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Mobility barriers and enablers and their implications for the wellbeing of disabled children and young people in Aotearoa New Zealand: A cross-sectional qualitative study

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ABSTRACT

Active participation in community and cultural life is a basic right of all children and young people (CYP) and is central to wellbeing. For disabled CYP, mobility can be constrained through a range of environmental and social/attitudinal barriers. The aim of this research was to understand the enablers and barriers to mobility from the perspectives of disabled CYP. Thirty-five disabled CYP aged between 12 and 25 years took part. Data were collected in Tāmaki Makaurau Auckland, Aotearoa New Zealand from mid-2016 to early 2018. Face-to-face interviews and go-along interviews were conducted and were transcribed verbatim. An iterative, thematic approach to analysis was undertaken. Mobility played an essential role in enabling wellbeing, connecting CYP to people, places and possibilities. While the possible impediments to smooth transit appeared infinite, numerous examples of overcoming barriers to mobility were evidenced across a range of factors. Dis/ableism was a pervasive barrier to mobility. The rights to access and experience the city for young people in this study were compromised by transport networks and social norms as well as values that privilege the movement of non-disabled bodies. The findings demonstrate that reducing ableist presumptions about preferences and abilities of disabled CYP, alongside ensuring practical enablers across the transport system must be key priorities for enhancing the wellbeing of this group.

Introduction

Active participation in community life is a basic right of all children and young people (CYP) and is fundamental to wellbeing (United Nations, 1989, Articles 23 & 31). Mobility (e.g., the ability to move about and engage in one's home and community (Warren et al., 2014)) is central to participation, granting access to opportunities and places of importance, enabling social connection and inclusion, and enhancing independence and freedom (Hammel et al., 2008). Yet, participation and mobility are not equally experienced by all CYP (Bedell et al., 2013; King et al., 2010) and concepts differ across disciplines and actors.

Conceptualising mobility

Underlying the concept of mobility is *movement* - of people, information, freight, transport - from one place to another. This movement has attributes and constraints and is interconnected with time, activities, purpose, experiential qualities, affordances, and assemblages (Hannam et al., 2006; Rodrigue et al., 2017). Mobility also has a politics in that it is a resource not equitably accessed or experienced (Cresswell 2010). Thus mobility exists within a large and complex ecological system involving multiple actors and layers (i.e., social and built environments, policy, and practice). Substantial and pervasive forces exist within this system that can drive what is valued (e.g., economic efficiency versus social cohesion) and lead to environmental designs and infrastructure that signal who is welcome or prioritised (e.g., car drivers

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versus pedestrians) (Perl et al., 2020). Here, we consider mobility as a complex and power-infused phenomenon; interrelated with, impacting, and dependent on an array of factors that may change over time; and requiring a multidisciplinary and ecological systems lens to be adequately understood.

Mobility and participation in disabled children and young people

For disabled CYP, mobility can be constrained through a range of environmental and social/attitudinal barriers (Bezyak et al., 2017) and evidence suggests lower levels of participation and mobility in disabled CYP compared with non-disabled peers (Murphy and Carbone, 2008; Statistics New Zealand, 2013b). Exactly what “participation” looks like can differ across disciplines and social actors (e.g., disabled individuals, researchers, health care professionals, policy-makers). Hästbacka et al. (2016) noted the lack of a clear definition of “societal participation” in their literature review focusing on working-age disabled people. They considered societal participation to encompass participation in a range of societal contexts including employment and civic life. This concept was seen to be narrower than social participation which included factors such as interpersonal interactions. Their review revealed a preponderance of research to focus on labour market participation, followed by leisure/sports participation. Societal or political participation featured to a lesser extent.

Lilja and Josephsson (2017) examined the concept of participation from the user perspective. They found participation was framed as being of the “everyday,” underpinned by socially constructed meaning drawing from external social and cultural resources. Participation was portrayed as multifaceted, dynamic, and formed by physical and social contexts. Söderström and Hemmingsson (2017, 170) also recognised participation as dynamic, an interaction between the individual and context, and comprising different types (e.g., physical, social, virtual). They viewed participation as “...involvement in life situations, which means taking part, being accepted, belonging, being included, being engaged in an area of life, or having access to needed resources.”

Here, we consider participation as a dynamic phenomenon than can be of the everyday, encompassing involvement, inclusion, engagement; comprising physical and social aspects; and recognising the interplay between participation and the broader social and physical realm. As part of this consideration, we bring an intersectional understanding of how socio-spatial structures and practices concerning both age and disability (as well as culture and gender) come together to shape the mobility experiences of disabled CYP. A substantial literature across youth studies and geographies of youth and childhood documents how CYP are informally displaced as well as formally “designed out” of public spaces (Freeman and Tranter, 2011; Hall and Kearns, 2001; Karsten, 2005; Kinoshita, 2009; Matthews, 1995; Valentine, 1996). Children and young people with perceptible disabilities affecting mobility may be especially marginalised in public spaces. In an ableist-ageist context, disabled CYP may stand out, and be subjected to staring and intrusive commentary as a consequence (Calder-Dawe et al., 2019). This combination of invisibility and hypervisibility may constitute a form of absent presence – visibility without recognition of personhood and full citizenship.

The importance of mobility and participation for disabled children and young people's wellbeing

Mobility and participation bring considerable benefits for disabled CYP, including helping develop positive identity and pathways to resilience (Porcelli et al., 2014), improving quality of life and wellbeing (Dahan-Oliel et al., 2012; Shikako-Thomas et al., 2014) increasing physical fitness (Rogers et al., 2008; Verschuren et al., 2008), and facilitating social relationships Skär and Tamm (2002). Participation can impact the feelings, emotions, and states that people might experience and is interrelated with sense of place and social practices (Lee and Potrac, 2020 in press). Ultimately these individual and external factors converge to

support wellbeing (Lee and Potrac, 2020 in press; Mitra, 2018). In the current paper, wellbeing is considered to be a multidimensional concept; being in a positive physical, mental, and social state, as opposed to the absence of disease (or impairment); and intrinsically related with the social and physical environments individuals experience.

Research context and study aim

In 2005, the Aotearoa New Zealand (NZ) Inquiry into Accessible Public Land Transport identified numerous barriers to the accessible journey – that is, one which “covers all the steps needed for a person to get from their home to their destination and return” Human Rights Commission (2005). Systemic discrimination against disabled people was observed across entire transport systems, from infrastructure to service information. A decade later, aspirations of the NZ Disability Strategy included being able to “access all places, services and information with ease and dignity” (Office for Disability Issues - Te Tari Mō Ngā Take Hauātanga, 2016). More recently, the Health and Disability System Review, charged with delivering recommendations to the NZ Government for a sustainable health and disability system that shifts from a focus on treatment of illness towards health and wellbeing, was completed (Health and Disability System Review, 2020). System-level recommendations recognised the importance of a “nondisabling approach to service design and delivery,” (Health and Disability System Review, 2020, 125) albeit this was focused on health service delivery and was not specific to transport or mobility.

NZ public transport organisations have stated aspirations of accessibility for all New Zealanders (including disabled people; e.g., see Auckland Transport (2020)); however, this does not by itself result in accessibility for all on the ground. At the time of writing, the Access Alliance (an umbrella group of NZ disability organisations with broad cross-party parliamentary support) has been lobbying for the introduction of an Accessibility for New Zealanders Bill by the end of 2021 which would ensure accessibility for disabled New Zealanders in all areas of NZ life – including transport. In July 2020 the Cabinet Social Wellbeing Committee agreed to push ahead with drafting the legislative framework for this by May 2021.

In this paper, we illuminate key barriers and enablers to mobility and theorise their significance for wellbeing in order to generate recommendations for improving the transport system. Here, we draw on the perspectives of disabled CYP in living in Tāmaki Makaurau Auckland, NZ. This is NZ's largest city (1100 km²) and home to 1.65 million people, over a third of the country's population. Approximately 90% of Auckland's population live in urban areas, which have wide ranging levels of socio-economic disparity and geographic characteristics. The city is also socio-demographically diverse - it has the largest proportion of people of Pacific Islands ethnicity of any city in the world, almost a quarter of its residents are of Asian ethnicity, and its population is younger than the national average (Statistics New Zealand (2013a). Further, as relevant to our analysis, 19% of its population identify as being disabled (lower than the national average of 24%; Statistics New Zealand (2013b)).

Next, we introduce the social model of disability and socio-ecological approaches to understanding mobility. We then explore concepts of ableism and disablism and present definitions and terminology used in this paper, before describing the research methods. The results are then discussed, including the themes of the burden of planning mobility, social support and ableism, mobility as a wellbeing enabler, and the need for bureaucratic system changes. In a final section, we conclude that mobility is important for wellbeing in disabled CYP yet substantive social and physical barriers to mobility remain.

The social model of disability

The Social Model of Disability (hereafter the social model) Oliver (1983) signalled a fundamental shift away from individual, biomedical models of disability, recognising economic, environmental,

and cultural barriers to participation. In this sense, proponents of the social model argue that people do not live *with* disability, but rather that they *experience* disability as a consequence of disabling environments and attitudes. A social model approach facilitates understanding barriers as social problems across the totality of disabling environments, and requires social action and change which ultimately benefits all (Oliver, 2009; Ross, 2013). The social model has been critiqued as being dualistic: neither accounting for individual impairment or intersectionality, nor recognising diversity of individual experience (Hughes and Paterson, 1997; Mitra, 2018; Owens, 2015; Thomas, 2004a; Thomas, 2004b), although arguments to the contrary have been presented (Campbell and Oliver, 1996; Oliver, 2009).

Here, we chose to draw from the social model with a focus on disabling social and spatial arrangements. Additionally, we build on Carol Thomas' call for a social relational approach that considers disability as "a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional wellbeing" (Thomas, 1999, 60). This use of the social model does not preclude the consideration of individual factors of importance (e.g., psycho-emotional wellbeing), but allows us to understand and highlight the potential impact for generating change for social justice within a disabling society.

Socio-ecological approaches, mobility, and participation

A socio-ecological approach is useful for understanding mobility as it considers the context of people's lives and types of participation across social and environmental dimensions and at differing scales. Variation in definitions and measurement of socio-ecological systems and theories exists (Bingham et al., 2016). From an anthropocentric and wellbeing perspective, the ecological system can be considered to be the built, organisational, economic, and political environments that influence health (Sallis et al., 2008). The social system exists at varying scales from the individual to societal (Binder et al., 2013). Brofenbrenner's (1979) ecology of human development considered ecological influence across micro, meso, exo and macro scales. The socio-ecological model of Sallis et al. (2006) complements the theorisation of disability underpinning this research, taking into account factors across the hierarchy of social systems (e.g., individual, family, society) and the external ecological framework. By drawing together a socio-ecological approach with the social model, this research sets out an analytical framework for understanding and describing the gamut of disabling environments.

Ableism and disablism

Barriers and discrimination associated with many forms of disability (disablism) arise from ableist social attitudes that favour particular abilities and devalue variation from normative values (Goodley (2018). In doing so ableism privileges and elevates various social groups in relation to "Other" groups (for example based on gender, ethnicity, socioeconomic status, or age) (Goodley, 2018; Wolbring, 2008). Fiona Campbell defines ableism as "a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical...human" (Campbell, 2012, 44). Gregor Wolbring writes of ableism as "a particular understanding of oneself, one's body and one's relationship with others of humanity, other species and the environment, and includes how one is judged by others" (Wolbring, 2008, 252). Ableist ideas, such as the notion that disabilities are a personal tragedy, and disablement a "diminished state of being" (Campbell (2012), give rise to inequitable and oppressive personal, relational, and institutional practices that disadvantage disabled people. By illuminating the hegemony of ableist ways of thinking (and their resultant disablism), disability scholars are challenging 'commonsense' perspectives across many sectors, including transport, emphasising the need for social and systemic transformation.

Definitions and terminology

We consider disability as outlined by Oliver (1996, 33) as "all the things that impose restrictions on disabled people; ranging from individual prejudice to institutional discrimination, from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on." Disablement is thus defined as "something that is experienced when people encounter restrictions due to disabling social barriers (and/or bodily impairment)" (Ross, 2013, 136).

The terms disabled CYP and disabled people have been prioritised in this paper, in keeping with the underpinning principles of the social model (i.e., that people are disabled by their environments rather than their impairment). We recognise alternative approaches are sometimes favoured, in particular people-first language. However, here we drew from the critical reflections of Ross (2013) and Titchkosky (2001) on the importance of language in reducing systematic disablement and the potential for people-first language to remove the possibility of disability as a social phenomenon. Impairment terminology has been used where relevant to participant recruitment or for clarification in cited literature, and where used by participants, including D/deaf, mobility impaired, vision impaired, and hearing impaired.

Methods

Protocol and research team

Data were drawn from a multiple methods cross-sectional study undertaken mid-2016 to early 2018 with young people experiencing mobility or hearing impairments or who were blind or low vision (Carroll et al., 2018). The study was led by researchers with expertise in public health, health geography, physical activity and mobility, rehabilitation, social justice, social psychology, and youth studies. Two team members have lived experience of disablement and of acquired physical impairments and another as a parent of a disabled child. A majority of the team had over a decade of experience working together in environmental and public health research, with a focus on how built/neighbourhood environments are linked to physical activity and mobility (Badland et al., 2009; Oliver et al., 2016; Oliver et al., 2011; Witten et al., 2012). This previous research focused on non-disabled populations, leading to calls from the disability community to build on this work to understand the experiences and aspirations of disabled children and young people. The current project was thus designed to understand experiences of mobility and activity, mobility practices and participation in daily life of disabled children and young people. We used an iterative approach whereby research processes and focus evolved in response to the data collection process, and with guidance from the disability community including a youth advisory group, and academic and cultural advisors. Ethical approval was provided by the host institutional ethics committee (MUHECN15/044).

Participants

Participants were invited through schools, specialist education facilities, disability groups, service providers, recreation providers, civic organisations, team networks, websites, publicly available blogs, and on-line newsletters. We used a snowballing approach to recruit additional participants.

Individuals needed to have qualified for On-going Resource Scheme (ORS) funding with regard to hearing, vision, or physical needs for inclusion. This scheme provides educational support for students to enable participation in the school system. Researchers visited participants in their homes or schools/learning institutions and provided a participant information sheet and assent form (if aged 12-15 years) or consent form (if aged 16 years or older) to participate. Parent consent was also required for participants aged under 16 years.

Data collection

We conducted face-to-face interviews (in a location of the participants' choice – usually their home) and go-along interviews [Carpiano \(2009\)](#) (in neighbourhood settings of participants' choosing) with participants. Communication assistance was provided by New Zealand Sign Language interpreters and Alternative and Augmentative Communication devices. Interviews were audio-recorded and transcribed verbatim. Transcripts were edited and pseudonyms were used to ensure participant confidentiality. Quotes are annotated to indicate whether the individual was blind or low vision (V), had a hearing impairment (H), or had a mobility impairment (M).

Data analysis

Initial scans of the entire dataset by OC and PC were used to identify candidate themes and coding structures. Thereafter, individual case studies and coding (completed by all authors, findings not reported here) were used to support initial coding structures, including the addition of any new relevant codes. Next, coding of all transcript data was undertaken in two sweeps by OC and JL over three months. Extracts coded to the broad theme of 'mobility' were extracted and read multiple times by the first author. Attention was paid to identifying enablers, barriers, and experiences of mobility. We adopted a structural approach to understanding these factors, resulting in a preliminary 'decision tree' illustrating the multiple and wide-reaching factors relating to mobility (available on request).

Preliminary results, reflections, and possible interpretations of this decision tree and associated material were shared with a subset of participants and/or significant family members at a research workshop. Participants and family members provided insights in terms of the appropriateness of the focus of the research and interpretation of results, supporting the topics and issues identified from the data, and contextualising the research findings. Themes were then finalised by the lead author and refined with the research team.

Results and discussion

Participants

Thirty-five participants aged between 12 and 25 years took part in the research. Twelve participants were blind or low vision, ten were D/deaf or hearing impaired, and thirteen were mobility impaired. Some participants used physical mobility supports including canes, guide dogs, wheelchairs, and mobility scooters, while others used none.

Overview of findings

Findings aligned with previous studies, confirming the essential role of mobility in enabling social connections ([Skär & Tamm, 2002](#)), physical wellbeing ([Rogers et al., 2008](#); [Verschuren et al., 2008](#)), and in doing so enhancing participation and quality of life ([Dahan-Oliel et al., 2012](#); [Shikako-Thomas et al., 2014](#)). However, fifteen years on from the Human Rights Commission Inquiry (Human Rights Commission, 2005) a number of pragmatic barriers to the accessible journey remain. These barriers align with previous research with adults ([Bezyak et al., 2017](#)) and highlight the numerous opportunities to resolve issues that could have substantive benefits for disabled CYP. Dominant themes are discussed below.

The study also identified the fragility of mobility opportunities; arrangements executed one day, thereby enabling the experience and wellbeing benefits of participation (e.g., see [Lee and Potrac, 2020](#) (in press); [Bates et al. \(2019\)](#)), could fail another day. While the possible impediments to smooth transit appeared infinite, numerous examples of overcoming barriers to mobility were evidenced. Personal mobility decision-making and actualisation were informed by a constellation of powerfully

determining factors external to the individual. These factors included but were not limited to: the goodwill and availability of other people, the availability and accessibility of technology, the nature of the physical environment, weather conditions, and the suitability of public transport systems. Further challenges included psychological readiness to handle 'everyday ableism', including discrimination, staring and questioning from members of the public and transport providers (e.g., see [Calder-Dawe et al. \(2019\)](#)). The findings demonstrate the importance of reducing ableist presumptions about preferences and abilities of individuals with disabilities, alongside ensuring enabling social and physical environments.

It is worth noting that substantial variability in mobility enablers and barriers existed between those participants with mobility, vision, or hearing impairments ([Table 1](#)). The volume of issues raised may also be indicative of existing mobility levels and age (i.e., those with higher levels of mobility may have more experiences to draw from when reflecting on enablers and barriers). However, this variability was nuanced, with individuals within groups having substantially different needs and preferences, and others reflecting on their own varying needs over time and space. For example, Rebecca (V) stated "...one day I'll walk down the street and be fine, and then the next day I might, you know, hit into a bench or a person...I can't see too well today because you just wake up like that..." Moreover, as well as the mental load of planning a trip, the actual act of getting out and about had a mental and physical burden, which changed depending on the activity.

The research focused predominantly on understanding social and physical environmental barriers to participation and mobility. However, it also highlighted nuances in individual experience and the importance of acknowledging these differences when considering disabling environments ([Thomas, 2004a](#); [Thomas, 2004b](#)). In particular, it is essential to acknowledge how these "situational mismatches" between a person's needs and the environment ([Hästbacka et al., 2016](#)) can differ across time, context, and individuals. [Söderström and Hemmingson \(2017\)](#) describe this scenario aptly: "...people are not disabled all the time, but they are made and unmade able and disabled in particular situations, under particular conditions, and in particular practices and relations" (171).

The exquisitely planned journey

Participants bore significant mental, physical, time, and financial burdens associated with mobility. Extraordinary problem-solving requirements, adaptability, and acceptance of trips simply not occurring were commonplace. Substantial planning was required to enact a journey, including considering environmental and social factors and individual problem-solving for possible impediments to the trip, as described by Saamir (M): "...I'm thinking three steps ahead like oh we're going to the cinema, I'm thinking oh yeah how am I going to get on and off the bus? If I'm taking an Uber there who's going to put my wheelchair in the back? ... and that's like a big effort." Greer (M) saw her need to anticipate and think through every step of a daily journey as akin to the effort others would put into preparing for international travel, adding, that even then it may not be possible to "to execute it the way you thought you could."

For blind or low vision participants, this planning could involve multiple accompanied practices of a route and memorisation before being able to navigate that route independently. In the absence of route memorisation, some participants had extremely limited independent mobility. Alice (V) spoke of being "able to go to more things" if she was able to get about the city more independently, but reflected on the fact it would take "quite a lot of effort to learn it in order to go to three things in the year in that area..."

Even where and when considerable planning and organisation were put in place, unanticipated 'roadblocks' were common such as multiple buses not stopping or accessible taxis being unavailable, ultimately leading to a lack of spontaneity. Kevin (M) reflected on specific challenges

Table 1
Enablers and barriers to mobility across the socio-ecological spectrum.

Enablers	Mobility	Vision	Hearing
Relationships and social support	People – physical support from family and friends to be mobile (e.g., lifting), as well as considering and choosing enabling environments (e.g., considering accessibility when planning social events) Flexible practitioners (understanding variation in individual mobility needs and preferences)	People – support from friends, family, guides, support workers, bus drivers, general public (especially for crossing roads or working out where to stop on bus route)	Being part of the Deaf community
Education and health systems/services	Disability services (in the community and at educational institutions) Occupational therapists Be. Lab accessibility activities and programmes (www.belab.co.nz)	Formal orientation and mobility training (e.g., Blind & Low Vision Education Network NZ Kick Start programme)	NZ Sign Language training and fluency and access to NZ Sign Language interpreters
Technological, informational, aids	Smartphones (particularly apps for travel planning and updates) Mobility equipment (e.g., scooters/triride) Modified equipment Google Maps – for identification of routes Real time tracking of PT Augmentative and alternative communication technology	Smartphones (especially to take photos and expand them for visibility) Google Maps (albeit could be improved – e.g., being told where to cross the road or if footpaths disappear) Blind Square App (https://www.blindsquare.com/about/ - PT stop notification although this needs to be set up appropriately it needs to be open during the trip which can become annoying due to ongoing alerts) Regional transport agency's mobile app, in particular the real-time boards feature Voiceovers on trains (but are needed for buses) Equipment – canes, glasses, wide brimmed hats Guide dogs (availability of and access to) Shade (e.g., through natural or man-made canopies) “obstacle free” paths Destination accessibility reducing burden of memorising long routes Physical symbols in footpaths and at crossings for tracking location	Cochlear implants Hearing aids
Physical environment	Wide spaces Handrails at stairs Ramps Smooth surfaces Places to rest Automatic doors Good weather Lift availability and accessibility Mobility parking cards and spaces PT stops near key destinations Circular bus routes (“you can’t get lost”) Buses with clear branding (e.g., “the red bus”) New trains with larger turnaround spaces Improved ramps to board trains (wide, easy to mount/dismount and travel across) Taxis Modified cars	Taxis	Destination accessibility – including to public open spaces, walkways, gym, waterways, and friends) Good weather Cars and licensing Taxis
Transport systems	Transport subsidies, particularly for PT/taxis (although noting there were conditions and bureaucracy around these that made this challenging)	Transport funding – for PT/taxis Regulations around where guide dogs are allowed	Transport funding – for PT/taxis
Policy	Barriers Relationships and social support	Barriers People – ableist attitudes Crowds and noise make it extremely hard to navigate	Barriers People – ableist attitudes
Environment/context	Mobility People – ableist attitudes, bus drivers refusing to help boarding buses, visible difference/social discomfort due to time taken getting on/off PT and questioning the right to use disability seating Crowds make it hard to move around easily Distance to destinations Tight/narrow spaces, tight turning circles Stairs “Lips” into spaces – including on wheelchair ramps Truncated domes/tactile paving Exposed tree trunks in pavements/uneven paths Heavy doors Topography – steep ramps/streets Rain and wet surfaces (e.g., slippery floors at pools) Soft surfaces (e.g., sand, grass) Roundabout ways of getting to places (e.g., to lifts/ramps placed in suboptimal positions) Carrying loads	Vision Roadworks – and temporary issues with crossing lights not working or working differently than usual (e.g. not beeping) Crossing major roads (tactiles and beeping essential) Crossings without lights Bumpy surfaces/uneven ground (e.g., cracks, potholes, grilles) Inclement weather Temporary barriers (e.g., bins) Barriers on pathways (e.g., poles in the middle of pathways) Low-hanging barriers (e.g., signs at head height that are missed by a cane). Glare/sunlight Uneven surfaces (challenging for depth perception)	

(continued on next page)

Table 1 (continued)

Enablers	Mobility	Vision	Hearing
Transport systems	Numerous barriers linked to bus travel (e.g., bus drivers refusing to help boarding bus or not stopping at all, drivers challenging ID cards, challenges navigating the tight/narrow turn on to the bus, need for strong wheelchair brakes and something strong to hold on to, bus not stopping at exact point, unreliable scheduling, bus stops at steep locations) Trains not being level at platform	Numerous barriers linked to bus travel (e.g., multiple buses arriving at the same time and not knowing which one is the right one, not knowing when/where to get off, bus drivers not advising when at correct stop, not being able to read bus numbers, needing to know/memorise stop numbers) Buses not arriving at the scheduled time Multiple buses arriving at once Trains not being aligned with tactile surfaces at platform	Unclear public transport announcements (e.g., announcements being hard to hear or follow)
Policy	Bureaucracy (e.g., issues with renewing disability cards) Cost – petrol, PT, taxis	Bureaucracy Cost – PT, taxis	

Notes: This is not a comprehensive list of enablers and barriers, but rather a collection of key enablers and barriers that were noted by participants in this research; NZ = New Zealand; PT = public transport

with booking taxis: "...[it] is actually quite hard. Some taxi companies, you've got to give them 24 hours' notice..." Kevin (M)

In some cases, as explained by Jason (M) the burden of planning the journey was such that the plan was never actualised: "Because if I don't plan that sort of stuff out I usually wake up feeling like I didn't put in much planning and so I shouldn't really go ahead with it."

New technologies were appreciated and quickly harnessed by youth in this research – but were often piece-meal in their delivery/availability, or not consistent across transport modes. When planning journeys, technology was utilised in traditional/expected ways (e.g., checking public transport schedules, booking accessible taxis). Technology was also harnessed for planning journeys and associated events. However, these technologies were not without their limitations. For example, some participants reported a lack of information on where to cross roads safely (important for blind or low vision participants), or up-to-date information on roadworks and detours. Access to technology was essential to enable participation and mobility, yet this came at a price – whether it be for equipment, broadband, or transport technology. Previous research with disabled adults in the United Kingdom revealed the cost of mainstream and specialist technologies to be prohibitive for their uptake and use [Harris \(2010\)](#). The downstream consequences can be significant and cyclical, through reducing mobility to places of employment and education, and the perpetuation of an ableist and disabling society where disabled people's physical, mental, and social wellbeing is compromised.

Navigating the socio-cultural realm: social support and ableism

Social support was fundamental to successful and enjoyable mobility. For example, Millie (M) noted "I can do anything I want to as long as I have a good team of people behind me". However, this was contingent on receiving the right support, from the right people, in appropriate and respectful ways. Autonomy over how and when support was provided, and by whom, was important for participants, in particular for maintaining their dignity and being treated respectfully:

"Accessibility is really, really difficult to navigate for me. Everything's accessible when I have close friends around me, if that makes sense. Everything is accessible if I have people who know me around me." Saamir (M)

It is possible that ableist social environments restricted this 'comfort zone' to a limited number of known/proximal friends and family. Social support is not equitably experienced by all, and a number of barriers to perceived social support have been identified for adults with physical disabilities ([Devereux et al., 2015](#)). An improved community culture around understanding the needs and preferences of others could provide important opportunities to extend this comfort zone and facilitate greater and more pleasurable mobility.

While support from family, friends, and caregivers was appropriate and welcome, being visibly different in the outside world also invited unsolicited support from unfamiliar people. Strangers' assumptions that participants required help led to uncomfortable and sometimes invasive situations and the need to assert their independence, capability, and autonomy as exemplified by Greer (M) "...and I was going back [across the road] and this man just came up behind me and started pushing me."

Conversely, the support of strangers, when on participants' terms, was welcomed and appreciated. Gemma's (M) comment reflects this scenario but also highlights the cognitive and emotional burden in navigating these situations: "...I had no choice but to get off the curb and this lady saw me struggling, like 'cause I was kind of like having inner conflict with myself like 'should I go down this or should I take the long way round?' and then she decided to help me and so I was really grateful for that."

Being visibly different impacted the mobility experience of some participants, making it hard to 'fit in' socially. Environmental and technological designs both exacerbated and mitigated visible difference. Technology that enabled easy and fast boarding of buses and trains reduced negative feelings of visible difference as Gemma (M) described: "...getting on a bus everybody knows 'cause the bus has to stop and the bus has to put down a special thing and everybody has to wait for you". Similarly, Kevin (M) reflected on improvements to trains that made boarding easier and in doing so reduced the intensity of unwelcome stares:

"Yeah, plus with the old trains... because we don't like to be stared at and a lot of people stare because it's something new to them, they don't see that every day, someone getting on the train like that. Having less people staring, is actually a good thing..... For one, there's no huge giant cheese grater [on new trains] and it's a straight push in, where before, they had to carry this huge metal rack belt and then someone had to back this, push you right in." Kevin (M)

The pervasiveness of scenarios where individuals experience everyday ableist intrusions through visible difference has been highlighted by [Calder-Dawe et al. \(2019\)](#). Diagnostic staring, exchanges, and judgement prevailed, with preconceived biomedical and binary notions of disability flavouring exchanges (often unprompted and unwanted) between participants and the general public. Multiple dehumanising elements existed across these exchanges, with perceptible differences seemingly justifying acts of scrutiny, classification, "othering," and intruding uninvited into peoples' everyday lives. Participants mainly focused on these experiences as an embodied social phenomenon, aligning with Thomas' assertion of disability as social oppression ultimately undermining psycho-emotional wellbeing ([Thomas, 1999, 60](#)). These issues are additionally interwoven with environmental structures and messaging that alienates and designs disabled CYP out of places ([Imrie, 2000a, b; Imrie and Kumar, 1998](#)). Additionally, socio-cultural cues can further effect and maintain these scenarios ([Lantolf, 2000; Vygotsky, 1978](#)).

These social and built realms that perpetuate “normative” expectations of movement and capabilities can exacerbate visible difference, encourage diagnostic encounters, and make simply being out and about a negative and uncomfortable experience. As Saxton (2018) notes: “Barriers to exercising may seem even more daunting than in these other areas, in that barriers to physical movement brightly illuminate *the bodily reasons for exclusion*” (37).

Saamir (M) explained the numerous and unpredictable challenges experienced with bus travel and ableist attitudes: “Cause sometimes bus drivers are really grumpy and they don’t want to help you, or it’s a burden to help you. I hate that. I’ve had bus drivers open the doors up, see me and just sigh. It’s like, yeah, do it, please man, come on, do it, it’s your job. Please. Come on. Or I’ve had someone open the door and say, “Should you even be out at this time of the night?” And I was like, what? Where are you from?” Here, Saamir’s right to occupy and move around the city is challenged by a bus driver (‘should you even be out at this time of night?’), who is reading Saamir’s body through the prism of ableism and ageism. This utterance relates not only to Saamir’s embodiment as a wheelchair user, but the patronising, almost parental tone also indexes his position as a young person. This example illustrates how assumptions and norms based on age and disability status can *combine*, leaving disabled young people doubly marginalised from public transport.

Counter to this scenario, not ‘looking the part’ and fitting societal expectations of what disability should look like also had negative impacts. Participants were expected to justify and prove their right to access disability-specific transport scenarios as described by Gemma (M): “I was on the bus and I was sitting in the disabled, one of the disabled seats, and the lady told me that I had to move because she’s an elderly person but I couldn’t really, I didn’t really have the voice to say that I had a disability and I had a right to sit there... I shouldn’t have to explain myself to other people.”

These findings showed a mixture of systems failures, intrinsically linked with ableist attitudes and exacerbated through visible difference (Calder-Dawe et al., 2019). For example, multiple buses arriving at once are indicative of failures in the transport system and affect all users negatively. However, the impact is greater for someone who is hard of hearing, finds it hard to get from place to place easily, or is unable to see bus numbers. This scenario can intensify when visible difference and ableist attitudes converge to the point that a bus driver chooses not to stop for an individual. Experiences of participants in this study reveal numerous insights regarding ableism in public transport – including judgment on participants’ rights to be using public transport and perceptions of the individual being burdensome (e.g., in terms of boarding a bus).

The cumulative effect of being in ableist social environments was an additional burden for some participants in terms of awareness of others and deciding how to deal with them – from planning the trip to actualising it, negotiating uncomfortable situations including protecting personal space and approaching strangers for help. Ultimately the consequence is a sense of exclusion, not belonging, being othered through everyday ableism, embodied in the form of reduced participation and mobility.

In certain situations, technology such as canes and wheelchairs were used strategically, for example to protect participants’ physical personal space, to counter ableist attitudes and/or to avoid unwanted discussions and having to prove their disability status. These findings reflect earlier work with blind or low vision youth, who employed a range of strategies to manage their mobility experiences and to encourage others to see them as competent spatial actors Worth (2013). Having control over revealing or concealing difference was fundamental and decision-making was dependent on social context and accompaniment (e.g., being able to link arms with a friend while walking). Consistent with the current research, canes were used strategically to ‘communicate’ with the general public and avoid having to navigate uncomfortable social encounters.

Mobility and accessibility as an enabler for wellbeing and participation

Numerous facets of wellbeing were noted through mobility and positive mobility experiences, aligning with earlier research (Bates et al., 2019; Lee and Potrac, 2020 in press). Access to natural environments and the salutogenic effect of being in nature were valued by participants with particular regard to mental wellbeing, providing the opportunity to get relief from external pressures, to be somewhere calming, and be able to “switch off.” Natural settings were among those that afforded pleasure and freedom, and supported wellbeing, aligning with findings in non-disabled CYP (Tillmann et al., 2018) and blind or low vision adults (Bell, 2019; Shaw et al., 2015). While these benefits were noted across all participant groups, they were particularly prevalent in interviews with participants who were D/deaf or hard of hearing, for example May (H) described going “...running, we go there and sit down, watch the water, watch the waves, do a bit of daydreaming – it’s a really nice calm place for me to be, watch the sunset.”

However, natural environments themselves were not always accessible. Sand on beaches and uneven paths in outdoor spaces were challenging for those with mobility impairments, which may, to some extent explain why they were less likely to reflect on the salutogenic impacts of natural environments. However, Gemma (M) noted these barriers were not insurmountable: “Yeah like even if it’s difficult for me to walk on the sand and stuff like I still want to go anyway because I enjoy, it’s a place I enjoy coming and my disability shouldn’t stop me from doing that.” In John Horton’s work with parents of disabled children, parents also noted the profound wellbeing benefits of outdoor/nature-based play for their child Horton (2017). The substantial barriers raised by parents were consistent with the current research (i.e., ableist physical and social environments reducing accessibility, participation, and enjoyment). Parents also focused strongly on *anticipated* barriers to enjoyment – noting emotions of ‘dread’ and ‘resignation’ and reflecting on the amount of planning required when considering taking their child for outdoor play. Together, these findings reveal the complex nature of mobility and participation in such environments for disabled CYP and their parents and inequity in terms of the burden required to engage in, and benefit from, nature-based activities.

Alongside reducing ableist social and physical environments, increasing everyday contact with nature for all people could be achieved via a biophilic approach to urban design (Beatley and Newman, 2013). Edward Wilson’s biophilic concept recognises humankind’s innate connection with nature and is particularly relevant in understanding connections between urban design and human wellbeing Wilson (1984). Beatley notes “...children or adults should be able to leave their front door and move through a series of green features and biophilic elements, moving if they choose from garden and courtyard to green street and municipal forest and then to larger expanses of regional nature” (Beatley, 2011, 83). He goes on to provide a ‘palette’ of biophilic urban design elements across varying scales, for example streets with urban trees or sidewalk gardens, blocks with green courtyards, neighbourhoods with pocket parks, and communities with urban ecological networks. Such approaches could enable equitable access to natural environments that may provide disabled CYP with respite from everyday stressors.

Mobility facilitated access to destinations where young people could socialise with others. Kevin (M) spoke about enjoying the sociability of a shopping mall: “I’m always running into people that I know.” For those who were able to drive, gaining a drivers’ license was an important rite of passage towards independence, increased mobility, and facilitating social contact as Eru (H) described: “now that I’ve got my license I do go visit people, for me it’s important to visit people.” Others talked of valuing the alternative of home-based entertaining where “everything is accessible” (Millie (M)), and sometimes avoided activities outside home because of inaccessibility.

A notable finding was how mobility could provide participants with opportunities to experience freedom, risk and enjoyment. For Saamir (M), being out of his comfort zone was appreciated. For others, the opportunity to explore new places was important. Alan (H) liked to “bike pretty far” while Andrew (M) noted a preferred activity would be to “wander around, maybe go over to Devonport [a suburb on the north side of Auckland’s harbour] and explore and something like that.” These observations align with Barbara Gibson’s (2017) work in understanding activity/setting assemblages for disabled young people. In Gibson’s research, participants discussed feelings of pleasure, exhilaration, and freedom facilitated through positive activity/setting assemblages. When mobility opportunities offered these positive experiences they provided a divergence and distraction for many of the young people whose lives were often highly structured and controlled, punctuated with activities more rehabilitative than wellbeing and pleasure focused.

Participation in physical activity, formal and informal recreational activities, and employment were obvious physical wellbeing benefits of mobility. However, there was a wide geographic spread of places of importance for participants. Friendships forged through disability units at school (which are dispersed across the city and not in every school) meant friends did not often live in the same neighborhood. Funding support for taxis, discounted public transport, and mobility equipment (and sometimes car modifications) were harnessed, but were insufficient to enable full access to places and spaces of importance, as Gemma (M) noted: “...you have to be careful, make your decisions about what you want to spend your taxi [funding allocation] on.” It is also worth noting that factors interacted to the point that the overall sum effect of these can be greater than its parts, as observed in research with adults (Asplund et al., 2012; Øksenholt & Aarhaug, 2015). An example is the impact of distance as a barrier to mobility, which interacted with destination accessibility (not in the traditional sense but in terms of distance to friends and family, and disability-specific activities) and cost. Many participants had attended schools outside their local neighborhood that had specific units to support their learning requirements. Similarly, disability-specific recreational activities were small in number and geographically spread (e.g., wheelchair basketball, see Bates et al. (2019)). Consequently, the destinations of importance to participants often existed outside their immediate neighborhood area, restricting travel mode to public transport or motor vehicles. This limitation also made car travel and driver licensing a desirable ‘rite of passage’ for older participants, although we note this was not an option for blind or low vision participants. While many of their non-disabled peers are advocating for climate change strategies and reduction of motorised car use (although exceptions exist, e.g., Hopkins et al. (2019)), participants in this study were reliant on motorised transport modes, further excluding them from the boundaries of social norms.

Fundamental changes in bureaucratic systems are needed

While numerous physical and technological ‘conditions’ have made use of public transport easier and more pleasant, bus travel remains riddled with pragmatic and socio-cultural barriers to use (as reflected in international literature, e.g., see Øksenholt and Aarhaug (2015)). The impact of the financial and practical costs associated with these transport modes, coupled with bureaucratic and social-cultural barriers were wide-reaching, including trips not actually being made. These barriers to mobility (e.g., for public transport and taxis) were compounded by bureaucratic systems, including requiring ongoing proof of disability, and lack of synchronicity and communication across agencies. Saamir (M) provided poignant examples that together encapsulated a bureaucratic system failure. He was required to repeatedly have his disability status reassessed when transport concession cards expired. As he said “[it] is ridiculous to me.....they’ve got to prove I’m disabled, even though I had their card before they have to do the whole assessment again.” The difficulties were compounded when the renewal of one mobility card was reliant on the renewal of another that had a different expiry date and

was authorized by a different agency. This necessitated navigating multiple bureaucratic, fragmented and siloed systems across transport and health bureaucracies. The 2020 Health and Disability System Review highlighted this issue (albeit specific to health service delivery) noting “*this suggests* there is considerable scope to reduce multiple reassessments when impairments and support needs are stable” (Health and Disability System Review, 2020, 135). This statement alone demonstrates the embedded ableism present in NZ health service delivery systems. A number of improvements were recommended, including a need for national consistency and information sharing regarding needs assessment and funding allocation (so that people who move do not need to re-enrol/be re-assessed), those with stable impairment and support needs only engage with the system as required, and evidence of impairment needs only to be provided once then updated if this changes.

These suggested changes have the potential to reduce undue pressure on disabled individuals as well as the health system. It is essential that such approaches are integrated with the transport (and other related) systems, as these challenges are pervasive and not unique to the health system alone. The degree to which such changes make a difference will be limited unless significant efforts are made to reduce (and ultimately remove) ableist approaches and intangible barriers to optimal service design and delivery across systems (e.g., language, discourse, and conceptualisations of disability and accessibility (Ross, 2013)). While the review also noted the need for a “nondisabling approach to service design and delivery” (Health and Disability System Review, 2020, 125) and for better inclusion and participation of disabled people, it is unclear how this will be achieved. Critical ableist approaches (Campbell, 2012; Goodley, 2014; Wolbring, 2008) are important to draw on in the design and evaluation of these systems – as Ross and Buliung (2019, 289) note: such approaches can facilitate “explicit recognition of ableist elements and the unsettling of normalized, exclusionary designs and practices.”

Conclusion

Mobility enables access to social, economic and community life. Without mobility disabled young people can be excluded from the everyday activities that support wellbeing and engender a sense of place and belonging. Their right to access and experience the city is compromised by transport networks and social norms that privilege the movement of non-disabled bodies and additionally impede the mobility of disabled young people. The findings highlighted pervasive inequities in mobility and participation. The integral role of social support was equally clear – but not all participants had equal access to it. One solution does not fit all and comprehensive approaches are necessary. Relational factors played an integral role in actualising planned trips and overcoming the material and social manifestations of ableism in an unsupportive transport environment. Although a range of enablers to mobility were observed – including technological and infrastructural advances – ableism and disablism remained omnipresent forces negatively impacting mobility experiences and activities. Individual embodiment of ableism reduced a sense of entitlement to mobility, reinforced by attitudes and behaviors of community members. Ableism was reflected in bureaucratic systems, inaccessible built environments and transport modes, and technology that was not fit for purpose. This is further evidence confirming Cresswell’s (2010) view that there is a politics to mobility. There is a need to break through embedded systems that fail to meet the needs of disabled CYP. Creating change in these entrenched systems is essential. To do so can create windows of opportunity to confront ableist norms and disabling practices and support CYP to undertake, enjoy, and benefit from increased mobility.

While centred on disability in NZ’s largest and most spatially-extensive city, this research has also sought to engage intersectional conversations exploring how identities and identity-related social assumptions inflected participants’ experiences with mobility, ableism and disablism. Future work exploring more complex identity profiles and associated experiences is essential. We are aware this focus risks pro-

viding a relatively narrow understanding of disability and accessibility. Yet, for the most part, the findings align with earlier work across broader groups and settings. For example Imrie (2000a); Imrie (2000b); Imrie and Kumar (1998) reflected on the normalization of discourses, socio-cultural values, attitudes, and approaches that “alienate impaired bodies” and design out disabled CYP from environments (Imrie, 2000a, 1641). Visible difference findings align with earlier discussions around the “dys-appearing body” (Allen, 2004; Imrie, 2000a) where these normalized social and spatial arrangements collude such that “one’s impaired body ‘dys-appears’ – is made present as a thematic focus of attention” (Patterson and Hughes, 1999, 603). The considerable issues experienced with public transport (and taxis) are well acknowledged in research with adults, and highlighted in considerable detail by Gaete-Reyes (2015). The role of natural environments in enhancing wellbeing through positive affect, general wellbeing, a sense of escape and freedom mirror work with blind or low vision adults. This earlier research also highlighted how these benefits were conditional on safety, and the cognitive burden of navigating these environments (Bell, 2019; Shaw et al., 2015).

Children and young people have the right to have their perspectives heard, be given due weight and to be reflected in policy and practice (United Nations, 1989, Article 12). This research makes an important contribution through prioritizing the voices of CYP, in an evidence base that is largely adult-centric. The study has highlighted the value of mobility and participation for CYP wellbeing, particularly regarding experiencing freedom, risk and enjoyment, as well as the importance of natural settings in supporting wellbeing. Barriers to participation and mobility are consistent with those highlighted over decades of research with adults. Generating change is not simple and will require sustained attention and effort across socio-ecological systems. All actors across the system need to recognise and change ableist language, symbology, attitudes, policies, and practices that exist in their spheres, ultimately making meaningful shifts across the system. Full and direct participation from the disability community is essential to achieve meaningful change (Charlton, 1998). Yet, examples of representation in decision-making processes are often piece-meal, restricted to consultation with disability community groups or representatives, or invited participation when topics are disability-specific. A priority must be to ensure meaningful representation from disabled CYP and the disability community, including setting normative expectations for funded roles across the transport system.

Declaration of Competing Interests

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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