



The Impact of Policies and Legislation on the Structure and Delivery of Support Services for Children With Cerebral Palsy and Their Families in Aotearoa New Zealand: A Professional Perspective

Meg Smith, MHMgt(Hons), RN¹ ^a, Julie Blamires, DHSc, RN¹ , Mandie Foster, PhD, RN¹ 

¹ Nursing, Auckland University of Technology, New Zealand

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Nursing Praxis in Aotearoa New Zealand

The Aotearoa New Zealand health system in Aotearoa New Zealand currently provides disability support services to children living with cerebral palsy and their families built on key policy and legislation which has created two distinct disability support pathways. One pathway is provided through the Accident Compensation Corporation and the other through Te Whatu Ora (Health New Zealand) districts. There is consensus that these pathways result in significant inequities in terms of support service delivery. Māori and Pacific People are particularly impacted by this inequity. In the absence of literature that critically analyses this situation, the purpose of this paper is to examine, understand and critique how disability support services are structured and delivered to children living with cerebral palsy and their families in Aotearoa New Zealand. Two clinical vignettes illustrate the challenges and inequities faced by families and demonstrates how the two separate pathways impact service delivery, opportunities to thrive and health outcomes. This paper will highlight that there is a need for a review of the current system which is timely considering the recent establishment of Te Whatu Ora - Health New Zealand, Te Aka Whai Ora - Māori Health Authority, and Whaikaha - the Ministry for Disabled Peoples.

TE REO MĀORI TRANSLATION

Te pānga o ngā kaupapa here me ngā ture ki te hanganga me te horanga o ngā ratonga tautoko mō ngā tamariki kua pāngia e te mate whakatīmohea, me ō rātou whānau i Aotearoa: He tirohanga ngaio

Ngā Ariā Matua

Ko tā te pūnaha Hauora o Aotearoa o tēnei wā he hora ratonga tautoko ki ngā tamariki kua pāngia e te mate whakatīmohea me ō rātou whānau. E rua ngā ara tautoko hauātanga motuhake kua waihangatia, i roto i ngā whakatau kaupapa here me ngā ture matua. Ko tētahi ara he mea whāngai ki te pūtea, he mea hora hoki mā roto i te Kāporeihana Āwhina Hunga Whara, he Whakahaere Karauna; ko tētahi ka horaina mā ngā rohe o Te Whatu Ora (Health New Zealand). Ko te whakaaro o te nuinga, nā ēnei ara e rua he maha ngā korenga e ōrite o ngā horanga ratonga tautoko. Ko ngāi Māori me Ngā Iwi o Te Moana-nui-a-Kiwa te hunga ka tino pāngia e ēnei korenga e ōrite. Mā ētahi pūrākau poto taurima tūroro e rua, kotahi pūrākau mō tētahi, mō tētahi, e whakaahua ngā rerekētanga o te wātea me te horanga i ngā ratonga hauora, tautoko hoki. E anga ana tēnei pepa ki te whakaahua he pēhea te waihanga o ngā ratonga tautoko hauātanga ki ngā tamariki kua pāngia e te mate whakatīmohea me ō rātou whānau i Aotearoa, me te whakakite i ngā taumahatanga me ngā korenga e ōrite kei mua i ngā whānau, e pēhi nei i ō rātou whāinga wāhi kia puāwai, me ō rātou pūtanga hauora. E akiaki ana tēnei pepa kia whakahoutia wawetia te pūnaha o nāianei, ā, he mea tika mō tēnei wā, i muri i te whakatūrangā i tēnei tau o Te Whatu Ora, o Te Aka Whai Ora (Māori Health Authority) me Whaikaha (Ministry of Disabled People).

Ngā kupu matua: te mate whakatīmohea, tamariki, ngā whānau, ture, kaupapa here

INTRODUCTION

In January 2022, the parents of a 10-year-old boy Ben Dickson, finally won their case to receive injury related Accident Compensation Corporation (ACC) cover following a difficult birth (Bradley, 2022). The ACC is a Crown entity set up to provide no-fault personal injury cover for Aotearoa New Zealand residents and visitors. This includes support for medical treatment, rehabilitation, loss of income and other ongoing costs following injury. Ben suffered from a lack of oxygen during a difficult birth but was not diagnosed with cerebral palsy until he turned six years old. The case rested on establishing that the cerebral palsy was caused by accident or injury, which could or should have been anticipated by the healthcare team and therefore, was preventable (Bradley, 2022).

The scenario highlighted the inequities of the two-tiered health system available for people living with cerebral palsy. Those who receive funding for healthcare and rehabilitation through the ACC system are significantly advantaged over those whose disability is caused congenitally or through illness, and so does not fit the definition of injury to qualify for ACC cover. A report to the ACC Minister in 2021 highlighted how people left disabled through injury were treated far better through ACC than those people born with a disability or acquired a disability through illness (Bradley, 2021).

Cerebral palsy is a complex neurodevelopmental disorder and the leading cause of neurological impairment and physical disability in children globally (Davis et al., 2010; Rosenbaum et al., 2007). The underlying pathophysiology is an injury to the developing brain that occurs in either the prenatal or neonatal period. This results in a range of motor disorders including impairments such as weakness, spasticity, and poor co-ordination, and can include several non-physical challenges such as epilepsy, sensory and perceptual disorders, learning, social, communication, and behavioural difficulties (Amatya & Khan, 2011; Rosenbaum et al., 2007). Any of these symptoms can impact on the quality of life and activities of daily living for the child and family.

Internationally, it is estimated that approximately two children for every 1,000 babies born will develop cerebral palsy and around 8,000-10,000 infants globally will be diagnosed each year (Oskoui et al., 2013). In Aotearoa New Zealand, this would equate to around 2,490 children aged 19 years and under living with cerebral palsy, with an estimated 120 new cases being diagnosed each year (Mackey et al., 2022; A. Sorhage, personal communication, August 27, 2021). Data on people living with cerebral palsy in Aotearoa New Zealand is limited. In 2015, the New Zealand Cerebral Palsy Register was launched to collect information on people living with cerebral palsy to inform care pathways for prevention, diagnosis, management and support. The Register captures approximately 55% of the paediatric population living with cerebral palsy and 26% of Māori children living with cerebral palsy (Mackey et al., 2022).

It is estimated that approximately 1,500 Māori are living with cerebral palsy of which around 400 are 19 years of age or under (A. Sorhage, personal communication, August 27, 2021). Māori children living with cerebral palsy have a

greater level of disability, are more likely to live in poverty, and more likely to be admitted to hospital with a respiratory illness than their non-Māori counterparts (Sorhage et al., 2022). This adds further layers of inequity to these children and their whānau (families) as well as the additional stress when faced with cultural barriers, financial constraints, potentially lower levels of education, and the stigma of having a child with a disability (Smith & Blamires, 2022).

In Aotearoa New Zealand, children who are diagnosed with cerebral palsy and their families are provided disability support services through two distinct pathways. One pathway stems from the application of the ACC legislation; and the other pathway from Disability Support Services where care is delivered by Te Whatu Ora districts (previously district health boards) (Whaikaha Ministry of Disabled People, 2022b). These pathways dictate how treatment and interventions are structured and delivered to children living with cerebral palsy and subsequently result in significant variation in service delivery based on post code and pathway allocation (Ministry of Health, 2017b; Whaikaha Ministry of Disabled People, 2022a). Māori, and Pacific, whānau face additional challenges and barriers to comprehensive care based on the limited culturally specific services within these two pathways (Ratima & Ratima, 2007). Learning to understand how to navigate these two complex systems creates additional anxiety and stress for whānau who are already living a complex life (Smith & Blamires, 2022). Service gaps and inequity are evident in the current model of service delivery, and it is timely to highlight these, given the recent establishment of Te Whatu Ora, Te Aka Whai Ora, and Whaikaha - Ministry for Disabled People in July 2022.

Given there is limited literature available, this paper seeks to describe how the disability support services are structured and delivered to children living with cerebral palsy and their families in Aotearoa New Zealand through policy and legislation. Two clinical vignettes are used to illustrate the challenges and inequities faced by families and how the two separate pathways impact service delivery and the child's health outcomes and opportunity to thrive. This paper argues for an urgent revision of the current system and is timely given the 2022 health reforms and recent establishment of Te Whatu Ora (Health New Zealand) (Future of Health, 2022b), Te Aka Whai Ora (Māori Health Authority) (Future of Health, 2022a) and Whaikaha - Ministry of Disabled People (2022a).

LITERATURE REVIEW

The search strategy intended to identify key documents and legislation relating to disability support services for children (16 years and under) and their families living with cerebral palsy in Aotearoa New Zealand. The sources searched included key governmental and service provider websites: Ministry of Health, Ministry of Justice, Office for Disability Issues, Parliamentary Counsel Offices, Accident Compensation Corporation, Office of the Auditor General, Taikura Trust, ABI Rehabilitation, Ohomairangi Trust, Starship Child Health, Southern Health, Counties Manukau

Health, and Waitematā Health. Legislation relating to disability support services within the education system were excluded.

Children with cerebral palsy and their families, are able to access taxpayer funded, free disability related healthcare services (New Zealand Government, n.d.). The system is grounded on seven key documents (Table 1) and five significant legislative acts (Table 2). Together these provide a framework which underpin the expectations, policy, responsibilities, strategies and plans for how the health system should operate and deliver healthcare services to children living with cerebral palsy. Included in these key documents is the *New Zealand Disability Strategy* (Office for Disability Issues, 2016), developed from the *United Nations Convention on the Rights of Persons with Disabilities* (United Nations, 2022); the *United Nations Convention on the Rights of the Child*, ratified in Aotearoa New Zealand (Ministry of Justice, 2020a); and Aotearoa New Zealand's founding human rights and governance document, *Te Tiriti o Waitangi* (Ministry of Justice, 2020b). The New Zealand Disability Strategy spans 10 years from 2016 to 2026 and states the vision that, "New Zealand is a non-disabling society – a place where disabled people have an equal opportunity to achieve their goals and aspirations, and all of New Zealand works together to make this happen" (Office for Disability Issues, 2016, p. 6). The Strategy is predicated on eight key outcomes that focus on: education; employment and money; health and wellbeing; accessibility; people with disabilities as leaders; people with disabilities having choices and control over their own lives; protecting the rights of people with disabilities; and attitudes towards disability (Office for Disability Issues, 2019).

In order to actualise the goals set out in the Disability Strategy, action plans were developed including the *New Zealand Disability Action Plan 2019-2023* (Office for Disability Issues, 2019); *Whāia Te Ao Mārama: The Māori Disability Action Plan 2017-2022* (MoH, 2018b); and *Faiva Ora: National Pasifika Disability Plan 2016-2021* (MoH, 2017a). The details of these key documents are outlined in Table 1. The New Zealand Disability Action Plan is presented as 25 work programmes delivered by 14 government agencies, which simultaneously work to achieve the strategy outcomes and aim to bring programmes together under one umbrella in a co-ordinated manner (Office for Disability Issues, 2019). *Whāia Te Ao Mārama* (MoH, 2018b) is based on the principles of Te Tiriti o Waitangi and reflects Aotearoa New Zealand's obligations to the *United Nations Convention on the Rights of the Child* (United Nations, 2022). This plan describes the pathway for supporting Māori with disabilities (tāngata whaikaha) and their whānau (MoH, 2018b). In addition, *Faiva Ora* was developed to help address the under representation of people with disabilities that identify as Pacifica (MoH, 2017a).

Key legislative acts

Along with the key documents shown in Table 1, there are five legislative acts that provide the legal framework for Aotearoa New Zealand's health and disability system and have a significant role to play in how children and

young people with cerebral palsy and their families experience health care. The key features of these are outlined in Table 2. Both the *Health and Disability Commissioner Act 1994* and the *New Zealand Public Health & Disability Act 2000* (repealed in 2022) provided a framework for how the health system was organised and services delivered. The Public Health & Disability Act essentially enacted legislation to establish district health boards (DHBs) with the responsibility to promote the health and wellbeing of people within a defined geographic location by providing or purchasing health and disability services. This Act has since been repealed and DHBs abolished after the enactment of the Pae Ora (Health Futures) Act 2022 as part of the new health reforms. The ACC Amendment Act 2010 is significant as it guides the law about preventing injuries and the rehabilitation and entitlements of injured people (Employment, 2022). The Act provides a framework for ACC to work within to ensure it provides comprehensive, no-fault personal injury cover for all New Zealanders (Employment, 2022). The Social Security Act 2018 makes financial provisions by way of disability allowance payments to carers of children with cerebral palsy, and the Children's Act 2014 works to protect vulnerable children, theoretically adding another layer of protection for children with cerebral palsy (Oranga Tamariki, 2022).

CURRENT SERVICES

Services for children in Aotearoa New Zealand with cerebral palsy are delivered by two Ministry of Health funded distinct disability support pathways (MoH, 2017b; Whaikaha Ministry of Disabled People, 2022a). Children may be eligible for a variety of support services within the primary, secondary and tertiary healthcare setting depending on the specifics of their diagnoses, where they live and which pathway they are allocated to (MoH, 2017b; Whaikaha Ministry of Disabled People, 2022a). Each pathway has different inclusion criteria depending on the aetiology of the child's brain injury. The two clinical vignettes presented in this paper will illustrate hypothetical examples of how children and families experience the two disability pathways (Table 3 and 4). The vignettes were developed with the advice of Dr Pauline Penney, ABI Rehabilitation operations manager and Dr Nichola Wilson, a paediatric consultant, at Starship Child Health. They do not represent actual patients and are intended to illustrate the complexity, inequity, and gaps in service delivery for those living with cerebral palsy.

The Accident Compensation Corporation pathway

If the child's injury and resulting disability is related to an accident, trauma, or treatment (including medical misadventure), they are likely to be accepted by ACC under the ACC Amendment Act 2010 (ACC, 2017). The ACC scheme provides no-fault personal injury cover for residents and visitors which includes support for medical treatment, rehabilitation, loss of income and other ongoing costs as represented in Alex's case study (Table 3). It is funded by the

Table 1. Summary of relevant documents

Summary of key characteristics of relevant documents	
The United Nations Convention Rights of the Persons with Disabilities (United Nations, 2022) (UNCRPD)	<ul style="list-style-type: none"> Lays out the expectations of what countries need to do to ensure people living with disabilities have the same rights as everybody else. Promote, protect, and ensure people living with disabilities have the following: <ul style="list-style-type: none"> Enjoyment of all human rights and fundamental freedoms. Respect for their inherent dignity. Equal opportunities and access. Children living with a disability are respected. Duty of care to ensure they are not discriminated against.
The United Nations Convention Rights of the Child (Ministry of Justice, 2020a).	<ul style="list-style-type: none"> All children are equal and have the same rights. Every child has the right to have his or her basic needs fulfilled. Every child has the right to protection from abuse and exploitation. Every child has the right to express his or her opinion and to be respected.
Te Tiriti o Waitangi (The Treaty of Waitangi) (Ministry of Justice, 2020b).	<ul style="list-style-type: none"> Significant founding human rights document signed in 1840 between the British Crown and Māori. Intention to establish governance by the Crown and to protect Māori rights, sovereignty & land. Difference in the meaning of the English and Māori versions of Te Tiriti o Waitangi have had significant negative impacts on all aspects of Māori life, health, and wellbeing. As with many aspects of society, Te Tiriti o Waitangi also guides decision making for how disability services should be delivered within this unique cultural context.
New Zealand Disability Strategy 2016-2026 (Office for Disability Issues, 2016) (NZDS)	<ul style="list-style-type: none"> High-level picture of how the NZ government will do what it has committed to at the UN Convention on the Rights of Persons with Disabilities. Underpinned on eight key outcomes: education, jobs & money, health & wellbeing, accessibility, disabled people as leaders, disabled people having choices & control over their own lives, protecting the rights of disabled people, attitudes towards disability.
The New Zealand Disability Action Plan (Office for Disability Issues, 2019).	<ul style="list-style-type: none"> Action plan for the NZDS presented as 25 work programmes that simultaneously work to achieve the Strategy's outcomes. They are spread across the eight key outcomes and include: <ul style="list-style-type: none"> The Ministry of Education learning support action plan (education). The Ministry of Social Development disability employment action plan (employment). Improving accessibility across the NZ housing system
Whāia Te Ao Mārama (Māori Disability Action Plan) 2018-2022 (MoH, 2018b).	<ul style="list-style-type: none"> Based on the principles of Te Tiriti o Waitangi. Reflects NZ's obligations to the UNCRPD. Connected with other Māori outcome improvement work across Government, such as He Korowai Oranga (Māori Health Strategy), Whānau Ora and the NZDS. Provides pathway for supporting Māori with disabilities (tāngata whaikaha) and their whānau. Aims to reduce barriers and improve the health outcomes. Six goals: to participate in the development of health and disability services; to have control over their disability support; to participate in Te Ao Māori (Māori world view); to participate in their community; to receive disability support services that are responsive to Te Ao Māori; and to have informed responsive communities.
Faiva Ora: National Pasifika Disability Plan 2016-2021 (MoH, 2017a).	<ul style="list-style-type: none"> Developed to help address the under representation of disabled people that identify as Pacifica. The plan's goals are to improve health outcomes; encourage better engagement and support with Pacific communities; ensure disability services and supports meet the needs of Pacific people; and encourage key stakeholders to work in partnerships to address challenges experienced by Pacific disabled people and their families.

MoH: Ministry of Health; NZ: New Zealand; NZDS: New Zealand Disability Service; UNCRPD: United Nations Convention on the Rights of Persons with Disabilities

Government via taxes where services are purchased directly with health and disability providers (New Zealand Government, n.d.). Of the 1,380 children included on the New Zealand Cerebral Palsy Register (Mackey et al., 2022), only 8 % (or 110) are funded by ACC (A. Sorhage, personal communication, August 27, 2021). Children under this pathway are provided with lifelong care, support and therapy based on their individual needs.

The Disability Support Services pathway

If the child's brain injury and resulting disability was related to an unexplained cerebral event such as a stroke or infection, such as meningitis, and they do not meet the ACC criteria, they will follow the Disability Support Services pathway as represented in Charlie's case study (Table 4) (MoH 2018a). The Disability Support Service pathway was developed and funded through the Ministry of Health informed by the Disability Strategy and Action Plan (Office for Disability Issues, 2016, 2019). It provides whatever support and treatment is available within a public system that

Table 2. Summary of five legislative acts

Summary of key characteristics of 5 relevant legislation	
The Health and Disability Commissioner Act 1994.	<p>This Act mandated the Health and Disability Commissioner (HDC) to promote and protect the rights of health consumers and disability consumers.</p> <p>The Act is established to ensure:</p> <ul style="list-style-type: none"> • secure the fair & efficient resolution of complaints relating to infringements of rights. • have a HDC to investigate complaints against providers. • a Health and Disability Services Consumer Advocacy Service. • provide for the promulgation of a Code of Health and Disability Services Consumers' Rights.
New Zealand Public Health and Disability Act 2000.*	<p>The Act:</p> <ul style="list-style-type: none"> • Established the structure for public sector funding and the organisation of health and disability services, including DHBs and other Crown entities. • Mandated the NZ Health Strategy and NZ Disability Strategy. <p>Two key positions for the disability sector are described within this Act:</p> <ol style="list-style-type: none"> 1. The Minister of Health: overall responsibility for setting strategic direction for HDS and MoH; establishing and reporting on health strategies. 2. Minister for Disability Issues: establish and report on the NZ Disability Strategy, and to advocate for disability issues and their specific duties are laid out in this Act.
The Social Security Act, 2018.	<p>The main purpose of this act is to provide financial and other support as appropriate.</p> <p>Of significant is two financial provisions it allows for:</p> <ol style="list-style-type: none"> 1. Child Disability Allowance (CDA) - issued Irrespective of the level of disability or financial status of the family and is available through the MSD to the main carer of a child under 18 years. It's a fortnightly payment of approximately \$100 and paid in recognition of extra care needed. 2. Disability allowance - has the same qualifying criteria as CDA except that it is means tested. A person may be eligible to receive both allowances.
The Children's Act 2014.	<p>This act was designed to:</p> <ul style="list-style-type: none"> • Protect and improve the lives of vulnerable children • Ensure the Police, Ministries of Health, Education, Justice, Social Development, and children work together and be held accountable for protecting and improving the lives of vulnerable children
The Accident Compensation Corporation Amendment Act 2010.	<p>This legislation guides the law with regards to:</p> <ul style="list-style-type: none"> • Preventing injuries. • Rehabilitation and entitlements of injured people. • The Act provides a framework for the ACC to work within to ensure that it provides comprehensive, no-fault personal injury cover for all New Zealanders.

*Note that the New Zealand Public Health and Disability Act 2000 was repealed in July 2022 and replaced by the Pae Ora (Healthy Futures) Act 2022.

ACC: Accident Compensation Corporation; CDA: Child Disability Allowance; HDC: Health and Disability Commissioner; HDS: Health Disability Service; MSD: Ministry Social Development; NZ: New Zealand

is variable and complex. Children on this pathway are likely to be more impacted by their parents' ability to understand and navigate the system (Williams et al., 2021). There are 1,270 children (19 years and under) registered on the New Zealand Cerebral Palsy Register who are not funded by ACC; however, the Register estimates that there are likely to be up to double this number (A. Sorhage, personal communication, August 27, 2021).

DISCUSSION

Aotearoa New Zealand's disability system is complex with a range of legislative, policy and strategic documentation in place directing how disability services are shaped and delivered (New Zealand Cerebral Palsy, n.d.; Whaikaha Ministry of Disabled People, 2022a). However, the way these various documents have been translated into practice has led to a wide range of inequities in care delivery to children and families living with cerebral palsy, as explored in the two clinical vignettes. The current system allows for children with the same level of cerebral palsy related disability, albeit caused by different events, a different path-

way of care. A child on the ACC pathway can access one stop case managed wrap around care (Table 3), while a child with cerebral palsy on the Disability Support Services pathway, may experience difficulty in navigating a more complex and less well-resourced system (Table 4). These children are less likely to receive the care and treatment they need and are even more reliant on their parents' ability to understand the system, ask the right questions, have money to spare (Williams et al., 2021; Wynd, 2015), as was highlighted in Ben Dickson's case (Bradley, 2022).

Additionally, the present system does not provide adequate and appropriate culturally relevant care to children of Māori, and Pacific People. One of the key issues influencing this is how Te Tiriti o Waitangi and Maori cultural values were acknowledged only after the ACC and Disability Support System were designed. This has inadvertently caused more health inequity for Māori (Craig et al., 2011; Waitangi Tribunal, 2019). Māori experience disparities in outcomes compared to non-Māori across all areas of health, including access to disability services (Bowden et al., 2015; Reid et al., 2017). Socio-economic deprivation together with poorer health literacy result in those whānau Māori living with dis-

Table 3. Clinical Vignette - Alex's Case Study

Alex suffered a hypoxic brain injury following a treatment injury (or accident) during a complicated labour. They were therefore accepted under the ACC pathway and referred to ABI Rehabilitation (an ACC contracted service provider). Following the ACC pathway means that Alex will be allocated a case manager who can provide a coordinated, holistic wrap around service that starts with a support needs assessment.

Support services provided

Alex and their family are assigned a support coordinator who considers all the needs of Alex and their family including carer support, home help, relief care, and teacher aide support for school (when the time arises). Alex may be referred for other assessments or therapies as required. In addition, the support needs assessment will support Alex and their parents to understand and navigate the health care system to ensure that Alex receives the best care. They will have access to a multi-disciplinary team (including an occupational therapist, physiotherapist, neurophysiologist, and rehabilitation nurse) based on their needs as well as any equipment requirements such as a walker, a chair, or toilet seat. ACC will provide transport to attend appointments. A care plan with specific goals will be developed by the support needs assessment in collaboration with the family that could include weekly visits to provide the prescribed therapy. Alex and their family will also be supported to access services outside those provided by ABI Rehabilitation. These include services on the Disability Support Services pathway such as disability related surgery at Starship Children's Hospital which is paid directly by ACC (MoH, 2017b). Alex can stay on the ACC pathway for life which could include long term case management and therapy. Alex will also be able to access financial support for loss of income on reaching adulthood.

Challenges and barriers

Despite the ACC pathway being considered 'the gold standard of care' following this pathway will not make Alex immune from fragmented service delivery. It is likely Alex, and their family may experience a lack of co-ordination leading to multiple hospitals visits and/or challenges with communication between multiple health service providers. No system is perfect or comes without a financial cost. It is estimated that one person on the ACC pathway over their lifetime may cost up to \$40 million. It is not surprising therefore that ACC has such a rigorous process for accepting cases, especially given that the etiology of brain trauma is not always clear, and the costs involved with a lifelong condition such as cerebral palsy are high. This process can take many years to resolve which can have a significant additional impact on the health and well-being of parents (Smith & Blamires, 2022).

ability (whānau hauā) experiencing additional challenges to their Pākehā counterparts (Neuwelt-Kearns et al., 2020; Waitangi Tribunal, 2019). Newelt-Kearns et al. describe how the system:

"[P]rivileges those who have networks, disposable time and resources, and navigational knowledge of Pākehā systems. Given that Māori and Pacific peoples are disproportionately represented among those with disability, the status quo of an underfunded disability support system is worsening gross inequities in health and economic outcomes" (p. 5).

Te Tiriti o Waitangi is the founding governance and human rights document for Aotearoa New Zealand providing guidance on how legislation, policy, and service delivery are structured (Ministry of Justice, 2020b). However, despite there being documents that identify the health and disability needs for Māori, such as the Māori Health Strategy (2014) and the Māori Disability Action Plan (2018-2022), such needs are not being met (Waitangi Tribunal, 2019). The Māori Disability Action plan 2018-2022 (MoH, 2018b) states that all organisations must have capability and ca-

capacity to provide services responsive to Māori cultural needs, yet the barriers faced by Māori tamariki (children) and whānau accessing disability services remain in place. Boshier et al. (2020) state: "Tāngata whaikaha [disabled Māori] are further marginalised, faring worse than their non-disabled Māori peers, with lower labour force participation and lower rates of educational achievement" (p. 13). There is a long way to go before the principles of Te Tiriti o Waitangi are fully acknowledged, honoured, and enacted, ensuring that strategies and action plans are culturally responsive and safe and effectively operationalised in practice that promotes equity for Māori.

The new Te Aka Whai Ora has been established to work in partnership with Te Whatu Ora and provides great promise for the future. It is positioned to lead a "for Māori by Māori" model which has potential for improving health outcomes and inequities for Māori and is the most significant advancement in the history of the New Zealand Health and Disability system (Future of Health, 2022a). Te Aka Whai Ora provides a platform for Māori to enhance rangatiratanga (self-determination) by leading change. It will take time to know if and how the impact of these struc-

Table 4. Clinical Vignette: Charlie's Case Study

Charlie is delivered at term after an uncomplicated labour. At one week of age, they suffer an unexplained stroke which results in being clinically assessed with the same level of disability as Alex. Charlie's brain injury wasn't the result of an injury or accident; therefore, they are not eligible for ACC. Charlie is referred internally to the district's Child Development Service (Whaikaha Ministry of Disabled People, 2022a). This community-based service consists of a team of multi-disciplinary allied health professionals, however models of care delivery and age criteria for services vary by Te Whatu Ora district (replacing district health boards).

Support services provided

As with the ACC pathway, Charlie is assessed, and their needs are identified. Charlie will be seen by a Child Development Service until they turn five years of age. Charlie's care is then transferred to the Ministry of Education (2022) for education and continues with the local district's disability support. Charlie is likely to receive therapy support as indicated in 6-week blocks of care that equates to three appointments: one to teach the parent how to help their child achieve their self-made goal; the next to assess the parents' ability and ensure they are on track; and the third to assess whether the goal has been met and to close the care episode. This, like the ACC pathway, relies on parents doing daily therapy with their child. If Charlie were to require surgical intervention (e.g., Botox) or have a medical episode related to their disability the Child Development Service can provide support. In addition, equipment and home modifications can be provided (such as frames, wheelchairs, assistive speech devices, and so on), and specialist input is available. However, this care is often delivered in a fragmented uncoordinated way (Whaikaha Ministry of Disabled People, 2022a). No financial support for loss of learnings or assistance with transport to and from appointments is available, and there is reduced access to a multi-disciplinary team, including, for example, counselling.

Challenges and barriers

One of the challenges and barriers related to this pathway is the large variation in the models of care delivery dependent on the district's capacity. Charlie is fortunate to live in Auckland where they have access to a paediatric rehabilitation team. Children living outside Auckland and under different districts will experience variation to this process depending on how their local district has chosen to structure its services. There is free access to a needs assessment and service coordination provider, who are a not-for-profit organisation funded by the Ministry of Health. In Auckland, the main provider is Taikura Trust who support people (65 years and under) who are living with disabilities (and their families) (Taikura Trust, n.d.). Taikura Trust would assess how Charlie's disability affects them and their family so that their needs can be matched to available support services. However, these supports are limited, generic and mainly comprise of support for the main caregiver (respite support) or allocated capped individual funding (Taikura Trust, n.d.). In response to COVID-19 this support has become more flexible and can now be used to purchase items that allow the main caregiver to have time out while at home with their child, such as games and trampolines. There are further variations for people living in Christchurch, the Waikato region, or Palmerston North where there is access to an alternative need assessment support coordination option called Enabling Good Lives. Enabling Good Lives (2022) focuses on enabling people living with a disability to do everyday things in everyday places within the community as opposed to being in special places for people with disabilities. This model allows an individualised approach to planning and funding which promotes wellbeing, participation, and inclusion by supporting people with disabilities to live their life as best they can.

tural changes are felt by Māori tamariki living with cerebral palsy and their whānau. Together with the establishment of the Whaikaha - Ministry for Disabled Peoples in 2022, there is renewed hope that these inequities will be illuminated and addressed. However, there is currently a lack of both research and information on ethnic disparities in this area (Mackey et al., 2022).

Although the ACC pathway claims to manage cases in an evidence-based way and have sought the views of its claimants and providers to find out what works well, there has been some critique that they could use this evidence and feedback better to manage cases and integrate it into

its systems (Bradley, 2021; Provost, 2014). In addition, Provost's report highlighted how ACC needed to review the adequacy and appropriateness of their case management services for long-term clients with complex needs who do not meet the serious injury criteria. The Health and Disability System Review (2020) report describes a complex and unnecessarily fragmented system where significant duplication of activity and variation creates a post code lottery when it comes to accessing services. Where you live should not determine what access you have to health services (Future of Health, 2022b). Although the ACC pathway appears to have more resources available for children and

families living with cerebral palsy, it is often difficult and time consuming to be accepted (Bradley, 2022). Neuwelt-Kearns et al. (2020) reveal the financial and social burden of families of children living with disabilities and urges the Government to provide more financial assistance and capture meaningful data so support and resource allocation can be based on evidence (Neuwelt-Kearns et al., 2020). The Government could benefit from considering an initiative such as the Australian National Disability Insurance Scheme, which aligns with the Enabling Good Lives (2022) programme that is available in some parts of Aotearoa New Zealand. Such a scheme would provide the same high level of support to all not just some and could reduce the burden on families, with the potential to improve health equity.

The Australia and New Zealand Cerebral Palsy Strategy (2020) has identified four key four key goals, including intervention and disability support to provide equitable evidence-based healthcare. Work being undertaken through the New Zealand Cerebral Palsy Clinical Network and the New Zealand Cerebral Palsy Register provides a start for understanding these inequities and the work needed to improve the lives of people living with cerebral palsy. As Aotearoa New Zealand commences the process of going through the biggest health and disability system restructuring in 20 years, there is the potential to instigate change now. With the disestablishment of the DHBs and their governing structures and a move to centralised control and funding through Te Whatu Ora and Te Aka Whai Ora, as well as the enactment of the Pae Ora (Healthy Futures) Act 2022, it would be timely to undertake further research to explore the child and family's experience of living with cerebral palsy and the transformations needed to optimise quality of life and opportunities.

This paper has identified that the New Zealand Disability Support Services lack coordination and have unexplained variations affecting children with cerebral palsy across the Te Whatu Ora districts. Those who are eligible to receive ACC funding are likely to have better health and social outcomes. This paper highlights that there is a significant anomaly in the system resulting in the unequal and unfair

distribution of resources depending on whether the etiology of cerebral palsy diagnosis has been caused through injury, accident, or by illness. Additionally, there are further inequities for Māori and Pacific, for those who are socio-economically disadvantaged, and for those with poorer health literacy. There is a lack of evidence about the lived experiences of living with cerebral palsy; accessing health-care services and information; and on culturally appropriate care delivery models. For positive changes to be made more research and data is needed and work needs to occur in a careful, coordinated, and timely manner with strategy, policy and legislative changes that can equitably respond to the needs of all children living with cerebral palsy and their whānau.

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None

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