour) and a pamphlet outlining what they do. The CCW subsequently encouraged John to bring his wife along, so that she could interact and socialise with other women and improve her English skills at the same time.

### *Increased knowledge*

KIs spoke about the importance of educating CALD families about life in New Zealand. This was considered particularly important in relation to how health and social services are structured within this country, given that similar services in their home country are likely to be organised very differently, or may not exist at all.

Both the case studies and interviews and discussions with KIs identified that a key benefit for families had been an improvement in their level of knowledge about a range of issues. This included knowledge of: the New Zealand health (and other) systems; financial and other entitlements; and, health issues relating to their child:

*He give me morally, he 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]*

*An example from the research:* Sarah was engaged with the CDS service and was described as having very high expectations and demands. This led to a situation where both the mother and service were becoming frustrated. When the CCW became involved in the case the first thing he did was educate the mother about what the service could and could not do, giving her clear guidelines about what she could expect from them. The CCW then set about working alongside the other health professionals and services involved in her case, facilitating a multi-disciplinary meeting, divvying up tasks, and reporting back to the mother on the progress that was being made. The CCW also explained to the mother what the New Zealand health and education system is like, and what her responsibilities towards her child are. The CCW notes that even though she is not included in this process (of attending the meetings), she remains involved in the background, and her attitude has slowly changed. The CCW reports that Sarah is now very happy with the progress that is being made in her son's case.

### *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, as well as facilitating access to furniture and food parcels:

*She said he 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 it's rejection, she's not eligible for the Housing New Zealand houses. He even asked her if she's intending to move out, then she will need furniture so the easy way is to look for second-hand furniture. He helped her with that, he brought her himself the furniture from other people who are going overseas so that she can put it on one side in the garage whenever she moves out. Still helping her to find a house for rental. So she's very, very grateful. He made all the difference. [Rachael]*

Moreover, it was reported that the involvement of the CCW – and subsequent resolution of on-going problems – had resulted in a reduction of stress for families and had increased their happiness and well-being:

*He [CCW] worked with the family and the result is we've got a toilet chair that works for him, we've got a very happy father, very happy mother, and it's just made my whole process incredibly easy. [P13]*

### **b) Benefits for services**

The key benefits for services, as reported by KIs, can be grouped as follows: improved cultural knowledge and understanding; improved relationship between health services and families; and, streamlining of processes. A description of each benefit is provided in the following pages.

#### *Improved cultural knowledge and understanding*

As a result of engaging with the CDS Project, KIs reported that their cultural understanding of the families they worked with had improved. This related to issues around the families' ethnicity, culture, religion and migrant or refugee background, religion, as well as the culture of disability amongst CALD families. The following interview extracts provide an insight into how KIs reported improvement in their cultural knowledge:

*I had a shared client with [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 [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]*

*Much more culturally aware and the competence is developing. The confidence is, I think, in working with the families is developing, but having the ability to come back to the office and say to [CCW] I've just met this family and this is what they're like and this is what the mum needs and what do you think, it's huge in lightening our workload and understanding these families and understanding their needs and being able to work with them effectively and appropriately, it's huge. A huge benefit to our service. [P13]*

One of the CCWs acknowledged the importance of increasing cultural understanding amongst their colleagues, including insights into CALD families' lives before arriving in New Zealand, and highlighted the knock-on benefits that this had for families:

*Even our colleagues to tell them point of the cultural view what these families culture that they came from, what that culture believes, what difficulty they were experiencing before they come to New Zealand, what is their expectation and demand in New Zealand is about. All those things. Our colleagues are having better knowledge, I believe the family will have better knowledge. [P7]*

As a result of increasing their knowledge of cultural issues, KIs reported that they had developed a greater understanding of the families they worked with and were able to provide a more culturally appropriate service. They also spoke about feeling more confident in working with their clients. An additional benefit of improved cultural knowledge and understanding identified by KIs was the potential for building capacity more broadly within health services, so that 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 service and hopefully in the wider child health services to meet needs. [P16]*

A KI suggested that workforce development in this area would continue to grow via ongoing cultural competence training. One of the CCWs added that it was particularly encouraging that there was a drive for all staff members to participate in the training. It was believed that those who had done so were better placed to understand the cultural context within which they worked, and better able to envisage how the CCW service could benefit them and the families.

*An example from the research:* A health worker was having trouble getting a migrant CALD family to engage in services that would help the development of their child. Reaching an impasse, the health worker made a referral to the CCWs believing the reason for declining the service may have been cultural. The CCWs ascertained that the parents came from a hierarchical structure where the decision maker in the family was the grandfather who lived back in their homeland. Importantly, the grandfather believed there was nothing wrong with the child in comparison to his other grandchildren and this was the reason the family had continued to refuse the service. The CCWs are continuing to work with the family recognising that as the family become more exposed to New Zealand's way of life, they will need to be supported and educated, but accept this will be a slow process.

*An example from the research:* A refugee family had been resisting a health provider's attempts to block a balcony within their home to improve child safety because the family enjoyed their view and wanted to keep it. The CCW was able to provide the health worker with background information on the family, including the fact that the father had previously held a very good job and the family were wealthy in their homeland. The CCW explained that the father was having difficulty in reconciling the fact that they were now refugees, and he felt powerless since being in New Zealand, so retaining their view was something that was important. An alternative barrier for the balcony was therefore devised by the CCW, who used his community networks to fund and complete the work for the family.

### *Improved relationship between health services and families*

As highlighted previously in the report, findings suggest that CCWs have played a key role in liaising between families and other agencies, particularly where there have been areas of conflict or difficulties in resolving problems. In such circumstances, CCWs have acted as mediators between different health and disability services and families, and provided information and cultural insights for the parties involved. As a result, a key benefit for services, as identified by KIs, was an improved relationship between families and health services.

Indeed, several KIs spoke about the role that the CCW had played, and the difference that their involvement had made in this capacity. One interviewee highlighted an example where communication with a particular 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 (specifically the information they provided to the service provider working with the family), the therapist gained a better understanding of the family's background and relations had subsequently improved:

*I could see more 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 and we both say thank you, it was helpful, 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]*

In one case, the CCW's education of the family, with regard to informing them about their responsibility for their child, resulted in the resolution of an ongoing issue around child safety. The health professional working with the family was subsequently able to find a workable solution to the problem that satisfied all parties involved.

*An example from the research:* Due to language barriers, a health provider was having difficulty communicating with a family about the equipment needed for their child – which meant that the child did not have access to important apparatus that they needed. However, the family did not want to involve an interpreter as they viewed them as an 'outsider'. In contrast, the CCW was perceived as part of the health service, and thus the family were more willing to engage with them. The CCW mediated between the family and the health provider, and was able to establish and communicate what the needs of the family were. The health provider was subsequently able to organise the appropriate equipment. As a result, relations between the family and the service improved significantly, and the parents were much happier knowing that their son had been provided with important equipment.

### *Streamlining of processes*

A number of KIs who had made referrals to a CCW spoke about the difference that engaging with the project had made in terms of streamlining some of the processes

involved when working with CALD families. Particularly in instances where there was a problem or issue to be resolved, it was reported that the CCWs undertook a number of the background tasks. This included activities such as setting up meetings, liaising with other providers, and collecting information from family members and other stakeholders:

*So a lot of the contact I had with the family was through [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]*

As a result of these different forms of support, KIs spoke about the subsequent reductions to their own workload – and the additional time and space it gave them to concentrate on other duties. Particularly where KIs such as physiotherapists and occupational therapists were working with large number of families, this was viewed as a key benefit of engaging with the project:

*Sometimes you're overloaded and you've got to take the children on anyway. So it adds a lot of stress to your workload and you work longer days, because you've got to, there's no other way to do it. But the benefits of [CCW] being in our service, I don't know what we would do without him. He's made things so much easier, facilitated so much benefit for the families he's seen.....To be able to say to him, can you make an appointment with the fencing family, and can you make an appointment with this mum who needs support, and can you help this family because they need some help with a housing modification. Well, I don't know what I'd do without him. [P13]*

One KI also highlighted that the CCWs' ability to communicate with families in their first language was key to reducing her own involvement in on-going discussions with a particular family. It meant that she did not have to attend as many meetings with the family, and avoided having to employ the services of an interpreter:

*I know that he'll update Mum because there's a bit of a language barrier...[Otherwise] I would have had to have arranged a meeting to meet with mum every time I wanted to inform her of something... I would have had to have phoned mum and got an appointment and set a time, but actually given enough notice to an interpreting agency to actually get somebody there and sometimes you can be there and they don't come until half an hour or forty minutes later than they should. [P18]*

In the extract above, whilst there were clear benefits for the health worker in terms of working in a more effective and efficient manner with the family, it also highlights how the CCW's involvement streamlined the family's journey through the service.

## **Strengths of the project**

The research identified a number of strengths associated with the project, as summarised below.

### **CCWs have a good understanding of – and ability to relate to – CALD families and the issues they face**

*What's been particularly helpful with [CCW] is that he, because our service deals with families with disability, him having that personal knowledge of disability as well has actually enhanced his role so he comes with two specialties, really, which must be wonderful for families because not only can they reach each other culturally but actually they can share experiences which is so valuable, too, so he's got an extra bit of chocolate, really. [P2]*

*[Name of CCW] has been a huge resource for us in terms of his refugee experience and his, again the male role and the male role in Muslim families and how we should be, I think sometimes we may be making assumptions or making in a mindset that we believe is right but he comes and brings a completely different viewpoint. You just think my god, this is what it's really like. [P1b]*

*As members of their own communities they do have networks and also having been through the refugee resettlements and immigration streams they have that experience and that knowledge. They can navigate their way through systems and ways and communities and be accepted in communities in ways that non-refugees and non-migrants won't be. Language obviously is a huge advantage and also similar religious background to families that you're working with is also a huge advantage. [P16]*

*I think there's a sort of a psychosocial component in terms of families possibly accepting more help than they may have otherwise because the cultural caseworkers can relate in a very real way to what it is to move country, to have lost everything, etc. [P16]*

*Being not new themselves to the Kiwi culture is probably an advantage and having a good understanding of the Kiwi disability culture, as well as different cultural disability perspectives [P1a]*

### **CCWs are effective advocates**

*What I see is best for cultural workers or what I see how it's worked best is that they have a feel of it. They go in there. This is what my people need, and they can make relationships while they're doing it. [P11]*

*I see that the case workers would very much be champions and advocates, for as I was saying earlier on they would be the ones highlighting where the gaps are because they're working with the families. [P24]*

## CCWs are effective at engaging families

*It's their ability to spend that extra time and listen to the families and also their ability to work holistically so not only be focused on the little bit that's service-related so they take the overall view of the whole family, as the child and their family as the unit. [P9]*

## Accessibility of the service

*Certainly having them based in our office is that constant reminder that they're there which I think if they were offsite or in another office I don't think that discussion would happen, so I certainly think that's a positive with them being in the actual office. You see them and you think oh I need to speak to them about something. [P12]*

*Having the ability to come back to the office and say to [CCW] I've just met this family and this is what they're like and this is what the mum needs and what do you think, it's huge in lightening our workload and understanding these families and understanding their needs and being able to work with them effectively and appropriately, it's huge. A huge benefit to our service. [P13]*

## CCWs have well established community networks

*As members of their own communities do have networks and also having been through the refugee resettlements and immigration streams they have that experience and that knowledge. They can navigate their way through systems and ways and communities and be accepted in communities in ways that non-refugees and non-migrants won't be. [P16].*

*I feel very proud to have somebody working within our team that I know is recognised as being quite a spokesperson, maybe, or a really strong representative within the Muslim community within New Zealand. [P1a]*

*One of the things is that the two workers are very different in the experience they bring and with looking at [CCW] he's negotiating his network with those agencies whereas [CCW] has a high profile with Housing. He came with that. That comes in his kite. So he can pull on that... But they're both getting very well connected because of the forums they've set up through the project, people are interested. And the thing that happens with projects and you get people as articulate as those two men... is they get engaged in conversations because people ask them. [P10]*

## Case studies

This section contains a summary of the case study accounts of five CALD families who had previously or, at the time of the research, were using the services of a CCW. These have been presented in narrative form, as a way of representing the participants' 'stories'.

The accounts below provide an overview of what life was like before the families came to New Zealand, their experiences when they arrived in New Zealand, when and how they came into contact with Child Health Services, and their experience of working with the CCWs. The level of detail provided within each case study varies, as interviews with the family members differed in terms of the content and nature of discussions, with participants sharing varying levels of information. Additional contextual information is provided, based on the researcher's observations and other information provided by the CCWs. Further analysis and interpretation of the stories was provided by the taskforce members. Pseudonyms have been used to protect the identity of participants, and the names of countries (outside of New Zealand) have been replaced with the names of stars in the solar system.

### a) Case study one

*Note:* Interviews for this case study were conducted separately with Moses (father of Abraham) and Eva (mother) at two different time points for each participant. The CCW was asked to support Eva, translating where needed throughout the interviews.

This story begins in one of the Red Sea countries, called Alamak, a nation that had been invaded by a neighbouring country. Moses recalls that as an 18 year old, he was studying, working part-time and fighting to free his country. By the age of 23, he became a fulltime active fighter and married a fellow freedom fighter; together they had two children. Moses recalls that their children were born in the forests of Alamak. These were dangerous times as they had to hide during the day for fear of being seen and killed; the men would stand guard while the women and children slept. Most domestic duties were done at night including cooking on a very small fire. In time, though, Moses became worn down by this way of life and fled to Chara. Alone, Moses arrived in Chara, where life seemed brighter and his tertiary qualifications enabled him to get a well paying job. He subsequently, remarried and had three more children. However, the conflict back in Alamak, and a fear of being discovered in Chara, led to him leaving. Moses then arrived in the country of Mira, but soon after Mira was invaded and he again found himself on the road, this time to the country of Kastr.

Eva's story begins with her having escaped her homeland of Alamak early during its occupation. She sought a safe haven within a refugee camp in the country of Chara. Eva recalls living in the Chara refugee camp for eight years and the feelings of depression that she felt living in these conditions. She was given a tourist visa, although it was obvious "*she was no tourist.*" With passport in hand, she made her way to Mira and stayed there for a year, but Mira was also invaded and, with no other option, she made her way to the country of Kastr.

Moses and Eva met along the journey from Mira to Kastr. They became good friends and they recognised the protection that marriage could bring, as the soldiers were known for raping the women and hurting the men. In the relative safety of the refugee camp in Kastr, Moses was given permission to leave the camp to work for the same company that had employed him in Chara. This, he explains, was a rarity and afforded his family a few luxuries that other refugees did not have. Eva became pregnant and the extra

money that Moses earned enabled them to pay for a foreign doctor to examine Eva, with tests revealing that the foetus was not developing normally. Eva gave birth to the couple's first child in a village near the camp but conditions were very poor and very unhygienic. There was little medical assistance so the couple had to travel to the nearest United Nation High Commission for Refugee (UNHCR) doctor. Where further tests revealed that their son, Abraham, had a severe disability. Two years later the couple had another child; this child was healthy and the couple were overjoyed. The difficulties and stress of caring for a disabled child in a refugee camp were rising for the couple and the Catholic Church the family had been attending whilst in the camp recognised the family's need for help. Investigations were made to see what options the family had, and New Zealand proved to be one of only a few countries that had a disability quota<sup>5</sup>. When the family were chosen to come and live in New Zealand, Moses explained that this was *"like a dream."*

Upon arrival in New Zealand in 1995, Abraham was immediately admitted into Starship Hospital with gastrointestinal problems and Eva stayed with him. As a consequence she had missed a lot of information presented to other new refugees about what life is like in New Zealand. Abraham is assessed as having a number of health problems requiring around the clock care. Six weeks after the family arrived in New Zealand, they were integrated into the community and they received help from their sponsors (members of a local Church). Their sponsors helped the family for a period of six months with the following: finding accommodation, transport and schools for the children; applying for their benefits; and finding the appropriate health services such as a General Practitioner.

Over a period of nine years, the family were provided with equipment for Abraham – bed, a lift, a vehicle, wheelchair, toileting equipment and a wide range of services from doctors, specialists, surgeons, nurses,<sup>6</sup> CDS and Wilson Centre Respite services. Eva recalls that it was difficult caring for her son around the clock. In particular, feeding him was hard, due to his inability to swallow. Eva recalls that Abraham had to go to hospital for surgery and this gave her *"a little break"* because ordinarily she got little sleep through the night. Moses has mixed emotions about the services that the family have received over the years. He recalled feelings of frustration due to a lack of knowledge around Abraham's care. However, he acknowledged that Abraham's carers have worked tirelessly and despite being *"very busy people they are kind."*

Circumstances changed for the family when Moses and Eva separated, and following this Eva's mental health problems re-surfaced. She needed care and support for her illness, and Abraham was placed into respite care.

As Abraham approached adulthood, there was a need for his family to find alternative care for him (due to the fact that the facility he was staying in was only able to provide care until he was 18 years old). When asked what difference having the CCW had made, Eva shares her deep concern at not being informed about her son's care. Eva says *"I was worried, worry, worry all, I didn't know about Abraham's life."* Since connecting with the CCW she felt that she is better informed as the CCW gave her regular updates about Abraham's care. Moses adds that the CCW in effect has acted as an advocate for the family, in terms of finding a solution that will allow their son to come home. Moses states that the CCW has on occasion *"knocked on every door that he knows and some doors was open."* He is optimistic that the family will see the benefits of the CCW involvement in his family's case. Moses asserts that *"I think we have now very concrete hope, proof of things to start with"* given the progress he has already observed in his son's case.

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<sup>5</sup> New Zealand has a commitment to ensuring that refugees with a disability are not excluded from the country's refugee resettlement quota; the CCW shared that the quota is 20 families per year.

<sup>6</sup> Within Waitemata DHB, Starship and Middlemore Hospital.

### **Other contextual information**

Information collected via interviews conducted with KIs and observations of the CCW's interaction with the family and the services providers involved in this case is outlined below to supplement Moses and Eva's story.

- The CCW has facilitated a number of meetings, including: meeting and liaising with the NGO Co-ordinator facilitating Abraham's transition from his current care-providers to Eva's home; organising meetings between the transition coordinator and Eva; meeting the mother's mental health team and doctor to see whether there are concerns around Eva having Abraham back at home; discussions with MOE refugee coordinator to cater for Abraham's schooling needs; regular updates between the current care providers and Eva and Moses.
- The CCW acts as a mediator between Eva and Moses. In particular, the CCW facilitated communication between the parents and secured their joint support for their son's future care plan.
- The researcher observed evidence of a good rapport between the CCW and Eva and Moses. He was also providing practical help and assistance in a number of ways, including assisting with lawns, encouraging the youngest son to renew his relationship with his mother, assisting with other family member's immigration matters and meeting for an informal men's coffee/support group.

### *Key learning from this case study*

#### **Family background**

- Both Moses and Eva had lived in refugee camps for a number of years before coming to New Zealand.
- The story demonstrates Eva and Moses' desire to survive and their resilience and adaptability to each situation they found themselves in.
- Refugee family members may have psychological issues (such as depression, anxiety, or sleep disorder) relating to the trauma they have experienced. This may impact on their ability to function in the settlement society.
- Eva largely missed much of the induction information provided about life in New Zealand that was given to new refugees; as such her adjustment may have taken longer.
- The family were reliant on volunteer sponsors to facilitate adjustment to New Zealand's way of life. However the family had high and complex needs which were on-going and the sponsor's role finished after only six months.

#### **Health related issues**

- Eva's mental health and well-being suffered in trying to care for her son full-time. She was fatigued, stressed and isolated.
- Both Eva and Moses were frustrated at the lack of communication surrounding Abraham's care.

#### **CCW role**

- The CCW was at times a mediator between Eva and Moses.

- The CCW was able to open the lines of communications between the services and both parents, by discussing and clarifying points of concern.
- The CCW was able to act as an advocate for each member of the family depending on the situation being discussed (e.g. by taking care of where Abraham would attend school).
- The CCW seemed to have developed a close relationship with the family, including working with the family in his own time.

### **b) Case study two**

*Note:* This case study interview was conducted with John (father) and Mary (mother). John speaks very good but broken English; his wife Mary speaks a little English but for the most part John translates for her.

John and Mary are a migrant family living in New Zealand with their three children. John came to New Zealand first (in 2002) and he used this time to find work and to assess what living in New Zealand would be like. Once he felt confident that this new country held opportunities for his family, he set about finding a house for them to live in and then brought Mary and their two year old son Adam to New Zealand on a visitor's visa.

John reports that Mary fell pregnant in 2005 and gave birth to the couple's second child, Peter. Peter was born in Auckland's Starship Hospital. John adds that it was apparent that Peter had an under-developed brain and the doctors and specialists assessed that Peter had a permanent disability and would need a range of on-going health services to help with his development; at the time of the research he was receiving help with his speech.

In 2008, the couple had a third child, Simon, but this time Mary travelled back to their homeland because she wanted the extra support to cope through the pregnancy.<sup>7</sup> After Mary and the children returned to New Zealand, Simon was taken to the doctors and specialists, who determined that this baby had the same condition as Peter but Simon also had a serious heart problem that could only be fixed with surgery. When asked if he had a good understanding of what was happening during this period, John says "yes" and reports "*they explained things and he understood that they were trying to help the children*".

John states that the process of waiting for Simon's surgery was long and drawn out, because surgeries would be booked and cancelled either due to the surgeons being too busy or not having enough staff, as well as other problems (which he does not elaborate on). After Simon had the surgery, John explains that this was a difficult time because he and Mary were kept busy constantly cleaning the house they lived in (due to it being poorly insulated); and they both worried that not only would Simon get sicker but that they all would. John adds that during the time that his youngest son was in hospital he felt "*mentally disturbed*" by the stress of balancing work and attending hospital appointments. John adds that it was also difficult to take Peter to kindergarten, because of the difficulty in dropping him off and picking him up.

Following the non-attendance of Peter at kindergarten, a referral was made to the CCW via CDS. When

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<sup>7</sup> It was not always clear which child the services provided relate to, due to a lack of information provided. Where possible, this is indicated.

asked what difference having the CCW had made for the family, John reports that he has helped link them with an NGO that provides information and food parcels. The CCW also introduced the family to a social worker who spoke the family's language. The social worker shared some coping strategies with Mary to reduce her isolation (e.g. suggesting that she goes to a local playground to meet and interact with other children and parents) and John to cope with the stress of maintaining a work/life balance. Despite living in New Zealand for eight years, John did not know much about what support services were available for them. He explains that he just doesn't have the time to find out because he works all the time. John adds that the CCW has been helping sort out their benefit payments because these had stopped.

Both parents are grateful for all the help that they have received; however, they speak of their on-going frustrations in getting what they need. For example, Mary is particularly concerned that Peter's eyesight needs to be checked but despite asking the doctors and service providers a referral has not been made. She adds we "*will just keep asking*" until it is addressed. John reports that Peter also needs help with his language development and that the family will need financial support to ensure he gets the on-going assistance required. John also reports that he would like to help Adam take part in extra-curricular activities at school but these are expensive and it is not easy for him to provide. Mary adds that she would like to help her husband, but getting a job is not possible while she has to look after the children.

#### **Other contextual information**

Further information relating to John and Mary's story was gathered during the pre-interview meeting and in discussions with the family and the CCW. This revealed what had happened since the CCW became involved in their case:

- A referral was made to the CCW to ascertain the reason why Peter was not attending kindergarten. The CCW met with the family to find out why. The CCW then organised a meeting between a representative from the MOE and the kindergarten teacher, asking that consideration for this situation be taken into account. After the circumstances surrounding the transport issue and the family's youngest child being in hospital were explained, Peter was permitted to attend kindergarten again.
- The CCW asked John to accompany him to an NGO that could provide support with information, food parcels and provide a social support group for Mary.
- Other issues that were of concern to the family were discussed including: concerns about their benefit being stopped; how to go about getting the internet connected; and how to use a computer. The CCW told the family that he would follow-up on the stopping of the family's benefit with the social worker to investigate and he advised John to ring their telecommunication provider about connecting to the internet.

#### *Key learning from this case study*

##### **Family background**

- Despite living in New Zealand for eight years John did not know what support services were available for his family, due to his work commitments.
- There were multiple opportunities for a social work assessment and intervention for this family including: after the birth of Peter; as part of his follow up care; during the ante-natal period for the birth of the Simon; and, during the subsequent heart surgery. Early social work intervention could have included managing transport, WINZ, access to English for Speakers of Other Languages (ESOL) classes, disability allowance and home help.

- The case study shows how easily Mary was isolated, due to having limited English, being reliant on her husband to drive her about and to translate for her, and being confined to the home to care for the youngest child.

### **Health related issues**

- This family lived in a poorly insulated rented house; these conditions could lead to on-going health problems.
- The case study demonstrates the stress put on the father due to his demanding work commitments which could lead to mental health concerns.
- It appears that, for this family, interpreters were not used (or used appropriately) for the reported health episodes. This may have contributed to Mary's lack of understanding regarding the services being provided, and what support was available to her and her children.
- The scarcity of resources to meet a migrant family's need is evident in this case study – e.g. money, information and knowledge, and time to spend together and to integrate into New Zealand society.
- Both parents voiced their frustration about their children's care (e.g. cancellations of their son's surgery and the delay in having Peter's eyesight checked).

### **CCW role**

- The CCW was effective at linking the family with a culturally appropriate NGO who could help the family and assist Mary with her English, computer skills, and access to support from other women.
- This case study demonstrates how inter-agency collaboration can work as the CCW and MOE representative worked together in approaching the kindergarten to find a way of enabling Peter to continue attending kindergarten.
- The case study shows how the CCW can use his knowledge and networks to link the family with community assistance, in this case to a social worker who spoke the family's language. This social worker was then able to provide the family with further practical help and support such as coping strategies for the mother to reduce her isolation and for the father in coping with work.

### ***c) Case study three***

*Note:* This case study interview was conducted with Anna (grandmother) and Rachael, the mother of the CALD child receiving child health services. The services of an interpreter were employed during the interview.

Anna is a grandmother in her sixties. She recalls that she and her family - her husband and their four children, three daughters and a son (aged 8-16 years) - were living a very good life in the country of Polaris. She speaks fondly of this country and recalls how easy it was to live there in relative

freedom, moving freely across borders to neighbouring countries.

Rachael, the eldest daughter, adds that she left her parents' home when she married her husband in 2001. Her husband was from Nash, but he worked and owned a business in Polaris, and as he had a passport he could move between countries without hassle. She and her husband had a son named Eli; he was a happy healthy child. She speaks with some sadness as she recalls that her marriage was "very bad".

In 2003, Polaris was attacked and the situation was "very volatile". Anna and her husband decided to leave their home with their remaining three children. They fled to a refugee camp in Nash. Anna reports that they lived in a refugee camp for two years, living in tents that were attacked and burnt down twice, but they had little choice but to stay there.

Anna recalls that "presenters" would come from different parts of the world, countries such as Sweden, Brazil, Canada and New Zealand. In 2006, Anna recalls being one of five families lucky enough to be chosen to come to New Zealand on the basis of humanitarian reasons. She adds her brother and his family were chosen to go to Canada.

In the meantime, Rachael's relationship with her husband was still strained but spurred by the unrest he also decided that they should try to leave Polaris and cross back into Nash. However, this proved impossible because her husband was the only one who possessed a passport and so escape for Rachael and their son was denied. Rachael's husband refused to leave without his wife and child, and so they were trapped. Rachael goes on to explain that because her husband was from Nash, he was constantly under threat of being killed or kidnapped and some time later Rachael's husband did go missing. Rachael was left in a desperate situation, she had just found out she was expecting another child, she was living by herself and her parents were unable to help her because, although her husband was missing, she was still a married woman. With little choice, she sought a divorce.

By 2006, Anna, her husband and three children were welcomed to New Zealand, where they were given a house, guided to the places to shop that were cheaper than others, like Pak'n'Save, and given money for their necessities. In 2008, an application to reunite Rachael and her two boys with her parents in New Zealand was accepted, conditional on Rachael not applying for income support for a two year period. Rachael recounts that she thought things would be better in New Zealand and that once she settled in she could start studying and make a new future. However, once there, with no money she could not afford to study, look for her own house or get started with anything.

Triggered by concern at school, a paediatrician made a referral to the CCW and outlined concern that Rachael's youngest child, Luke was displaying anti-social behaviour at school. In turn, a number of health checks were carried out with different health providers to check Luke's eyes, ears, teeth and a referral is made to a psychologist and the CCW.<sup>8</sup>

In speaking about the CCW role, Rachael appears to have a fairly good understanding of the CCW as someone who is assigned to look after her son's physical and mental issues. Rachael outlines that the CCW has made a difference for her by attending a Work and Income (WINZ) appointment to sort out her benefit; he has also helped her find a house (he tried from both sources, Housing New Zealand (HNZ) and rental agencies) and he has dropped off furniture from other people who have moved overseas in preparation for when she finally moves into her own home. Anna adds that the biggest obstacle to adjusting to New Zealand life is the language barrier and that having the CCW has helped with translating.

When asked what difference having a CCW has made in addressing the health and education issues related to Luke, Rachael outlines that many of his health concerns have been addressed, and

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<sup>8</sup> The CCW outlines that this referral prompted him to make a call to the MOE Refugee Co-ordinator, who had not heard of the school's concern.

education-wise he is doing well. Before ending our discussions, Anna asks whether it is possible to clarify the CCW role, because she does not understand what he does for them that is part of his role and what he has done as a personal favour. She adds that this clarification is important to her, because she doesn't want to feel uneasy in asking for help.

### **Other contextual information**

Further information was gathered during the pre-interview meeting and in additional discussions with the CCW, which revealed additional background on what had happened since the CCW became involved in their case.

- The CCW expressed frustration with the delays that the family faced. There was a delay in the family being referred to the CCW due to paediatrician's not being able to make referrals to the Project at this stage.<sup>9</sup> The CCW highlighted that there would have been further delays for the family in accessing services if he had not been involved. For example, Rachael entered New Zealand on a family reunification visa, and was not eligible to apply for a benefit for two years. Despite this, the CCW took Rachael to WINZ within the first week and made a special case on her behalf which resulted in her receiving financial assistance.
- The CCW contacted the MOE Refugee coordinator, who in turn worked with the family and the school putting a plan into place that would involve some one-on-one teaching time for the child.

### *Key learning from this case study*

#### **Family background**

- This family were a minority in the country that they called home – as such it is possible that they may have felt or been isolated even before they arrived in New Zealand.
- In this story it is important to make the distinction that the parents (Anna and her husband) arrived here under the refugee quota and thus were well supported. However, the story of Rachael was an example of family reunification and as such she received less support.
- Language is a tangible barrier that, as this story highlights, can be difficult to overcome.
- Adjusting to New Zealand's way of life may take time for refugee CALD families.
- This story raised a question of whether women need extra support if living in a male dominated household – for example from an NGO. An NGO may be able to provide women support groups and/or social services, that could possibly inspire or lead some women to entering into the refugee and migrant workforce (as a volunteer or as a career).

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<sup>9</sup> Since this time the referral guidelines have been extended to include paediatricians.

### Health related issues

- The benefits of early intervention are clearly demonstrated in this case study due to the referral to the CCW, and the action plan that was put into place to address the child's learning difficulties at school.
- CALD families need their emotional and mental health needs to be taken into consideration to make sure they can provide the best care for their disabled child.
- The researcher observed the CCW's frustration at wanting to make things happen quickly and resolve health and other issues for the family, but being restrained by the referral process and other delays.

### CCW role

- Priority for the family appears to be survival, and often families require practical help and support in a holistic way (e.g. if they are living with limited space then this may lead to other emotional problems that may affect the child's health too).
- Holistic support for families is required due to an awareness that the needs of the CALD families are high. The CCW working with refugees may feel that they have to 'clear the mess' around the family in order to care for the well being of the child.
- This story highlights the benefits of inter-agency collaboration in working with CALD families and their children (e.g. the school involved learned what supports were available through the MOE, and the child's behavioural problems at school were addressed with some one-on-one teaching time).
- There may be unease for some families as to whether the CCW is performing tasks as a friend or as an "*officer of the government.*" This story highlights that the blurring of the CCW role may be problematic where the family was uncertain about what was reasonable to ask – and may leave them feeling uncomfortable. Clearly communicated expectations are important for both family and the CCW.

### ***d) Case study four***

*Note:* This case study interview was conducted with Sarah (mother), with the assistance of an interpreter. However, for the most part, Sarah was able to answer on her own behalf.

Sarah is a young mother and sole parent of pre-school child with a disability. Sarah explains that she left her homeland and had the choice of moving to New Zealand or Canada and she chose New Zealand.

Sarah arrived in New Zealand in 2003. At first it was difficult adjusting to living in New Zealand. When she first arrived she got part-time work in a food-court, but was suffering from depression which worsened over time. She went to the doctor because she was extremely fatigued and was diagnosed with a mental illness. Unable to work, she wasn't able to make any new friends and the few friends she did have were married. Sarah adds, however, that she never thought of herself as a very sociable

person, not even in her homeland. Whether related to her illness or not, she found that she just did not want friends, even those of her own ethnicity. In time, Sarah met her New Zealand-born husband, her health improved and she gave birth to their son Mike in 2006. However, the marriage broke down and although the separation has been difficult, the strained relationship is slowly improving.

When Mike was born, Sarah was prescribed medications to help alleviate her mental illness. During this time though, she believed that her illness affected her ability to communicate with her son. In particular, she explains that there was a time when Mike's speech may not have developed because her interaction and contact with him was minimal. However, she adds that she did try to get help for Mike by taking him to the doctor many times. Eventually, the doctor made a referral to a paediatrician who in turn made a wrong diagnosis. One year later, her health was slowly getting better, she was well supported by a number of agencies, but she was still concerned about Mike's health.

When Mike was three years old, his kindergarten teacher contacted CDS. A CDS social worker and a physiotherapist were asked to assess his condition. Three months later Mike's behavioural problems at kindergarten had improved but despite this assistance, Sarah still felt frustrated by the time delay in helping Mike with his speech. By the time Mike was four years old, the CDS speech language therapist had begun therapy.

Sarah was very proactive in getting the assistance she needed for her son. She rang CDS directly and requested a CCW whom she had learnt about via her internet searching and talking with friends. Since having met the CCW, she reports that he has made a huge difference for her. In particular, having built a trusting relationship she feels that he knows her well and thus he knows how to help her. Sarah shares she can contact the CCW to get any service in CDS, including getting the right person to help or equipment, and that this is now easier since engaging with the CCW. Sarah knows that a team of health workers related to her and her son's case meet periodically to discuss her son's case; she doesn't fully understand what happens in these meetings except that they are all trying to help Mike. When asked what she saw as the CCW role during these meetings, she agrees that he can act as an advocate on her and Mike's behalf, being their 'voice'. Sarah adds that the CCW keeps her well informed, and explains what is happening and why. In turn she feels more comfortable leaving the CCW to sort out pertinent issues.

### **Other contextual information**

Further information was gathered during the pre-interview meeting, via discussions with the CCW, and whilst observing a multi-disciplinary meeting.<sup>10</sup>

- It was apparent that Sarah was not entirely clear about the roles of each of the health professionals, and a resource provided by the MOE special group educators she assumed had been provided by the CCW.
- The multi-disciplinary meeting, facilitated by the CCW, brought together a team of workers involved in this case. Everyone was assigned different tasks following the meeting (e.g. MOE educators took photos and created books for the child to develop language and speech skills, and the CCW was making a funding application for her child to attend a special school).
- When Sarah was first asked to take photos of her son that could be included in a book, she was reluctant, but after seeing how much her son enjoyed the books that had been made for him by MOE special education providers, Sarah could see the benefit.
- The CCW reported that Sarah had high expectations and demands of services leading to tensions in her relationships with them. The CCW was able to provide Sarah with an overview of what the services could and could not provide, thereby alleviating her anxiety and reducing the tension.

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<sup>10</sup> In attendance were a team of health professionals working with this family including: mental health support workers, Ministry of Education special education workers, a speech therapist, a psychiatrist and the CCW.

## *Key learning from this case study*

### **Family background**

- Sarah appeared more reticent in sharing her personal story and background about her life before coming to New Zealand, but indicated that she chose to immigrate to New Zealand.
- This migrant mother displayed a high level of determination and a level of ability (computer literacy and English skills) to find the resources and information that would help her and her son.

### **Health related issues**

- The frustration and concern displayed by this mother at not having her son's issues looked at early were clearly demonstrated in this case.
- It was apparent that Sarah did not seem entirely clear about the roles of each of the health professionals, and despite being given an overview of the services, there was still some confusion in understanding how the New Zealand health and education sectors worked. Educating CALD families likely needs to be sustained until this knowledge becomes embedded.

### **CCW role**

- This case showed the benefit of having a CCW who spoke the same language as Sarah.
- In addition, the CCW could provide an overall broad understanding of what was happening and why, and what could or could not be provided.
- The relationship between the services and the family improved as Sarah's anxiety reduced after coming to an understanding of the system.
- Despite this, there is evidence that not all services will be readily accepted (as can be seen with the use of the photo books). In some cases the benefits may need to be demonstrated first before they are accepted. This story shows that on-going time and patience whilst supporting the family may be needed.
- This case study is a good example of how the CCW can act as the key worker with some CALD families. This mostly occurred due to the rapport the CCW had developed with Sarah.
- This case study shows that the CCW role has the ability to meet the needs of CALD families by developing and implementing an overall joined-up plan with other services via the multi-disciplinary meeting process.

### ***e) Case study five***

*Note:* This case study interview was conducted with Stephen (father) and Kathy (mother), with the assistance of an interpreter.

Stephen and Kathy have been in New Zealand since 2006. They came to New Zealand initially in preparation for Stephen's tertiary studies and to learn English. When they got to New Zealand, they report loving the country for its beauty, clean air and clean environment. In terms of the support available to the family when they first arrived in New Zealand Stephen and Kathy say that, despite having an uncle living in New Zealand, they received little help. Stephen shares that help was available from members of their church, who provided information on finding a house on websites like Trade Me and opening a bank account in banks where employees were of their ethnicity. However, much of what they learnt they taught themselves by reading their ethnic newspaper and searching popular ethnic websites for information. Stephen adds that he had an international driver's licence and taught himself to read maps to navigate around Auckland.

The opportunity to study English fulltime did not eventuate as the couple realised that, financially, they could not afford to study but had to work. Circumstances changed further when Kathy became pregnant. A risk of complications meant that Kathy needed to take care of herself during the pregnancy. As it was, their son Sam was born prematurely.

Stephen and Kathy were told that because Sam was premature he would have a lot of health complications and would need on-going care as he grows up - they were extremely distressed to hear this news. Stephen and Kathy explain that their involvement with the New Zealand Health care system was not easy, but that the initial care they received from the nurses, occupational therapists and other health professionals at Starship Hospital was wonderful and very caring. The family used the services of an interpreter, who they still regularly use.<sup>11</sup> They were extremely grateful to those who helped them cope through that period of Sam's early life.

When asked if there was anything about the health services provided that could have been done differently, Stephen states that the inconsistency of the home visits concerned him, especially when his son was particularly unwell and needed extra care and close monitoring. Stephen felt that his son's development in watching what he was doing and how he was playing was not being catered for, because some home visits would be weekly, but the follow-up visits would not happen for a month to six weeks later. The father's main concern centres on his belief that this inconsistency of service may have delayed Sam's development, especially in relation to his communication skills.

The family were working with CDS allied health workers when a referral was made to the CCW. When asked what difference having the CCW had made to their family both Stephen and Kathy are positive about this. They report positively that having the CCW has made communication with the service easier. Both parents report that language was a big barrier, and having a CCW meant that they could get the right information earlier, and thus know what they were entitled to. Stephen and Kathy add though that the CCW has helped them in so many more ways than just overcoming the language difficulty they take turns listing all that he has done for their family. For example the CCW has provided advice on their son's play and interaction with his friends that would aid in developing the child's social interaction skills. The CCW has also provided the parents with encouragement to meet other families to develop their own social and language skills, and he has provided the family with other information, on one occasion he gave them a book to help them deal with their son's constipation problems.

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<sup>11</sup> The interpreter came from WATIS which is managed by Waitemata DHB's Asian Health Support Services.

**Other contextual information**

Further information relating to Stephen and Kathy's story was gathered during the pre-interview meeting, and in discussions with the CCW:

- The CCW shared that the parents were also concerned at the short notice and inconsistency in the home visits they received, and that this was particularly disconcerting for them because they did not always know who was visiting or why.

*Key learning from this case study***Family background**

- The ethnic community of this migrant family is well established in New Zealand and in particular Auckland, so more support systems are in place than for some other migrant or refugee groups. As many of their community were employed across different services in the city, communication was easier and facilitated activities such as setting up bank accounts.
- The family in this case study had the ability to find the information they needed through their ethnic community newspaper and websites.

**Health related issues**

- Receiving the news of Sam's prognosis (and on-going health problems) was devastating for Stephen and Kathy.
- The family reported positively on the care they had received at Starship hospital. However, they were frustrated and concerned by the inconsistency in the home based health services they received after this (e.g. short notice for visits, not knowing who was visiting and why, and the irregularity of visits).
- This family were early users of the interpreter service and developed a good relationship with a specific interpreter (at the time of the research, the relationship was on-going). This helped reduce their anxiety about what was happening with their son's care.

**CCW Role**

- Because accessing the New Zealand health system may involve a number of steps it is often difficult for a family to know who does what, when and why. CALD families may need to be given a thorough overview or 'big picture' of what is going on, so as to reduce their anxiety.
- It is important to note that, although language support is an important function of the CCWs, findings from the research suggest that there is much more to the level of support that they provide families (e.g. such as their knowledge of the health system, advocacy, etc.). Otherwise, in the case of this family, the interpreter service alone that they had used in an on-going fashion, would have been sufficient.

## Challenges for the Project

When the evaluation commenced the Project had been operational – with the CCWs able to receive referrals – for around two months. In seeking to better understand the workings of the project over that time period, the research identified areas where challenges existed. These are detailed below and include: clarification and communication of the CCW role; sustainability of the Project; staff challenges; and, a small number of other challenges.

### **a) Clarification and communication of the CCW role**

Key informants referred to the relative infancy of the project, and some highlighted that they were still at the stage of getting to know the individual CCWs – as well as the broader remit and specific activities of the project. For some KIs, there was a lack of knowledge and understanding of the CCW role. In particular, as reported previously, they indicated that they felt unsure about: the appropriate time for referrals; what CCWs delivered in terms of service offerings; and, the level of support CCWs are able to provide families:

*I don't really know [what CCW can do]. Whenever we've met, we've met in meetings and neither of us have had the time to actually really... we should have a separate meeting and perhaps that might come from what we're doing now for me to fully understand what it is [CCW] is doing and how he can actually support the family and at what depth, and in which directions. [P18]*

The KI above indicated that they were also unsure about the length of engagement that CCWs would have with families, and reported that they had, to date, made a range of assumptions about this (“As far as I am aware, I might have this slightly wrong but for me, my interpretation is that yes, he [CCW] is involved in the child but predominantly he's done a lot more family work than I have and so I would assume that he would still stay involved with the family”). A KI who worked in the health sector, was seeking clarification of the CCW model at a broader level:

*I'm not saying they're not trying but again it's that how you set up a service is when you put in outcome you need to define what you are trying to do. It's so simple that you say I'll put a cultural, it's like someone putting, if you have a service say an emergency and you employ a [ethnicity removed] nurse and you say OK, I've addressed inequality, I've got cultural staff. What does that mean? Nothing. It's as simple as that. [P15]*

Linked to these issues was uncertainty over the boundaries of the CCW role. In particular this related to the degree of autonomy the CCWs had in terms of the types of activities they could become involved with – particularly compared to their colleagues working in mainstream health roles. For one KI, not knowing who the CCWs were employed by, meant that she was unsure of their role restrictions, and what she were able to subsequently expect in terms of the level and nature of support they could provide to families:

*I know what I can and can't do, I don't know what [CCW] can and can't do...I mean is he and employee of the Ministry of Health and he has to follow the same policies as I do? Or is he an employee of cultural? I don't really know, and has he got that kind of freedom that would allow him to go with the family in a shop and buy something. [P14]*

Whilst KIs noted role clarification was a challenge for the Project, it was not always viewed as a weakness, and some acknowledged that it was not an unexpected issue

for a project still 'finding its feet'. Moreover, it was recognised by some that the nature of the CCW model called for a degree of flexibility, given the communities that the Project sought to work with, and the type of work involved:

*It's definitely work outside the 8 to 4.30, I think we have to be quite clear about that, because they do work, they have amazing commitments to the communities. It needs to be work that, especially if they are working with other team members, it needs to be collaborative work so it's almost like within the agreement of the family, the therapists, and quite open...that role blurring is happening and so I don't think we are ever going to get clearly defined roles. [P1a]*

It is interesting to note that KIs who spoke about this issue indicated that defining and communicating the CCW role more clearly would not only increase their knowledge of the service – and potentially result in more referrals to the CCW – but was an important consideration with regard to staff safety. This included, for example, ensuring that staff were not overloaded with unrealistic demands, and that they did not place themselves at risk in term of the duties they carried out on behalf of their clients. Moreover, findings from the research suggest that CCW support was considered crucial to protect the staff from 'burnout', and families from dependency, due to the blurring of boundaries around the CCW role. These issues are discussed further later in this section (under 'staff challenges').

### **b) Sustainability of the Project**

At the time of the research, the project was funded until June 2011, and was waiting confirmation of further sustainable funding. It was perceived amongst some KIs that the Project was either a pilot or was time-limited and funded for a specific period. This aspect of the Project was felt to present a number of challenges. In the first instance – and particularly amongst KIs who viewed the model as working well to date – the issue of accessing funding to secure the Project in the longer term was an important consideration.

In considering its future, some research participants expressed general frustration about government-initiated projects which receive time-limited funding and are terminated after a short period. In particular, they highlighted the short-sightedness of such an approach, given that initiatives of this type cannot be expected to make an impact for communities within short time-frames. One KI also highlighted the risk of building expectation within a community, and the subsequent impact should the service cease to exist:

*They also need to be assured that it is ongoing because I hate being involved in a project which is a pilot then somewhere it stops and so the people outside there, they will, say, be wanting something and you, here, you're not able to do that because the project ceased. So all the hopes and aspirations would have been raised for nothing. [P21]*

The uncertainty over the longevity of the Project and its impact on staff was highlighted by some KIs. In particular, this included the instability of short-term employment, and the risk of staff leaving roles:

*I think it's a wonderful initiative and it offers our teams and families a lot but I feel like it's just really baby steps and right at the beginning – and I just hope we can hold both of them for a long period of time and develop some resources so it's not all in their head. [P1a and b]*

It is interesting to note that the Project's success was perceived by some to present a challenge in the longer term. Beyond the necessity to access on-going funding, issues were also raised around the potential higher demand that this may place on the project – and how this might impact on service delivery:

*The only issue there would be if they became so inundated with referrals that they amount of time they could spend with the families reduced significantly. The service would still be great, it just wouldn't be as great. [P9]*

*How our communities also work, it's word of mouth. You've accessed something and you think oh, they really looked after me and treated me well, and look at all the information, I can go here and I can go there and so forth, so you tell the next person who might have a disabled, so it's word of mouth which in some ways will put a heavier demand on your services which means the managers will have to be advocating for more and policy people more funding. [P24]*

One KI viewed the Project as one pathway to building workforce capacity within services working with migrant and refugee communities, and suggested, therefore, that it would not be needed in the longer term. However, another research participant did not view this as a realistic outcome, given the complexities of working with this population group.

### **c) Staff challenges**

A number of issues relating to staffing of the Project were identified during discussions with KIs – these were reported by both project staff themselves, as well as others who were working in a range of roles.

- *Uniqueness of the CCW role:* project staff and other KIs indicated the unique role that the CCWs are fulfilling, and its difference from other mainstream health positions. In particular, they highlighted the specific challenges of the communities that the Project works with, the need for flexibility in terms of activities undertaken, and the difference in resource and time allocations:

*The second thing is the amount of time. This project is quite a new project to the service and the service leaders used to manage only therapists. Now this is a different role, different understanding, so what they are expecting is to have a same system of the therapist which is not quite equal or relevant. For me, if I'm a therapist, it could be easier to go, deliver my session within forty-five minutes and come back. But as you witnessed our last visit, the families they feel cultural belonging, they feel that because of the other cultural case workers they belong to us and we belong to them. So they ask from their needs including everything. Sometimes they may ask you their electricity, their telecommunication, and we can't say no, this is not my area, no this is not my area, no. We may think if we can give guidance for them, we may tell them to be patient, wait for a little. We have to tell them something. So that sort of flexibility is not in the system. So what I would like to see in the system is more flexibility, a responsibility in this role. [P7]*

- *A clash of cultures:* the research identified the challenge for CCWs in acting as advocates for families (and working in a holistic and flexible manner), whilst also operating within the parameters of a mainstream health system and all that that entails (e.g. 'working within a bureaucracy and an organisation that he's answerable to people'). For example, one of the CCWs described how they provided their time voluntarily to resolve a problem where a family's request was not able to be met due to funding and other DHB restrictions:

*Did our service pay for that? AccessAble already refused. So how is it possible? I have to do it voluntarily. This is where I can do what the family expecting from me. The family expecting to bring a solution and I know that the family they are having their cultural point of view and my team are having their professional point of view. So when these two collided or come against each other or contradict I have to come in between and mediate and bring a solution. And that solution sometimes not all the time, sometimes needs a resource and that resource is not available, so that is why I picked up as a volunteer. Otherwise our work would not make difference. [P7]*

- **Managing CCW workloads:** given the flexible nature of the CCW role, some KIs spoke about the need to ensure that workloads are manageable and that the CCWs do not become “overloaded”. One KI emphasised that some families become very attached to the CCWs and may develop fairly extensive demands on their time and energy. This was further confirmed by a CCW who highlighted the intensive nature of working with CALD families and their often high and complex needs – and the challenges posed when they fail to acknowledge the service being provided. An additional workload-related issue raised by the CCWs was the fact that management of a caseload was only one aspect of the job, with community work also taking up a significant proportion of the role:

*Balance is very important. We are very heavily involved in the community work. [CCW] has a huge support from his community, volunteering for many years and then I'm involved in my community trust. Yes to get good balance with our caseload and community work is very important so I need to talk to my leader, and team leaders, and yes, to make more customers sometimes good but sometimes compromise the quality. [P7 and 8]*

Whilst not looking for the role to become overly prescriptive, KIs who raised this as an issue indicated a preference for some role boundaries to be established, as well as ensuring that there was adequate supervision and support for the CCWs.

- **Staff recruitment and retention:** as highlighted previously, some KIs spoke about the advantages of securing staff on a long-term basis. Additional issues raised included concern about the lack of security for staff on short-term contracts, and the challenge of hiring a new CCW following the departure of the previous individual in that role.

#### **d) Other challenges**

A small number of other challenges were identified in the research, as follows:

- One KI spoke about the difficulty in implementing the Project due to it having largely been a ‘bottom-up’ initiative, without the backing of central Government (e.g. MOH) policies, and the potential for this to contribute to a lack of ‘buy in’ from health services staff.
- Another KI highlighted that a lack of standardised data on the ethnic background and/or disability issues of CALD families presented difficulties for the Project, in terms of future planning (e.g. knowing the potential size of populations, which ethnic groups the Project may need to cater for).
- A KI who had experienced a similar problem within her own practice, identified the challenge of protecting the privacy of CALD families when working with people from a small community. In particular, this related to CCWs potentially being required to work with families that they have an existing relationship with.

## **4. DISCUSSION**

This document has presented findings from an evaluation of the Waitemata DHB Child Disability Service project for CALD families. At the time that the evaluation commenced, the project had been operational for two months. Thus, a formative evaluation was undertaken, which focused on examining the delivery of the project, with a view to identifying strengths and weakness as well as barriers and unexpected opportunities.

### **CALD families**

The evaluation gathered information on the experiences and needs of CALD families who have relocated to New Zealand, with a child with specific health needs. It has identified differences in migrant and refugee families in terms of their needs, and the resources they are likely to have available to them when arriving in New Zealand – and highlighted the importance of services being adaptable to these requirements. For example, refugee families entering under the disability quota have high and complex needs (e.g. due to forced migration) and will likely require assistance over a longer period. Moreover, children and adults from refugee families may enter New Zealand with pre-existing mental health issues due to the trauma they have experienced, compounded by adjusting to life in a new country. For both migrant and refugee families there is a need for health and disability support services to consider the cultural and familial dynamics in operation within CALD families – for example, gender roles, as well as issues of stigma surrounding disability in some communities.

Findings from the research highlight the frustration and difficulties experienced by CALD families in accessing health services and disability support for their child/ren. This was due to a lack of knowledge amongst families of what was available and the processes for accessing health services, as well as a result of health services sometimes being provided in an ad hoc fashion without clear communication. Of note, there was evidence that the delivery of health services was not necessarily a well co-ordinated process and sometimes proved confusing and overwhelming for families. This was compounded by the possible stress and anxiety for parents adjusting to life in New Zealand, and the challenge of navigating unfamiliar health and social systems. Importantly, this means that CALD families may come to the Project with high needs, and be looking for the CCW to mediate in somewhat tense relationships with other service providers.

Overall, the research further highlighted the importance of health providers having an understanding of migrant and refugees' experiences. An awareness of their circumstances gives the service provider information about families' knowledge of access to the health and disability services, the access barriers they may face, and the additional social support and services that they may need.

## The Project

In documenting the Project's progress to date, the evaluation has identified that the CCW roles have been developed and staff recruited to fill these positions, with informal peer support and networking well established. The research has identified a broad base of support for the Project as a whole, and findings suggest that it is meeting a very real need. In terms of support provided to families, the research has confirmed that, in keeping with the intended activities for the project (see programme logic model), the focus of work to date has been on building relationships, providing advocacy, arranging transport and other practical support, and the provision of information. In addition, examples of the Project staff linking families to health and other services were identified. As a result, families had experienced improved access to health and other services, reduced isolation, increased knowledge and an improved living situation. The research has highlighted the importance of educating families about health and other social systems in New Zealand, given that similar services in their home country are either organised very differently, or do not exist at all.

In mediating between families and health and other services within a 'cultural broker' or CCW role, it has been identified that two elements are essential: the capacity to build and maintain trust; and, the ability to dedicate adequate time to build a meaningful relationship between the provider and the client (National Center for Cultural Competence, 2004). The evaluation further confirmed the importance of relationship building and the establishment of trust between CCWs and the families that they work with; in particular, that it formed the foundation from which other work flowed. It is important to highlight that this facet of the role took many guises, some of which may not fit comfortably within a mainstream health structure such as a DHB (e.g. the provision of practical support, such as sourcing second-hand furniture, as a way of building trust and a relationship with a family).

Support and advice to staff and external colleagues (e.g. Allied Health staff) has formed an integral part of the Project activities to date. In particular, this has included language and cultural support, liaison between services and families, and cultural education. There was evidence of CCWs taking on a coordination role, with regard to facilitating the engagement of different stakeholders working with CALD families. Activities have been undertaken in both formal settings (e.g. organised meetings) as well as via more informal networking and peer support. Enhanced cultural knowledge and understanding, and improved relationships between health services and families, were identified as key benefits for services. On a practical level, engagement with the CCWs resulted in more streamlined processes. Overall, there was evidence that services were better able to engage with CALD families – resulting in improved outcomes for families themselves.

The apparent increased cultural knowledge of staff working within health services as a result of engaging with the CCWs (which was sometimes happening in combination with CALD training) would suggest that organisational cultural competence may also be improving. It was outside the scope of this evaluation to measure the extent of this, but learning and skills gained are likely to be filtering through as health services

staff work with other families in the future, and share their learning with colleagues along the way.

## **Future challenges for the Project**

Many of the challenges facing the Project are what could be expected from a service of this type in its infancy and still 'finding its feet'. In particular, this includes the lack of awareness and/or understanding of the Project and its offerings amongst some health services staff, as well as issues surrounding clarity of the CCW role (in terms of managing expectations, defining boundaries, etc.). These issues are likely to have been compounded by the unique (and unfamiliar) qualities of the CCW position, and its point of difference from mainstream health roles and the overall medical model. In taking the Project forward, it is recommended that the following key issues are considered:

- The staff and their associated skills and experience are a clear asset for the Project, in particular their ability to engage with families, and their wide community networks. This is both in terms of the existing networks they bring to the role as well as their ability to more quickly build networks because of being 'insiders' themselves (i.e. migrants/refugees). These qualities also bring a level of responsibility for the CCWs, and the fact that they are part of the community in which they are working needs to be explicitly acknowledged, particularly in relation to the potential 'blurring of boundaries' between work and personal responsibilities.
- Indeed, work with immigrant clients has been shown to be more extensive and demanding than work with mainstream clients, given that processes such as establishing rapport require additional time and effort (Russell & White, 2001). As has been identified elsewhere, (Russell & White, 2001), the CCWs expressed feeling a high level of responsibility for the families that they worked with. Whilst there are indications that some role clarity is required – to reduce the risk of staff 'burnout', and to manage the expectations of both families and other stakeholders – it will be important to ensure that the role does not become too bound by restrictions.
- There has been much research undertaken in relation to the issue of cultural matching of clients and health workers (Lu et al., 2004). Whilst there are practical advantages of workers and clients speaking the same language, it has been identified that ethnic matching alone does not ensure better treatment outcomes (Bhugra, 1997; Lu, et al., 2004) and that training, world view, and understanding of another person's culture and ethnicity may have a greater influence/impact (O'Hara, 2003). In particular, the literature suggests that they must have the trust and respect of the communities they work with, knowledge of values and health practices different cultures; an understanding of wellness and healing networks within diverse communities; and experience navigating health and support systems within communities (National Center for Cultural Competence, 2004). Cultural matching of the Project's CCWs with families that they work with is not a realistic possibility, given the wide range of ethnic groups

which comprise New Zealand's migrant and refugee populations. Moreover, the research identified that the personal attributes of the individual employed in the role were considered most important, including their ability to connect with the families they worked with, their knowledge and understanding of different cultural, religious and disability issues, and personality traits such as compassion, honesty, warmth and openness. This further reinforces the importance of CCWs being able to tap into a range of community networks and refer families on to other places that can help, and the ability to recognise when this is needed. As highlighted above, the experiences that the CCWs share with CALD families in relation to being from a migrant or refugee community also go some way to overcoming the potential limitations of their different ethnic backgrounds.

- The research has identified the tension of working holistically within a medical model and a resource constrained service. Of note, the unique qualities of the CCW role need to be acknowledged by management and other key stakeholders, including that it may not fit a typical template of other family advocate or health service roles within the DHB. This includes recognition that what might not be seen as a defined aspect of the position is in fact a key part of the relationship building required.
- Other issues to be considered with regard to staff safety and protection, include the provision of accessible and appropriate (cultural) supervision, careful management of job sizing (in particular caseload sizes), as well as time off from the role. Cultural caseworkers also need to take responsibility for managing their level of efforts with each family – and ensure that these do not exceed their resources (Russell & White, 2001) and result in stress or fatigue.
- The issue of job sizing (i.e. the relative time and resources allocated to each aspect of the role) is important. At the time of the research, the general allocation for the role was casework (50%), networking (25%) and project work (25%). Project work included developmental work such as parent seminars and focus groups, and identification of materials for translation. In particular, it will be important to define the size of the CCWs' caseloads, in terms of the number of families that they engage with. This includes decisions around whether the Project works in-depth with a smaller number of families, or provides lower level services for a larger client group. This is a consideration both in terms of the cost of the Project relative to numbers of families 'served', as well as ensuring that the CCWs do not become overloaded. It is worth bearing in mind that project work will likely reduce over time as a pool of resources is developed.
- Currently, where appropriate, CCWs are able to act as key workers (i.e. co-ordinate all visits to a family, and act as a first point of contact for the family). There was some (limited) evidence of this identified in the evaluation, and findings suggest that this may be beneficial in certain circumstances. Of note, the case study data have further reinforced the stress and anxiety experienced by CALD families when attempting to navigate not only a new country, but also often complex and disjointed health services – and the benefits of a CCW in facilitating this process.

- The advantages of early involvement of the CCW, rather than waiting until problems or issues develop, may also need to be reinforced and communicated clearly with health staff able to make referrals to the Project. Of note, the research found that the CCWs were sometimes seen as a ‘last resort’ or ‘chronic problem fixers’, rather than necessary support for families with special needs.
- The restructure and management changes early in the Project resulted in some additional responsibility for the team leaders of the CCWs, although not to the extent that was first anticipated. Working across services may continue to present some challenges in relation to the management of the CCWs, in particular who has ultimate responsibility for their supervision, and their accountability for the work they are doing within their individual cases.
- In sustaining projects of this type, buy-in and acceptance by health service staff – including personnel at all levels of organisations – is necessary (National Center for Cultural Competence, 2004). The research highlighted that the project is not fully embedded within the WDHB structure, with some health staff unable to envisage benefits of engaging with the CCW. Moreover, given that CCWs are a new concept, and not part of an established health service, there may be greater uncertainty over what they have to offer. In particular, service users may not see value in the Project until they have used it, and thus non-engagement is an important consideration. Findings from the research indicate that:
  - staff who have previously worked with CCWs will play a key role in communicating the benefits of the project to other potential service users;
  - further communication of what the CCWs do (e.g. via on-going presentations) would be beneficial in generating additional referrals from potential service users (e.g. allied health staff);
  - there is a need to communicate with potential service users about appropriate time points for making a referral;
  - given that the CCWs are in the unique position of working across multiple Child Health services, a stakeholder group of representatives from the various services within WDHB could be a good support mechanism for the Project staff. Such a group could assist with facilitating communication about the CCW roles, identify pertinent issues, and help to improve buy-in from other areas (particularly at upper management levels).
- The Project may wish to consider how to demonstrate to its key stakeholders the outcomes it is achieving, both in terms of the quantity and quality of services provided. This may involve, for example, the establishment of key indicators for the Project (e.g. how many people are benefitting and what difference is being made) as well as the integration of self-evaluation into routine processes.

### **Limitations of the research**

The research was qualitative in nature, and thus whilst it provides rich information on the experiences of families and other individuals who participated, the information is not intended to be generalised. In addition, the evaluation took a formative approach and thus focussed on processes, rather than outcomes. Although project impacts have been indicated where possible, further research is warranted to explore these in depth, particularly as the Project becomes further established.

The research did not seek the views or experiences of families who had not engaged with the project. Thus, whilst some insight into potential barriers for families in accessing the service was gained via KI interviews and other data, it is not known whether other issues exist for these CALD families, or others who may choose to decline the offer of engaging with a CCW. It is also acknowledged that all case study families were introduced by the CCWs; thus, there is the possibility of a selection bias. It should be noted, however, that families were given the option of declining participating in the research, which a small number of families did.

The researchers did not speak any of the community languages of the case study families. Whilst interpreters were utilised where appropriate to facilitate communication during interviews, it is possible that some of the meaning (and contextual information) was lost through this process. Moreover, participants may have revealed different information if interviewed by someone of the same culture.

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## **APPENDICES**

## Appendix A: Project Referral Guide

### Child Health Service: Referral Guide for CALD Cultural Caseworkers

#### *Who can refer?*

**Inclusions:** Referrals will be accepted from any Waitemata DHB Child Health Service team.

**Exclusions:** Referrals will not be accepted from other Waitemata DHB services or from external agencies.

#### *Access criteria*

##### **Inclusions:**

- Children who are eligible for publically funded health services
- Children from culturally and linguistically different backgrounds (CALD) and their families who:
  - Are current users of Child Health Services where one or more team members is actively involved and
  - Meet MoH criteria for disability or
  - Are infants/children under 5 years of age with developmental concerns or
  - Are a current inpatient or outpatient of the Child Rehabilitation or
  - Are a current user of Out of Home Respite Services

##### **Exclusions:**

- Referrals where needs are social and behavioural ONLY (i.e. must be impairment-related)
- Paediatric O/P referrals where the paediatrician does not have ongoing involvement

#### ***Referral process***

- Referrals are made by completing the Child Health referral form (please ensure that child and family's ethnicity, religion, language spoken are recorded on the referral)
- Referrals will be managed through the weekly CDS referral and allocation meetings
- Referrals should be forwarded to CDS North or CDS West depending on the referrer's location.

#### ***Prioritisation of referrals***

**Priority 1:** social risk, family engagement in an acute episode

**Priority 2:** family engagement, parent education

## Appendix B: CCW Job Description

<b>Job Title</b>	: <b>Cultural Case Worker</b>
<b>Department</b>	: Child Health Services
<b>Location</b>	: Child Development (Waitakere base, required to work in multiple locations)
<b>Reporting To</b>	: Operations Manager Child Development Service
<b>Direct Reports</b>	: None
<b>Functional Relationships with</b>	: <ul style="list-style-type: none"> <li><u>Internal</u></li> <li>Team Leaders / Manager's for Child Health Services</li> <li>Social Workers across Child Health Services</li> <li>Interpreting Services</li> <li>Paediatricians</li> <li>Multi-disciplinary team members</li> <li>WDHB Asian Health Services</li>   <li><u>External</u></li> <li>Regional linkages with other Cultural Case Workers in DHB's Disability sector NGO's</li> <li>Refugee and Migrant community and government agencies</li> <li>NASC</li> <li>Other agencies</li> </ul>
<b>Purpose</b>	: <p>To assist with the establishment of a model of service for Cultural Case Workers within WDHB Child Health Services.</p> <p>To provide accessible and culturally appropriate support to children and families from culturally and linguistically diverse (CALD) backgrounds.</p> <p>To support the Child Health teams in the provision of culturally appropriate services for children and families from refugee and CALD backgrounds.</p>

KEY TASKS	EXPECTED OUTCOMES
<b>Area: Project Work</b>	
<p><b>Work alongside Project Leader and Operations Manager to establish the model of service for cultural case workers within child health services</b></p>	<ul style="list-style-type: none"> <li>Collaborative working relationship established with Project Leader and Operations Manager</li> <li>Participation in activities pertaining to the establishment of the model of service</li> <li>Agreed tasks are completed within expected timeframes and to a professional standard</li> <li>The Cultural Case Worker/s have an understanding of the evaluation design and the importance of data collection to support the project evaluation</li> </ul>
	<ul style="list-style-type: none"> <li>Monthly reports are submitted to the Operations</li> </ul>

KEY TASKS	EXPECTED OUTCOMES
<p><b>Keep abreast of specialist defined area of working with children and families from CALD backgrounds</b></p>	<p>Manager which includes a narrative about trends, service gaps and changing needs in the community</p> <ul style="list-style-type: none"> <li>• Information regarding refugee settlement in the district is obtained and utilised for service planning</li> <li>• Services available in the greater Auckland area for children and families from CALD backgrounds are well known and referral pathways clear</li> <li>• The cross-cultural resources and training available through Waitemata DHB are well understood</li> <li>• The NASC system and other methods for accessing resources for disabled people in New Zealand are well understood</li> </ul>
<p><b>Contribute to service development and service review as appropriate</b></p>	<ul style="list-style-type: none"> <li>• Administrative tasks related to the requirements of the project are completed in a timely manner and to a professional standard</li> <li>• Data and information required for evaluation is collected and stored as required</li> <li>• Participation in review periods as determined by project plan occurs</li> </ul>
<p><b>Area: Networking</b></p>	
<p><b>Establish and maintain linkages and networks</b></p>	<ul style="list-style-type: none"> <li>• Strong linkages with relevant internal and external services/organisations/communities are established and maintained</li> <li>• Support is given to child health service team members as needed, to deliver services which are appropriately linked with and integrated into all other services that the child may be accessing (E.g. Refugee Services, service from CYFS, Ministry of Education)</li> </ul>
<p><b>Area: Clinical</b></p>	
<p><b>Provide advice and support as needed to assist child health team members in the delivery of culturally appropriate services to children and families from CALD backgrounds</b></p>	<ul style="list-style-type: none"> <li>• Knowledge and understanding of the Treaty of Waitangi is demonstrated</li> <li>• You are a recognised member of the multidisciplinary team and work within all collaborative team processes</li> <li>• Contribution and attendance at staff meetings and case review/discussion occurs</li> </ul>
<p><b>Provide community and hospital based cultural support services to children and families from CALD backgrounds</b></p>	<ul style="list-style-type: none"> <li>• Relationships are developed with children and their families enabling them to meet their own needs</li> <li>• Parent education about NZ perspectives of disability and the principals of developmental support and enhancement is provided in an appropriate manner</li> <li>• Parent education about the NZ Health and Disability sector is provided in an appropriate manner</li> <li>• Plans are developed by multi-disciplinary team</li> </ul>

KEY TASKS	EXPECTED OUTCOMES
	<p>members in partnership with the family / whanau and the cultural case worker to meet the needs of the child and their family, within a developmental, cultural, and environmental context</p> <ul style="list-style-type: none"> <li>• The cultural case worker is the key worker for children and families from CALD backgrounds where appropriate</li> <li>• Where transport is an issue for families the support options are discussed with management</li> <li>• Where risk or safety is identified as an issue, consultation takes place with Operations Manager, Social Work Professional Advisor, and/or statutory agency</li> <li>• Advocacy is undertaken as needed to ensure the allocation of support services for children and families from CALD backgrounds are adequate</li> <li>• All work practices are maintained within the WDHB policy framework (i.e. Privacy Act, Patient Code of Rights, Child Protection and all relevant policies)</li> <li>• Documentation is up to date, legible, complete, and is written in accordance with Waitemata District Health Board Standards and Documentation policy</li> </ul>
<p><b>Participation in supervision, professional development and training is undertaken in an ongoing and regular basis</b></p>	<ul style="list-style-type: none"> <li>• Professional skills and standards of care are achieved and maintained</li> <li>• Regular individual supervision is undertaken as per supervision policy</li> <li>• Peer supervision and review is undertaken in consultation with manager when required</li> </ul>
<p><b>Area: Occupational health and Safety</b></p>	
<p><b>To recognise Individual Responsibility for Workplace Health and Safety under the Health and Safety in Employment Act 1992</b></p>	<ul style="list-style-type: none"> <li>• Company health and safety policies are read and understood and relevant procedures applied to their own work activities</li> <li>• Workplace hazards are identified and reported, including self management of hazards where appropriate</li> <li>• Can identify health and safety representative for area</li> </ul>

## Behavioural Competencies

<b>Adheres to Waitemata District Health Boards 5 organisational Values of:</b>	
Respect Integrity Compassion Openness Customer Focus	
<b>Behavioural Competencies</b>	<b>Behaviour Demonstrated</b>
<b>Communicates and Works Co-operatively</b>	<ul style="list-style-type: none"> <li>Actively looks for ways to collaborate with and assist others to improve the experience of the healthcare workforce, patients &amp; their families and the community &amp; Iwi.</li> </ul>
<b>Is Committed to Learning</b>	<ul style="list-style-type: none"> <li>Proactively follows up development needs and learning opportunities for oneself and direct reports.</li> </ul>
<b>Is Transparent</b>	<ul style="list-style-type: none"> <li>Communicates openly and engages widely across the organisation.</li> <li>Enacts agreed decisions with integrity.</li> </ul>
<b>Is Customer Focused</b>	<ul style="list-style-type: none"> <li>Responds to peoples needs appropriately and with effective results</li> <li>Identifies opportunities for innovation and improvement</li> </ul>
<b>Works in Partnership to Reduce Inequality in Outcomes</b>	Works in a way that: <ul style="list-style-type: none"> <li>Demonstrates awareness of partnership obligations under the Treaty of Waitangi.</li> <li>Shows sensitivity to cultural complexity in the workforce and patient population.</li> <li>Ensures service provision that does not vary because of peoples' personal characteristics.</li> </ul>
<b>Improves health</b>	<ul style="list-style-type: none"> <li>Work practices show a concern for the promotion of health and well-being for self and others.</li> </ul>
<b>Prevents Harm</b>	<ul style="list-style-type: none"> <li>Follows policies and guidelines designed to prevent harm.</li> <li>Acts to ensure the safety of themselves and others.</li> </ul>

### VERIFICATION:

Employee: \_\_\_\_\_

Manager: \_\_\_\_\_

Date: \_\_\_\_\_

Review Date: \_\_\_\_\_

**Note:** *This job description forms part of an individual's contract of employment with WDHB and must be attached to that contract.*

**Person specification**

	<b>Minimum</b>	<b>Preferred</b>
<b>Qualification</b>	<ul style="list-style-type: none"> <li>• Full driver's license</li> </ul>	<ul style="list-style-type: none"> <li>• A related tertiary qualification</li> </ul>
<b>Experience</b>	<ul style="list-style-type: none"> <li>• A minimum of 2 years work experience in the community, disability or health sectors (either voluntary or paid)</li> <li>• Experience working as a team member</li> <li>• Experience working cross-culturally with families/individuals from CALD backgrounds</li> </ul>	<ul style="list-style-type: none"> <li>• Experience in working with parents and providing parent education to support informed choice</li> <li>• Experience providing consultation and specialised cultural advice to team members</li> </ul>
<b>Skills/Knowledge/Behaviour</b>	<ul style="list-style-type: none"> <li>• Ability to relate to and work with people of different cultures and religious backgrounds</li> <li>• Confident with computers</li> <li>• Proficient in written and spoken English</li> <li>• Time management and organisational ability</li> <li>• Networking ability</li> <li>• Is effective both individually and as a part of a wider team</li> <li>• Understands concepts of cultural competency and standards for culturally appropriate services</li> <li>• Knowledge of and a commitment to the Treaty of Waitangi</li> <li>• An understanding of the principles of the New Zealand Disability Strategy</li> </ul>	<ul style="list-style-type: none"> <li>• Commitment to ongoing education</li> <li>• Knowledge of how disability/impairment impacts on children and their families</li> <li>• Advocacy and negotiation skills</li> <li>• Leadership and mentoring skills</li> <li>• A creative approach to problem solving</li> <li>• A passion for working in partnership with families, to support their children as they grow, change and develop</li> <li>• An ability to articulate a vision of inclusion for disabled children</li> </ul>

## Appendix C: Key Informant Participant Information Sheet

### Key Informant Participant Information Sheet Evaluation of Waitemata DHB Child Disability Service Project for Culturally and Linguistically Diverse (CALD) families

HELLO, مرحبا , □□, □□□□□, KIA ORA, TALOFA LAVA, FAKALOFA LAHI ATU, NI SA BULA VINAKA, MALO E  
LELEI, TALOHA NI, KIA ORANA, NAMASTE, □□□□□...

**Can you help us?** You are invited to take part in a study evaluating a project that established two cultural caseworker positions within the Waitemata DHB Child Health Service. This information sheet will tell you more about what we would like you to do. When you have read the sheet, you can decide if you want to take part or not. It is your choice - **you do not have to take part** if you don't want to. If you want, you can take some time to think about it. You can ask a friend or family member to help you understand this information if you wish.

**What is this study about?** This study is an evaluation of the Waitemata DHB Child Disability Service Project for Culturally and Linguistically Diverse (CALD) Families. The study will evaluate the progress of this new project. The research aims to discover the strengths and weaknesses of the project to provide recommendations about what the project is doing well and where it could make improvements.

The study starts in May 2010 and will end in March 2011.

**Why is this study important?** Increasing numbers of children from refugee and CALD migrant backgrounds need to use child disability services in New Zealand. Families from culturally diverse backgrounds need services to be provided in a culturally appropriate way and to know that services can deal with issues related to the refugee experience, migration and settlement in a new society. The Child Disability Service Project for CALD Families aims to ensure that families can access WDH B Child Disability Services and that they receive the support they need. It is important that we evaluate this new project as it develops. This will help the project leaders understand what is working and what needs to be improved.

**You can take part if:** you have been identified by the taskforce as being a key stakeholder in the Child Disability Service Project for CALD Families. For example key stakeholders include: project funders, management and staff, as well as representatives of collaborating teams and services. Key stakeholders are also those people who use the project's services and representatives of migrant and refugee communities targeted by the project.

**What do you have to do?** We would like you to take part in a face-to-face interview with a researcher. Interviews will last for up to an hour, depending on how much you have to say. We would like to find out about the following topics:

- How the project was established
- The project's aims
- What progress has been made to date in: establishing internal and external networks; provision of advice and support to Child Health team members; and building cultural competence of the Child Health teams
- What barriers there may be preventing the project from progressing as intended
- What activities are achieving success, for whom and in what ways

We can arrange for interpreting and/or translation support if you need it. The interview can be arranged at a place and time that is convenient and comfortable for you.

**Do you have to take part?** It is your choice. This means that **you do not have to take part** if you don't want to. If you decide not to take part, any future care or treatment will not be affected. **Will anyone know you are involved?** The study is **anonymous and confidential**. This means that any information you provide will not have your name on it and there will be no way of knowing that you were involved.

**What are the benefits?** If you choose to take part, the information you give us will help us identify the strengths, weaknesses and barriers to the project. This will help improve health services for CALD children and their families.

**Are there any risks?** We believe it is not risky to take part. The interviewer will not ask you for any sensitive information. None of the questions are intended to be upsetting for those taking part in the study. However, if you feel upset **you are allowed to stop** and please **ask the researcher for help**. You can also contact any member of the research team. Contact details are at the end of the sheet.

If you would like to know the results of this project then you can contact us (address below) and we will send you a **summary of the findings**.

**Who is funding the research?** The Waitemata DHB Child, Women and Family Services is funding this research and is being undertaken by research staff at the Clinical Research and Resource Centre (CRRC) within Waitemata DHB.

### **Compensation**

In the unlikely event of a physical injury as a result of your participation in this study, you may be covered by ACC under the Injury Prevention, Rehabilitation and Compensation Act. ACC cover is not automatic and your case will need to be assessed by ACC according to the provisions of the 2002 Injury Prevention Rehabilitation and Compensation Act. If your claim is accepted by ACC, you still might not get any compensation. This depends on a number of factors such as whether you are an earner or non-earner. ACC usually provides only partial reimbursement of costs and expenses and there may be no lump sum compensation payable. There is no cover for mental injury unless it is a result of physical injury. If you have ACC cover, generally this will affect your right to sue the investigators. If you have any questions about ACC, contact your nearest ACC office or the investigator.

**What are your rights?** If you have any queries or concerns regarding your rights as a health professional participant in this research study, you may wish to contact your professional organisation or as a service user you may wish to contact an independent health and disability advocate:

Free phone: 0800 555 050

Free fax: 0800 2 SUPPORT (0800 2787 7678)

Email: [advocacy@hdc.org.nz](mailto:advocacy@hdc.org.nz)

**Thank you very much for your help.**

This study has received ethical approval from the Northern X Regional Ethics Committee, ethics reference number NTX/10/03/020

**Please feel free to contact the researcher if you have any questions about this study.**

### **Research team:**

Principal Investigator: **Dr Amanda Wheeler**. Ph: (09)8381882. Email: [Amanda.wheeler@waitematadhb.govt.nz](mailto:Amanda.wheeler@waitematadhb.govt.nz)

Other investigators: **Lucy Dunbar**. Ph: (09)8381882. Email: [lucy.dunbar@waitematadhb.govt.nz](mailto:lucy.dunbar@waitematadhb.govt.nz)

**Stella Black**. Ph: (09)8381882. Email: [stella.black@waitematadhb.govt.nz](mailto:stella.black@waitematadhb.govt.nz)

Address: Clinical Research and Resource Centre, WDHB, Level 3, Snelgar Building, Private Bag 93115, Henderson, Waitakere 0650.

## Appendix D: Research Participant Consent Form



### Consent Form



#### Evaluation of Waitemata DHB Child Disability Service Project for Culturally and Linguistically Diverse (CALD) families

I have read and I understand the information sheet dated May 2010.

**Please tick the boxes**

- |  |                              |                               |
|--|------------------------------|-------------------------------|
| ➤ I wish to have an interpreter                                    | Yes <input type="checkbox"/> | No <input type="checkbox"/>   |
| ➤ I wish to have a NZ sign language interpreter                    | Yes <input type="checkbox"/> | No <input type="checkbox"/>   |
| ➤ اريد مترجم   | نعم <input type="checkbox"/> | لا <input type="checkbox"/>   |
| ➤ □□□□ □□□□□   | <input type="checkbox"/>     | <input type="checkbox"/>      |
| ➤ □□□□□□□□   | <input type="checkbox"/>     | <input type="checkbox"/>      |
| ➤ E hiahia ana ahau ki tetahi Kaiwhakamaori/kaiwhaka pakeha korero | Ae <input type="checkbox"/>  | Kao <input type="checkbox"/>  |
| ➤ Ou te mana'o ia I ai se fa'amatala upu                           | loe <input type="checkbox"/> | Leai <input type="checkbox"/> |
| ➤ Oku ou fiema'u ha fakatonulea                                    | Io <input type="checkbox"/>  | Ikai <input type="checkbox"/> |

*Other languages to be added following consultation with relevant communities*

- |   |                              |                             |
|---|------------------------------|-----------------------------|
| ➤ I have read and I understand the attached information sheet and I have had an opportunity to discuss it.  | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| ➤ I understand that taking part in the study is voluntary. I know I can withdraw from the study at any time, and this will in no way affect my future health care.  | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| ➤ I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study.   | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| ➤ I have had enough time to consider whether to take part in the study and I know I can contact a researcher (see the information sheet) or my cultural caseworker if I have any questions or concerns about the study. | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| ➤ I consent to my interview being audiotaped/videotaped.  | Yes <input type="checkbox"/> | No <input type="checkbox"/> |

I ..... consent to take part in the study.  
*(first name and surname)*

**Signature** .....

**Date** .....

Study explained by .....on .... / ... / ....

If you would like a copy of the results sent to you please supply your address below. If you need a translated copy please indicate which language.

.....  
 .....

## **Appendix E: Topic areas for KI interviews**

### **Evaluation of Waitemata DHB Child Disability Service Project for Culturally and Linguistically Diverse (CALD) families**

#### **INTERVIEW SCHEDULE - Key Informant interviews**

##### **Introduction**

Thank you for agreeing to take part in this research. Before we get to the questions, I need to go over some information with you.

GO THROUGH THE PARTICIPANT INFORMATION SHEET AND CONSENT FORM.

If you're ready to start I will switch on the recorder and begin my questions.

##### **Master sheet of Key informant questions**

Questions were tailored depending on the KI's background and/or role. Broad topic areas included:

1. The KI's background and role
2. Knowledge and awareness of the Project
3. Level and nature of interactions with CCWs
4. Perceived strengths and weaknesses of the Project
5. Project reach
6. Barriers accessing the Project (families and services)
7. Suggested improvements
8. What difference has CCWs made – and for whom?

In addition, for Project staff:

1. Background to the establishment of the Project
2. What's working well?
3. What's not working well? (challenges).

**THANK YOU FOR YOUR TIME! 😊**

## Appendix F : Case Studies Protocol Document



### Evaluation of Waitemata DHB Child Disability Service Project for Culturally and Linguistically Diverse (CALD) families



#### PROTOCOL DOCUMENT Case Studies Guidelines

Cultural Caseworkers (CCWs) to arrange a **pre-interview meeting** between the families and the researcher.

The purpose of his meeting will:

- give the researcher a more informal way to get to know the family;
- discuss the purpose of the study;
- discuss the process involved, whether they object to being recorded or would prefer notes to be written, if so then ask if they would mind another person attending to take the notes. Discuss in-depth the purpose of taking notes;
- discuss having the services of a professional interpreter, what language and whether the family would prefer a male or female;
- allow the family to feel more comfortable in being able to discuss their experiences with the researcher during the next visit;
- discuss the option of interviewing the family without the CCW being present;
- discuss who will attend the interview – we would encourage the involvement of both parents, if appropriate. Families would also be welcome to invite another support person to attend;
- discuss where they would like to be interviewed;
- discuss the amount of time the interview may take (up to 2 hours);
- make a suitable time to meet.

#### **Before engaging with CALD families consider the following aspects:**

##### *Information prior to the interview*

- Translated 'Participant Information Sheet' and 'Consent Form'
- Researcher to give the family a (translated) copy of the questions that will be asked

##### *Respect and Avoiding cultural taboos*

- remove shoes when entering the house of CALD family participants;
- wear appropriate modest attire, either trousers or a long skirt;
- when greeting Korean families a bow is proper, for Muslim families handshakes between women is appropriate, a verbal greeting for male members of the family is appropriate;
- seating arrangements, female interviewer to seat in a single chair, rather than sit with the male member of the family;
- allow time for 'stream' of conversation, to listen to the families concerns that may be raised;
- accept the hospitality by the CALD families, if a beverage or food is offered it is customary to accept;
- before leaving, thank the family, acknowledge the importance of their collaboration, and inform them that they will receive a (translated) summary of the outcomes of the study.

##### *Privacy*

- ensure the families understand that the information that they provide will not affect the service they receive;
- ensure full parental consent has been granted, if the children are to be interviewed

- discuss the protection of families' identities in this type of research

#### *Confidentiality*

- information collected during interviews will be de-identified by the researcher as far as is possible, such as names, addresses and other information that could be used to identify people who take part.

#### *Control and decision-making*

- participant families are free to withdraw from the study at any time.

#### *Support*

- discuss who will provide advice and support

#### *Professional misconduct*

- where any issues of professional or serious misconduct arise in interviewing the participants and the Consumer Complaints process is not sufficient the Waitemata DHB Discipline and Dismissal procedure shall be followed.

#### *Thank you*

- re-imburse expenses
- take food, preferably fruit

## Appendix G: Case Study Participant Information Sheet



### Case Study Participant Information Sheet

#### Evaluation of Waitemata DHB Child Disability Service Project for Culturally and Linguistically Diverse (CALD) families

HELLO, مرحبا , □□, □□□□□, KIA ORA, TALOFA LAVA, FAKALOFA LAHI ATU, NI SA BULA VINAKA, MALO E LELEI, TALOHA NI, KIA ORANA, NAMASTE, □□□□□...

**Can you help us?** You are invited to take part in a study evaluating a project that established two cultural caseworker positions within the Waitemata DHB Child Health Service. This information sheet will tell you more about what we would like you to do. When you have read the sheet, you can decide if you want to take part or not. It is your choice - **you do not have to take part** if you don't want to. If you want, you can take some time to think about it. You can ask a friend or family member to help you understand this information if you wish.

**What is this study about?** This study is an evaluation of the Waitemata DHB Child Disability Service Project for Culturally and Linguistically Diverse (CALD) Families. The study will evaluate the progress of this new project. The research aims to discover the strengths and weaknesses of the project to provide recommendations about what the project is doing well and where it could make improvements. The study starts in May 2010 and will end in March 2011.

**Why is this study important?** Increasing numbers of children from refugee and CALD migrant backgrounds need to use child disability services in New Zealand. Families from culturally diverse backgrounds need services to be provided in a culturally appropriate way and to know that services can deal with issues related to the refugee experience, migration and settlement in a new society. The Child Disability Service Project for CALD Families aims to ensure that families can access WDH B Child Disability Services and that they receive the support they need. It is important that we evaluate this new project as it develops. This will help the project leaders understand what is working and what needs to be improved.

**You can take part if:** you have been identified by the Cultural Caseworker as a CALD child/family using the service.

**What do you have to do?** We would like to observe and take notes during your interactions with the Cultural Caseworkers or the Child Health teams. The observations will explore how the project is experienced in 'real life' for those involved.

We would also like you to take part in a face-to-face interview with a researcher. Interviews will last for up to an hour, depending on how much you have to say. We would like to find out about your perspectives that may include some of the following topics:

- Impacts of the project
- Barriers and facilitators to making full use of the project
- Ideal project delivery

We can arrange for interpreting and/or translation support if you need it. The interview can be arranged at a place and time that is convenient and comfortable for you.

**Do you have to take part?** It is your choice. This means that **you do not have to take part** if you don't want to. If you decide not to take part, any future care or treatment will not be affected.

**Will anyone know you are involved?** The study is **anonymous and confidential**. This means that any information you provide will not have your name on it and there will be no way of knowing that you were involved.

**What are the benefits?** If you choose to take part, the information you give us will help us identify the strengths, weaknesses and barriers to the project. This will help improve health services for CALD children and their families. All out of pocket expenses incurred as a result of taking part in this study (e.g. petrol, parking, etc) will be reimbursed.

**Are there any risks?** We believe it is not risky to take part. The interviewer will not ask you for any sensitive information. None of the questions are intended to be upsetting for those taking part in the study. However, if you feel upset **you are allowed to stop** and please **ask the researcher for help**. You can also contact any member of the research team. Contact details are at the end of the sheet.

If you would like to know the results of this project then you can contact us (address below) and we will send you a **summary of the findings**.

**Who is funding the research?** The Waitemata DHB Child, Women and Family Services are funding this research and is being undertaken by research staff at the Clinical Research and Resource Centre (CRRC) within Waitemata DHB.

### **Compensation**

In the unlikely event of a physical injury as a result of your participation in this study, you may be covered by ACC under the Injury Prevention, Rehabilitation and Compensation Act. ACC cover is not automatic and your case will need to be assessed by ACC according to the provisions of the 2002 Injury Prevention Rehabilitation and Compensation Act. If your claim is accepted by ACC, you still might not get any compensation. This depends on a number of factors such as whether you are an earner or non-earner. ACC usually provides only partial reimbursement of costs and expenses and there may be no lump sum compensation payable. There is no cover for mental injury unless it is a result of physical injury. If you have ACC cover, generally this will affect your right to sue the investigators. If you have any questions about ACC, contact your nearest ACC office or the investigator.

**What are your rights?** If you have any queries or concerns regarding your rights as a participant in this research study, you may wish to contact an independent health and disability advocate:

Free phone: 0800 555 050

Free fax: 0800 2 SUPPORT (0800 2787 7678)

Email: [advocacy@hdc.org.nz](mailto:advocacy@hdc.org.nz)

**Thank you very much for your help.**

This study has received ethical approval from the Northern X Regional Ethics Committee, ethics reference number NTX/10/03/020

**Please feel free to contact the researcher if you have any questions about this study.**

#### **Research team:**

Principal Investigator: **Dr Amanda Wheeler**. Ph: (09)8381882. Email: [Amanda.wheeler@waitematadhb.govt.nz](mailto:Amanda.wheeler@waitematadhb.govt.nz)

Other investigators: **Lucy Dunbar**. Ph: (09)8381882. Email: [lucy.dunbar@waitematadhb.govt.nz](mailto:lucy.dunbar@waitematadhb.govt.nz)

**Stella Black** Ph: (09)8381882. Email: [stella.black@waitematadhb.govt.nz](mailto:stella.black@waitematadhb.govt.nz)

Address: Clinical Research and Resource Centre, WDHB, Level 3, Snelgar Building, Private Bag 93115, Henderson, Waitakere 0650.

## Appendix H: Case Study Question Schedule for Interviews



### Evaluation of Waitemata DHB Child Disability Service Project for Culturally and Linguistically Diverse (CALD) families

#### Case Study Questions

[Note: Not all questions will be relevant for all families taking part in the CALD Case Studies. These will be amended where appropriate.]

1. What Child Health services at Waitemata DHB do you and your family use?
2. Can you tell me what your experiences were like using these services, before you had a Cultural Caseworker?
3. What changes have you noticed about Child Health Services since you have had a Cultural Caseworker?
4.
  - a) Can you tell me about a time when you found Child Health Services difficult to access?
    - What happened?
    - How did that make you feel?
  - b) Can you tell me about a time when you felt Child Health Services were easy to access?
5. What changes have you noticed about your family since you have had a Cultural Caseworker?
6. In what ways do you feel things would have been different for you if the Cultural Caseworker had been a different:
  - gender
  - age
  - ethnicity
  - spirituality/religion.

**THANK YOU FOR YOUR TIME! 😊**