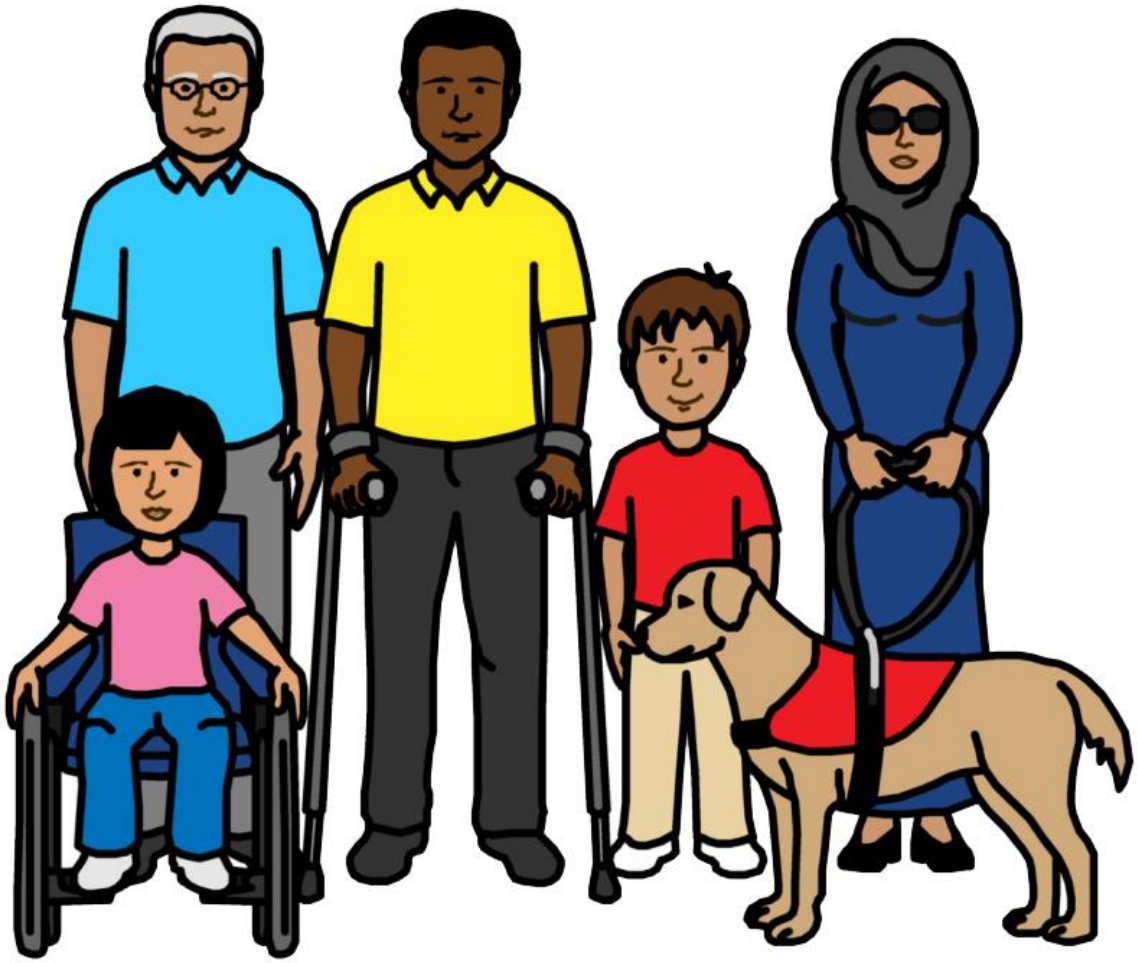
Service responses for people with disabilities from refugee backgrounds in northern Melbourne

victorian refugee health network

July 2018



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Disclaimer: This is the first time that this material has been brought together. The service systems covered in this report are undergoing significant change processes. Accuracy is important – please let us know if you identify an error and we will amend future work. Organisations described and referenced in this report are also invited to write submissions or responses, which will be posted alongside the report on the Victorian Refugee Health Network website.

About the Victorian Refugee Health Network

The Victorian Refugee Health Network (the Network) (www.refugeehealthnetwork.org.au) is auspiced by the Victorian Foundation for Survivors of Torture Inc. (Foundation House) and was established in June 2007. The Network aims to facilitate greater coordination and collaboration among health and community services to provide more accessible and appropriate health services for people from refugee backgrounds.

Foundation House was established in 1987 to meet the needs of people in Victoria who have been subjected to torture or other traumatic events in their country of origin, or while escaping those countries. Foundation House is a not-for-profit organisation funded by the Victorian and Commonwealth governments, charitable trusts and donations, and provides direct torture and trauma counselling services as well as considerable work in research and policy.

Foundation House and the Network have a respected history of building relationships within a range of sectors, and more specifically developing resources, referral guides and clinical supports for general practitioners. This project, *Service responses for people with disabilities from refugee backgrounds in the northern metropolitan region*, builds on existing and historical supports with settlement and health services to provide high-quality, coordinated care to people from refugee backgrounds.

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Many people including those from settlement, disability, health and education services and government made this report possible through their contributions. In particular we wish to thank:

- our project advisory group for their wisdom,
- the people who gave up time to be interviewed to offer their experiences and understanding of the sector,
- those that participated in the sector roundtable,
- people who met with the project team to help interpret the data, and
- those who provided feedback on the report.

This report is only possible because of the contributions of over 50 people.

The writing team Philippa Duell-Piening, Sue Casey and Assunta Hunter would also like to thank their colleagues at Foundation House and Rebecca Cole for copy editing assistance.

Definitions

Disability

For the purposes of this paper we have adopted the definition of disability developed by the World Health Organization: 'Disability is ... not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers'[1] as well as interventions and supports to address issues arising from physical, sensory, mental and/or cognitive impairments.

People from refugee backgrounds

The term 'people from refugee backgrounds' is used throughout this report to refer to those who: have arrived in Australia with, or who have subsequently been granted, permanent or temporary humanitarian visas; people seeking asylum; and those who come from refugee backgrounds who have another visa type, including family migration and skilled migration.[2(p5)] Where the immigration status a person currently has or had on entry to Australia is significant, this will be noted.

Abbreviations

A&S	Access and Support
ACAS	Aged Care Assessment Services
ACCO	Aboriginal Community Controlled Organisation
ADEC	Action on Disability within Ethnic Communities Inc
AMEP	Adult Migrant Education Program
APMH	Aged Persons Mental Health
CALD	Culturally and Linguistically Diverse
CCS	Complex Case Support
COAG	Council of Australian Governments
CoS	Continuity of Support
CRPD	Convention on the Rights of People with Disabilities
DET	Department of Education and Training (Victorian)
DHC	Departure Health Check
DHHS	Department of Health and Human Services (Victorian)
DSS	Department of Social Services (Commonwealth)
EAL	English as an Additional Language
ECCV	Ethnic Communities Council of Victoria
ECEI	Early Childhood Early Intervention
ECIS	Early Childhood Intervention Services
FASSTT	Forum of Australian Services for Survivors of Torture and Trauma
HACC	Home and Community Care
HCWA	Helping Children With Autism
Home Affairs	Department of Home Affairs (Commonwealth)
HSP	Humanitarian Settlement Program
ILC	Information, Linkages and Capacity Building
IME	Immigration Medical Examination
IOM	International Organization for Migration
LAC	Local Area Coordination
MBS	Medicare Benefits Schedule
MCH	Maternal and Child Health
MEA	Multicultural Education Assistant
MHCSS	Mental Health Community Support Service
NEDA	National Ethnic Disability Alliance
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme

PAG	Project Advisory Group
PASTT	Program of Assistance for Survivors of Torture and Trauma
PSD	Program for Students with Disabilities
RCOA	Refugee Council of Australia
RHeaNA	Refugee Health Network of Australia
RHP	Refugee Health Program
SRSS	Status Resolution Support Services
SSS	Student Support Services
SWEP	State-wide Equipment Program
TIS	Translating and Interpreting Services
TPV	Temporary Protection Visa
UNHCR	United Nations High Commissioner for Refugees
VASS	Victorian Arabic Social Services

Executive summary

As part of the *Absolutely everyone: State disability plan 2017–2020* the Victorian Government funded the Victorian Refugee Health Network (the Network) 'to complete a needs assessment of the responsiveness of the disability and refugee health service system in northern Melbourne'.[3(p28)] This report details the outcomes of the needs assessment and makes recommendations for service and policy changes and future activities to improve service responsiveness.

The issues facing people with disabilities from refugee backgrounds are multi-faceted. The service pathways for people living with a disability can be complex when accessing supports needed; discussing concerns with a general practitioner, maternal and child health nurse or teacher; seeking and negotiating services for diagnosis and other assessments; and accessing ongoing support services as required. Services in Victoria are typically organised across the life stages – early intervention, school years, adulthood and older adulthood – for most conditions, and/or a service pathway that starts with hospitalisation following an accident or major illness.

For people born with a disability-related condition there is a focus in the early years – and sometimes in primary school – on identification of concerns, assessment and then access to required services. For those who acquire a disability through a major accident or illness, the pathway to disability supports typically starts with hospital-based care, with discharge predicated on access to aids and equipment and rehabilitation services as needed.

For the broader Victorian community, there are significant barriers to service access, including long wait times for some services, and sometimes multiple appointments for diagnostic and other assessments to access the necessary ongoing supports.

These challenges are compounded for new arrivals from refugee backgrounds who may:

- arrive with a condition that is undiagnosed or not formally diagnosed, or which may or may not be familiar to Australian practitioners
- arrive with a poorly managed condition, which may or may not be familiar to Australian practitioners
- be an adult presenting with a condition that is typically diagnosed in childhood
- arrive without necessary aids and equipment (for example, a wheelchair or walking aids).

These challenges are in addition to the broader settlement challenges facing new arrivals from refugee backgrounds. These include negotiating access to housing, transport, income support, education and employment in a new country; typically trying to learn a new language; and communicating via interpreting services. Settlement is further complicated by the impact of torture and other traumatic events (such as exposure to war and conflict) and the complexities of negotiating access to services cross-culturally.

This report has been written at a time when there have been significant changes in service arrangements with the progressive roll-out of the National Disability Insurance Scheme (NDIS) and the suite of aged care reforms that has accompanied the introduction of My Aged Care (such as changes to home support, including Home Care Packages and the Commonwealth Home Support Programme).

At a population level, there has been an increase of new arrivals from refugee backgrounds in the outer northern metropolitan region of Victoria, in particular the Hume local government area. The welcome introduction in 2012 of a waiver of visa health requirements (the health waiver) for humanitarian visa holders has also led to an increase in numbers of humanitarian entrants who are living with a disability.

The focus of this report is on:

- service provision to people from refugee backgrounds arriving on humanitarian visas, who have a disability or impairment before they reach Australia
- access to services for people who have a disability or impairment and who are seeking asylum while living in the community.

Recommendations

We recommend:

Recommendation 1: The Commonwealth Government departments of Home Affairs and Social Services provide access to free interpreting services for allied health MBS funded consultations through TIS.

Recommendation 2: The Commonwealth Government Department of Home Affairs, through its Status Resolution Support Services (SRSS) contracts, provides NDIS equivalent packages of support for people seeking asylum who meet the non-residency related requirements for NDIS.

Recommendation 3: The Commonwealth and Victorian governments fund NDIS equivalent packages of support for people holding temporary protection visas who meet the non-residency related requirements for NDIS.

Recommendation 4: The NDIA develops a comprehensive language service policy to guide its service provision and that of funded service providers to improve clarity about use of language services. This policy should emphasise choice for people with low English proficiency and promote effective communication between service providers and participants.

Recommendation 5: The Victorian Government Department of Education and Training review the EAL learning support needs of special schools, including approaches to EAL assessment and learning plans.

Recommendation 6: The Foundation House School Support Program and the Refugee Education Support Program continue to provide professional development and broader school support for special schools.

Recommendation 7: The Victorian Refugee Health Network, through the Victorian Network of Asylum Seeker Agencies, conducts a survey to understand better the number of people seeking asylum who have disabilities.

Recommendation 8: The NDIA includes identifiers in its dataset to assist in ascertaining participation rates of people from refugee backgrounds in the NDIS.

Recommendation 9: Local refugee health networks develop care pathways across health, disability and settlement services for people with significant impairments from refugee backgrounds. This should be through a consensus process including all relevant services and, where appropriate, people with disabilities and their carers.

Recommendation 10: Foundation House, Ethnic Communities Council of Victoria and the Centre for Culture, Ethnicity and Health in their work with advisory groups of people with disabilities from refugee backgrounds and their carers explore what is required to support them with self-advocacy.

Recommendation 11: The NDIA and the Commonwealth Government Department of Health review consumer-driven care models implemented by NDIS and aged care reforms to take into account the particular needs of people from refugee backgrounds, including longer appointment times, interpreters, flexible service delivery systems, and planners

who are skilled in working cross culturally and have an understanding of the refugee experience.

Recommendation 12: The Commonwealth Government Department of Social Services explores methods to deliver accessible community transport options for new humanitarian arrivals with significant impairments.

Recommendation 13: All services have policies and procedures in place to assess whether an interpreter is required and to engage interpreting services.

Recommendation 14: All services provide training to staff about assessing the need for an interpreter, accessing an interpreter and facilitating an interpreter mediated conversation.

Recommendation 15: The Commonwealth Government Department of Social Services, Humanitarian Settlement Providers, Refugee Health Programs and Primary Health Networks provide community based accessible information to new arrival communities regarding My Health Record to support implementation including information to address privacy concerns.

Recommendation 16: The Refugee Health Program explore using a shared health record, possibly My Health Record, adhering to appropriate privacy laws and in consultation with people from refugee backgrounds, to support continuity of care. This should include exploring using records that could be shared with other primary health care providers, settlement and disability services.

Recommendation 17: The Victorian Government Department of Health and Human Services review the findings of their Refugee Immunisation Project to consider broader application of the appointment tracking and reminder system for the provision of on arrival health services for people from refugee backgrounds.

Recommendation 18: The Commonwealth Government departments of Social Services and of Home Affairs, the Victorian Government Department of Health and Human Services and contracted services work to implement a system that supports health information transfer from offshore to health services that will be conducting the on-arrival health assessments.

Recommendation 19: The Commonwealth Government Department of Home Affairs and the Australian Digital Health Agency develop a mechanism to transfer appropriate summary medical information, gathered prior to arrival in Australia, to My Health Record.

Recommendation 20: Primary Health Networks, Refugee Health Programs and specialist refugee services target capacity-building at general practices that are well utilised by communities from refugee backgrounds (including multilingual practices).

Recommendation 21: Primary Health Networks develop and maintain resources to assist general practice with referral pathways for people from refugee backgrounds with disabilities.

Recommendation 22: Primary Health Networks work closely with settlement, Refugee Health Programs and Refugee Health Fellows to identify practices that are undertaking good quality health assessments and follow-up care.

Recommendation 23: All service providers engage with communities to find a common dialogue to address stigma associated with some disabilities.

Recommendation 24: Foundation House and specialist paediatric refugee services provide professional learning for psychologists and other practitioners undertaking developmental and cognitive assessments for children and adolescents.

Recommendation 25: The Victorian Government Department of Education and Training take into account additional considerations required in assessing students from refugee

backgrounds in developing the new three-tiered funding model for Program for Students with Disabilities.

Recommendation 26: The Commonwealth Government Department of Social Services extends funding for hiring of mobility aids until new humanitarian entrants have access to Victorian Aids and Equipment Programs or the NDIS.

Recommendation 27: Services and policy makers consider the compounding effect of long waiting times on newly arrived people with disabilities from refugee backgrounds when reviewing frameworks for providing priority access.

Recommendation 28: The Victorian Government Department of Education and Training take into account particular transition support needs of children with disabilities from refugee backgrounds.

Recommendation 29: Carers organisations, including young carers organisations, provide culturally appropriate responses to carers from refugee backgrounds who may be isolated due to their caring responsibilities.

Recommendation 30: The Commonwealth Government Department of Social Services provide early notification to Humanitarian Settlement Program providers of mobility restrictions experienced by Refugee and Humanitarian Programme entrants to assist with sourcing appropriate housing.

Recommendation 31: Disability Employment Services build cultural competence and have strategic approaches to engaging with people with disabilities from refugee backgrounds.

Recommendation 32: The Commonwealth Government Department of Social Services investigates different approaches to the provision of employment support services to people with disabilities from refugee backgrounds, which may include Customised Employment.

Recommendation 33: The Victorian Refugee Health Network identifies a network or working group who may undertake stage 2 of this project - the facilitation of an inter-sectoral working group that will pursue actions to implement the recommendations of this report.

Please note: Recommendations that are directed at Foundation House and the Victorian Refugee Health Network (authors of this report) are possible within current program funding.

1 Project summary

1.1 Background

As part of the *Absolutely everyone: State disability plan 2017–2020* the Victorian Government funded the Victorian Refugee Health Network (the Network) 'to complete a needs assessment of the responsiveness of the disability and refugee health service system in northern Melbourne'.[3(p28)] This report details the outcomes of the needs assessment and makes recommendations for service and policy changes and future activities to improve service responsiveness.

A complementary piece of work, funded by the Victorian Department of Health and Human Services (DHHS), will be undertaken by Foundation House in 2018–19 to recruit and work with a community advisory group of people with disabilities from refugee backgrounds. Discussions will be facilitated with the community advisory group and service providers to identify needed service and system improvements.

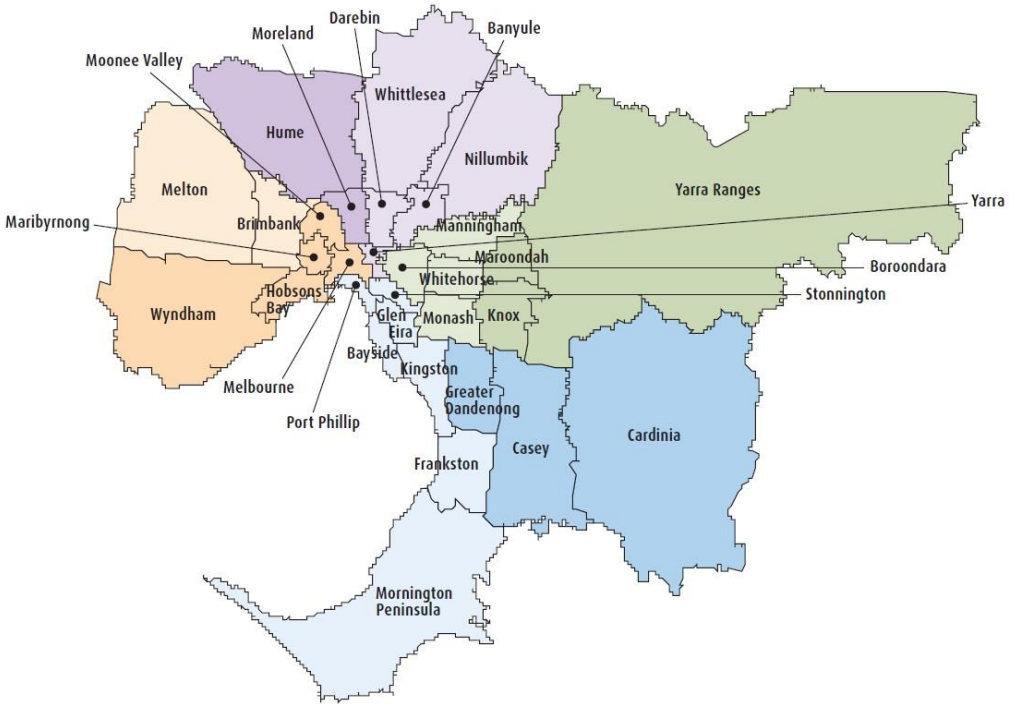
1.2 Project aims and scope

This needs assessment project aimed to better understand service responses to people from refugee backgrounds who:

- had impairments before they arrived in Australia,
- lived in northern Melbourne, and
- were within the first 24 months of their arrival.

Northern Melbourne was defined as the local government areas that comprise the metropolitan section of the Department of Health and Human Services Northern Region. That is, Banyule, Darebin, Hume, Moreland, Nillumbik, Yarra and Whittlesea.

Figure 1: Map of metropolitan Melbourne with local government areas[4]



The original scope of the project was to consider service responses to people with disability of refugee backgrounds who had arrived in Australia on a humanitarian visa. This scope was slightly expanded to include the needs of asylum seekers and people who are holders of temporary protection visas, as it became clear during consultations there was considerable confusion about service access for these groups and their particular service access barriers.

1.3 Project Advisory Group

This project was guided by a multi-sectoral Project Advisory Group (PAG) with representatives from the settlement, health and disability service sectors who met in the period March to May 2017. PAG members included settlement, health and disability practitioners, academics and policy advisors. The PAG met three times; the third meeting being a round table with a broader group of invitees from the relevant sectors (see section 1.5.3).

The purpose of the PAG was to:

- provide high-level strategic, content, process and technical advice about the development and implementation of the needs assessment
- provide strategies for identifying key stakeholders.

The PAG had an important influence on the project through shaping the interview protocol, suggesting informants and providing advice about the structure of the report.

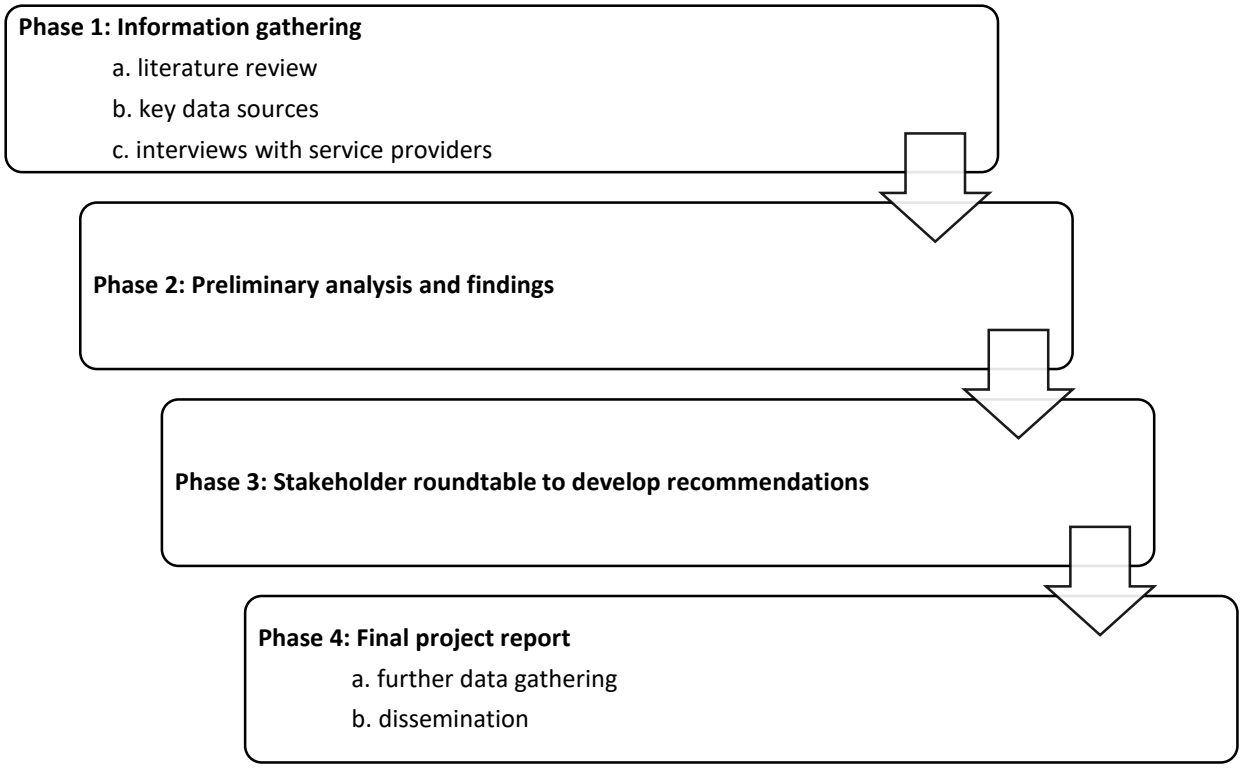
1.4 Project implementation group

A Sector Development and Policy Advisor was appointed to project manage this research, their role included developing a project plan, conducting desk-based research including a literature review, providing secretariat support to the project advisory group, leading the development of the interview protocol, preparing the human research ethics application, identifying and recruiting interview participants, conducting and documenting interviews, and commencing the write up of this report. The final data analysis and report was completed by the Coordinator of the Victorian Refugee Health Network and the Foundation House Manager of Sector Development and Partnerships.

1.5 Project methodology

The project had four phases, as described in Figure 1. These phases are discussed in more detail below.

Figure 2: Project phases



1.5.1 Phase 1: Information gathering

The information gathered in Phase 1 of the project is presented in Sections 2, 3 and 4 of this report. Each element of the information gathering process is briefly described below.

1.5.1.1 Literature review

A literature review was undertaken. Search terms included 'disability', 'refugee' and 'service access' (this included settlement, health and social services as search terms). Additionally, PAG members and other projects stakeholders provided documents (academic literature, project reports, evaluation reports and policy documents) to inform this review. Government websites were accessed for policy documents through online search engine Google to assist in finding specific information. Footnotes of policy documents assisted in locating historical/foundational documents.

1.5.1.2 Key data sources

The Department of Social Services Settlement Database, since decommissioned, was accessed to extract reports about the settlement demographics in northern Melbourne. The NDIS data and other programmatic data were reviewed but most did not have sufficient data points to identify people from refugee backgrounds. This is discussed further in section 3.

1.5.1.3 Interviews with service providers

Interviews were undertaken with service providers to gather detailed information about on arrival experience of people from refugee backgrounds with disabilities as this is largely undocumented in other places.

The PAG suggested a number of informants for the project. The researcher refined this list to ensure a balanced range of services were represented. Service provider informants were approached directly by phone and email with the request to engage in an interview.

A screening question was asked of informants prior to booking an interview: ‘Do you or your organisation provide services to people from refugee backgrounds with disabilities?’ Only

one person answered ‘no’. This low rate of negative responses was likely due to the targeted recruitment of interviewees.

A total of sixteen semi-structured interviews using open-ended questions were conducted between late March and late May 2017 with a range of different service providers with experience of delivering services to people with disabilities of refugee backgrounds. This included:

- settlement service providers (three)
- health practitioners (two paediatricians, one refugee health nurse)
- settlement health coordinators (three)
- mental health service providers (two)
- community support workers and advocates (two)
- a school welfare coordinator
- a special school teacher
- a maternal and child health nurse

The informants were from a variety of agencies that may be categorised as mainstream, ethno-specific and multicultural, as well as generalist and specialist. Three of these informants came from outside northern Melbourne and were included for their expertise in working with people with disabilities from refugee backgrounds. Fourteen interviews were conducted face to face and two by phone. Interviews were conducted in confidential spaces within workplaces or in the informants’ preferred locations.

Questions were formulated to elicit information from service providers on:

- the perceived needs of recently arrived people with disabilities from refugee backgrounds
- the services they currently provide
- how they thought services could be improved and the resources necessary to achieve this
- their perceptions of support networks and resources already available

The Victorian Foundation for Survivors of Torture Inc. Institutional Ethics Committee reviewed and approved the interview protocol at Table 1.

Table 1: Interview protocol

Introduction: While answering these questions consider people from refugee backgrounds with disabilities in their first 24 months after arrival (discuss with participants their understanding of the population, i.e. humanitarian entrants, impairments etc).
What do people from refugee backgrounds with disabilities and/or their carers define and prioritise as their needs?
What do you and/or your service observe as the needs of people from refugee backgrounds with disabilities and their carers?
How do you and/or your service meet these needs?
How do you think these needs may be better met?
What will it take to get there?
What do you and/or your service observe as the support networks and resources of people from refugee backgrounds with disabilities and their carers?

1.5.2 Phase 2: Preliminary analysis and findings

Early interview data were coded by the Sector Development and Policy Advisor and the Coordinator together to compile a report for the sector roundtable for comment.

When the interviews were complete the Sector Development and Policy Advisor and Coordinator thematically analysed the interview data independently and major themes were compared and negotiated.

1.5.3 Phase 3: Stakeholder round table

Preliminary findings were discussed at a half day round table in May 2017 chaired by Philip O'Meara, Diversity, Community Participation, Sport and Recreation, Department of Health and Human Services and facilitated by Sue Casey Manager, Sector Development & Partnerships, Foundation House. There were a total of 23 attendees from settlement, health, education and peak bodies (this included PAG members).

The aim of the round table was to check the validity of the findings from the interviews and to formulate recommendations. Following a presentation of the findings, round table attendees worked in small groups to consider 'What's next?', according to the major themes that were prominent in the initial coding of the interview data. These themes were:

- pre-arrival assessments and notifications: planning on-arrival supports
- on arrival health assessment: diagnosis
- confusion about roles: buck passing, gate keeping and silos
- case management: getting connected to services
- overloaded services and waiting lists
- supporting continuity of care: sharing information and supporting families to stay engaged
- the introduction of the NDIS
- access to appropriate support and pathways to schools.

Key points were recorded and have informed this report.

1.5.4 Phase 4: Final report

1.5.4.1 Further information gathering and clarification

Following the round table, information was further clarified through:

- presentation and discussion at key forums including Refugee Health Program Networking Day (32 attendees), the Schools and Health Forum in the north (100 attendees) and the Victorian Refugee Health Network Reference Group (13 attendees)
- telephone and email correspondence with policy advisors and service providers
- a further three stakeholder meetings with DHHS, the Department of Education and Training (DET) and AMES Australia.

1.5.4.2 Dissemination of findings

Preliminary findings from the project were presented at the Forum of Australian Services for Survivors of Torture and Trauma (FASSTT) Conference in Sydney (March 2017) and the North American Refugee Health Conference in Vancouver (June 2017).

The final Project Report (this document) will be shared on the Victorian Refugee Health Network website and e-Bulletin, in addition to being disseminated to key stakeholders and project informants.

2 Policy and service context

This section is a summary of policy, guidelines and other documents gathered in Phase 1 of the project. These documents outline the way services and systems are intended to run to meet the needs of people with disabilities of refugee backgrounds in Victoria. Section 4, by contrast, contains observations from practitioners working in these systems, or alongside these systems, about how the services and systems are operating in practice. Section 2 and 4 are intended to complement and not duplicate each other.

2.1 Commonwealth Government jurisdiction

The Commonwealth is responsible for deciding who will migrate to Australia, for contracting settlement support programs for people who are newly arrived, and for administering social security through Centrelink, Medicare and the NDIS.

2.1.1 Australia's Refugee and Humanitarian Programme

Australia receives a large number of immigrants each year, a small proportion of whom are Refugee and Humanitarian Programme entrants. This group has particular needs to which the Commonwealth Government responds through a range of programs.

The Refugee and Humanitarian Programme is Australia's 'contribution to the international protection of refugees',[5] providing protection to people who:

> *…owing to well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, [are] outside of the country of [their] nationality and [are] unable or, owing to such fear, [are] unwilling to avail [them]self of the protection of that country… (Convention Relating to the Status of Refugees, 1951, Article 1A(2))*

Those who may not meet this definition but 'are subject to substantial discrimination amounting to gross violation of their human rights in their home country' are also included in the program through the Special Humanitarian visa sub-classes (e.g. visa subclass 202).[6]

People may apply for protection visas offered through this program while living overseas (visa subclasses 200–204) or after they arrive in Australia (visa subclass 866). Some people who arrive in Australia without a valid visa, often by boat, may only apply for protection visas that are temporary (visa subclass 785 Temporary Protection Visa and visa subclass 790 Safe Haven Enterprise visa).[7]

The Refugee and Humanitarian Programme is a planned immigration program, and each year the number of visa places allocated to the program is set out in the federal budget. The Commonwealth is currently increasing the intake to 18,750 in the 2018–19 financial year 'and thereafter'.[8(p5)] Transitioning to this increase, the intake in 2017-18 will be 16,250.[8(p8)] In September 2015, the Commonwealth Government made a commitment to 12,000 additional places for people fleeing from the Syrian and Iraqi conflicts,[8(p8)] with the majority of these entrants arriving in 2016–17. People who receive permanent protection visas through the Refugee and Humanitarian Programme are permanent residents on arrival in Australia (for holders of visa subclasses 200–204) or following visa grant (for holders of subclass 866).[9,10]

Different visa subclasses in this program have slightly different requirements and entitlements. Most significantly, visa subclass 202 requires an Australian resident or citizen, an eligible New Zealand citizen or an organisation operating in Australia to propose a person for entry.[11] Proposers and applicants must cover the cost of travel or access a no-interest loan through the International Organization for Migration (IOM) and proposers assist in the settlement of the entrant, including transport from the airport, accommodation and linking the

person(s) to services.[11] Humanitarian Settlement Program (HSP) service providers assess the proposer's capacity to assist new arrivals.[12] The Department of Social Services (DSS) observes: 'Often Proposers have only recently settled in Australia and may overestimate their capacity to provide settlement support'[12(p5)] and 'Based on need, the [Humanitarian Settlement Program] Service Provider must deliver the Settlement Services to a Client where their Proposer is unable to provide support.'[12(p9)]

2.1.1.1 Visa medicals and other health checks prior to immigration

Prior to arrival in Australia, all offshore humanitarian entrants undergo an Immigration Medical Examination (IME), which may be performed up to 12 months prior to departure.[6] The purpose of the IME is to establish the health status of Refugee and Humanitarian Programme applicants. In addition, a voluntary Departure Health Check (DHC) may also be undertaken within 72 hours of departure where critical health issues are flagged and if necessary a medical escort is requested.[13] Not all new arrivals will have had access to or undertake a DHC, particularly if they are being proposed by family or community members who are expected to facilitate their contact with medical services. All pre-departure and/or pre-visa grant health information is recorded in the Home Affairs HAP system.[13]

2.1.1.2 Expansion of the health waiver: Australia's immigration policy response to the Convention on the Rights of Persons with Disabilities

Like most people applying for a permanent visa, Refugee and Humanitarian Programme entrants must meet a government health requirement. This is designed to protect public health, contain health and welfare expenditure, and protect demands on the Australian health care system.[14] If a disease or condition is deemed to be likely to result in significant health care costs, or require use of services that are in short supply, then the health requirement will not be met and a visa will not granted unless a health waiver is available and exercised.[15] Health waivers are available to certain refugee and humanitarian visa classes, and the conditions under which such waivers are granted was expanded in 2012.

In 2008, Australia became a signatory to the Convention on the Rights of Persons with Disabilities, which prohibits discrimination on the basis of disability. The Convention is also:

> *Concerned about the difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status.*[16(Preamble[p])]

In response to the Australian Government's treaty review process, the 2010 *Inquiry into Migration Treatment of Disability* by the Australian Parliament's Joint Standing Committee on Migration recommended 'that offshore refugee applicants who have a disability or other health condition have access to the consideration of a waiver of the Health Requirement'.[17(pxii,para1.9)]

In November 2012 the Australian Government responded to the Committee's recommendations stating that from 1 July 2012, 'a humanitarian visa processing officer will not consider any costs for health or community care services undue'.[18(p8)] This remained policy according to the Home Affairs *Procedure Advice Manual* in December 2017.[19] In effect, this means that, under current Home Affairs policy, in most cases a person with a disability who applies for a refugee or humanitarian visa and meets all other visa requirements should have the health requirement waived and be able to be granted a visa. There are still certain circumstances where the waiver will not be granted, such as where finite services in short supply (such as organ transplants) are protected to remain available to Australian citizens and permanent residents.[20(p8)]

2.1.1.3 People seeking asylum

People who have arrived in Australia by boat or by aeroplane and have then applied for a protection visa are referred to as 'asylum seekers' while they are waiting for their protection

applications to be assessed. Depending on when they arrived, the mode of their arrival and at what stage their application is up to, they will have varying entitlements to Australian government services.

2.1.2 Commonwealth programs for Refugee and Humanitarian Programme entrants

People who have been granted a Refugee and Humanitarian Programme visa offshore are permanent residents on arrival in Australia. Those who apply onshore and are granted a subclass 866 visa become permanent residents when their visa is issued. Permanent residents have access to health and human services including Medicare and Centrelink payments, furthermore people who 'reside in Australia and are either a refugee or a former refugee' may access the disability support pension if they meet all other criteria.[21] People with humanitarian visas that were issued before arriving in Australia (subclasses 200–204) are eligible for a range of services including Humanitarian Settlement Program (HSP) services, Translating and Interpreting Services (TIS), English language classes under the Adult Migrant Education Program (AMEP), settlement grant services, and torture and trauma counselling under the Program for Assistance for Survivors of Torture and Trauma (PASTT). People who receive protection visas (permanent or temporary) after arriving in Australia are able to access some of these programs.

2.1.2.1 Humanitarian Settlement Program (HSP)

The majority of people who arrive through the Refugee and Humanitarian Programme receive support through the DSS-funded HSP currently delivered by AMES Australia and its partners in Victoria.[22] The HSP assists people to find a place to live, to set up that home with furniture, register with government agencies, orient themselves to the local area and enrol in English classes. Settlement case managers also link newly arrived humanitarian entrants with a general practitioner within four weeks of arrival.

HSP services are provided according to client needs and the complexity of their situation. Clients are allocated a tier that indicates the intensity of service provision: Tier 1 indicates least and Tier 3 the most intensive service provision.[12] Most humanitarian entrants are expected to require Tier 2 support. Tier 3 'specialised and intensive services' are for clients who are unable to 'independently engage with appropriate supports and may be impacted by multiple and complex barriers'.[12] Tier 3 support requires prior written approval from DSS, and, unlike Tiers 1 and 2, is available to a broader range of visa holders including subclasses 866, 785 and 790.[12] People from refugee backgrounds are eligible for these services for five years from the time of arrival in Australia or visa grant date (for those that applied after they arrived in Australia). If a person has been on Tier 3 support for six months, HSP service providers must seek approval from DSS to extend the period of specialised and intensive services.[12]

2.1.2.2 Medicare Benefits Schedule (MBS) health assessment for refugees

HSP providers are required to support attendance at a health assessment within 28 days of the person's arrival in Australia.[12(p20)] This is in line with the Australasian Society for Infectious Diseases (ASID) and Refugee Health Network of Australia (RHeaNA) recommendations that all people from refugee backgrounds should be offered a comprehensive refugee health assessment within one month of arrival.[23(12)] The *Medicare Benefits Schedule (MBS) Health assessment for refugees and other humanitarian entrants* may be completed over a number of consultations within 12 months of arrival or visa grant date.[24] In Victoria, this is often completed in association with the state-funded Refugee Health Program or in consultation with a Refugee Health Fellow for more complex presentations (see section 2.2.3).

Other MBS items and assessments are available to people who are newly arrived when necessary as per other Australians, e.g. general practitioner may undertake a health assessment 'for people aged 45-49 who are at risk of developing chronic disease'.[25]

2.1.2.3 TIS: Doctors Priority Line

Medical practitioners and their reception staff who are providing Medicare rebateable services in private practice have access to fee-free interpreting through the Translating and Interpreting Services (TIS) National's Free Interpreting Service, as do pharmacists to assist with dispensing medicines.[26]

A significant gap for access to MBS-funded allied health assessment and treatment for people with low English proficiency is a lack of interpreting funding for practitioners providing MBS-funded services in private practice.

> Recommendation 1: The Commonwealth Government departments of Home Affairs and Social Services provide access to free interpreting services for allied health MBS funded consultations through TIS.

2.1.2.4 Income support for people who are newly arrived

HSP providers or proposers link people who are newly arrived with Centrelink to receive income support payments, while people are getting established, learning English and finding a job. People are also provided assistance through Job Active providers.

The Australian government provides various forms of support for people with disabilities under programs such as the Disability Support Pension and the Mobility Allowance when a person's ability to work or participate in activities is impaired due to a disability. To access these payments, applicants must have evidence of a diagnosed, treated and stabilised condition.[27(p28)]

The Carer Allowance is available to people that provide daily care to someone who has a disability.[28] In addition to this the Child Disability Assistance Payment and the Youth Disability Supplement provide financial support to parents of a child with disability and to a young person up to 21 years old with a disability, respectively.[29,30]

2.1.2.5 Commonwealth program for people seeking asylum: Status Resolution Support Services (SRSS)

The SRSS program provides support to people seeking asylum who meet the eligibility criteria. Support may include access to accommodation, assistance accessing health care, financial assistance and case work support.[31] New eligibility criteria introduced in May 2018 have made this program more restricted in who may access the program and the services they may receive.[32]

2.1.3 National Disability Strategy (Council of Australian Governments)

The *National Disability Strategy 2010–2020* sets out 'a national plan for improving life for Australians with disability and their families and carers'.[33] It was informed by consultations reported in *Shut Out: The Experience of People with Disabilities and their Families in Australia* (2009).[34] Consultations were prepared by the National People with Disabilities and Carer Council. The aim of this strategy is to create 'an inclusive Australian society that enables people with disabilities to fulfil their potential as equal citizens'.[33(p8)]

The National Disability Strategy is focused on six broad outcome areas based on issues raised during the consultation and are aligned to principles underpinning the Convention on the Rights of People with Disabilities (CRPD). These are:

- inclusive and accessible communities
- rights protection, justice and legislation
- economic security
- personal and community support
- learning and skills
- health and wellbeing

The strategy notes: 'People from culturally and linguistically diverse backgrounds – in particular newly arrived immigrants such as refugees and special humanitarian entrants – can be particularly vulnerable.'[33(p14)]

2.1.4 National Disability Insurance Scheme (NDIS)

The NDIS is a Commonwealth-administered support scheme for people with disabilities, their families and carers. When it is fully operational it is expected to provide 'reasonable and necessary supports' to 460,000 people aged under 65 living in Australia to assist them to 'live an ordinary life'.[35,36]

The NDIS implementation is managed by the National Disability Insurance Agency (NDIA). This major reform necessitates the transitioning of funding for disability support from the state to the Commonwealth government. Following trials, one of which occurred in Barwon Victoria from 1 July 2013, the NDIS has been introduced in a staggered roll-out Australia-wide over three years from 1 July 2016.[35,36] Northern Melbourne (as defined in this project) has been divided into two NDIS regions. The NDIS became available in north east Melbourne, including Banyule, Darebin, Nillumbik, Whittlesea and Yarra, from 1 July 2016 and has been available in Hume and Moreland since in 1 March 2018.[37]

The NDIS is made up of two distinct programs: individually funded packages; and Information, Linkage and Capacity Building (ILC). People who are permanent residents are eligible for NDIS individually funded packages,[38] meaning people who entered Australia with, or were subsequently granted, Refugee and Humanitarian Programme visas (subclasses 200-204, 866) meet the residency requirements. The residency criteria of NDIS individually funded packages excludes asylum seekers and people who are holding temporary protection visas from the program. ILC supports have no access requirements[39] and therefore are available to all people with disabilities from refugee backgrounds, including people seeking asylum. These two programs are further described in sections 2.1.4.1 and 2.1.4.3 respectively.

2.1.4.1 Individually funded packages

People who meet the residency and disability or early intervention requirements of the NDIS are eligible for individual plans and funded supports.

Applying to access the individually funded packages is a multi-staged process requiring documentation of assessment, an established diagnosis, and a history of treatment. This must be accompanied by information about the individual's functional capacity which demonstrates 'substantially reduced capacity' in areas such as communication, learning, mobility, social interactions, self-care or self-management. Getting a diagnosis, and an assessment of functional impairment is required in order to be able to make an application for funding to the NDIA. It is the responsibility of health and aged care services to undertake assessments that are used to provide evidence of impairment to the NDIA.[40(p11-12)]

For those who are eligible, the NDIS planning process promotes self-direction for participants, providing participants with 'control over what, when, where and by whom, most of their support is provided'.[41] This includes people with disabilities or their nominated person or organisation choosing, purchasing and paying for supports.[41]

NDIS plans are made over the phone or face-to-face with the person with a disability or their nominee.[42] The NDIA website indicates that planners will take into account the goals and aspirations of the person with a disability and will fund 'reasonable and necessary supports'.[43] Plans and associated resources may be managed by individuals or they can nominate another person, organisation or the NDIA to manage the plan.[44] People with disabilities have opportunities to review and revise their plans over time[44] and the NDIA factsheets report that plans will routinely be reviewed every 12 months.[43] If support needs change, a participant may request a plan review.[41]

Importantly, there will be some people currently receiving state-funded services who will not be eligible for the NDIS due to its residency criteria. There are 'continuity of support arrangements' between the Commonwealth and state governments[45(pE-1-6)] – during the transition period to the NDIS all existing supports should continue.[44]

In Victoria, a number of programs which provide services equivalent to the NDIS individually funded packages will transition to the NDIS including Shared Supported Accommodation, Individual Support Packages and Futures for Young Adults, Disability Block-Funded Activities, Mental Health Community Support Services, Home and Community Care Program for Younger People and State-wide Contracts[46(p4)] and early intervention services.

CASE STUDY

Transition from state-funded service to NDIS

A man with a mental illness that impacts his functioning receives support from a mental health community support service (MHCSS). He requires assistance to complete activities of daily living and to remain in secure accommodation. This man is on a temporary protection visa. When his region transitions to the NDIS he will not be eligible for NDIS because he does not meet the residency criteria. It is unclear if his MHCSS agency will receive funding to provide services to people who are NDIS ineligible.

Recommendation 2: The Commonwealth Government Department of Home Affairs, through its Status Resolution Support Services (SRSS) contracts, provides NDIS equivalent packages of support for people seeking asylum who meet the non-residency related requirements for NDIS.

Recommendation 3: The Commonwealth and Victorian governments fund NDIS equivalent packages of support for people holding temporary protection visas who meet the non-residency related requirements for NDIS.

2.1.4.2 NDIS and interpreting

Interpreting is available during planning with NDIA planners and when NDIS participants engage with NDIA registered service providers.[47,48] Interpreting does not need to be listed as a funded support in an NDIS participant's plan for them to be able to access interpreting, but it is only available 'for funded supports in the participant's plan'.[48] Local Area Coordination (LAC) and Early Childhood Early Intervention providers (described below) may also access TIS when working with participants with low English proficiency.[47]

The NDIA's approach to language service provision has evolved during the rollout of the NDIS, with the NDIA entering into a contractual arrangement with TIS in 2017 for the provision of language services to NDIS participants. Concerningly, the NDIA information sheet Translation and Interpreting Services (TIS): Frequently Asked Questions in July 2018 stated 'the NDIA planner/LAC/Support Coordinator will be able to assist you to access mainstream interpreter services and coordinate informal language supports'.[47] It is not clear what is intended by 'informal language supports'.

People with low English proficiency are encouraged to engage service providers who have language concordance.[49] The earlier referenced NDIA information sheet also states that 'NDIA recognises there will be times where a provider who speaks my primary language of choice is not available'.[47] This statement should not be taken to mean that a NDIS participant with low English proficiency's choice of providers is restricted to those that are language concordant. People with disabilities who have low English proficiency should be able to access the provider of their choice (as do other NDIA participants) despite the provider's language concordance. Should a person choose a provider that is not language concordant over one that is, the NDIA should provide access to language services.

Recommendation 4: The NDIA develops a comprehensive language service policy to guide its service provision and that of funded service providers to improve clarity about use of language services. This policy should emphasise choice for people with low English proficiency and promote effective communication between service providers and participants.

2.1.4.3 *Information, Linkages and Capacity Building (ILC)*

The ILC program of the NDIS was not part of the trial, but implemented based on community feedback. It is viewed by the NDIA as the second integral part of the NDIS along with individual funded packages.[50]

Broadly, the ILC program aims to achieve:

- personal capacity building – to build skills and confidence of people to engage in their community and access resources and services
- community capacity building – mainstream services and community organisations become more inclusive.[51]

The Disability Reform Council of the Council of Australian Governments' (COAG's) ILC policy framework defines five streams of ILC:[39]

- information, linkage and referrals
- capacity building for mainstream services
- community awareness and capacity building
- individual capacity building
- Local Area Coordination (LAC)

The NDIA has set priorities for funding which are called 'ILC focus areas'. One of the five focus areas is 'cohort-focused delivery' which includes in its definition reference to targeted approaches for people from culturally and linguistically diverse (CALD) backgrounds.[50(p18)]

Two organisations that work with CALD communities were able to secure ILC 'National Readiness' grants:

- Action On Disability Within Ethnic Communities Inc (ADEC) received $262,108 for 'building the cultural competency of mainstream services' Victoria-wide[52]
- Ethnic Community Services Co-Operative Limited (leading a consortium) received $837,080 for the Diversity Safe Place project which will 'co-design and trial disability and cultural competency resources for community organisations' in NSW, Queensland and Victoria[52]

In Victoria, the state-funded Building Inclusive Communities and Information Services programs will transition to NDIS. The 2017-18 financial year has been a transition period where these two programs were funded by the Victorian government 'to enable providers to deliver ILC activities as part of the NDIS'.[46(p3)] From 2018-19 these activities will fall under the NDIS ILC program.

2.1.4.4 *Local Area Coordination (LAC)*

LAC is the biggest component of the ILC. LAC services work directly with people:

- who have NDIS plans and funded packages to connect them with services
- who have disabilities but no NDIS plan short term to connect them with mainstream services and community activities
- where necessary, to assist them to make an Access Request for the NDIS.[45(pD-8),50]

LAC services also work with the local community to make it more accessible.[50]

LAC services do not offer case management and cannot sign off on an NDIS plan. LAC services are expected to work with CALD background clients and to have a cross-culturally

sensitive approach to these clients. In addition they 'will also facilitate the provision of NDIS information in the correct format and language and organise interpreters when meeting and developing plans for participants'.[53]

2.1.4.5 Early Childhood Early Intervention (ECEI)

The ECEI focuses on children aged 0-6 years who have a disability or developmental delay/s.[45(p3)] ECEI services are commissioned to work with families to link the child into mainstream support and the program 'provides a range of flexible and responsive supports',[45(p3)] including short term interventions. For children that require more intensive support ECEI services are required to support families to make an access request to the NDIS.[45(ppE-1-14)]. For children who are provided a package, ECEI services may also assist in developing a plan and reviewing the plan.[45(ppE-1-15, 20)]

There is only one LAC and one ECEI partner in each NDIS region. In some areas they are the same organisation and the same organisation may also provide services over multiple areas.[54] Organisations that deliver LAC and ECEI are referred to as Partners in the Community Program, and NDIS Early Childhood Access Partners. In northern Melbourne the provider is the Brotherhood of St Lawrence.

2.2 Victorian Government jurisdiction

The Victorian government also has significant policy and program responsibility for people with disabilities.

2.2.1 State Disability Plan 2017-2020

The publication *Absolutely Everyone: State Disability Plan 2017-2020* contains a strategy for the promotion of inclusion for Victorians with disabilities.[3] This state-wide plan builds on a human rights approach to disability and covers the period of Victoria's transition to the NDIS. The plan makes specific mention of working with stakeholders in the refugee health sector to 'identify and respond to issues for people with a disability from refugee backgrounds, including those seeking asylum in Victoria'.[55(p28)] There is particular mention of improving access to the NDIS for people from refugee backgrounds. The State Disability Plan is a whole of government approach to disability which includes improving access to employment for people with disabilities, supporting people with disabilities to work in leadership roles, ensuring accessible communities through design and improving access to public transport and education for people with disabilities. It acknowledges the multiple domains in which change needs to be implemented.

2.2.2 Community health

Victorian community health services provide priority access to people from refugee backgrounds, including asylum seekers, along with six other priority groups.[56] Services include community nursing, allied health, dental and health promotion. Some community health services also have general practice; community-based mental health and a range of other services. The key services and programs used by people from refugee backgrounds post-settlement include settlement and case management services, language services, primary care services, and specialist services (including paediatrics, mental health, optometry and audiology).[56(p3)]

2.2.3 Refugee health services

Victoria has a primary health care model to providing on-arrival health assessments which is delivered across community health services and general practices both supported by specialist services.

2.2.3.1 *Refugee Health Program (RHP)*

The RHP supports access to primary care and coordination of care for people from refugee backgrounds.[56] It is funded by DHHS and delivered through community health services in 17 local government areas where there is significant number of people from refugee backgrounds settling. In northern Melbourne the RHP is delivered by Dianella Community Health Service, Plenty Valley Community Health Service, cohealth, and Your Community Health. The RHP triages clients according to complexity.[57(p22)] Various models of care exist across the north which include elements of assessment, case coordination, supported referral, health promotion, clinical care, health and service literacy orientation, and provision of skills and tools for self-management.[57,58]

2.2.3.2 *Refugee Health Fellows*

Refugee Health Fellows are specialist positions at The Royal Children's and The Royal Melbourne hospitals and Monash Health in Dandenong. The Refugee Health Fellow Program coordinates primary and tertiary health care for refugees by offering advice and secondary consultations to Refugee Health Nurses, GPs and metropolitan and regional health services. In northern Melbourne, the Immigrant Health Service at The Royal Children's Hospital and The Royal Melbourne Hospital's Victorian Infectious Disease Service host the Refugee Health Fellows. Different models operate across the Refugee Health Fellow program, both programs in northern Melbourne provide outreach clinics often co-located with community health in outer metropolitan Melbourne.

2.2.3.3 *Asylum seeker health services*

People seeking asylum who hold Medicare cards have access to primary health. They do not have access to health care cards, so cannot access discounted pharmaceuticals even if they have a very small income.

For people in northern Melbourne who are seeking asylum and do not have Medicare the Cabrini Asylum Seeker and Refugee Health Hub in Brunswick has been established to provide pro-bono General Practice and other services generally funded by Medicare.[59] People seeking asylum without Medicare cards continue to have access to most state-funded health services including community health services and hospital services free of charge.[60]

2.2.4 Home and Community Care (HACC)

Support and maintenance services provided by HACC help people with disabilities to remain living at home.[61] There is a wide variety of services covered by HACC including nursing, personal care, domestic assistance, allied health services and food services.[62(p9)] Services are provided by local councils, hospitals, community health services, nursing services, Aboriginal Community Controlled Organisations (ACCOs), ethno-specific and multicultural organisations and a range of other non-government community organisations.[62(p8)] Local councils in Victoria also make significant financial contributions to the program.[61]

Importantly for people from refugee backgrounds, there is no restriction to access HACC services based on residency status or visa type.[62(p65)] People from CALD backgrounds are identified as one of five special-need groups for priority access to HACC services.[62(p9)]

HACC is undergoing significant change with aged care reform and the introduction of the NDIS. Since July 2015 funding and services for older adults (65 and over and for indigenous Australians aged 50 and over) have been consolidated into the Commonwealth Home Support Program[63] (see section 2.3.3). About a quarter of people under 65 currently receiving services funded by the Victorian HACC Program for Younger People are expected to be eligible for the NDIS, particularly those receiving substantial support from State Disability Services.[64] For people who are not eligible for the NDIS, the HACC Program for Younger People will continue to provide the same services while the NDIS rolls out.[64] It is not clear what will happen after this.

2.2.4.1 Access and Support (A&S) and diversity planning

A&S is a HACC funded program that supports people who face greater access barriers to engage with a range of services in the community. A&S workers are often located at HACC funded services that have strong links with the population group that face access barriers.[65(p9)] Agencies that deliver this program include multicultural or ethno-specific agencies, ACCOs, homelessness services or other agencies such as community health services.[66(p12)] A&S workers provide support to:

> *individuals who lack the knowledge or confidence to access HACC and other services, or are concerned that the service response will not meet their diverse needs. The A&S worker supports the person using a person centred-care and self-advocacy approach to build the person's confidence in accessing the service system.*[66(p12)]

A&S workers are supported by HACC diversity advisers who undertake regional diversity planning and coordination with the DHHS and other sector stakeholders.[65(p7)]

2.2.4.2 Linkages packages

Update: Since the commencement of NDIS in northern Melbourne Linkages has not been taking new referrals.

People with complex care needs that cannot be fully met by the usual level of HACC services, or who would gain particular benefit from case management, may apply for Linkages packages which are:

> *... essentially flexible funding to purchase additional hours and/or a greater range of services than would otherwise be available. Funding is typically used to employ staff, purchase or subcontract services and buy equipment'.*[62(p160)]

It is not clear what will happen to Linkages packages after the NDIS is fully operational, which is expected to be by mid-2019. It is expected however that most recipients of Linkages packages will be eligible for NDIS.[64]

2.2.5 State-wide Equipment Program (SWEP)

SWEP delivers a range of aids and equipment programs within Victoria funded by both state and Commonwealth government departments. SWEP provides subsidies for the frail aged and people with disabilities of a permanent or long-term nature with aids and equipment needs. It includes the Aids and Equipment Program, Continence Aids Program, Domiciliary Oxygen Program, Supported Accommodation Equipment Assistance Scheme, the Vehicle Modification Subsidy Scheme and the Top-up Fund for Children.[67] There is also a Continence Aids Payments Scheme, a Commonwealth government scheme that provides a payment to assist eligible people (older than 5 years old) who have permanent and severe incontinence to meet some of the cost of their continence products.[68] For aids and equipment there is a system of prioritisation using a risk management approach to the provision of equipment. This system prioritises clients on the basis of the risks and harms associated with the consequences of non-provision.[69,70] The potential risk is analysed within three risk categories – safety, independence and health maintenance – to structure a system of priority of access that ensures those who need the equipment urgently are readily identified. There is also a maximum subsidy outlined in policy after which the client contributes the rest of the funds.[70,71] In Victoria, SWEP is a service provider to the NDIA and SWEP is the program responsible for meeting most participants' approved equipment needs.

People seeking asylum are eligible to apply to the Victorian funded Aids and Equipment program delivered by SWEP.[60]

All allied health, nursing, and domiciliary oxygen prescribers must be registered with SWEP to have prescriptions accepted and acted upon. Prescribers are registered as individuals and

not as organisations. It is of note that not all relevant allied health staff in community health services are prescribers.[72]

2.3 Service context by age

Eligibility for services is often determined by age. Services that cater to specific age groups are discussed below. Where relevant some Commonwealth programs are also described.

2.3.1 Services for children and adolescents (ages 0-17)

2.3.1.1 Specialist paediatric clinics in hospitals

The specialist paediatric service system is where almost all diagnosis, and a great deal of care for children and adolescents with disabilities occurs. In northern Melbourne the two state funded hospitals that contain paediatric services are the Royal Children's and Northern hospitals. Relevant units at Royal Children's Hospital include Developmental Medicine, the Statewide Rehabilitation Service, Neurology, Genetics, Metabolic Medicine, Complex Care, General Medicine, Orthopaedics, Gastroenterology and Clinical Nutrition, Ophthalmology, Otolaryngology clinics and others.[73] All the other hospitals that see children also have services seeing children with disability - many the same as above; some services are centralised.

Immigrant Health Service at The Royal Children's Hospital provides multidisciplinary assessment and paediatric services for recently arrived children from refugee backgrounds. This includes educational and developmental assessments; oral health assessments, TB testing and associated radiology and diagnostic testing. Asylum seeker children and children in community detention are also seen. Post-arrival health screening can be provided through the Immigrant Health Service. Outreach Paediatric Refugee Health Clinics have been established in areas of high refugee settlements including at The Royal Children's Hospital Outreach Craigieburn.

2.3.1.2 Early years

Maternal and Child Health (MCH) services provided in collaboration with local governments and DET offer the Universal MCH service which includes consultations and assessments with families from birth to school age. The Enhanced MCH service provides more intensive support for families at risk.[74]

Pre-School Field Officer Program supports the access and participation of children with additional needs to inclusive kindergarten programs.[75] These additional needs may include developmental concerns from language delays or challenging behaviours through to children with multiple disabilities.[76]

The **Inclusion Support Programme** is a Commonwealth government program which provides funding for 'early childhood and child care services to build their capacity and capability to include children with additional needs'.[77]

2.3.1.3 Early years programs transitioning to NDIS

The ECEI approach uses the existing referral pathways into early childhood intervention through maternal and child health, paediatricians and GPs.

Early Childhood Intervention Services (ECIS) currently support children with disabilities or developmental delays and provide support, planning and service coordination and individual learning and development programs for children from birth to school entry. ECIS services will be accessed in a different way with the roll-out of the NDIS.[78]

Better Start for Children with Disability Initiative (Better Start) and **Helping Children With Autism (HCWA)** provide funding for early intervention for children up to the age of seven years old.[79–81] Children with an eligible diagnosis must be registered with these

programs before they turn six years old. A child will have until they turn seven to access funding. Registered children can access up to $12,000 (maximum $6,000 per year) to pay for early intervention services. These services may include: audiology; occupational therapy; orthoptics; physiotherapy; psychology and speech pathology. The HCWA and Better Start programs are being wound down in sites where the NDIS is available.[82] Children receiving funding through the NDIS will no longer receive funding through the HCWA and Better Start. According to DSS: 'If a child is assessed as ineligible for the NDIS they will continue to access early intervention support under HCWA or Better Start until they exit the program (that is, until their funds are fully expended, or they reach 7 years of age, whichever happens first)'.[83] See section 2.1.4 for more information about NDIS eligibility criteria. It is unclear what supports are available to children who do not qualify for the NDIS and who are still in need of services of this kind once the NDIS has been fully rolled out.

2.3.1.4 School aged

Most children in Victoria attend DET (public) schools, it is likely therefore that most children from refugee backgrounds attend DET schools however data does not exist to confirm this. A significant proportion of children from refugee backgrounds attend Catholic schools, including the more recent arrivals from Syria and Iraq. There are also children from refugee backgrounds attending independent schools including schools with a Christian or Islamic ethos. The programs outlined below are available in DET schools.

The **Primary School Nursing Program** is provided through primary schools to identify children with health-related learning difficulties and provides health assessments for children and health education for parents. The school nurses typically visit a school once (or twice) a year to provide assessment services. **Secondary School Nurses** are located in particular schools of high need and provide support for a wide variety of student health and well-being issues including health prevention and health promotion. Secondary School Nurses work with the school wellbeing team.

The **Program for Students with Disabilities (PSD)** primarily relates to educational attainment (including teaching, learning assistance and aids, school building modifications and transport between school activities).[84] Eligibility for the PSD includes: physical disability; visual impairment; hearing impairment; severe behaviour disorder; intellectual disability; autism spectrum disorder; and severe language disorder with critical educational needs. Evidence of these impairments and disorders is required from various allied health and/or specialist services depending on the nature of the disability or impairment.[85]

Assessments Australia are the contracted provider for assessment of intellectual disability and severe language disorder with critical educational needs.[85]

Resources from the PSD can be used in several ways to support students, including providing:

- teaching staff
- specialist staff (for example, Special Needs Coordinator, occupational therapists and speech pathologists)
- teacher professional development
- specialist equipment/materials, including assistive technology
- education support staff

Student Support Services (SSS) work as part of a broader area based multi-disciplinary team that typically includes Senior Education Improvement Leaders, English as an Additional Language (EAL) program, disability co-ordination and primary and secondary school nurses. The SSS team comprises a mix of allied health specialists, including psychologists, social workers and speech pathologists. They co-ordinate and deliver support to schools for individual students; for example, referrals, PSD assessments, specialist advice; capacity building; and relationship brokerage with community organisations.[86]

A review of the PSD was completed in 2016.[87,88] It includes recommendations to develop a new tiered funding model based on a strength-based functional needs approach, with three tiers of funding: base funding for all schools; teaching and learning loading allocated to schools to support students with disabilities who require reasonable adjustment; and targeted funding allocated to schools to support students with disabilities and higher adjustment needs. This approach is under development.

Along with making mainstream schools accessible for children with disabilities, there are a range of **special schools** that cater for children who have disabilities. Some schools specialise in one disability while others cater for a range of disabilities.[89]

Students learning **EAL** are a significant group in Victorian government schools; around 13 per cent of all students receive EAL support.[90] However EAL support is not available for children with disabilities in special schools.

Multicultural Education Aides (MEA) assist with 'integrating EAL learners into school activities'.[91] Special schools are not funded for MEAs as this funding is derived from EAL funding. However, schools that do not receive EAL funding (including Catholic Schools and Independent Schools), often employ bicultural/ bilingual workers to support students from refugee backgrounds and EAL students. These staff members often have very similar roles to MEAs, but do not have that official title.

Special schools are eligible for the **Refugee and Asylum Seeker welfare supplement**, which provides a range of supports. This flexible funding to 'support the improvement of wellbeing' of students from refugee and asylum seeker backgrounds may be used for: the development of outside-of-school-hours learning support programs, provision of welfare support, subsidising or purchasing resources, equipment, laptops or tablets for individual student use, and supplementing camps, sports and excursions.[92] In the case study below this funding was used to employ a bicultural worker to great effect.

All DET schools have access to interpreting services provided through VITS Language Loop to communicate with parents and guardians for certain activities such as parent teacher interviews, transition planning and student enrolment.[93,94]

CASE STUDY

Refugee background children and bicultural support staff

An education provider working with refugee children in a special school reported that when a bicultural support worker was introduced into the classroom and explained educational tasks and activities to students in their first language, teachers noted that these students had a greater capacity to be involved in classroom activity. The role of the worker was to scaffold and explain the tasks required in student's first language (e.g., the meaning of 'brainstorming'). Classroom teachers noted that these students had a greater capacity to be involved in the classroom activities than they had expected and that the students were functioning at a higher level with this learning support in place.

Recommendation 5: The Victorian Government Department of Education and Training review the EAL learning support needs of special schools, including approaches to EAL assessment and learning plans.

Recommendation 6: The Foundation House School Support Program and the Refugee Education Support Program continue to provide professional development and broader school support for special schools.

Child and Adolescent Mental Health Services offer targeted assessment, diagnosis and treatment services for children with severe emotional disturbances and psychiatric disorders.[95] These services are available for children up to the age of 18 years old and

include mobile outreach teams who work with challenging behaviours, at risk youth and suicidal behaviours. Services include: crisis intervention; on-going case management; and individual, family and group therapy. Acute in-patient services and day programs are also included in some areas of Victoria. These are typically centre-based, appointment-based services which may present access challenges for many newly arrived families of refugee backgrounds.

Announced in the 2016/17 budget, Orygen Youth Mental Health is leading the establishment of the 'Better access to mental health services for young Syrian and Iraqi refugees', designed in partnership with public mental health services and key non-government organisations. Foundation House is establishing a community of practice in child and youth refugee mental health and a community mental health promotion program.[96]

Focussing on the north and northwest of Melbourne these complementary programs will support refugee children, young people and their families with or at risk of mental illness or mental disorder, through a triage and assessment program for child adolescent and youth mental health, practice development for specialist mental health and other relevant services, and community mental health programs with a focus on children and young people.

2.3.2 Adult services (ages 18-64)

2.3.2.1 Disability Intake and Referral Service

DHHS' Disability Intake and Referral Service is also available to assist individuals with disabilities and their families to get supports, services and planning help if they have a disability that impacts on mobility, communication, self-care or self-management.[97] Many clients that received this service are transitioning to the NDIS. There is no current indication about whether this service will continue after the complete roll-out of the NDIS. Further, since the commencement of NDIS health service providers have found it more difficult to refer to the Disability Intake and Referral Service even in regions where NDIS was not yet available.

2.3.2.2 Services for people with psychiatric disabilities

Adult Mental Health Services include the Early Psychosis Program for young adults 16-25 years old, Area Mental Health Services (which provide intensive community treatment, mobile support and continuing care in the community) and specialist refugee psychological services such as Foundation House.

2.3.3 Older adult services (ages 65+)

2.3.3.1 Aged care reforms

Aged Care reforms are being implemented over a ten-year period between 2012 and 2022 during which several programs will be, or are being, consolidated into Commonwealth administered programs. These are described below.

My Aged Care, introduced on 1 July 2013, is the main entry point for the aged care system in Australia providing website and phone access to help people access information about aged care services.[98] My Aged Care has a central phone intake service for all referrals for Aged Care Assessment Services (ACAS) and other home based supports including district nursing and local government-administered home help and personal care services.

Home Support Program provides 'entry-level home support for frail older people' who need help with daily tasks to continue to live independently at home.[99] The Home Support Program provides similar services to that which were provided by HACC, such as help with housework, personal care, meals, social support (including group activities), nursing care, allied health and home maintenance.[100] Older adults that were receiving HACC services on 30 June 2016 were transitioned to the Home Support Program.[100]

Aged Care Assessment Services (ACAS) assists older people in Victoria to assess their at home needs. ACAS assessments provide access to Commonwealth-funded residential aged care, residential respite care, transition care and home care packages.[101]

2.3.3.2 Commonwealth Continuity of Support (CoS) Programme

The **CoS Programme** provides ongoing support for older people (aged 65 years and over or 50 years and over if from an Aboriginal and Torres Strait Island background) with disabilities who have been receiving state and territory-managed specialist disability services and who are not able to access the National Disability Insurance Scheme (NDIS).[102]

2.3.3.3 Aged Persons Mental Health (APMH) services

APMH services are available for older people with psychiatric or severe behavioural difficulties associated with organic disorders such as dementia. APMH can provide specialist residential care for older people with a mental illness who cannot live at home or be managed in mainstream aged care residential services. The Intensive Community Treatment program enables people to be treated in their own homes rather than in a hospital setting.

3 People from refugee backgrounds living with a disability in the northern metro region

People with a disability from refugee backgrounds are likely to experience multiple disadvantages. Lack of accessible information, communication difficulties or cross-cultural sensitivities and differences can create barriers to services and support. This section provides information on the demographics of people from refugee backgrounds who have recently arrived in the northern metropolitan region of Melbourne and the likely prevalence of people living with disability among these entrants. As such data is vital for need-responsive service planning, this section also explores gaps in data availability that need to be addressed.

3.1 Demographics

Northern Melbourne as defined by DHHS comprises of the Local Government Areas of Hume, Whittlesea, Nillumbik, Moreland, Darebin, Banyule and Yarra.

Northern Melbourne contains three of Australia's fastest growing Local Government Areas (Hume, Whittlesea and Yarra).[103(p55)]

There has been unprecedented humanitarian settlement in northern Melbourne in the 2016-17 financial year. People arriving in this area through the Refugee and Humanitarian Programme increased by 220% compared to the previous financial year. Of the 7,539 people that settled in Victoria in 2016-17, 3,828 (51%) opted to live in northern Melbourne, 3,121 of these in Hume (see Table 2). As the Commonwealth government have committed to increasing the Australian Refugee and Humanitarian Programme, and the priority regions from which Australia are accepting people for resettlement remain the same, it is likely that people will continue to arrive to this region in large numbers.[8]

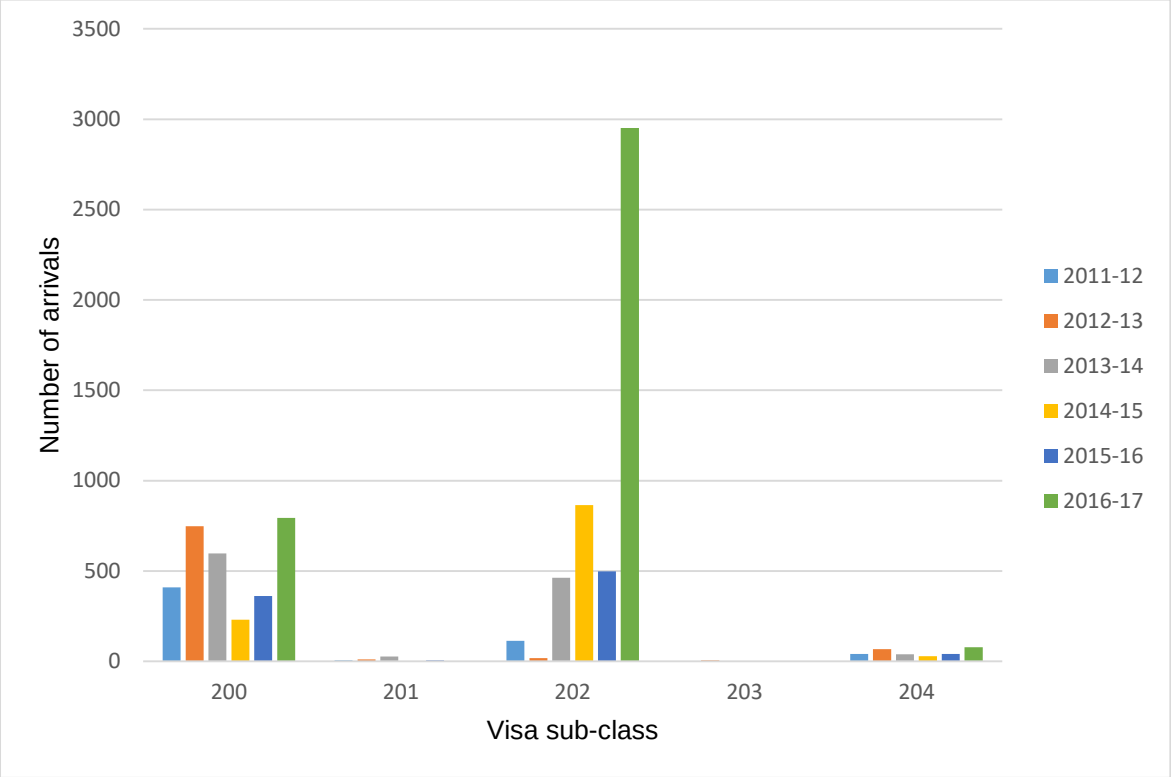
Table 2: Top 10 LGAs receiving humanitarian arrivals in Melbourne[104,*]

2006–07		2011–12		2016–17	
LGA	**# of arrivals**	**LGA**	**# of arrivals**	**LGA**	**# of arrivals**
Wyndham	709	Greater Dandenong	964	Hume	3121
Casey	608	Casey	802	Brimbank	540
Greater Dandenong	606	Hume	577	Melton	501
Hume	490	Brimbank	544	Casey	481
Brimbank	362	Wyndham	422	Greater Dandenong	388
Melton	278	Whittlesea	395	Wyndham	365
Whittlesea	173	Maroondah	324	Whittlesea	324
Maroondah	169	Melton	223	Greater Geelong	315
Greater Shepparton	143	Maribyrnong	166	Moreland	266
Maribyrnong	119	Greater Geelong	122	Maroondah	193

In 2016–17 there were significantly more people arriving on 202 visas, who had an Australian proposer. Graph 1 compares the intake by financial year according to visa subclass.

* LGAs highlighted in orange are those in northern Melbourne.

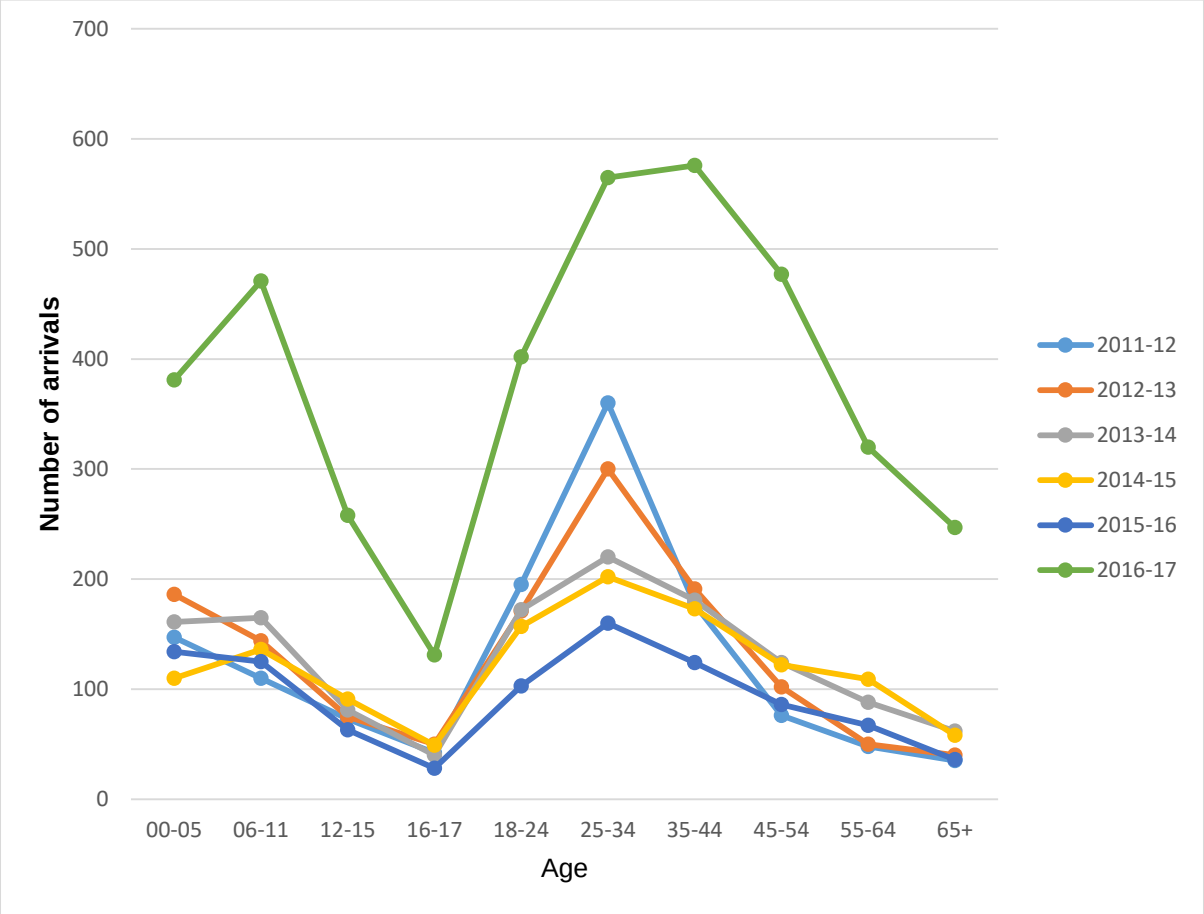
Graph 1: Refugee and Humanitarian Programme entrants by visa subclass (northern metropolitan Melbourne)[104],†



In addition, there was a change in the age profile of humanitarian entrants. As Graph 2 shows there have been significant increases in older age-groups in 2016–17, particularly the over 65-year age group, increasing 325% from previous intakes.

† Visa sub-class titles: 200 Refugee visa, 201 In-country Special Humanitarian visa, 202 Global Special Humanitarian visa, 203 Emergency Rescue visa, 204 Women at Risk visa.

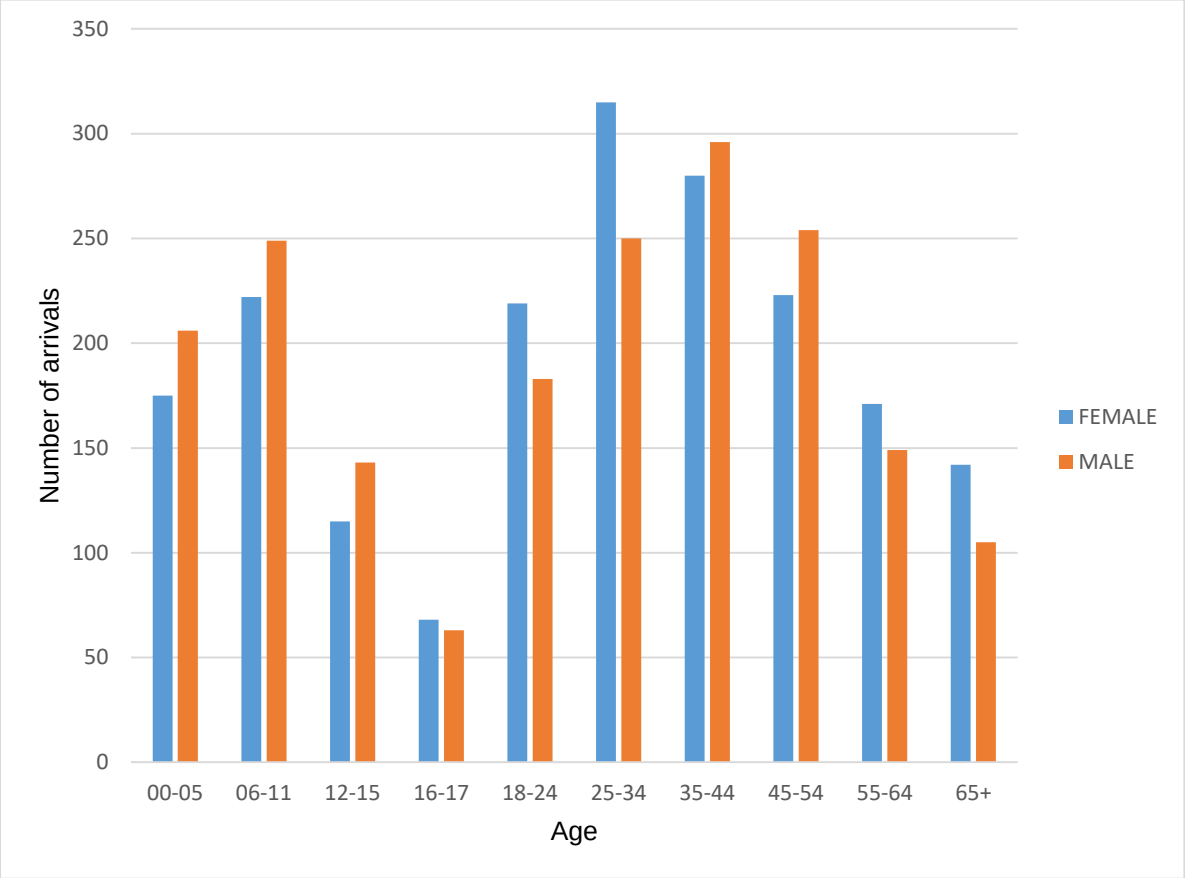
Graph 2: Refugee and Humanitarian Programme entrants by age group (northern metropolitan Melbourne)[104]



Children (0-17) continue to make up a significant proportion of the cohort, in 2016–17 they made up 32.4% of the humanitarian entrants in northern Melbourne. Adults (18-64) comprised the largest cohort (61.1%) and older adults (65+) made up 6.5% of new humanitarian arrivals.

Overall the gender of arrivals was fairly equally divided in 2016–17, with 1930 females and 1898 males making up the cohort. Graph 3 shows slightly higher proportions of women in the 18-24 and 25-34 age categories, perhaps reflecting that female headed households were a priority group for settlement in the Syrian and Iraq intake.[8(p8)]

Graph 3: Refugee and Humanitarian Programme entrants in 2016–17 by age and gender (northern metropolitan Melbourne)[104]



As Table 3 shows, most people from refugee backgrounds who settled in northern Melbourne in 2016–17 were from Iraq and Syria. As the table also shows, migration of the Iraqi community to northern Melbourne has been long standing with established communities and community infrastructure in the region.

Table 3: Top 10 countries of birth for Refugee and Humanitarian Programme by financial year (northern metropolitan Melbourne)[104]

2006–07		2011–12		2016–17	
Country of birth	**# of arrivals**	**Country of birth**	**# of arrivals**	**Country of birth**	**# of arrivals**
Iraq	479	Iraq	492	Syria	1843
Sudan	80	Iran	319	Iraq	1786
Sri Lanka	47	Afghanistan	67	Lebanon*	45
Iran	44	Bhutan	41	Eritrea	23
China	25	Pakistan*	40	Bhutan	21

*These countries are transit countries for large numbers of people fleeing persecution in neighbouring countries. These numbers may be children born during transit.

Over the past 5 years (2012-17) people fleeing Iraq and Syria made up most of the humanitarian settlement to northern Melbourne at 50.5% and 31.4% respectively.[104] The ethnic groups that people from Iraq identified with were Iraqi (35%), Chaldean (35%), Arab (14%) and Assyrian (12%).[104] People from Syria identified with two major ethnic groups, Assyrian (47%) and Syrian (45%).[104] 64% of people who arrived over this period spoke no English, 31% spoke poor English, 4% spoke good English and 1% spoke very good English.[105] The language spoken by most people was Arabic (65%), but Assyrian (17.2%), and Chaldean (3.4%) were also spoken.[104]

3.2 People living with disabilities

More than one million people with disabilities live in Victoria.[3(p3)] There is a lack of reliable data about people with disabilities who are from CALD backgrounds, which includes people from refugee backgrounds.

In New South Wales, National Disability Services calculated with the limited data available that only between 5-10% of people with disabilities who are CALD are accessing services.[106(p4)] Highlighting a significant underrepresentation, they estimate '50-80% of people from CALD backgrounds with disability are missing out on services'.[106(p4)]

This section explores what data is available to inform service planning for people with disabilities from refugee backgrounds, as well as highlighting significant data gaps.

3.2.1 Are there more humanitarian entrants arriving with disabilities?

Since 2012 there has been a streamlining of health waiver provisions for Refugee and Humanitarian Programme applicants providing an opportunity for people who do not meet the visa health requirements to receive a waiver (see section 2.1.1.2 above).

The number of Refugee and Humanitarian Programme applicants who receive visa health waivers is collected but not routinely published by Home Affairs. Information released following a Freedom of Information request by the Refugee Council of Australia indicates while there has been an overall growth in the number of health waivers granted (from 76 to approximately 248), as a percentage of the overall program, the number has remained fairly consistent (see Tables 5 and 6).

Table 4: Australian Refugee and Humanitarian Programme health waivers, by financial year[107]

Visa sub-class	2011–12	2011–2013	2103–14	2014–2015	2015–2016
200 Refugee	60	95	90	77	93
201 In-country special humanitarian	0	0	<5	<5	<5
202 Global special humanitarian	6	9	71	43	95
203 Emergency Rescue	0	<5	0	<5	<5
204 Woman at Risk	10	18	24	21	50

Table 5: Australian Refugee and Humanitarian Programme health waivers as a proportion of overall visa grants by financial year

	2011–12	2011–2013	2103–14	2014–2015	2015–2016
Total health waivers[107]	76	~127	~190	~151	~248
Total program visa grants[108]	6707	12483	10996	11001	15552
% of overall program	1.13	1.02	1.73	1.37	1.59

~ denotes approximately. Some of the categories had <5 people therefore it was rounded up for the purposes of these calculations. Range of error is 2-5 people less in each instance.

The Victorian Refugee Health Network circulated this data to refugee health services nationally to ask for their feedback about whether they have seen an increase in the incidence of disability beyond that reflected in the Home Affairs health waiver data. Responses received indicate that service providers are experiencing an increase in both the number of arrivals with cognitive and physical disabilities and in the range and complexity of disabilities people are living with.

3.2.2 Settlement support intensive case management numbers

Prior to the new Humanitarian Settlement Program (HSP), the intensive case management stream established in 2008 was called Complex Case Support (CCS).[109(p3)] CCS data from DSS annual reports may be a useful data source for understanding trends in the number of new arrivals living with disability with complex needs (see Table 7). Since its inception there have been changing guidelines which may have impacted on the rates of referral, but are also indicative of changing need. In 2013 the then Department of Immigration and Citizenship noted 'disability: physical health including disability' as the third reason someone may need intensive case management[110(p242)]. The recent guidelines for Tier 3 of the HSP list the first reason a person may be referred for intensive case management as 'disability: physical, intellectual or psychiatric'.[111(appendix A, p6)] Table 7 also includes the less intensive case management Humanitarian Settlement Support (HSS) as an indicator of the size of the settlement program. CCS accepted people who were not eligible for HSS and allowed referral up to five years post settlement therefore it cannot be directly compared to the HSS program.

Table 6: Australian Complex Case Support data by financial year

	2012–13	2013–14	2014–15	2015–16	2016–17
Complex Case Support[112,113]	501	425	741	1,290	2,350
Humanitarian Settlement Support[112,113]	15,827	14,205	11,130	10,961	24,376

CCS referral data for 2016–17 provided by one of the largest service providers in northern Melbourne indicates that of the 90 case referrals, 34 gave disability (or mobility issues) as the primary reason for referral. In a further 12 cases, disability was listed as a secondary issue, the primary reason for referral being physical health issues. Two additional referrals listed carer support as the reason for the referral, indicating some kind of disability. There

were also three elderly clients who were referred for support for whom disability was listed as a secondary reason for referral. In total, 52 of 90 cases (58%) referred for CCS gave disability as a primary or secondary reason for referral.

3.2.3 Asylum seekers with disabilities

There is no available population level data about the number of people seeking asylum who are living with disabilities. For those who engage in services, there may be some data, but this is not representative of the broader population.

> Recommendation 7: The Victorian Refugee Health Network, through the Victorian Network of Asylum Seeker Agencies, conducts a survey to understand better the number of people seeking asylum who have disabilities.

3.2.4 NDIS statistics about participation by people from refugee backgrounds

Since the introduction of the NDIS, data demonstrate a low uptake for CALD communities (2.2% of Victorians who had approved NDIS plans in March 2016 were from CALD backgrounds).[114] This is the only proxy or indication available in public data sources that could relate to refugee background.

The NDIA reported in September 2017 that they have 'tailored pathways to ensure NDIA has the right response for all participants, including…those from culturally and linguistically diverse backgrounds'.[115] Table 8 shows the NDIA data for CALD participation in Victoria during the first quarter of 2017–18 was 5.8%, a slight increase from the previous quarter of 0.4% (though this may be largely due to better data recording, noting 2% of participants did not have CALD/not CALD stated in the previous quarter).

Table 7: Reproduction of table from COAG Disability Reform Council Quarterly Report[115]

Table D.12 Participant profile per quarter by culturally and linguistically diverse (CALD) status – VIC

	Prior Quarters		2017-18 Q1		Total	
Participant profile	**N**	**%**	**N**	**%**	**N**	**%**
CALD	823	5.4%	196	5.8%	**1,019**	**5.5%**
Not CALD	14,015	92.6%	3,195	94.2%	**17,210**	**92.9%**
Not Stated	305	2.0%	1	0.0%	**306**	**1.7%**
Total	**15,143**	**100%**	**3,392**	**100%**	**18,535**	**100%**

> Recommendation 8: The NDIA includes identifiers in its dataset to assist in ascertaining participation rates of people from refugee backgrounds in the NDIS.

3.3 Lack of data for service planning

3.3.1 Population level data

Population level Australian data sets that include prevalence of disability or impairment based on country of birth or ethnicity include:

- the National Disability Agreement Minimum Data Set that measures service utilisation;[116]
- the Survey of Disability, Ageing and Carers;[117]
- the Census of Population and Housing;[118]and
- the General Social Survey.[119]

Surveys, however, are inherently problematic for newly arrived people from refugee backgrounds as a majority have low-English proficiency and low engagement with population surveys. Disaggregated data which present the prevalence of disability experienced by people from refugee source countries is not readily available in the public domain, with the exception of one report by NEDA in 2010 focusing on people from non-English speaking backgrounds.[120]

3.3.2 Service level data

The collection of data in administrative datasets has high utility for monitoring population health and inequalities in health as well as for understanding access to services and being able to plan service distribution.[121] The four data items recommended by practitioners, policy advisors and researchers are Country of Birth, Language Spoken, Interpreter Required and Year of Arrival.[122][123] In some service settings, Refugee or Asylum seeker on arrival is also collected.

Better identification of people living with disabilities from refugee backgrounds would:

- assist in understanding service access
- strengthen referral pathways
- inform service and policy planning

This process is intrinsically linked to greater clarity around the costs of providing services and infrastructure for this cohort.

There are a number of government datasets which could potentially be used as a basis for identifying information about people from refugee backgrounds. Disability Employment Services, the Australian Government's national employment services system catering for job seekers with a disability, is one of a number of government services which could collect data which identifies people from refugee backgrounds. The Employment Services Outcomes Report[124] could also be used to identify refugee background job seekers with disabilities.

The Nationally Consistent Collection of Data on School Students with Disability provides a basis on which data could be collected to support planning and policy goals. However, data is not currently collected in a form that enables the identification of children from refugee backgrounds. Data is available by school for EAL provision and Country of Birth, for students who arrived in Australia from 2014 onwards. Schools also note support needs for children as well as their migration status.

As discussed earlier, Refugee Health Program service providers and specialist refugee health services have been reporting over a number of years that there is an increase in people arriving with significant impairments and disabilities. All programs keep narrative medical records with details of a person's on arrival health assessment and any impairments that have been identified during this process. These health services do not see all newly arrived people from refugee backgrounds, therefore may not be seeing a representative sample of people arriving.

Despite the lack of data to quantify the growing number of people with disabilities from refugee backgrounds, services across Australia consistently report increasing numbers of people presenting with growing complexity. Section 4 explores how services in northern metropolitan Melbourne are responding to this.

4 Service responses for people from refugee backgrounds with disabilities in the northern metropolitan region

This section is largely informed by the themes from interviews conducted with 16 service providers. Other data is drawn upon to clarify, support or challenge the themes that emerged from the consultations. Where it was unclear about whether an experience or anecdote was a universal or an isolated example, further information was sought from other sources through meetings or correspondence where the informant was asked directly about the issue described. This further information gathering was not counted in the interview numbers.

4.1 Accessing health and disability services

For people born with a disability-related condition there is a focus in the early years (and sometimes primary school) on identification of concerns, assessment and then access to required services. For those who acquire a disability through a major accident or illness, the pathway to disability supports typically starts with hospital-based care, with discharge predicated on access to aids and equipment and rehabilitation services as needed.

For the broader Victorian community, there are significant barriers to service access, including long wait times for some services, and sometimes multiple appointments for diagnostic and other assessments to access the necessary ongoing supports.

These challenges are compounded for new arrivals from refugee backgrounds who may:

- arrive with a condition that is undiagnosed or not formally diagnosed, which may or may not be familiar to Australian practitioners
- arrive with a poorly managed condition, which may or may not be familiar to Australian practitioners
- be an adult presenting with a condition that is typically diagnosed in childhood
- arrive without necessary aids and equipment (for example, a wheelchair or walking aids).

These challenges are in addition to the broader settlement challenges facing new arrivals from refugee backgrounds. These include negotiating access to housing, transport, income support, education and employment in a new country; typically trying to learn a new language; and communicating via interpreting services. Settlement is further complicated by the impact of torture and other traumatic events (such as exposure to war and conflict) and the complexities of negotiating access to services cross-culturally.

One of the two strongest themes from the consultation, raised by almost every informant, was the challenges for newly arrived humanitarian entrants in navigating the health, disability and community service systems. The key access issues identified by informants were:

- cost of travelling to appointments (for people without a clear diagnosis there may multiple appointments)
- distance to appointments from people's home
- long waitlists for specialist appointments
- navigation of unfamiliar environments
- language barriers, including completing forms in English
- proposers not understanding the disability service system
- people having no formal diagnosis or documentation of diagnosis which is required by some services

- some diagnoses require assessment over a period of time, despite a person's immediate need for support services
- newly arrived families moving accommodation multiple times in the early periods of settlement which may place them into different service catchment areas and hence different waiting lists

Solutions proposed included:

- 'no wrong door', illustrating multiple and flexible entry points to access services
- home visits to help engage families
- priority access for people from refugee backgrounds
- 'easier' referral pathways
- assistance with service navigation including NDIS applications

4.1.1 Case management

The importance of having care coordinators, either a case manager or refugee health nurse was the strongest sub-theme in this area. One interviewee recommended that families need a case manager who can talk to services on their behalf, including for children with disabilities providing advocacy with special schools, kindergartens, and school holiday programs.

Tier 3 HSP case managers may provide short term intensive case management for people with disabilities and initiate a process to get a diagnosis, functional assessment and then generate an access request for the NDIS or other support services. Refugee Health Nurses, also provided some health case management, to follow up assessments and explain their meaning, providing explanation of services and of support available.

Despite the good work being done by case workers, there was general agreement that longer term case work was required, around two years for some people with disabilities. Interviewees commented that ongoing case management and continuity of support for people with disabilities from refugee backgrounds required longer consultations (using interpreters), building of health and service literacy, and linking to resources.

PRACTICE EXAMPLE

Settlement Health Coordinators

The Settlement Health Coordinators role includes providing advice and support to settlement service providers and clients with more complex health concerns. The Settlement Health Coordinators are co-located with settlement services in the northern region (Dallas) and western region (Footscray) and are subject to a separate evaluation process being undertaken by Hume Whittlesea Primary Care Partnership established in 2017.

Recommendation 9: Local refugee health networks develop care pathways across health, disability and settlement services for people with significant impairments from refugee backgrounds. This should be through a consensus process including all relevant services and, where appropriate, people with disabilities and their carers.

4.1.2 Self-advocacy: consumer-driven care

One informant noted that the capacity of individuals and families to self-advocate within service systems were variable, depending on their education, life experience and belief systems. Other informants reported that the Syrian and Iraqi families that they had seen were resourceful and able to familiarise themselves with the health system, and some brought health records and forms they needed to have signed to appointments. However, the same informants also commented that advocating for oneself or a child or other family

member with a disability is difficult. They reported that not all families were well placed or had a good understanding of services and the needs of their family member with a disability, noting that some impairments had remained undiagnosed. One informant commented:

> *[Newly arrived families] have no idea what they need, no previous services, no diagnosis, no early interventions. Developmental opportunities missed. [I] worry about these families and [their] access to NDIS. – informant 1*

Many respondents noted the confusion of families from refugee backgrounds about the health care system, observing that families did not understand referrals or what appointments were for and were often unable to report the outcome of the appointment. Some informants reported that building health and service literacy, and an understanding of patient rights, was a focus of their work.

The NDIS and aged care reforms are focused on consumer-driven care. Should an NDIS Access Request application be successful a number of informants suggested that choosing and designing a suite of disability support services may be a difficult task for families from refugee backgrounds. Creating an appropriate NDIS plan requires a knowledge of the service system and the supports that are available. For people from refugee backgrounds this process requires language support, assistance to navigate the service system, education about available services and planners that are skilled working cross-culturally. Likewise, one informant reported that My Aged Care created confusion among families from refugee backgrounds they work with – it created fear that the assessments may lead to the older adult in their family being placed in an aged care facility.

A number of projects have been funded recently with a focus on service literacy, including the Centre for Culture, Ethnicity and Health who are developing NDIS glossaries to assist interpreters convey the meaning of language used by the NDIS,[125] the Ethnic Communities Council of Victoria are facilitating community education sessions and Foundation House are convening an advisory group of people with disabilities from refugee backgrounds and their carers.[126]

Recommendation 10: Foundation House, Ethnic Communities Council of Victoria and the Centre for Culture, Ethnicity and Health in their work with advisory groups of people with disabilities from refugee backgrounds and their carers explore what is required to support them with self-advocacy.

Recommendation 11: The NDIA and the Commonwealth Government Department of Health review consumer-driven care models implemented by NDIS and aged care reforms to take into account the particular needs of people from refugee backgrounds, including longer appointment times, interpreters, flexible service delivery systems, and planners who are skilled in working cross culturally and have an understanding of the refugee experience.

4.1.3 Transport

The importance of safe, accessible transport was a strong theme from the interviews. Transport is an issue for all new arrivals but is more complicated for people with mobility impairments, one informant pointed out. Mobility equipment is required sometimes before clients can access taxis in order to attend appointments, another informant explained. Another informant spoke about how this has a cascading effect preventing access to school:

> *Access to a suitable wheelchair is a pre-requisite for safe bus transport to school. – Informant 1*

Home visits were spoken about by one informant as a strategy to engage families; they assessed it was difficult for families to get out and about in the early days. Where mobility access was not an issue, one informant spoke about teaching people how to use local transport systems as a priority after arrival. A number of informants noted that those with

limited transport options faced the same barriers as those who had multiple and distant appointments to attend, such as specialist appointments in the city. One informant lamented, 'hospitals don't appear to consider how their patients arrive' (informant 16).

Recommendation 12: The Commonwealth Government Department of Social Services explores methods to deliver accessible community transport options for new humanitarian arrivals with significant impairments.

4.1.4 Interpreters

Many informants spoke about the importance of interpreters, as 'language barriers are high' (informant 5). One informant added that continuity of interpreters and confidentiality of interpreters is also essential. Learning how to use the translating and interpreting services was viewed as important for new arrivals.

There were various concerns about health professionals, with funded access to interpreters, who did not use interpreters and the impact that this has on the interaction and the outcome of the appointment. Informants highlighted the structural barriers of some services not having funding for interpreting, a notable example is MBS funded allied health services (see 2.1.2.3). This impacts on referral options and has a marked effect on the period when evidence of impairment and functioning is being gathered to apply for various support services including NDIS.

Schools were another area where interpreting was important and variably used. Engagement of interpreters was seen as important to engage with families with low English proficiency to develop plans for children with disabilities. Nonetheless, this didn't appear to happen always, in part due to lack of awareness.

Recommendation 13: All services have policies and procedures in place to assess whether an interpreter is required and to engage interpreting services.

Recommendation 14: All services provide training to staff about assessing the need for an interpreter, accessing an interpreter and facilitating an interpreter mediated conversation.

4.1.5 Supporting continuity of care: sharing information and keeping families engaged

Informants reported that lack of communication between practitioners and services compounds the difficulties of negotiating the medical system for people with disabilities from refugee backgrounds. Many health and settlement service providers reported difficulties knowing about appointments their clients had attended, medical tests that had been done, results that had been obtained, recommendations that had been made and services that they had received. They reported this was especially difficult for people from refugee backgrounds living with disabilities. This was because of the numerous referrals, long wait lists and the number of different locations and appointments people had to attend in the early settlement period. In addition, informants reported that secondary settlement could create loss of links with services and difficulty in maintaining continuity of referrals.

The lack of access to complete health and service records by members of the team working with people with disabilities from refugee backgrounds was considered problematic. Shared health records were raised by a few informants as were shared systems that kept track of appointments (including noting if a person attended and any outcomes of the appointment). One informant described wanting a lot of detail in a shared health record including medical reports, case history and a register of equipment that had been issued to the person. Empowering people from refugee backgrounds with a hand-held health record that they keep in their possession, or with a card which lists all of the organisations providing services, were ways informants felt communication and care may also be improved.

Other possible solutions to improve the links and communication between services that were mentioned were phone applications such as New Roots which can be used to store medical information and can be used by health and settlement services and clients.[127] Another informant, a non-health care provider, suggested a checklist of 'things' that should already have happened to the child and family would be useful, to know what the person with a disability and their family had already been through.

Referrals between services were viewed as inefficient due to many different and complicated referral systems. One informant explained that privacy concerns were cited as reasons for not providing information in referrals by other services, then adding 'client information should be shareable with the client's consent' (informant 8).

Poor coordination and communication about referrals lead to new arrivals with disabilities waiting on two or three different waiting lists, leading to duplication of services because families did not understand the purpose of the appointment or test/assessments being undertaken.

Case conferences within and between services were also suggested to improve communication about service provision for people who are engaging with a number of services.

The universal introduction of My Health Record from July to October 2018 will provide an opportunity for sharing summary health information between registered health providers.[128] It is important that new arrivals are oriented to the purpose of these records and privacy concerns are explored. Further, a DHHS immunisation project which has a strong focus on referral and tracking in northern Melbourne may provide learnings to assist settlement and the Refugee Health Program with coordination of early post settlement health care.[129]

Recommendation 15: The Commonwealth Government Department of Social Services, Humanitarian Settlement Providers, Refugee Health Programs and Primary Health Networks provide community based accessible information to new arrival communities regarding My Health Record to support implementation including information to address privacy concerns.

Recommendation 16: The Refugee Health Program explore using a shared health record, possibly My Health Record, adhering to appropriate privacy laws and in consultation with people from refugee backgrounds, to support continuity of care. This should include exploring using records that could be shared with other primary health care providers, settlement and disability services.

Recommendation 17: The Victorian Government Department of Health and Human Services review the findings of their Refugee Immunisation Project to consider broader application of the appointment tracking and reminder system for the provision of on arrival health services for people from refugee backgrounds.

4.1.6 Accessing the NDIS

Advocacy for NDIS is very time-consuming and many health providers won't do it. – Informant 12

Service providers expressed concerns about how people from refugee backgrounds were going to apply for NDIS packages. The NDIS application process was described by one service provider working in an area where the NDIS has been rolled out as 'a slow and complex process; hard to navigate and hard to understand' (informant 7). It can take a considerable length of time for an individual with a disability from a refugee background to complete assessment, diagnosis and treatment planning.[130]

The NDIS does not fund any assessment. Informants with experience making applications reported that gathering evidence to make an application is time consuming and may be expensive for the applicant. They also pointed out that the standard of evidence is high and

an application may be sent back for more information. There are waiting lists to access assessments for evidence and then there is a wait while the NDIA assesses the application, one informant reported this taking five to six months. Another informant reported that systems that gave access to assessments are disappearing as the NDIS is rolled out. (See section 4.2 for more information about gathering evidence).

Assessments with allied health services in the community health system have very long wait lists. Private allied health providers are financially inaccessible for most newly arrived people from refugee backgrounds and do not have funded access to interpreter services. One informant, a disability advocate who had worked with the NDIS, reported that linking people with disabilities from refugee backgrounds to diagnosis and functional assessment, and the submission of Access Request Forms, requires many hours of support from trained workers.

Informants reported concerns regarding lack of cultural competence of NDIS planners who are helping people with disabilities from refugee backgrounds to file the Access Request Forms. One informant reported that during a consultation with an NDIS planner, conducted using an interpreter, the planner referred a client with low-English proficiency to MyPortal, and its English language resources.

4.2 Evidence of disability and functioning

To access services, equipment, schools, funding and other supports, a person often requires documented evidence of their impairment and/or their level of functioning. The assessment and diagnosis of people from refugee backgrounds is a complex and sometimes extended process, perhaps, as one informant pointed out, because conditions worsen due to lack of adequate pre-migration medical care.

Families and individuals often have to attend multiple appointments in multiple locations, sometimes with inadequate interpreting. One informant reported that many families don't pursue getting a diagnosis – especially of autism, speech pathologies and developmental disabilities – as the diagnosis and assessment process is too complicated. Another informant reported that people give up as it is too hard.

One informant suggested that there were very serious consequences such as hospital admission and lifelong impairments for people who have not been properly assessed, or who have delayed diagnosis.

This section will explore some of the stages where evidence of impairment, disability and functioning may be gathered and some of the barriers that have been identified.

4.2.1 Pre-arrival assessments and notifications

Prior to the new HSP contract commencing in October/November 2017, health information collected prior to resettlement was summarised in a Settlement Report provided to settlement caseworkers prior to the person's arrival in Australia. Settlement Reports were reportedly of very variable quality, completeness and accuracy. In some instances, they contained information from 12 months before a person's arrival in Australia and therefore may have been out of date. It was also reported that this information did not always seem to arrive in a timely manner or contain enough information to enable case managers to start notifications to service providers in advance of the person's arrival. For example:

> *[A] child had cerebral palsy, seizures and an intellectual disability … [settlement services] did not realise what the child's needs were. No prior information was given re needs and equipment. – Informant 8*

Another example was given of a man with paraplegia, unable to move his lower limbs, which was not recorded on information provided to settlement services. The Settlement Report was intended to notify settlement services of the arrival of people with complex needs, including

disabilities, prior to their arrival. HSP Tier 3 case managers and health service providers gave a number of specific examples of the Settlement Report failing to mention major disabilities and chronic diseases. For example, a person who uses a wheelchair arrived in Australia with no mention of this in the Settlement Report.

Since late 2017, a new database is being used by settlement services delivering the HSP contract. This system does not provide Settlement Reports for all new arrivals, only for people who have Critical Alerts which are very rare and are generated only if a pre-departure health check is undertaken. DSS has reported that they do not intend to reinstate the former process of manually extracting Settlement Reports from the Home Affairs health database 'HAP'.

Recommendation 18: The Commonwealth Government departments of Social Services and of Home Affairs, the Victorian Government Department of Health and Human Services and contracted services work to implement a system that supports health information transfer from offshore to health services that will be conducting the on-arrival health assessments.

Recommendation 19: The Commonwealth Government Department of Home Affairs and the Australian Digital Health Agency develop a mechanism to transfer appropriate summary medical information, gathered prior to arrival in Australia, to My Health Record.

4.2.2 On arrival health assessments

The MBS funded on arrival health assessment is a likely point where impairments may be identified that may not have been disclosed or identified in the IME, or by the settlement caseworker on arrival. This is particularly the case for those impairments that are not visible or immediately apparent.

The need for thoroughness was highlighted by a number of informants, with one expressing concern that important conditions are often not picked up. A number of informants suggested more training was needed about the health assessment and 'not just any GP' should be engaged to complete these assessments, rather GPs who had undertaken specialised training should do this work.

Informants also noted that referrals following the health assessment were often inappropriate, not considering the expense and navigation required by newly arrived families and, in some instances, required referrals were not made at all. When referrals had not been made by the GP, an informant expressed their frustration as often 'families are reliant on the doctor and written referrals to link them with occupational therapy and speech pathology' (informant 11). One informant noted that doctors may be unaware of referral pathways, especially for disabilities; another commented that GPs were not very good at referring perhaps because of the number of lengthy, detailed forms. It was noted that the quality of the referral also impacts on prioritisation for appointments. Triaging of specialist clinic waitlists is undertaken using information on the referral. Therefore, the quality of the GP referral determines the timeframe to access specialist assessment. A brief referral stating, 'please see this child with development delay', will often mean the child is allocated low priority in the hospital systems on the general waiting lists.

Arabic speaking doctors, while preferred by many community members, were reportedly overworked. One interviewee noted the amount of paperwork generated by on arrival health assessments and how this was incompatible with a busy general practice. Time pressure was also cited as a reason that GPs did not use interpreters when required. For example, one informant reported that:

> *One GP said, 'Our practice manager won't let us use TIS'. Setting up appointments with interpreters takes time, and the use of interpreters in consultations extends the time of the consultation. Some very busy practices*

with practice managers who are very cost concerned do not allow GPs and nurses to use these services. – Informant 11

A number of informants expressed concerns about GPs undertaking on arrival assessments without using interpreters; one informant observed that people with low English proficiency often do not know how to ask for interpreters.

PRACTICE EXAMPLE

SUB-POPULATION IMPACT

People who arrived on sub-class 202 visas are often taken by their proposer to their family GP, making it difficult to ensure that people are accessing GPs with sufficient knowledge of the on-arrival health assessment.

Adults from refugee backgrounds are presenting with untreated illnesses and secondary complications of conditions rarely seen in people of a similar age living in Australia.

Recommendation 20: Primary Health Networks, Refugee Health Programs and specialist refugee services target capacity-building at general practices that are well utilised by communities from refugee backgrounds (including multilingual practices).

Recommendation 21: Primary Health Networks develop and maintain resources to assist general practice with referral pathways for people from refugee backgrounds with disabilities.

Recommendation 22: Primary Health Networks work closely with settlement, Refugee Health Programs and Refugee Health Fellows to identify practices that are undertaking good quality health assessments and follow-up care.

4.2.3 Invisible disabilities

Two informants observed that, sometimes when a disability has been lived with and coped with for some time, attending to it is not a high priority. Other reasons that informants raised for why people may not readily disclose an impairment included fear of immigration consequences and stigma.

Accurate and thorough assessments require a trusting relationship between the person from a refugee background and the service provider. Informants including school teachers, maternal and child health nurses, and HACC access and support workers mentioned that people from refugee backgrounds needed to develop trust with services, perhaps over a number of consultations, before some kinds of disabilities were discussed. This applied especially to disabilities that may not be readily apparent and may carry some degree of stigma such as developmental delay, epilepsy and cognitive impairments.

A number of informants spoke about stigma associated with intellectual disabilities and epilepsy in some communities. Informants reported some people believed disability was a punishment for wrong-doing. One informant reported that a child did not attend school in the country of transit because of stigmatisation. People's belief systems varied depending on their life experience, including if they were from bigger cities or rural areas according to informants. Reportedly, depression and trauma may also be viewed as shameful. One informant spoke about their work providing education and normalising intellectual disabilities, reporting the community responded positively.

Another informant reported clients in need of more intensive case work support may miss out if their disability is not obvious or volunteered by the client.

Recommendation 23: All service providers engage with communities to find a common dialogue to address stigma associated with some disabilities.

4.2.4 Cognitive assessments for children and adolescents

It was reported that children with developmental delays, language delays and intellectual disabilities may not be adequately assessed and appropriate supports accessed for extended periods of time – in some instances two to three years after the child had started schooling in Australia. Contributing factors include reported misconceptions in the field that children cannot be assessed until their English language skills are sufficient to undertake formal assessments in English.

The added skills and knowledge required by practitioners to undertake cognitive and language assessments for children and adolescents from refugee backgrounds may also be a contributing factor in delays in assessment and diagnosis of disability related concerns and consequent delays in appropriate disability supports being put in place. The possible influence that exposure to traumatic events, English language proficiency, language(s) spoken at what life stages, literacy and school experiences may have on test performance does need to be taken into account,[131] as well as undiagnosed medical conditions and developmental delays, however, these factors should not cause delays in providing assessment and necessary additional support.

There is a growing literature addressing these issues that includes integrating contextual information into assessments, and drawing together converging lines of concern,[131,132] and where appropriate that a provisional diagnosis be provided to inform treatment and support. The recommendation from the Program for Students with Disabilities (PSD) review regarding a greater focus on strength-based functional needs in a new funding model should support this greater flexibility in approaches to assessment and provision of necessary support for children and adolescents from refugee backgrounds who are living with disabilities.

Within this context, there is a need for appropriate professional learning for psychologists, speech therapists and other allied health professionals working with children and adolescents in areas of significant settlement and for teachers and others who may be referring children for assessment. This training is provided through Foundation House on request and through the regular training calendar.

Recommendation 24: Foundation House and specialist paediatric refugee services provide professional learning for psychologists and other practitioners undertaking developmental and cognitive assessments for children and adolescents.

Recommendation 25: The Victorian Government Department of Education and Training take into account additional considerations required in assessing students from refugee backgrounds in developing the new three-tiered funding model for Program for Students with Disabilities.

4.3 Demands on services in the northern metropolitan region

People from refugee backgrounds living with disabilities were often reported to have arrived without aids or equipment, and/or with poorly diagnosed or undiagnosed conditions. Delays associated with identification of people from refugee backgrounds who are living with disabilities, and lack of existing documentation or diagnosis of disabilities, are further compounded by wait times for assessment and diagnosis on arrival. Informants expressed concern about the impacts of long wait lists for assessment and support services and the particular impact on daily living for people from refugee backgrounds living with disabilities

and their families. Wait times for assessment and diagnosis were reported to lead to further wait times for aids and equipment or access to appropriate disability services. For individuals using a wheelchair, the lack of a wheelchair might mean that they are unable to attend appointments or school.

Long wait lists for assessment by allied health practitioners and subsequent referrals to specialist disability services were reported for:

- community health allied health (even with priority access)
- refugee health nurses
- student support services
- Early Childhood Intervention Services (ECIS)
- audiology services
- HACC
- State-wide Equipment Program (SWEP)

For new arrivals who had no diagnosis or poorly described diagnosis, and/or no aids and equipment required for daily living, waiting had a profound impact on their settlement.

4.3.1 Impact of waiting times for access to aids and equipment

One year to 18 months wait was regularly mentioned as the waiting time for aids and equipment provided through the State-wide Equipment Program (SWEP). A special school teacher interviewed reported that the waitlist for a new wheelchair through SWEP, even if the child is identified as 'High Urgency' under SWEP Priority of Access Guidelines,[69] could take 12 – 18 months. A reconditioned, second-hand wheelchair could take two months if there was an appropriate child-size wheelchair available. Other aids and equipment may be faster but walking frames had a similar waitlist to wheelchairs. The lack of a wheelchair for a child planning to attend a special development school meant that she was unable to use the school bus.

While these waiting times are for all people with disabilities, disability services are predicated on stepwise progression through the health and disability service system. For instance, it would be assumed that an infant assessed as having an impairment that will cause an ongoing mobility issue would be engaged in services that would plan for them to have appropriate mobility aid(s) by the time they start school. For a school age child with a mobility issue that arrives in Australia with nothing the wait time may have significant implications for their ability to access school.

The DSS program to cover the cost of hiring mobility aids for a maximum of 28 days after arrival,[111(appendix A,p8)] addresses this lack of access to equipment in the short term but is not adequate to meet needs until other arrangements could be put in place. Further, aids and equipment require a qualified prescriber, such as an occupational therapist or physiotherapist, to ensure that the equipment is appropriate and will not cause any harm.[133] Waiting times for prescribers, particularly those that have access to interpreters (see section 2.1.2.3) may also be lengthy.

PRACTICE EXAMPLE

Pro bono services

Due to wait lists and/or lack of suitably registered and credentialed prescribers in the publicly funded system, AMES Australia and Settlement Health Co-ordinators reported that they have established a network of private providers identified through Occupational Therapy Australia and Speech Pathology Australia to assist with assessment and prescription of necessary equipment on a *pro bono* and Medicare funded basis. Interpreters for this *pro bono* service are currently being supported through additional funding allocated by DHHS to the Refugee Health Program.

There are emerging pathways for accessing equipment and aids on a temporary basis for people from refugee backgrounds on arrival and partnerships with organisations willing to provide re-conditioned equipment to people from refugee backgrounds with disabilities. However, these pathways rely on suitable reconditioned equipment being available.

Recommendation 26: The Commonwealth Government Department of Social Services extends funding for hiring of mobility aids until new humanitarian entrants have access to Victorian Aids and Equipment Programs or the NDIS.

4.3.2 Impact of waiting times for children and adolescents

Practitioners reported that the wait list for younger children (two to four-year olds) for Early Childhood Intervention Services (ECIS) in the north was 12 months in 2017. Waiting 12 – 18 months for an ECIS assessment could mean that the child was no longer eligible for the program, which only extends to school entry age, and that valuable opportunities for early intervention had been missed.

Refugee background children have often had a history of disrupted schooling in addition to trauma and dislocation as part of their transition to a country of refuge.[91] In some cases they may come from families who lack literacy in their own languages.[92] Schools are well located to address the many layers of 'social exclusion, mental health problems and poor educational outcomes'.[135]

Some schools had well developed strategies for supporting children from refugee backgrounds, including those requiring PSD support. These schools typically had programs of ongoing social and educational support for refugee background children and children with disabilities or with related concerns, including language or developmental delays.

Nevertheless, schools reported significant waiting times for assessment and then significant delays in the approval of funding. Waiting times are exacerbated for students of refugee backgrounds due to the multiple transitions that children and their families are negotiating. Many children and young people were unable to access English language schools or centres near where they live or only attended for six months, although DET policy indicates that students with interrupted schooling should attend for 12 months.[136] Children referred for assessment by English Language Schools often moved onto mainstream school before the assessment is commenced.

It was also reported that enrolment and attendance at school was sometimes delayed while assessments were undertaken. This is not consistent with DET policy, where all children have the right to be admitted to their designated neighbourhood government school at the beginning of the school year (or when relevant) unless an approved alternative placement has been arranged.[137] The DET community liaison officer is the first point of contact for parents and service providers if there is difficulty in enrolling a child in a local school.

Recommendation 27: Services and policy makers consider the compounding effect of long waiting times on newly arrived people with disabilities from refugee backgrounds when reviewing frameworks for providing priority access.

Recommendation 28: The Victorian Government Department of Education and Training take into account particular transition support needs of children with disabilities from refugee backgrounds.

4.4 Family, community and caring

Extended family was a strong theme emerging from the interviews. This is not surprising given the number of people who had recently settled with proposers (see Graph 1). One informant reflected that the degree of support from proposers varies. Another informant elaborated that 'if a sponsor is [a] recent [arrival] they may not understand the system' (informant 8). There seemed to be diverse observations about the roles taken on by extended families, with a number of informants observing the duty that many families felt to look after family members who had a disability:

> *People with disabilities and the elderly are very well looked after, they look after each other, everybody lives together, three generations. – informant 16*

Another informant noted the reliance in early settlement on proposers (extended family) for transport to appointments. Extended family cohesion, values and support were seen as important resources, but this cohesion and support was not universal.

4.4.1 Carers

Several informants reflected upon the impact of dislocation associated with refugee experiences that had left families separated or family members dead. Often no extended family members were in Australia to assist in caring for the person with a disability or support the primary carer. The impact of caring on single women and children was noted by a few informants, who reflected that women who are often carers for frail parents and children face isolation, have low chances of finding work, and face significant barriers in accessing English classes. One informant noted that:

> *Often there is one person allocated to care for disabled family members, a mother or a child. The care of the elderly or the disabled may take priority over even English language classes. – informant 11*

One informant noted that children sometimes miss school to care for parents.

The mental health of carers was raised by a couple of informants. Concerns included the fatigue, depression, grief and the impact of loss of other family members and other mental health issues that are compounded by the role of caring. It was noted by informants that carers may experience a sense of isolation from family and community, due to stigma within their community.

Recommendation 29: Carers organisations, including young carers organisations, provide culturally appropriate responses to carers from refugee backgrounds who may be isolated due to their caring responsibilities.

4.4.2 Reluctance to use respite care

Reluctance to use respite care was observed by a number of informants. One informant spoke about strategies they employed to encourage the use of respite care, including exploring the families' and community's values about attending school and going to work, 'which might entail the use of those [respite] services to look after grandma' (informant 3). There was a perception by informants of a common reluctance to use support services; there appeared to be different levels of acceptance. Help in the home and respite care were reluctantly accepted by some families, but there appeared to be a stronger concerns in relation to accessing residential care. One informant suggested that more Arabic speaking respite care was required; another informant observed that the existing Arabic speaking respite care are not used due to families' strong belief that they should care for their family member.

4.4.3 Misaligned expectations

A number of informants reported that the expectations of people who are humanitarian arrivals differ to the reality of life once they arrive in Australia. Some informants reported the high expectations people had of a cure in a land of plenty. This often resulted in grief when the cure was not realised, reported one informant. Two informants reflected on the difficulty when a family's and individual's expectations differed to that of the service provider:

> *What were people told when they come? What were they told about entitlements? What were they told about equipment? And how long it might take to get. – informant 7*

Another informant agreed that families are often very surprised about waitlists.

4.4.4 Community an important resource

The geographical closeness of cultural and faith communities in the north was viewed as an important resource. One informant observed that the strength of 'refugees is dependent on the strength of their connection to the community' (informant 5). Interviews reflected that communities speak to each other and their opinion holds sway. The Arabic speaking doctors and health workers in the northern region were identified as another vital resource to communities. Connecting families to their cultural or faith communities on arrival was seen as an important step in settlement, particularly for individuals with disabilities and their families. One informant observed that 'community engagement for these families is important … many of these families are used to high degrees of social connectedness' (informant 11) countering the effect of isolation for people with disabilities and their carers.

Faith communities and related events seems to be central to community connectedness for people from refugee backgrounds in northern Melbourne. Faith leaders were identified as a resource by one interviewee, another observed that families and individuals they had worked with from refugee backgrounds in the region were very strong believers in their faith traditions. The social life that surrounded the churches and mosques was observed as valued and important by individuals and families from refugee backgrounds in the north.

4.5 Meeting priority needs for families on first arrival: temporary housing, work and English acquisition

When asked 'what are the priorities for people when they first arrive?', most informants responded that meeting basic needs such as where to buy food, find appropriate accommodation, secure an income, learn to travel around, enrol children in school and adults in English classes were prioritised by newly arrived humanitarian entrants. A number of informants noted that priority setting for individuals with a disability and family members often changed depending on the nature of the impairments and disability, the impact on the individual or their family and the age of the person with the disability. One informant commented:

> *Families with a child with disabilities, it's all about the kid. They won't start English or even sort out health of family members and other settlement issues before the child with a disability is attended to, everything is on hold. – informant 13*

One person responded that for people with significant disabilities meeting basic needs on arrival often includes attending to these through appropriate housing and mobility equipment such as wheel chairs. Timely sourcing of suitable accommodation for new arrivals with disabilities was often dependent on advanced notice, prior to a person arriving, of their specific mobility or access needs. This was hampered by poor information flow of assessments completed prior to immigration (see 4.2.1). Examples of home modifications

that were required by new arrivals included bathing and support equipment, and ramps for families in temporary housing. For people in a private rental home, any modifications (such as support rails) must be referred to a landlord, a process which had been negotiated by some informants.

Recommendation 30: The Commonwealth Government Department of Social Services provide early notification to Humanitarian Settlement Program providers of mobility restrictions experienced by Refugee and Humanitarian Programme entrants to assist with sourcing appropriate housing.

4.5.1 Secondary movement

A number of informants noted 'secondary settlement', people moving from their first address on arrival in Australia, as problematic because people lose links with services and community. AMES have advised that, with significant numbers of people arriving at once, transitional accommodation arrangements needed to be put in place while permanent affordable private rental properties were sourced. In addition, if people are sponsored by family or community members their sponsors are responsible for providing on-arrival accommodation and this may not always be viable in the longer term. Secondary settlement is a frequent occurrence and one informant noted that it may be motivated by a desire to be closer to family, ethnic communities or to find jobs. It was noted that sometimes people move because permanent accessible housing becomes available; while meeting some needs it may also create dislocation in care, loss of connections and health records. Conversely, one informant noted that in northern Melbourne people were reluctant to move out of temporary accommodation as they wanted to stay in the area close to their strong community contacts.

4.5.2 Employment

Employment was noted by a number of informants as being important for people's mental health, sense of purpose, social connectedness and generally in 'getting established'. Informants also spoke about the strong desire of many of their clients to find work, including moving to find jobs. One informant observed that newly arrived humanitarian entrants are especially keen to contribute and want to volunteer. Given the multiple complexities and barriers to economic participation experienced by this group, specialised employment support processes such as Customised Employment could be beneficial.

Recommendation 31: Disability Employment Services build cultural competence and have strategic approaches to engaging with people with disabilities from refugee backgrounds.

Recommendation 32: The Commonwealth Government Department of Social Services investigates different approaches to the provision of employment support services to people with disabilities from refugee backgrounds, which may include Customised Employment.

4.6 Service providers: communication, role clarity and workforce development

Major reforms are occurring in disability services, aged care and settlement services. Keeping abreast of the changes, particularly when it is not part of someone's everyday work may be challenging. This was reflected in the interviews where informants raised issues relating to service providers' knowledge, understanding, and role (that is, who does what for people with disabilities when they first arrive).

4.6.1 Service providers' knowledge and understanding

A lack of familiarity with the broader service context for people from refugee backgrounds living with disabilities was a recurrent theme and this was reflected by health, settlement, education, disability and aged care services. Some informants reflected that it was when they had a client/student with particular needs that they learnt about the services available. This was true for services that rarely saw people with disabilities, and also settings that rarely identified people from refugee backgrounds. Some informants were even unaware of services provided by organisations they worked in.

Service providers from health, education and settlement services working with people from refugee backgrounds all reported a lack of knowledge and understanding of disability services, assessment processes and referral pathways. Complex case support workers (now Tier 3 HSP) were more familiar with referral pathways for assessment, however others working in refugee health were less able to identify appropriate services and referral pathways.

There was also a lack of familiarity in disability and aged care services of the role and capacity of settlement services and refugee health nurses. While some disability and aged care service providers reported knowledge of refugee health nurses and settlement case workers, many were less familiar with their role and capacity. Some were unfamiliar with complex case support and the ability of complex case support workers to support people from refugee backgrounds living with disabilities.

Some schools were not well linked with refugee health and settlement services; a teacher spoke about needing to know where and how to refer students with disabilities. Education providers spoke about difficulties within their school. A special school teacher struggled with her school's inability to communicate with people from refugee backgrounds and with their children.

PRACTICE EXAMPLE

Schools and health forum in the north

The Foundation House Schools Support Program coordinated and hosted the *Schools and Refugee Health* event that was held in Craigieburn in July 2017. The event was developed in response to high refugee re-settlement rates in the City of Hume and the associated high numbers of enrolments of refugee background students in schools in the area. Assessments of children referred to Foundation House found high numbers of students exhibiting significant trauma responses. This presented challenges for the schools and additional support required in the classroom environment. Referrals from schools to Foundation House also revealed gaps in knowledge about appropriate referrals for developmental and cognitive assessment for children who have experienced traumatic events and potential incorrect referral for cognitive assessment due to the complexity of this area.

The event had a number of aims: for schools to increase understanding of the health needs of refugee background students and families; for schools to increase their knowledge of relevant health services in the local area; to identify common emerging trends across health services and schools and to provide a networking opportunity for schools and health services. The event included three keynote presentations delivered by representatives from Foundation House and the Royal Children's Hospital Immigrant Health Clinic. This was followed by a 'World Café' style rotation in which the participants moved between nine tables, each hosted by representatives from local health services. The event was very successful, 113 people attended the event, including 55 staff from 33 schools and 47 staff from 22 organisations. Following the 'School's and Refugee Health' event Foundation House developed a specific professional learning session for teachers in the northern region to build awareness about indicators for referral for cognitive assessments and understanding

the impact of trauma (42 teachers attended from the Craigieburn and Broadmeadows areas).

4.6.2 Role clarity: who is responsible for providing services?

The newly emerging need to provide services to people from refugee backgrounds with disabilities, a population group rarely seen by health, disability or settlement services prior to 2012, has led to confusion about role clarity. Two informants spoke about ‘handballing’, ‘dumping’ and ‘gate keeping’. These terms reflect what they feel was an unfair referral or refusal of service, but may reflect assumptions about specialised services, including levels of health care co-ordination available to people from refugee backgrounds on arrival. This varies across Victoria.

As described earlier in the section 4.2, there are specific needs people with disabilities from refugee backgrounds have that are not seen in other population groups. This is because they often arrive with no or little documentary evidence of their impairment(s), have no Australian service system history, are without necessary aids and equipment and have no links with services. Settlement is a busy time, with many appointments and a multitude of settlement needs.

A number of interviewees raised questions about what other services did:

> *People with severe disabilities may be referred to a complex case manager, what does the complex case manager do? – informant 16*

5 Conclusion

Northern Melbourne has received increased numbers of refugee and humanitarian arrivals during a time of significant service system change. The NDIS and aged care reforms aim to take complicated service systems and simplify them, however, in order to provide services to people from refugee backgrounds they must be accessible. Significant issues are posed for those that do not meet eligibility criteria, such as asylum seekers, and those that are unable to access services to acquire the required evidence to make access applications.

Northern Melbourne has clusters of ethnic communities which possess good community links. Community based approaches may be an effective method to build capacity to support people with disabilities and their carers.

This project has sought to identify and understand the needs of people from refugee backgrounds with disabilities and how services in northern Melbourne are responding to these needs in early settlement. Desk based research, interviews with key stakeholders, follow up meetings with policy advisors and a sector round table identified the need to address:

- delays in access to comprehensive assessment services
- barriers that prevent accurate assessments
- delays in access to aids and equipment
- gaps in case coordination support
- models of service provision that rely on self-advocacy but do not provide the necessary tools for people from refugee backgrounds to engage
- service eligibility gaps for people seeking asylum and people with protection visas that are temporary
- lack of accessible transport
- gaps in the provision of interpreting
- poor information flow to support assessment and referral of people with disabilities
- service providers who are not clear about what their role is in assisting people from refugee backgrounds with disabilities

Areas that need further exploration include:

- the utility of MyHealthRecord to support greater continuity of care for people with disabilities from refugee backgrounds
- models of care that have been developed to maintain continuity of care with other transient population groups that can inform services to newly arrived people from refugee backgrounds
- streamlining referral forms and protocols
- support and guidance for speech therapists undertaking language assessment with children from refugee backgrounds
- how to build practitioners' knowledge to appropriately navigate waiting lists to ensure people have priority access
- support and work opportunities for carers and people with disabilities from refugee backgrounds
- the experiences of settlement and service access for people with disabilities from refugee backgrounds and their carers
- the supports needed for people with disabilities from refugee backgrounds to identify, gain and sustain meaningful employment
- the impact of the introduction HSP in October 2017

The scope of this project did not allow for direct consultation with community members. The complementary project *Resettling in Victoria – advice from people from refugee backgrounds*

who are living with disabilities will provide an opportunity for more direct advice from people with disabilities and their carers.

Recommendation 33: The Victorian Refugee Health Network identifies a network or working group who may undertake stage 2 of this project - the facilitation of an inter-sectoral working group that will pursue actions to implement the recommendations of this report.

Endnotes

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