



**ORANGA
TAMARIKI**
Ministry for Children

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Evidence Brief: Primary Healthcare Needs of Disabled Children in Care and Protection

The Oranga Tamariki Evidence Centre works to build the evidence base that helps us better understand wellbeing and what works to improve outcomes for New Zealand's children, young people and their whānau.

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Executive Summary



The brief

This evidence brief examined literature on the primary healthcare needs of disabled tamariki and rangatahi (tamariki whaikaha) in care, including youth justice and protection facilities. The brief required a specific focus on equity of access to, and engagement with, primary healthcare services, and health literacy.

Key agreed exclusions included mental health conditions and abuse in care.

Oranga Tamariki's research questions directing this brief were:

1. What are the primary healthcare needs of children and young people with disabilities in different age groups (0-4, 5-9, 10-13, 14-17) compared to children and young people who do not have disabilities, with a focus on their health literacy, and equity of access to, and engagement with, primary healthcare services?
2. What are the strengths, opportunities, gaps, or barriers to meeting these needs of children and young people in care including areas for attention, and including to reduce any disparities between non-Māori and Māori?

Context

Important context for this brief is that Aotearoa New Zealand is a signatory to the 2006 United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The UNCRPD definition of disabilities is used in this brief (Article 1). Two further articles of UNCRPD were considered as we examined the evidence; Article 7 Children with Disabilities; and Article 25 Health. These are important as they were developed and agreed with international stakeholders, and they provide guidance for Aotearoa New Zealand on disability policy.

Findings

National data reports that the number of children (aged 0-15) with disabilities in the general population is 10-11% (but higher for Māori and Māori boys in particular). Almost half have multiple impairments. The prevalence of disability among tamariki engaged with Oranga Tamariki is vastly higher, estimated to be anywhere between 47% to 87%, depending on dataset, age of children, and definition of disability. Other evidence from Oranga Tamariki found that 66% of tamariki whaikaha in out-of-home care were identified as having high or very high support needs.

Evidence on poorer health outcomes for young people with disabilities and young people in care and protection shows that tamariki whaikaha will have much worse health outcomes than their peers.

This evidence brief identified large gaps in the literature with no literature specifically on the primary healthcare needs of disabled children in care. This is a critical evidence gap. Broader literature on children and primary care, disabled children, and children in care, therefore, make up much of the evidence in this area. We draw on this and, at times, also literature on adults – to fill this critical evidence gap.

From the evidence we have, the following broad key themes were identified:

Need for GP registration, initial primary healthcare assessment, early intervention and regular review

Around half of young people entering care and protection are not registered with a General Practitioner (GP) and these and many others will not be having regular check-ups. Many of these are likely to be disabled youth in care.

Avoidable hospitalisations and other evidence reveal high levels of unmet need in primary health care to warrant urgent intervention and monitoring.

For many reasons, it is critical for tamariki whaikaha in care to undergo initial primary care assessment and screening for disabilities and needs. This should be comprehensive, in a multidisciplinary setting, with resourcing for regular review.

Barriers to accessing primary care

There are multiple barriers to accessing primary care for disabled children. These barriers included financial and other barriers parents or caregivers face due to caring and employment responsibilities, communication barriers. At the primary care level, the limited resourcing of health practitioners may also be a barrier.

Transition from paediatric to adult healthcare

Although some work is underway by Oranga Tamariki, there is a lack of professional support, planning, and referral systems linking youth with adult services, which require a holistic solution to healthcare and wider social needs. A transition plan from the treating GP should be a key component of this.

Inclusion of disabled voices in planning and strategy

There is a lack of research on the voices of tamariki whaikaha in care and their caregivers (foster and biological), which are critical to capture and should inform the identification of gaps and opportunities, decision-making, and best practice in this area.

Health literacy and communication

Health literacy is important not only for those with disabilities but also professionals, caregivers, and others who work with tamariki whaikaha in the care and justice sectors. It is also relevant and important at the institutional level to ensure sufficient resource and infrastructure to support tamariki whaikaha.

Indigenous approaches

It is critical to seek and incorporate Indigenous perspectives on disability, health, and holistic models of care into strategies to improve the health and support of tamariki whaikaha.

Limitations

Abuse in care and mental health conditions, although critical for tamariki whaikaha due to their high experience of these, were agreed exclusions in this review. A further limitation is that only evidence in the public domain was reviewed.

Conclusion

Several other actions can also be taken to better meet the needs of tamariki whaikaha in care and protection and youth justice environments. The evidence summarised here, and frameworks drawing on UNCRC articles and te Tiriti o Waitangi principles, provide important and locally relevant guidance.

Introduction



The brief

Oranga Tamariki commissioned *Allen + Clarke* to undertake an evidence review to identify what is known about primary healthcare needs of children and young people in care with disabilities (compared to those without disabilities).

Areas of particular interest included: equity of access to, and engagement with, primary healthcare services and health literacy.

For the purpose of this evidence review, children with disabilities includes those who identify as disabled, as well as those who may have impairments that have not been screened/recognised or who do not identify as disabled.

For this evidence brief, agreed exclusions included mental health conditions and abuse in care (except where they were found embedded in the literature or data).

The data range for this brief was evidence and literature from 2012 onwards.

Definition of disability

The definition of disability agreed with Oranga Tamariki used in this brief is that used by the United Nations Convention on the Rights of Persons with Disabilities (2006):

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. Article 1 Purpose.

Research questions

Oranga Tamariki's research questions directing this brief were:

- What are the primary healthcare needs of children and young people with disabilities in different age groups (0-4, 5-9, 10-13, 14-17) compared to children and young people who do not have disabilities, with a focus on their health literacy, equity of access to, and engagement with, primary healthcare services?
- What are the strengths, opportunities, gaps, or barriers to meeting these needs of children and young people in care including areas for attention, and including to reduce any disparities between non-Māori and Māori?

Methodology

Following discussions with Oranga Tamariki, our team undertook a scan and analysis of relevant literature across academic and general research platforms, based on agreed search terms (including synonyms) in Table 1.

Table 1: Agreed research search terms

Search term 1 (Primary Care)	Search term 2 (Population)	Search term 3 (Disabilities and conditions)	Search term 4 (Children in justice or care)	Search term 5 (Countries in scope)
Primary care guidelines	Tamariki	Special needs	Youth Justice	New Zealand
Paediatric healthcare	Rangatahi	Complex needs	Care and Protection facilities	Australia
Health indicators	Children	Autism	Foster care	Canada
Health literacy	Young people	ADHD*	Out of home care	United Kingdom
Accessibility	Teenagers	Spina bifida		Scandinavian countries
Wellbeing		Permanent hearing loss		Other countries (Brazil, France)
		Cerebral palsy		United States of America
		Cystic fibrosis		
		Epilepsy		
		Down syndrome		
		Developmental disabilities		
		Intellectual disabilities		

* Attention Deficit Hyperactivity Disorder

The search returned 74 documents. They were screened for relevance by a review of the abstract and title, resulting in 50 documents for full review. The length of the documents ranged from two to hundreds of pages, and included short evidence briefs, peer reviewed research articles, and a range of reports.

Context

Aotearoa New Zealand is a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). UNCRPD is an international agreement aiming to promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by people with disabilities.

The agreement was created through collaboration and participation of a range of stakeholders including disability rights advocates and organisations of people with disabilities.

Of particular relevance to this brief is **Article 7 – Children with disabilities** which states:

1. Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.
2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.
3. Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

Following our obligations as a signatory to UNCRPD, children with disabilities should have the same rights and freedoms as children without disabilities, the best interests of the child should prevail, and these children's voices should be heard on matters affecting them.

Also relevant is **Article 25 – Health**, in particular sections a-d, that state Parties shall:

- a) Provide persons with disabilities with the same range, quality and standard of free or affordable healthcare and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
- b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;
- c) Provide these health services as close as possible to people's own communities, including in rural areas;

- d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care.

In this context, children with disabilities therefore have the right to equal access to quality, accessible and appropriate primary health care, and early identification, intervention, and specialist disability health services designed to minimise their disability.

Report outline

The evidence brief begins with a high-level overview of the evidence base on primary care needs for disabled children and young people in care. It then outlines data on the number and type of disabilities experienced by young people in Aotearoa. This is followed by a high-level overview of data on the poorer health outcomes for young people with disabilities, and young people who have been in care and protection. The main findings are then presented under the key themes, with New Zealand evidence presented first, followed by evidence from other countries. The discussion includes key summary points, future directions, and the conclusion.

Findings



Overview

Considering the overall evidence reviewed, publicly available literature directly addressing the research questions in detail was non-existent. There was a body of literature on children and disability in New Zealand and internationally, literature on the health of children in care, and one review on New Zealand children *in care* with disabilities – however this was not focused on primary care needs (Donald Beasley Institute, 2022a). There is also a body of literature on healthcare outcomes of youth with disabilities and health outcomes of young people in care, although in more general terms so not specific to primary care. Therefore, none of the literature was *focused* on primary care needs of disabled children in care. This is a significant evidential gap.

Because of the lack of directly relevant literature, much of this evidence review draws on findings nested in the broader literature and associated literature on adults with disabilities and access to healthcare.

Adding complexity in the literature are the inconsistent definitions and classifications of disabilities, with the inclusion and exclusion criteria differing between studies. To manage these inconsistencies in disability definition and classification, we defer to how they are reported in the literature.

A further issue relates to the age groups of interest and those referred to in the literature. We did not find any literature covering the specific age groups of interest in this brief; most literature grouped children and young people into a single group (usually 4-18 years old) or as ‘babies’, ‘young children’, and ‘adolescence’. To manage this issue, for international literature we use the terms we find in the literature and the ages as they are reported.

For New Zealand literature, we also use the ages as reporting, but when referring in more general terms about the New Zealand evidence and context, we use the Māori terms, ‘rangatahi’ and ‘tamariki’, and ‘**tamariki whaikaha**’, when we refer to our tamariki and rangatahi with disabilities (whaikaha). We note that this te reo term is inclusive of children and young people *of all ethnicities and cultures*. Where tamariki Māori are directly referred to in the literature, this is stated.

Before we consider the evidence, it is useful for context to outline the prevalence and type of disabilities presented by New Zealand tamariki and rangatahi and how they are usually conceptualised.

We then consider the evidence on the poorer health outcomes for tamariki whaikaha and for tamariki and rangatahi in care and protection.

Prevalence among tamariki whaikaha

Survey data

The most recent evidence on the national prevalence of disabilities for tamariki and rangatahi is based on a survey conducted in 2013. While a new disability prevalence

survey is underway in 2023, the data presented here are based on the 10-year-old data. The 2013 survey used the following definition of disability:

‘any self-perceived limitation in activity resulting from a long-term condition or health problem lasting or expected to last 6 months or more and not completely eliminated by an assistive device (for example, glasses or crutches that eliminate their impairment)’

Of the survey sample of 23,000 adults and children living residentially and 1,000 adults living in residential care, the key relevant data are:

- 24% of adults (age 15 and over) had a disability.
- 11% of tamariki age 0-15 had a disability.
- 15% of Māori tamariki had a disability compared to 9% for non-Māori.
- 19% of Māori boys had a disability compared to 10% for Māori girls.

The survey highlights the main impairment types for tamariki aged 0-14 as; Sensory, Physical, Intellectual, Psychiatric/psychological, and Other. It also notes that:

- Learning and speaking disabilities, as well as psychological/psychiatric impairments were the most common for children.
- 48% of disabled children had multiple impairments.

The causes of these impairments identified in the survey were: Existed at birth, Disease or illness, Accident or injury, and Other.

Ministry of Health data

Additional information on the *type of disabilities* presented by tamariki comes from data on people with disabilities who were allocated Ministry of Health-funded disability support in 2018. According to the Ministry of Health (2019) disability support data, the main disabilities presented by New Zealand tamariki are:

- Learning disabilities: includes dyslexia, dyscalculia, and other conditions that affect ability to learn.
- Physical disabilities: conditions such as cerebral palsy, spina bifida, and muscular dystrophy, which can affect ability to move and perform daily activities.
- Sensory disabilities: hearing loss, vision impairment, and other conditions that can affect ability to communicate and interact with the world.
- Intellectual disabilities: conditions such as Down syndrome, fragile X syndrome, and other genetic conditions that affect abilities and adaptive functioning.
- Autism spectrum disorder (ASD): a neurodevelopmental disorder that affects the ability to interact socially, communicate, and engage in repetitive behaviours.

Detailed data

More detailed disability data, especially for Māori, are provided in *Te Ohonga Ake The Health of Māori Children and Young People with Chronic Conditions and Disabilities*

in *New Zealand Series Two* (Craig et al., 2014). This report covers a wide range of chronic health conditions presented in Māori tamariki and rangatahi, from congenital anomalies evident at birth; conditions in scope of this review such as Autism Spectrum Disorder (ASD), cerebral palsy, and permanent hearing loss; and other chronic medical conditions such as obesity, type 1 diabetes, and cancer. The report does not provide any data specific to children in care.

Prevalence among tamariki whaikaha in care

According to a 2021 review of *Good practice for disabled tamariki and rangatahi in care*, Oranga Tamariki cannot easily identify disability for children in care (Donald Beasley Institute, 2022a). This means that Oranga Tamariki has limited visibility over the extent to which children and young people in care are living with impairments.

Data from the Integrated Data Infrastructure (IDI) has identified that 10% of tamariki aged 0-17 with current or previous Oranga Tamariki involvement have at least one indicator of disability (Oranga Tamariki - Ministry for Children, 2020). This only refers to tamariki and rangatahi whaikaha who can be reliably identified. This is likely a significant undercount of the prevalence of disability among youth engaged with Oranga Tamariki (in care) due to definitional issues related to disability and age group, and undetected disabilities. The 10% figure also likely refers to those who have a formally diagnosed and more complex disability. Of this cohort:

- 87% had a primary diagnosis of intellectual disability.
- 11% had autism as their primary diagnosis.
- 3% had a physical, sensory, or neurological impairment (Oranga Tamariki - Ministry for Children, 2020).

However, it is acknowledged that research has reported *vastly different* estimates of disability amongst the population of tamariki and rangatahi engaged with Oranga Tamariki.

For example, the 2018 transitions cohort study – an interview-based study with 120 high needs rangatahi aged 15-17 (96 in care and protection and 24 in youth justice sites) – suggested the prevalence of disability amongst the transition cohort could be approximately 75%, when including psychosocial disability. Further, 47% had, or were suspected to have, a disability diagnosis. Other evidence from Oranga Tamariki found that 66% of tamariki whaikaha in out-of-home care were identified as having high or very high support needs (Oranga Tamariki, 2020, p.18).

Health outcomes of tamariki whaikaha

The large *Youth19 Survey* of the health and wellbeing of more than 7,000 school students in the North Island (Fleming et al., 2022) reported on the 646 participants who had a long-term disability, noting that:

- 58% of disabled youth rated their wellbeing as good, compared to 69% of non-disabled youth.
- 31% of disabled youth reported not getting the healthcare they needed in the previous year compared to 20% of non-disabled youth.
- 22% of disabled youth experienced discrimination in healthcare compared to 17% of non-disabled youth.
- 35% of young people with disabilities reported symptoms of depression compared with 25% of those without disabilities.
- 31% of young people with disabilities reported serious thoughts of suicide in the last year, compared to 21% of people without disabilities.

Health outcomes of tamariki and rangatahi in care and protection

Fleming (2021), also reporting on data from the *Youth19 Survey* – of which 9% (n=673) of school students had ever been involved with Oranga Tamariki, and, of these, 2% (n=143) were currently involved with Oranga Tamariki – found that those in care were:

- less likely to report good wellbeing as measured on the WHO-5 wellbeing index
- more than twice as likely to report depressive symptoms
- more than twice as likely to have had serious thoughts of suicide in the last year and more than four times as likely to have attempted suicide in the last year
- more likely to have sought professional help for feeling bad or having a hard time
- less likely to report having very good or excellent health
- close to twice as likely to report having a disabling condition
- among those who have had a menstrual period, close to three times as likely to have experienced period poverty and close to four times as likely to have missed school due to period poverty
- less likely to have accessed a health service in the last year, however more likely to have been seen by a health professional in private (without a parent or other people)
- more than twice as likely to have been unable to access a health provider when they needed to in the last year.

Additional New Zealand evidence based on IDI data also revealed that rates of hospitalisation and mortality are higher among in-care children than those not in care (in-care children were 1.32 times more likely to be hospitalised and 3.64 times more likely to die than those not in care). We note that this study precedes the formation of Oranga Tamariki in 2017. Although this data did not identify tamariki whaikaha

specifically, this is suggestive of evidence of the higher unmet primary care needs in this group as potentially contributing to higher hospitalisations (Pugh et al., 2023).

Similarly, New Zealand data from *Experiences of Care in Aotearoa* (2023) reported that care experienced tamariki and rangatahi had twice as many hospitalisations or emergency department presentations than non-care experienced tamariki and rangatahi (Transition Services Outcomes report 2023 unpublished). There were also similar trends for Potentially Avoidable Hospitalisations (PAH) – where hospitalisation could have been avoided by the provision of appropriate health care interventions, early disease management, public health interventions, or social policy interventions.

Perhaps most significantly, given the focus here on primary health care needs, findings from *Experiences of Care in Aotearoa* (2023) revealed that:

- only 53% of tamariki and rangatahi in care were registered with a specified doctor or medical provider, and
- Oranga Tamariki were unable to provide information on whether tamariki or rangatahi in care had an annual health check.

This means it is not possible to determine the extent to which youth in care are engaging with primary health care services, let alone if tamariki whaikaha are doing so.

What does the literature say about the primary health care needs of tamariki whaikaha in care?

We know from New Zealand research on tamariki whaikaha in care – contained in a previous literature review commissioned by Oranga Tamariki, focused on young people with complex disability – that Oranga Tamariki does not have an easy way of identifying disability for children in care. It therefore has limited visibility over the extent to which children and young people in care are living with impairments (Donald Beasley Institute, 2022a). Some recent data on the numbers of tamariki whaikaha in care contained in this review have been canvassed earlier in this brief.

In a commissioned submission, the Waitangi Tribunal for Stage Two of the Wai 2575 Health Services and Outcomes Kaupapa Inquiry (Wai 2575, #B22), King (2019) describes the limitations of the current data and data collection approaches for identifying tamariki whaikaha, and access to services.

‘the Crown does not have the appropriate monitoring mechanisms in place to be able to ensure that the health and disability support needs for Māori children and young people with lived experience of disability within its care and protection and youth justice residences are being met.’ (King, 2019, p276)

Further and more generally:

‘Current monitoring and data collection for identifying and addressing inequities in services and outcomes for Māori with lived experience of disability is not effective. The Ministry of Health does hold several national databases that contain information on Māori with lived experience of disability. However, the health status of the total disability population in Aotearoa/New Zealand – including Māori with lived experience of disability – is not measured, as disability is not able to be identified in the majority of the national health surveys. Though the Ministry of Health does collect routine disability support services data, the usefulness of this data regarding addressing health and well-being for Māori with lived experience of disability is limited to the level of examining trends in service utilisation’ (King, 2019, p282).

Also noted in the Beasley review, is the fact that children with complex disabilities find their way into care often due to whānau being unable to access the necessary support, as well as more overt care and protection issues. The review cites research from the United States confirming that tamariki whaikaha are at an increased risk of experiencing maltreatment, for example, abuse and neglect, and that this maltreatment can cause disability. This is an important part of the picture underlying some disabilities. The review also notes that while out-of-home care arrangements often are initially intended as a temporary measure, data on the duration and permanency of such placements for tamariki whaikaha is limited. It is also clear from the review that definitions of ‘care’ and ‘out-of-home care’ are many and varied. The report defined ‘out-of-home care’ as ‘any form of care in which tamariki whaikaha

predominantly lives away from their whānau in an alternative setting with an alternative caregiver(s), and that this arrangement is overseen by a child protection agency.’ It notes that the current options for out-of-home care in Aotearoa New Zealand include ‘emergency, respite, transitional, family home care with professional caregivers or staff, permanent care (home for life), and adoption’ and care and protection (and youth justice) residences. In collating the evidence for this brief, we do not know the numbers of tamariki whaikaha and rangatahi who are placed in these different arrangements.

Although this literature review does not cover the primary health care needs of tamariki whaikaha in care, it does provide some important insights (Donald Beasley Institute, 2022a). These are related to the inclusion of children’s voices in discussions around care, the journey into care, being in care, and the journey out of care and reunification (with family) – all of which provide important context for any consideration of the welfare of children with disabilities in care.

In the remainder of this section, we present the key evidence under the following major themes found in the literature:

- need for initial primary health care assessment and regular review
- importance of early intervention and collaboration
- barriers to accessing primary care
- transition from paediatric to adult health care
- inclusion of disabled voices in planning and strategy
- health literacy and communication
- indigenous approaches.

Need for initial primary health care assessment and regular review

New Zealand

In discussing the journey into out-of-home care for tamariki and rangatahi with complex disabilities, the literature review conducted by the Donald Beasley Institute (2022) notes that, superseding other factors, families and whānau caring for high needs children had reached ‘breaking point’. Further detail is provided in *‘Just surviving: talking with parents of children with very high disability support needs about how they get by’*.

Alternative care had become urgent for a combination of factors; lack of resources, pressures of care, and barriers to access. Parents felt they had no other option but to ‘surrender’ the day-to-day care of their child to the state – a situation referred to as relinquishment. Relinquishment occurs as an often-unplanned action, ‘in the context of unstable circumstances and in the absence of person or whānau-directed, stable support(s) and services being in place’. Financial pressure, often due to the impact of the day-to-day care on employment options and finances, stress and isolation, exhaustion and lack of sleep, together with concern for the impact on the care, and sometimes safety, of siblings also contributed to relinquishment.

Although primary care needs were not canvassed in the review, it describes the problem as one of a disability support system that is crisis-driven, lacking in respite

options, and characterised by inadequate resourcing and support, creating a pattern of unmet need. Underpinning this situation is the lack of foresight and planning that should occur in the public and population health system, and the primary health care system where GPs have a critical role as first potential point of contact into the health system. By implication, even before relinquishment, there appears to be an unmet need for assessment, re-assessment, and referral to support in the primary care system.

Australia

Nathanson & Tzioumi (2007) – reporting the results of comprehensive multidisciplinary health screens offered to children in out-of-home care in New South Wales (although not focused on children with disabilities) – found that 26% of the 96 children who underwent hearing tests, as part of an assessment provided in a health screening clinic for children living in out-of-home care in Sydney Children’s Hospital, failed their hearing test (in comparison to the hearing loss in the general child population at 3.4%). Additionally, they found that 30% of children in the study cohort had abnormal vision, compared to 7.4% of the general child population in New South Wales. They also found that, while children in the study cohort had medical conditions that were similar to conditions seen in a general paediatric clinic, many of the medical conditions present in the study cohort had been poorly managed or not previously recognised.

Nathanson & Tzioumi (2007) state that the rates of poor physical, developmental, and emotional health in children in out-of-home care in their sample are identical to the rates reported from the United States and United Kingdom, which suggest the results will be relevant for New Zealand. The authors note that the American Academy of Pediatrics made recommendations calling for an initial medical review shortly after a child is placed in care to identify acute health problems, followed by a comprehensive health assessment within the first month, which encompasses development and emotional health evaluation. Similarly, authorities in the United Kingdom have called for statutory annual health assessments. Nathanson & Tzioumi (2007) observe that the complex health needs of children in care may require comprehensive assessments in a setting that can provide multidisciplinary facilities, resources, and expertise, as well as the infrastructure to allow access to ongoing health care and referral networks.

A study by Baidawi and Piquero (2021) examined the prevalence and characteristics of neurodisabilities among Australian children involved in both child welfare and youth justice systems, using data from a sample of 300 children (68% male; mean age = 16.2 years, range 10-21) who were charged and appeared in three Australian children’s courts, and had statutory child protection involvement. This study found that high levels of parent/caregiver relinquishment experienced by youth with ADD/ADHD diagnoses in particular led to increased risk of being placed in residential care settings and the likelihood of their behaviour being criminalised. This demonstrates the need for greater responsiveness and support from the state, justice, and child welfare systems to young people with ADD/ADHD and their families.

A two-year study conducted with over 100 young people aged 10-17 in Australia's only youth detention centre, Banksia Hill, found that 89% had severe neurodevelopmental impairment and 36% had Foetal Alcohol Spectrum Disorder (FASD), with most of the

disabilities going undiagnosed. This is the highest known prevalence of FASD in a custodial setting worldwide. FASD is prevalent among Indigenous youth and often leads to impulsive behaviour and trouble with the law. The study recommends a formal neurodevelopmental assessment for all people entering the Youth Justice system, comprehensive training for detention centre staff, and disability-informed policies and procedures. The South Australian Youth Justice implemented its own Disability Screening Project and found that 9 out of 10 children had a below-average IQ and more than 50% had severely impaired visual motor integration. They recommended screening assessments upon entry to the detention centre, staff training (staff disability-related health literacy), and community support systems (Salerno, 2020). Of note here is, in New Zealand, FASD impairments currently are not supported by any Ministry or body and requires a diagnosis of an intellectual impairment.

Research by Shmerling et al. (2020) explores the health care needs of Aboriginal and Torres Strait children in out-of-home care. Although disabilities are not mentioned in this research, several unique primary health care needs for this population are identified that are relevant to the scope of this evidence brief. These are:

- Indigenous children in out-of-home care are more likely to have experience with trauma and experience long-lasting effects of this.
- Higher rates of chronic health conditions such as asthma, dental decay, and ear infections related to poverty, poor living conditions, and limited access to health care.

Overall, addressing the unique health needs of Indigenous children in out-of-home care requires a holistic approach that takes into account their physical, social, emotional, and cultural wellbeing.

Importance of early intervention and collaboration

United Kingdom

A report published by the Care Quality Commission (2012) reviewed the needs of disabled children and young people in England (including communication, sensory, and mobility needs) and how their needs are being met by healthcare providers through document reviews and information from disabled children and young people, caregivers, parents, primary care trusts and hospitals, and advocacy groups. The focus is not on their placement in youth justice care facilities, however, key findings of note in this report outline the need for a collaborative approach to addressing these health needs, including early intervention and transition to adulthood.

United States

Research from North America on home care for youth with complex needs found where there is concern of developmental disabilities due to medical history, developmental screening results, or an underlying diagnosis, it is crucial that the child receives the appropriate educational and related support services in order to fully participate in school programmes. Other impairments, such as those relating to vision

or hearing, should be screened so that early intervention can be implemented to achieve a positive outcome (Elias et al., 2012).

Additionally, Elias et al. (2012) find early intervention services and home occupational and physical therapy services may benefit those children to optimise mobility (and minimise any complications) through the use of exercise plans and appropriate assistive devices.

Case studies from the United States presented in *Opportunities for Improving Programs and Services for Children with Disabilities* (2018) highlight the importance of early intervention to achieve maximum outcomes, as well as the need for integration of service providers to create a collaborative approach to achieving those outcomes. The research also underscores the need for inclusion of disabled children, young people, and their families and/or caregivers in the planning and delivery of healthcare services with a person-centred approach to care provision.

Barriers to accessing primary care

There is a lack of evidence on barriers to accessing primary care for disabled children in care specifically, and disabled children generally. Because of this, we can only report here evidence from literature documenting barriers to primary care access for all children. We note that, in New Zealand, primary care visits for children (under 14) have been free for the family since 1997.

New Zealand

Jeffreys et al. (2021) analysed repeated waves of data collected from the mothers of children enrolled in the *Growing up in New Zealand (GUINZ)* cohort study. Although data were not presented for the groups of interest in this brief, it reported that at ages 1-2 years, 4.7% of children experienced barriers to seeing a GP in the previous year. This was more common in Māori compared to non-Māori (8.3% vs. 2.5%) and in Pacific compared to non-Pacific (7.0% vs. 4.1%) children.

For children aged 54 months (4.5 years), 5.5% of the cohort reported facing a barrier to seeing a GP. Again, this was more common for tamariki Māori compared to non-Māori (9.0% vs. 4.3%); and Pacific compared to non-Pacific (9.1% vs. 4.6%) children. These figures illustrate the disproportionate experience of barriers to seeing a GP amongst caregivers of tamariki Māori and Pacific.

Jeffreys et al. (2022) found that the most common barrier faced at ages 1-2 years and 54 months, was not being able to get an appointment (2.4% and 2.9%), followed by being after hours (1% and 1.3%), not having transport (0.8% and 0.3%), and not being able to spare the time (0.3% and 0.3%).

At 24 months, 0.2% of the cohort reported cost as a barrier, despite children under 14 years being eligible for free GP visits since 1997. None of the cohort reported cost as a barrier at age 54 months. Jeffreys et al. (2022) explain that the 'cost' of seeing the GP is not only the user charge made to the practice, but also, for example, the cost of travel or childcare and care for other dependents, and the cost of any time off work. Such barriers are not affected by the zero-fees policies in place in Aotearoa New

Zealand. This is supported by Elias & Murphy (2012), who found that families of children with disabilities face lost income related to the need to reduce employment outside the home.

Jeffreys et al. (2021) state that other barriers reported at 24 months were not being able to get in touch (no clarification provided) with the GP (0.1%), not having childcare (0.1%), and other unspecified reasons (1.1%). At 54 months, 0.1% of the cohort reported that they had experienced not being able to get in touch with a GP and 0.6% of the cohort reported that they had experienced another, unspecified barrier. Childcare was no longer reported as a barrier at age 54 months. Jeffreys et al. (2021) state that for each barrier, the frequency was higher in Māori than non-Māori, and Pacific than non-Pacific families, and that the most marked differences in barriers were not being able to get an appointment for tamariki Māori and being after hours for Pacific families.

Jeffreys et al. (2021) consider that further qualitative work is necessary to explore the impact of the barriers they reported, including work on the role that receptionists and other frontline staff play in either facilitating, or acting as a potential barrier to, appointments (with one potential explanation being unconscious bias).

Australia and the United States

Barriers to primary care access are not just physical but can be financial and/or programmatic (for example, a lack of printed materials or sign language interpreters) (Kripke, 2014; Paris, 2013b). Access issues are worsened when a primary health practitioner has a limited or dated understanding of health needs or the specific health conditions of particular disabilities or holds an attitude about disability that might not acknowledge current perspectives or understandings of disability (Paris, 2013b). This suggests an opportunity exists for professional training to achieve greater disability-related health literacy.

There is some research highlighting that effective collaboration is at the centre of access to primary care (Paris, 2013b, 2013a).

Australia

Raman et al. (2011) conducted a mixed-method evaluation of the KARI clinic (a non-governmental organisation that provides foster care services to Aboriginal children and young people in south-western Sydney, which provides comprehensive, multidisciplinary health and developmental assessments to all children entering care (via KARI). Raman et al. conducted 11 interviews with key stakeholders to assess the barriers to care faced by Aboriginal children entering out-of-home care placed with KARI. They found that under-resourcing of the KARI clinic means that children are assessed for health and developmental issues but are not provided with follow-up care. Further, some foster parents' lack of access to affordable transport and childcare were identified as significant barriers to care.

Kaltner & Rissel (2011), in a study of 63 children entering care in the North Brisbane area, found evidence that foster carers' evaluation of child health concerns may underestimate the health need of a child, as established through multidisciplinary

review. This highlights the necessity of child health training and support for carers. Kaltner & Rissel (2011) consider that the results of their study indicate that, where a foster carer cares for three or more foster children concurrently, for example, a sibling group, centralised health service provisions that incorporate varying specialist clinicians in one location may be necessary in order to minimise the demands on foster carers and to ensure that children in care receive the health services they require in a timely manner.

United States

In their United States-focused review of the prevalence and nature of barriers to healthcare delivery faced by children in foster care, Deutsch & Fortin (2015) found that resource shortages at the health provider level pose a potential barrier to optimal healthcare delivery within the child welfare system.

Deutsch & Fortin also identify that a foster parent is often relied upon to determine a child's need for care and to seek necessary medical and mental health care. Where this is the case, a lack of access to crucial historical information about the child, including the child's past medical, developmental, and mental health history can pose a barrier to the child receiving appropriate care.

Relatedly, the authors note that information about a child's health care utilisation prior to their placement in foster care is often hard to obtain, in part because the child may have had erratic contact with several different health care providers. A lack of continuity in care plans or sharing of medical information by social workers, case management, or physicians may subsequently contribute to lapses in care plans, and duplication or omission of health care interventions, such as immunisations and screening.

Deutsch & Fortin (2015) state that a further barrier may arise when a child in foster care has a diagnosed, special health care condition, as foster parents may be ill-equipped to identify health care issues or access the health system without guidance by child welfare services. This suggests an opportunity for improving health literacy of foster parents.

Additionally, Deutsch & Fortin (2015) highlight that, when a child's biological parents retain rights for medical decision-making, despite a child temporarily residing in care, legal consent issues may preclude obtaining needed care.

Deutsch & Fortin (2015) also identify that medical care for children in foster care with complex needs can be time consuming, require more referrals, and more diagnostic testing and that physicians may not be compensated commensurately to their effort. Deutsch & Fortin consider that, as a result, many health care providers may be deterred from involvement in the care of foster children, creating another barrier to care.

Transition from paediatric to adult health care

This section explores the evidence in the literature from Aotearoa New Zealand and the United States on the importance of adolescent to adult transition period and the

need for a transition to adulthood strategy for young people with disabilities. A key component of this process should be the development of a comprehensive medical summary by the primary care practitioner that knows the patient best.

New Zealand

Thanalingam et al. (2022) state that there are well recognised gaps in the availability and quality of transition services within Aotearoa New Zealand for young adults with neurodevelopmental disorders as they move from paediatric to adult health care services. More specifically, there is a lack of systems in place offering professional support or referral to an adult service. Furthermore, when these young adults are referred, the adult services are often not equipped to meet their needs. These issues are explained by inadequate communication between paediatric and adult services, limited resourcing, and a lack of knowledge of transition practices (Campbell et al., 2012, as cited in Thanalingam et al., 2022). Another challenge noted is the fear of new healthcare systems among young adults (Campbell et al., 2012, as cited in Thanalingam et al., 2022).

Just Sayin' Survey – Commissioned by Oranga Tamariki

From July 2019, Oranga Tamariki has provided the Transition Support Service (TSS) to support those aged 15-17 to transition to independence (Malatest International, 2021). The aim of the TSS was to develop a transition plan to respond to the needs and aspirations of young people, taking account of individual cultural and developmental needs. Holistic needs assessments are completed but some social workers may not fully understand young people's needs.

Just Sayin' is a new annual survey of young people eligible for transition worker support and designed to hear young people's voices about how they are being supported, what difference transition worker support has made for them, and to understand their living situations.

The first annual *Just Sayin'* survey of young people eligible for a transition worker was conducted between May and July 2020. The survey was completed by 141 young people eligible for transition worker support. A shorter survey was completed by 49 young people not eligible for a transition worker but potentially eligible for transition support (who heard about the survey independently).

Approximately three-quarters of young people who responded to the survey and were eligible for transition support thought their Oranga Tamariki social workers understood their support needs and that their social workers were there for them when needed. Young people also self-assessed their holistic wellbeing across the four dimensions of Te Whare Tapa Whā. Young people's responses to *Just Sayin'* showed that, while most young people had good general wellbeing, taha hinengaro (mental wellbeing) was challenging for 38%.

United States

Rehm et al. (2012) studied the transition of 64 youths (aged 14-26) with special health care needs and developmental disabilities within the United States. The authors

present their findings on the meaning of adulthood and the priorities for transition, for both the young people and their parents/carers. The definition of adulthood for the young people and parents/carers of this study was 'functioning as independently as possible with appropriate supports' (Rehm et al., 2012, p. 1). The authors reported that finding an adult health care provider was not a key concern for the (biological) parents in their study, and therefore suggest a need for health care transition goals to broaden to much wider-ranging quality of life issues. The parents were most concerned about 'general well-being, increasing health care self-management for youth, safety, and prevention of complications related to chronic health conditions' (Rehm et al., 2012, p. 16).

Rehm et al. conclude that there is an urgent need for 'comprehensive, holistic, and life-course planning during the transition to adulthood' (2012, p. 17). The authors explain that both health care (paediatric and adult) and education systems are overworked and inadequately financed, and subsequently do not routinely interact, share information, or plan for individual youth.

McCauley (2021) examines how youth with disabilities who age out of foster care in the United States face increased difficulty in transitioning to adulthood. The four key risk domains examined by McCauley include incarceration, homelessness, childbearing, and substance abuse. The results indicate that, for youth aging out of foster care, having an emotional or mental disability is associated with increased risk of incarceration and homelessness when transitioning to adulthood. Some of this risk is said to be explained by experiences in the child welfare system (that is, foster care, Child Protective Services). This study highlights the need for policies and programs that address the unique needs of this population to improve their outcomes in the transition to adulthood.

Based on several key research areas prioritised by the CYSHCNet national research agenda within the United States, Okumura et al. (2022) outlines the gaps in the current literature and recommends research required to advance health care transitions from paediatric to adult health care, specifically for children and youth with special health care needs. The authors explain that future research needs to focus on determining the optimal service models in partnership with young adults and their families, defining how to measure the adequacy of transition activities, and evaluating financial incentives for transition readiness development, transition, and continuity of care.

Inclusion of disabled voices in planning and strategy

A strong theme presented in the literature was the need for policies and strategies to be created in collaboration with the affected communities (Conder et al., 2016; Office for Disability Issues, 2016; Hickey & Wilson, 2017; Ministry of Health, 2018; Ingham et al., 2022). This section explores the evidence for the need to include voices of tamariki whaikaha in care (and carers affected) in planning and strategies to improve health provision and supports.

New Zealand

Aotearoa New Zealand is a signatory to the UNCRPD and the government has taken steps to implement its principles, including the adoption of the New Zealand Disability Strategy, the foundation of the Office for Disability Issues, and the recent establishment of Whaikaha – Ministry of Disabled People. However, New Zealand's first report on implementing the UNCRPD found that people with disabilities still face barriers to full participation in society, such as discrimination, lack of accessibility, and limited opportunities for education and employment (Office for Disability Issues, 2016).

To address these issues, the government has implemented a range of measures, including the establishment of the Disability Rights Unit within the Human Rights Commission, the development of accessibility standards for buildings and public spaces, and the provision of support services for people with disabilities. Also introduced is the Whāia Te Ao Mārama 2018 to 2022: The Māori Disability Action Plan, a four-year plan developed by the New Zealand government in partnership with disabled Māori and their communities. The plan aims to improve outcomes for Māori with disabilities by addressing the disparities that exist between Māori and non-Māori disabled people (Ministry of Health, 2018), with specific initiatives including the development of culturally responsive disability support services and the increase in participation of tāngata whaikaha Māori in decision-making processes that affect their lives.

Literature from Aotearoa New Zealand discuss the exclusion and discrimination felt by children with disabilities, which then can lead to negative outcomes such as reduced self-esteem and social isolation. Research by Conder et al. (2016) draws on a research project that involved children with disabilities in Aotearoa New Zealand who were aged 8-18 years (and their families) that gave them a voice and involved them in decisions that affected their own lives. This research found that through involvement in decision-making around their own lives, children felt empowered as they felt they had a sense of control, and additionally, felt valued and heard.

Through an inclusive process that has the perspectives of this community at its centre, potential blind spots and barriers that prevent access to primary care services, education, and employment can be identified.

Expanding on this, Ingham et al. (2022) and Hickey and Wilson (2017) discuss this theme further, emphasising the importance of including the voices and experiences of tāngata whaikaha Māori in policy and decision-making as a key strategy to address the inequalities experienced. Support and resources are needed to achieve the goal of inclusion, which includes providing accessible information and communication tools, and in some cases, trained facilitators, to ensure that these voices are heard.

Family and caregivers of tamariki whaikaha should also be considered, for they play a critical role in supporting and advocating for their children. For those children that are unable to participate, family involvement helps to ensure that decisions are made that are in the best interest of the child(ren).

Health literacy and communication

Health literacy is defined by the Ministry of Health as the capacity to find, interpret, and use information and health services to make effective decisions for health and wellbeing. This definition suggests people will be actively looking for relevant health information which is not always the case.

A good level of health literacy is important for empowerment and participation, and to achieve positive health outcomes and, any literacy programmes must include people with disabilities, as well as those who care for, work with, and advocate for them (Bittlingmayer & Sahrai, 2019, p. 694).

It is important to note that 'health literacy' is not a capability that resides solely at the individual level. Health literacy applies at the healthcare workforce, health organisations, welfare, and the wider system levels – all have roles to play. As noted in the document: A Framework for Health Literacy (Ministry of Health, 2015), health literacy includes that:

'Health organisations consider health literacy in all of aspects of their work. This is visible in the way that organisations communicate, provide information, present their facilities, and interact with people'.

For children *without* disabilities, stages of expected child health literacy, by age group, are outlined in the International Handbook of Health Literacy (2019) as shown in Table 2.

Table 21: Examples of health literacy levels according to age groups

Age stage	Prose/document literacy skills	Verbal/expression skills (oral literacy)	Numeracy skills	Systems-navigation skills
By age 4, a child should be able to...	N/A	Communicate with an adult, caregiver or health provider about health behaviours (e.g., tooth brushing, physical activity)	Recognise the relative value of health choices (e.g., food portion sizes)	N/A
By age 10, a child should be able to...	Understand the content of a child-oriented handout about bike helmet use	Describe ways to prevent common childhood injuries and health problems	Identify the characteristics of healthy versus non-healthy foods on the basis of sugar or fat content in nutrition labels	Describe how the media can influence health behaviours
By age 14, a child should be able to...	Develop a written plan to attain a personal health goal that addresses personal strengths, needs and risks	Demonstrate refusal, negotiation, and collaboration skills to enhance peer and family influence on health behaviours	Analyse personal susceptibility to injury, illness or death if engaging in unhealthy behaviours	Evaluate the validity of health information, products and services and access valid health information and counselling services
By age 18, a child should be able to...	Complete a document with a child's medical history and health needs and read and understand the patient's bill of rights	Identify a child or family's health behaviours and establish personal health goals for a family or child	Understand and use simple forms of medication and understand results of child health screening tests (e.g., newborn screening results, growth chart)	Complete the enrolment process for child health insurance and obtain school-based health services

Source: International Handbook of Health Literacy (2019)

Bröder and Carvalho, in their chapter *Health literacy of children and adolescents: Conceptual approaches and developmental considerations* in the *International Handbook of Health Literacy* (2019), note that the relevant health literacy research

relating to children and young people tends to focus on the health literacy of their parents, caregivers, and teachers, rather than the children/young people themselves. This is because these people are seen as important contributors to their health, yet there is insufficient data on family health literacy for parents/caregivers of children with developmental disabilities.

A systematic review conducted by Lindly et al. (2020) analysed 15 studies that investigated health literacy and its impact on health outcomes in children with developmental disabilities. The findings suggest that children with developmental disabilities often have limited health literacy skills, which can negatively impact their health outcomes. The review also identified the need for tailored health education programs that are designed to improve health literacy in children with developmental disabilities. Results from this research were shown to be of highly variable quality (Lindly et al., 2020) and further research is needed to include more diverse samples of children with disabilities, a greater range of health outcomes, and using greater methodological rigor, including the use of reliable health literacy assessments.

Kramer et al. (2018) report that, in the United States, parents of very young children (age 1-3) with developmental disabilities need to be able to identify and solve environmental barriers to their child's participation. The authors theorised that health literacy principles would be an important part of the optimal problem-solving approach for parents. Specifically, it was expected that incorporating health literacy principles into the approach would increase usability for parents most at risk of experiencing barriers and disparities. The authors found evidence that the approach supported effective problem solving by parents of young children with developmental disabilities.

A UK based paper by Chinn (2014) presents evidence that people with intellectual disabilities have been excluded from health literacy research. The author speculates that this is due to a presumption that people with intellectual disabilities would be unable to cope with the cognitive demands of critical thinking. Chinn (2014) reports that the lack of consideration of people with intellectual disabilities in health literacy research means that health promotion interventions for these people do not offer opportunities to develop capabilities to critically interact with health information.

Pleasant et al., in their chapter *Health literacy interventions for children or adolescents: An overview and insights into practical applications* in the *International Handbook of Health Literacy* (2019), reviewed health literacy programmes summarising best practice and lessons learned. The context for this work was overweight and obesity in youth and adolescents, a health issue that is out of scope for this evidence brief, however given the lack of research, these findings may have some limited relevance. The key points of Pleasant et al. (2019, p. 318) for consideration when building health literacy interventions for youth and adolescents are:

- careful consideration to those included in the intervention – youth alone, adults focusing on the youth alone, or adults and youth together
- help participants to be actively engaged in their own health literacy and health goals
- a focus on encouragement and practicality, and not solely on negative outcomes of low health literacy

- focus on the whole person, not just the conditions they have
- any informational materials should be fun, practical, and easy to use
- there is a need for rigorous evaluation of efforts and an establishment of a long-term methodology to determine the sustainability of any changes.

The authors conclude by advocating for the inclusion of health literacy in the school curriculum and the development of standardised health literacy testing.

New Zealand

Reid and White (2019) discuss the state of health literacy in Aotearoa New Zealand. The *Kōrero Mārama: Health literacy and Māori* report (Ministry of Health, 2010, as cited in Reid & White, 2019) found that 56% of the New Zealand adult population had low health literacy, and that, within the Māori population, 72% had low health literacy, with Māori aged 16-24 (and 50-65) having very low health literacy.

These findings led Te Kete Hauora (the Māori Health Directorate of the Ministry of Health) to contract three exploratory research projects on the impact of health literacy on health conditions with typically poor outcomes for Māori. One project examined skin infections in children and found difficulties in accessing information; specifically, obtaining reliable and current advice prior to accessing primary care, and issues with both the accuracy and relevance of the information available at early stages of infection.

These three research projects determined that the answers to health literacy barriers lay in process improvement in health services. The Ministry of Health has since completed much work toward creating a health-literate health system and released *A framework for health literacy* in 2015, which identifies the leadership and management actions, what skills and knowledge is needed by the public and health workforce, and system and service changes that build a health-literate health system. Reid and White (2019) conclude their chapter noting that the recent and increasing use of patient portals provides increased access to information and services, however difficulties with digital technology may mean some are isolated further.

Bittlingmayer and Sahrai (Chapter 44, 2019) report that people with disabilities are very rarely mentioned in health inequality and health literacy discourse. The authors note that people with disabilities were not discussed in the 2013 World Health Organisation publication *Health literacy: The solid facts*. Bittlingmayer and Sahrai (2019) proceed to explore the application of the concept of inclusion to the concept of health literacy. The authors report that a significant issue is the measurement of health literacy and of disability, due to a reliance on one's ability to complete a questionnaire. It is said that, from a 'traditional health literacy approach, people with disabilities, who are hardly or not able to read and write, have, by definition, no health literacy' (Bittlingmayer & Sahrai, 2019, p. 694). The authors explain that health literacy is important to patient empowerment and participation, and in order to achieve positive health outcomes for all, health literacy programs must include people with disabilities.

Paris (2013b, 2013a) suggests that education relating to primary health and disability should be offered to parents, carers, and those children and young people (where

appropriate) as an opportunity for them to develop skills to manage their own health needs.

Indigenous perspectives and approaches

This section explores Indigenous views and perspectives on disability and discusses the importance of cultural dimensions in discussion and assessment of disability. It also discusses Whānau Hauā, a Māori approach to disability.

The section provides evidence from research conducted in Aotearoa New Zealand, Australia, North America, and Canada on the importance of acknowledging cultural perspectives around health and wellbeing and decolonising the concept of disability (Hickey & Wilson, 2017; Fuentes & Lent, 2019; Raman et al., 2017; Ineese-Nash, 2020; Ingham et al., 2022; Donald Beasley Institute, 2022b, 2022a).

Limitations of the research covered are that the focus is not solely on the experiences of tamariki and/or rangatahi in out-of-home care; however, findings are relevant in terms of the importance of recognising the need for cultural inclusion in health and social services to achieve the best possible health outcomes.

Indigenous views on disability

The meaning of disability is socially and medically constructed, and there are differing views on disability within Western and Indigenous cultures.

The literature highlights the importance of cultural context in understanding disability and calls for a shift towards a more culturally sensitive and inclusive approach to understanding and supporting tamariki with disabilities (Hickey & Wilson, 2017; Fuentes & Lent, 2019; Ineese-Nash, 2020; Hamilton et al., 2020).

In some Indigenous cultures, for example, the concept of disability (as it is defined in a Western and Eurocentric context) did not exist pre-colonisation. Moreover, in some Indigenous communities, a disability is not perceived as a 'sickness', but a 'difference', and children are treated the same way regardless of their disability.

Literature from Aotearoa New Zealand states that the current worldview of disability is shaped from a northern hemisphere, colonial framework that conflicts with Aotearoa New Zealand and other Indigenous contexts (Hickey & Wilson, 2017). Indigenous people experience 'double disability' within the context of settler-colonialism and many developmental assessments are culturally biased, which, in turn, disproportionately disadvantages these communities; this is one of many factors contributing to oppression (Ineese-Nash, 2020).

The Western view of disability does not take into account wider holistic dimensions that play a role, as well as the impact of societal influences (Hickey & Wilson, 2017). The introduction of the social model of disability addresses this and aims to improve self-esteem and psychological wellbeing, as well as arguing that disability is a socially constructed notion, regarding the interaction of the environment and a person's body. However, this still does not address Indigenous understandings of disabilities.

Research done within Aotearoa New Zealand underscores the need for tāngata whaikaha Māori, as well as their whānau, to access quality health services with cultural competency; and that the current health and disability system is culturally unsafe. Accessing culturally appropriate disability services is limited, with only 33 of 980 disability providers (funded by the Ministry of Health) identified as Māori-owned and governed. This, in turn, creates barriers to accessing the services needed, the ability to build connections, and support their health and wellbeing aspirations (Ingham et al., 2022).

The importance of culture in disability discussion and assessment

New Zealand

Literature from Aotearoa (Ingham et al., 2022) underscores that health services that provide holistic and cultural connections to te ao Māori are essential in maintaining hauora. They further note that in their research some participants have had to adapt their self-identification to fit into a colonial, deficit-based idea of disability in order to access services needed.

Research conducted by the Donald Beasley Institute (2022a) confirms this, discussing the importance of understanding and respecting the cultural identity and background of tamariki whaikaha in care, which includes their whakapapa, tikanga, and mana. Supporting them to maintain their connection with their whānau, hapū, and iwi is significant in this, as well as participation in cultural activities and events.

Australia

The research conducted by Raman et al. (2017) within Australia highlights that the systematic neglect of culture in health is a barrier to obtaining a high standard of health. Their study of the impact of out-of-home care on the developmental health of Aboriginal children highlights the importance of cultural practices in service delivery, including out-of-home care programmes, in order to maintain identity and connection to their community, as well as the need for collaboration between Aboriginal communities, government agencies, and service providers. Though there may be challenges in implementation in a large metropolitan setting, this can be achieved if attention is paid to the context of each individual child, taking into account their risk and resilience factors.

Reinforcing Ineese-Nash's (2020) findings that assessments are culturally biased (discussed above), research by Hamilton et al. (2020) from Australia argues that traditional diagnostic methods for FASD are often inadequate for Indigenous populations who may have unique cultural experiences and may not fit into the diagnostic categories developed by non-Indigenous researchers. Hamilton et al. (2020) explored 'yarning' as an assessment method, defining this as 'an Indigenous cultural form of conversation' where exchange and listening are important, and each side showing empathy, connection, and interest in the other. This research suggests yarning as an effective way to engage with young people in detention who are undergoing assessment for FASD, as it is a way in which trust and understanding can be built between the young person and the diagnostic team. Yarning offers flexibility

in its use, such as having a walk with the person involved as a means to create a less 'formal' atmosphere and, thus, putting them at ease; though a challenge discussed is the need to have a culturally aware facilitator who is skilled in the understandings of the cultural traditions and values of the young person. Overall, Hamilton et al. (2020) suggest that yarning can improve future assessment processes and provide valuable information to participants, as well as provide insight as to how the young person makes sense of clinical assessment and identifying areas that need further refinement.

United States

Research conducted in the United States on Native American children and youth with disabilities (Fuentes & Lent, 2019) through in-depth interviews found that this population experienced intersectional discrimination (as with other studies mentioned). It also highlights the importance of cultural identity, which shapes their experiences and contributed to positive self-image and a sense of belonging, despite the multiple barriers they face. Overall, this study reflects previous findings, that the inclusion of culture is an important and necessary inclusion for healthcare and rehabilitation interventions.

Whānau Hauā

Further research conducted within Aotearoa New Zealand (Hickey & Wilson, 2017; Donald Beasley Institute, 2022a) critically examines the experiences of tāngata whaikaha Māori and current approaches to working with them, and introduces Whānau Hauā as an Indigenous approach to disability.

Whānau Hauā is informed by te ao Māori and is placed within historical and contemporary contexts. It is similar to the Western social model of disability in acknowledging that the barriers faced by a disabled person are a societal issue and do not originate from the person. What makes it distinct is that it has the added cultural dimension of whānau working collectively to uphold their responsibilities to each other (Hickey & Wilson, 2017; Donald Beasley Institute, 2022a). Much like other models within Aotearoa New Zealand, such as the Te Whare Tapa Whā model introduced by Sir Mason Durie, it has a wider view of contributing factors and how this influences wellbeing. Whānau Hauā can provide a range of tools with which caregivers can frame their participation in the wellbeing outcomes of those in their care.

Discussion



Summary

Tamariki whaikaha in out-of-home care are one of the most vulnerable and disadvantaged groups of tamariki in Aotearoa. In response to missing information and disparate evidence on the health care needs of tamariki whaikaha in care, Oranga Tamariki commissioned this evidence brief to identify the gaps, challenges, and opportunities to improve their care.

This section provides an overview of the evidence answering the research questions. The first of these questions was aimed at identifying the primary healthcare needs of children and young people with disabilities in different age groups compared to children and young people who do not have disabilities. A further related question required examining the evidence on the primary care needs into health literacy, equity of access to, and engagement with, primary healthcare services.

The second question aimed at drawing out the strengths, opportunities, gaps, and barriers to meeting these needs of children and young people in care, including areas for attention to reduce any disparities between non-Māori and Māori. In answer to the first question, as canvassed earlier in this evidence brief, it was not possible to examine the specific age groups in question or accurately assess the primary health care needs of tamariki whaikaha due to lack of relevant data and research.

Critical gaps

We understand that Oranga Tamariki currently does not have an easy way of identifying disability for children in care and, therefore, has limited visibility over the extent to which children and young people in care are living with impairments. This lack of data is the first critical gap. A further gap is evident in that Oranga Tamariki does not have information on the level of engagement of in-care tamariki and rangatahi in primary care services.

The second critical gap is the lack of research. We were unable to find any articles or reports specifically focused on the primary health care needs of tamariki whaikaha in care. This has meant we have had to fill the evidence gap by drawing on the broader, but intersecting, bodies of literature on primary health care of children, children with disabilities, and children in care or youth justice, and, occasionally, literature on adults with disabilities.

There is some information on the numbers of tamariki whaikaha in Aotearoa New Zealand, suggesting they comprise about 10-11% of young people in the general population, with numbers higher for Māori. We know that almost half of these tamariki whaikaha have multiple impairments.

However, the proportion of tamariki whaikaha in care are much higher, with estimates ranging from 44% to 87%, depending on several factors, with 66% of these having high and very high support needs. Much of these data are old, and the recent data we have are only indicative. The evidence available has confirmed that for many children in care, disabilities remain undetected and undiagnosed. It follows from this that there will be unmet needs.

Need for primary care registration, assessment, early intervention, and regular review

The evidence suggests that tamariki whaikaha in care first need to be registered with an accessible GP. There is also an urgent need for monitoring their engagement with primary care services. Children under care and protection should also undergo initial primary care assessment and screening specifically for disabilities. This is critical because a significant proportion of this group come into care in an unplanned manner, can be undiagnosed, have disabilities that have not been well managed, or have suffered from lack of continuity in care. Additionally, caregivers and foster carers often lack accessible historical health records.

The very high proportion of children in the youth justice sector with disabilities also suggests a high level of unmet need. This is likely contributing to poor outcomes and criminalisation in the justice sector. The justice sector should refer youth to primary care assessment and screening as soon as they enter the justice system and before sentencing.

Assessment and initial screening should be comprehensive, ideally multidisciplinary, occurring in a setting that provides the infrastructure for support and management, and provide planning and follow-up. The evidence also recommends regular review of diagnoses and plans.

Primary health care needs and barriers

We know from the evidence on health outcomes, that young people with disabilities and young people in care and protection will have much worse health outcomes without further intervention. Many of those entering care and protection are not registered with a GP (47%) and may not be having regular check-ups. Avoidable hospitalisations are high amongst those who have been in care and there is plenty of evidence of high levels of unmet need in primary health care to warrant intervention.

From the evidence we have, it is clear that disabled children can experience multiple barriers in achieving equitable access to primary healthcare. These barriers will be more acute for disabled children in state care or youth justice than for the broader population of disabled children. Also, children with disabilities often experience more than one condition, which, in turn, means they need more frequent and specialised primary health care.

Key issues they may encounter are:

- **Cost:** Some families face financial barriers to accessing primary health care for their disabled children. Financial barriers are not limited to the cost of visits and transport to get the doctor, but include time of work to visit primary care, loss of employment due to caregiving, and the cost of specialised care and disability supports. These are more pronounced for Māori.
- **Communication barriers:** Children with disabilities may experience difficulties in communicating their health concerns and healthcare providers may not be trained to communicate effectively with them. This can result in miscommunication and a lack of appropriate care. Additionally, although not a

focus of this review, is the added matter of consent, which can be difficult to obtain and can only exacerbate the problem around communication.

- Limited resources at the primary care level: Primary health care facilities may have limited resources, including specialised equipment and trained staff, to provide appropriate care for children with disabilities. The cost to the treating physicians of undertaking disability assessments will be high. Limited resources also result in very long wait times, where health conditions can worsen and even result in death.
- Stigma and discrimination: Children with disabilities may face stigma and discrimination from healthcare providers or other patients, which can make them feel unwelcome or uncomfortable in healthcare settings.
- Some primary care professionals may lack sufficient health literacy on disabilities and current understandings and views. Equally, foster parents may lack understanding of disability need or what help and support are available.

Although not often discussed in the evidence, physical accessibility will likely be another barrier for some tamariki whaikaha. Disability-specific access, for example transport to and from appointments (if not accessible), is an issue for some, so additional support can be required for taxi fares. Another issue is that healthcare treatment for some tamariki whaikaha also require different medical services or treatments, for example, some disabled youth might need to go under anaesthesia for dental work.

Addressing these issues requires a comprehensive approach that involves training healthcare providers to provide inclusive care, improving physical accessibility, and addressing financial and other barriers to care. It is also important to involve children with disabilities and their families in the design and delivery of healthcare services to ensure that their needs are adequately met.

Need for Transition to adulthood strategies

The research found gaps and challenges faced by rangatahi with neurodevelopmental disorders as they transition from paediatric to adult health care services in both Aotearoa New Zealand and the United States. It suggests that there is a lack of professional support and referral systems for adult services, inadequate communication between paediatric and adult services, limited resourcing, and a feeling of fear and apprehension of a new healthcare system.

Additionally, the research highlights a need for comprehensive and holistic planning during the transition to adulthood for all tamariki and rangatahi whaikaha, with a focus not only on health care, but also wider life issues. A key component of this planning requires a medical summary to be developed by the primary health care practitioner with the best knowledge of the individual. - The research also identifies the risks faced by rangatahi whaikaha who age out of care include experiencing housing instability, unemployment, lack of access to healthcare, less access to education, and increased risk of experiencing mental health challenges and substance abuse.

Inclusion of disabled voices in policy and decision-making

A key theme identified in the research was the need for policies and strategies to be developed in collaboration with tamariki and rangatahi whaikaha. It is important to include the voices and experiences of disabled people in policies and strategies that affect them. Literature and research from Aotearoa New Zealand emphasises that involving affected communities in decision-making processes can help identify potential blind spots and barriers that prevent access to necessary services and support.

Inclusive processes that prioritise the perspectives of disabled people, and making sure they are valued and heard, are not just empowering, but lead to better services and uptake. Additionally, involving the voices and experiences of family and caregivers of disabled people can help ensure that decisions can be reached that are in the best interest of tamariki whaikaha. Inclusion of disabled people in policy-making and decision-making is crucial for promoting their rights and ensuring full participation in society.

Health literacy and communication

Health literacy is important for all groups, not just those with disabilities. Health literacy is important for professionals, social workers, GPs, nurses, and social workers and youth justice workers, as well as family, caregivers, foster parents, and others who work with tamariki whaikaha in care and in the justice sectors. It is also important at the institutional level, that there are sufficient resources and infrastructure to support the consideration of the interest and needs of young people with disabilities, and systems for support and assistance.

Need for indigenous approaches

Research from both Aotearoa New Zealand and abroad underscores the importance of acknowledging cultural perspectives around health and wellbeing. It emphasises that the concept of disability needs to be decolonised. The literature addresses the conflict between Western and Indigenous thinking of disability, with an emphasis on the importance of cultural context and a more inclusive approach to understanding and supporting tamariki and rangatahi whaikaha.

The systematic neglect of culture in health creates a great barrier to being able to obtain a high standard of health, as well as creating a feeling of disconnection from community.

Whānau Hauā is an Indigenous approach informed by the principles of te ao Māori, which includes the whānau working collectively to uphold their responsibilities to each other.

Limitations

Research for this evidence brief found an absolute gap, with no literature focusing on the primary health care needs of children with disabilities who were also in care. Therefore, the scope was broadened to look at the primary health care needs of

children, needs of children with disabilities, and the needs of children in care. With this, there is somewhat of an underlying assumption that many of the primary health care needs of children with disabilities would be similar to the needs of these other groups of children, although exacerbated for those with disabilities.

Other limitations were inherent in the initial structure of this review, which excluded abuse in care, which is more common for tamariki whaikaha, and the exclusion of mental health conditions. This is an important limitation, given that children with disabilities and children in care often have multiple conditions and impairments prior to entering care and may be exacerbated by being in care. A further limitation is that only evidence in the public domain was reviewed.

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