Creative Works

Seen and Unseen Trails of Trust

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Abstract

This is the story of the making of a sculpture called the *Steps to Success* built in a Special Needs School in Umlazi Township in Durban, South Africa. It is a story not just about the stones, metal wire, concrete and paint of the steps. It is a story about all the people that made it possible and how those memories are hidden in the steps. The sculpture was built by the learners and teachers at the school and a Scottish organization called Crossing Countries. It is still being added to by the school and other organizations. It is a story about how art helps to build trust overtime between people who have different skills and come from different countries.

Keywords: disability, socially engaged art, South Africa, trust

Figure 1

Cathro, S. (2022) Seen and Unseen Trails of Trust

There are many kinds of trails. Seen and unseen, planned pathways to the future or unplanned marks left in a voyager's wake. Sometimes the track splits, and a narrow trail leads away from the main track then disappears into the unknown. A scuff on the floor, the whiff of perfume in a lift, a cup ring on a wooden tabletop, all leave a mark and tell a story.

This sculpture, named *Steps to Success* by the art educator, Njabulo Hlongwane, and the learners of Mason Lincoln Special School (http://masonlincolnschool.co.za/) in Umlazi Township, Durban, South Africa, stands next to the courtyard where they hold their daily morning assemblies. The seen and unseen trails that weave around and through this sculpture originate in relationships of trust forged over years and through art. One of these unseen trails hidden in the sculpture is the founding and journey of Crossing Countries (http://www.crossingcountries.org/), a Scottish social enterprise, and its relationship with socially engaged art and disability. Our original idea was to provide opportunities and

adventures for disabled and nondisabled people to volunteer and have a fun in Durban; we soon discovered that our path led towards the arts. Creativity was a road we could travel together as a team and with the people we met on the way. 'Art,' in its widest sense, and socially engaged art in particular, gave us the space to explore what it means to be uniquely human and how to build trust between and within diverse communities. Njabulo, the school staff and learners, see it as a reminder of the acceptance by the local community that learners with disabilities should be given a chance to attend school, learn and achieve their goals.

Throughout time humans have left their handprints, from cave walls to city sidewalks, their imprints marking their passage. The handprints on this sculpture mark its belonging to the learners but, for me, they also signify a personal unseen trail from an art activity I organized for the children in a street kids' project in Durban in 2012 to a digital photograph received in 2022. Living on the streets, often addicted to glue and running away from abuse, leaves street children vulnerable and alone. Creating their own 'family tree' from their multi-colored painted handprints was not only a fun respite but also symbolized a family that they had the power to create themselves. Time travel to 2016, many trips and projects later and a year after I founded Crossing Countries: A mural, covered with the rainbow painted handprints of learners, educators and Crossing Countries volunteers welcomes visitors into Mason Lincoln Special School. The school, which was once a hospital, looks down on V section in Umlazi, the ramshackle collection of buildings caters for approximately 230 children of all disabilities from the ages of 4 years to 24 years; some live in and others return home at the end of the day. Each name and brightly colored handprint on the mural shows the bonds and trust that had been made through the years. Each mark on the wall unique, a sign of personhood, and yet also, signifying a community. And now, in 2022, a sculpture started in 2019, bears the same motif, blue handprints, another physical reminder of our passage over

time and connections grown through trust.

The steps of the sculpture represent a decade of slowly building trust, relationships nurtured across physical and cultural similarities and differences. The foundation, a wire gabion, bent into the shape of steps, is filled with stones that were cast aside by others and collected by the learners. The metal mesh of the gabion simultaneously representing the constraints and the opportunities they face: fencing them in but also hinting at the possibility of escape, through the gaps, to success. The steps are wrapped in concrete, painted white, the stones and wire structure, now unseen but still there, embodying those learners whose disabilities are hidden.

Atop the steps rests a wheelchair, the international symbol of disability, and a crutch, both now discarded, no longer constraints to success, but rather, tools of empowerment. The wheelchair is adorned by a yellow crown, its colour signifying courage, wisdom, and happiness. The crown represents triumph but also the past and present power and symbolism of African kings and queens.

Just as these words leave a digital footprint online or an inky trail across the printed page, the blue words painted on the risers of the steps are there to inspire the learners. These words to live by also make visible the story of how socially engaged art and authentic collaboration over time build trust. Four steps, four words: vision, determination, perseverance, and achievement.

The first riser, inscribed with the word 'vision' is, literally and figuratively, the common ground on which the sculpture and the other steps to success rest. Vision: it is the foundation of the relationship between Njabulo and me, a shared vision: to see disabled people given the opportunities to flourish, to be valued members of their communities and the

world, to be able 'To make a difference' - the motto of the school. Our aim, to do this through socially engaged art, a space in which values and beliefs can be voiced and heard. Our friendship and collaboration comes from years of gifting each other time and trust. It is a slow process of being open both personally and professionally, taking time to share and listen to each other's experiences and beliefs, creating a place together where we can be interdependent and equitable. There was no formal invitation to collaborate, just a chance meeting and then years of small acts of recognition, of shared future possibilities, and common dreams.

The second riser is inscribed with the word 'determination.' The government of the United Arab Emirates uses the term 'people of determination' instead of disabled people. Although, based on the medical/charity model of disability, 'people of determination', captures not only the state of mind that disabled people need to succeed in this ableist world but also one of their often-unrecognized strengths. The word determination evokes positive emotions; it hints of agency and motivation to reach a goal. It took our entire trip in 2019 for Njabulo and me to create a design and source a gabion. Two days before we left the learners, Njabulo scoured the school compound to find stones and bend the wires into shape so we could see the fruits of our joint determination before we flew home.

The third riser is inscribed with the word 'perseverance.' The steadfast quality of patience and the heroic virtue of perseverance go hand in hand. The shiny, silver trail of the snail on a concrete path, the whirling dust of the cheetah running on the savannah grasslands, the legacy of the now dead struggling artist, the drips of sweat from the Olympian's brow, all describe trails of seen and unseen perseverance. Challenges and obstacles are met and overcome, trust in others and self to forge new paths when barriers block the way to old ones. An authentic collaboration builds into it this flexibility, this acceptance of a joint venture, the

ability to change but hold steadfast to the vision, to not give up. Although physically separated, Njabulo and I are still able to share the process. After we left Durban. and as Njabulo and learners built the first version of the sculpture, I was still able to write the words explaining the sculpture's meaning back in Scotland.

And finally, inscribed on the final step is 'achievement.' In 2022, I received a ping, a photo on Whatsapp from Njabulo. There I was smiling from ear to ear. I felt many emotions, one of them was achievement. With the support of another organization, the sculpture had been re-painted, and a new seating area added, an 'epaki' (park), as the learners call it. Achievement is often seen as a realized end goal. The painting was accepted for an exhibition; an award was given for an art project that created social change. What if achievement is not about the artifact or the acknowledgment but about the process and the unknown future of infinite collaborative relationships? Socially engaged art, and in particular collaboration, involves knowing when to let go, to give others agency and ownership, when to acknowledge interdependency and diversity and the quest for mutual benefits, and when to recognize that commitment to a vision does not mean commitment to one path. The relationships nurtured through this sculpture led Njabulo, me and a Crossing Countries volunteer to write an article for an edited volume for Routledge Press on the Hierarchies of Disability Human Rights. Without the trust built between us over the years, this would not have been possible. It is trail not visible but one that can be traced back.

These traces and marks, visible and invisible, known and unknown, will wind their way into the future and like green shoots and plump rhizomes grow both above and below the soil nourishing new trails, seen and unseen.

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Creative Works

'The Matutu Girl'

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Abstract

Production stills from DemWaMa3, a web series about a young woman with albinism.

Keywords: photography, albinism, web, Africa

These production stills are taken from DemWaMa3, a 3-episode web series about a young woman with albinism, directed by Karolina Wambui and executively produced by Black Women Disrupt the Web, a competition that seeks to highlight the creativity and brilliance of Black women filmmakers. The web series seeks to highlight the challenges faced by persons with albinism in their daily life, focusing on a young woman with albinism working in the matatu (bus) industry. The images were taken at Korogocho - one of the largest slum neighborhoods of Nairobi, Kenya. Korogocho is home to 150,000 to 200,000 people pressed into an area of only 1.5 square kilometers and is located to the northeast of the city center.

This young lady with Albinism lives in an in-between world where she is white but not white enough, black but not black enough. She is educated but has not managed to secure a job in her area of study. She is hired as a tout (a person who solicits business) by a man who owns a fleet of matatu. In this male-dominated industry, she encounters a different challenge every day. Sharon works alongside Kadere, the driver of the matatu. Kadere doesn't like working with her and is always complaining about how she is slowing him down and that he is afraid that Sharon is an informer. His wish is to have a male tout with whom he will make deals and make extra cash without the owner of the matatu finding out. Sharon's biggest dream is to own a fleet of a matatus, which she believes will earn her the acceptance she craves in a society that doesn't understand exactly how to treat her.

Figure 1

Image 1: Photo of Sharon, a woman with albinism, working as a tout on a matutu bus in

Korogocho, Nairobi.

Figure 1

Figure 2

Image 2: Photo of Sharon counting money as she leans from the window of the matutu bus.

Figure 3

Image 3: Photo of Sharon leaning out of a matutu bus as it comes to a halt.

Figure 4

Image 4: Photo of Sharon. She holds on to a rail as she leans from the doorway.

Figure 4

Sharon faces a different challenge in every episode. Episode one focuses on her search for a partner. Over the years, she has received little male attention because most men do not understand her condition and fear it might be a curse. Thus, they shy away from approaching her, but she eventually finds acceptance by a young man who makes passes at her. In the second episode, a young lady who is irritated by a middle-aged commuter begins verbally abusing Sharon because of Sharon's visual impairment. Sharon brings the money close to her eyes, and the young lady asks if she is blind or whether she wants to eat that money, questioning why her eyes dart back and forth. In episode three, Sharon is attacked by angry commuters who accuse her of collaborating with thieves to steal a passenger's phone. They become very angry and start making remarks about selling her to a neighboring country because they have heard that her skin and her body parts are worth a lot of money.

These challenges highlight assumptions and misconceptions about disability. Many of these were also experienced during the shooting of the series. There were instances where the bystanders would point at the main character, Sharon, and whisper to each other. There were also instances where they would shout "Mnatembea na pesa" [You are walking with cash]. By this, they meant that we are walking with a person whose body parts are worth a lot of money. The series aims at highlighting the traditional and religious beliefs that make the lives of persons with albinism so difficult, and through its diary format, demystify these beliefs.

Creative Works
FOURTEEN CRITICAL QUESTIONS

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Abstract

A poem composed of a series of questions.

Keywords: poetry, disability

FOURTEEN CRITICAL QUESTIONS

(In No Particular Order)

Ask her.

Ask her   if smoke stings?

Ask her   if the flames changed colour as they ate through the seven layers
                                   of her skin?

Ask her   if she knows when the smell started?

Ask her   if she knows at what point burning skin stops feeling anything
                                   and just blackens?

Ask her   if she knows the price of any of the following:
                        .   half a litre of 98 octane
                        .   a box of Lion matches
                        .   an old car tyre
                        .   ten bricks, broken into halves?

Ask her   if she really can fly?

Ask her   what happened to her legs, and if that is why she can fly?

Ask her   if the reason she has no husband
                        is because of what happened to her legs when she was born?

Ask her   if she knows what happened to that little boy, the one from over there,
       behind   that clump of trees?

Ask her   if she knows the price of any of the following:
                        .   half a litre of 98 octane
                        .   a box of Lion matches
                        .   an old car tyre
                        .   ten bricks, broken into halves?

Ask her   if it is true that she can understand what the trees are saying?

Ask her   if she ever touched the bottom of the deep lake?

Ask her   if she knows whether heads can grow back
                                   like lizards' tails?
Ask her   if she knows how long it takes for bone to break down into dirt?

Ask her.

Go on.

A Critical Tiriti Analysis of the New Zealand Disability Strategy 2016-2026

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Abstract

Health policy is one mechanism to address inequities and protect Indigenous people's access to the shared human right to health. Te Tiriti o Waitangi (the Māori text) negotiated between the British Crown and Māori (the Indigenous peoples of Aotearoa) outlines the social contract between Māori and Non-Māori. It was negotiated in part to protect Māori health. Within Aotearoa there continues to be significant ethnic inequities in disabilities. This paper undertakes a retrospective Critical Tiriti Analysis of the *New Zealand Disability Strategy* to determine its compliance with Te Tiriti. It also considers whether such an analysis might strengthen responsiveness to Indigenous peoples elsewhere. This analysis involved a five-phase process of review. Through our analysis we identified poor to fair engagement with the responsibilities outlined in Te Tiriti o Waitangi. There were promising statements about the special relationship between the Crown and Māori, conflicting statements about governance and self-determination, and limited engagement with ethnic specific equity concerns or spirituality. To strengthen the Strategy the authors determined Tāngata whaikaha (Māori disabled people's) views needed to be more strongly centered within the structure and content. The historical and contemporary determinants of Māori health needed to be included along with deeper engagement with intersectionality and Te Tiriti o Waitangi responsibilities. Undertaking critical policy analysis is an effective method to inform and review policy that may be applicable in other settler-colonial contexts with significant ethnic health inequities.

Keywords: disabilities, policy analysis, Te Tiriti o Waitangi, health inequities, Māori, human rights, Indigenous

A Critical Tiriti Analysis of the New Zealand Disability Strategy 2016-2026

Tāngata whaikaha are a vibrant part of the rich diversity of communities that make up Aotearoa. Tāngata whaikaha run businesses, compete in sports, contribute to the arts, to families, political and community work. They have the same right to health care, education, shelter and freedom from discrimination that all New Zealanders enjoy. This commitment to the human rights of disabled people is proclaimed in our government's endorsements of human rights instruments such as the *Convention on the Rights of Persons with Disabilities* (UN, 2008) and the *Declaration on the Rights of Indigenous Peoples* (UN, 2007).

Despite statements that disability services will be accessible to and culturally appropriate for disabled Māori and their whānau promulgated in the *New Zealand Disability Strategy* (NZDS) (Office for Disability Issues, 2016), there are severe disparities between the experiences and outcomes of Māori with impairments and disabilities and those of non-Māori. Disabled people continue to have poorer social and economic outcomes than non-disabled people (Statistics New Zealand, 2014). These inequities impact the ability of tāngata whaikaha to participate fully in society. Some 24% of New Zealanders live with a disability; for Māori that rate increases to 32% (Statistics New Zealand, 2015).

A review by Ratima and Ratima (2007) notes major differences between tāngata whaikaha and other people with disabilities, including rates, severity, and age ranges of impairment. These disparities are exacerbated by social inequalities, access to appropriate services and levels of unmet need for care and equipment, but this state of affairs has not yet prompted any adequate response from the health system:

> Despite compelling evidence of wide inequalities, there has not yet been a comprehensive effort to identify distinctive Māori disability support needs nationally and to action a strategy to address those needs in a coordinated way.
> (Ratima and Ratima, 2007, p.192)

The 2013 Disability Survey (Statistics New Zealand, 2014) noted that for tāngata whaikaha, material wellbeing was compromised by high unemployment, lower incomes, and access to housing. These factors impacted quality of life with low qualification rates, poor self-ratings on health, personal safety, racism/discrimination and participation in leisure activities. These negative social outcomes provide an incomplete picture of the complex diverse lived experiences of tāngata whaikaha (Hickey & Wilson, 2017; McGruer et al., 2019).

To address these concerns, Māori have been developing identities, analyses, models and frameworks for understanding and addressing disability (Hickey & Wilson, 2017; Smiler & McKee, 2007). Ratima (1995) developed Te Anga Whakamana, for instance, as a model that could work for all New Zealanders and Māori in particular, based on the principles of enablement, participation, safety, effectiveness, accessibility and integration. It acknowledges the need to get 'mainstream' providers on board with these principles but also that many tāngata whaikaha will only be fully comfortable when their needs can be met by properly resourced Māori practitioners.

Hickey (2006) has argued for an approach based on Te Whare Tapa Whā (Durie, 1998), that centers on equitable access to resources and amenities for people of differing abilities. Brewer, McCann, Harwood and Worrall (2015) working in the domain of Māori with aphasia found that outcomes depended on factors relating to clinicians, resources, and practices. The understandings, attitudes, and connections of staff members along with the funding, assessment processes and therapies available, as well as the culture of teams, their expectations. and processes, were central to outcomes for tāngata whaikaha.

Such inequities in disability and health outcomes for Indigenous peoples and disabled Indigenous people is a global problem (Department of Economic and Social Affairs, 2009). A literature review around tobacco use which is a key cause of disparate burdens of illness and disability among indigenous peoples in the US, Canada, Australia and New Zealand

(DiGiacomo et al., 2011) found a paucity of tailored cessation interventions, exacerbating entrenched inequities. Hollinsworth (2013) noted that for Australian indigenous peoples, these disparities are mostly ignored by health policy and authorities, such that their elimination requires analyses of colonization, intergenerational racism and intersectionality with other oppressions. Colonization, intersectionality and neoliberalism are also called out by Stienstra (2018) who argues that even recognized human rights provisions in policy, are insufficient to ensure indigenous inclusion in the Canadian setting. The marginalization of indigenous ontologies relevant to conditions defined as disability in medicalized discourses is seen as critical to the suppression of enabling, inclusive indigenous perspectives and thereby, the maintenance of colonial assimilation and harms (Ineese-Nash, 2020). Dew et al. (2020) in their study of Anangu people with disabilities found being connected to lands, and family, sharing and working together were essential to well-being.

The point of difference between Aotearoa and other settler-colonial countries in relation to Indigenous health is our foundational document Te Tiriti o Waitangi. Te Tiriti was negotiated between the British Crown and Māori rangatira (chiefs) and reaffirmed Māori sovereignty, granted limited governance to the British to mind their people and granted Māori the same rights and privileges as British subjects (Berghan et al., 2017). This social contract lies at the heart of the relationship between Māori and non-Māori, and its protection of Māori health and wellbeing is embedded within health legislation and policy.

Given the enduring ethnic inequities in disability within Aotearoa, it seems likely that the protections of Te Tiriti have not historically been upheld. Given that the Waitangi Tribunal, a permanent independent commission of inquiry into alleged breaches of te Tiriti, is currently investigating the health sector through WAI 2575 (Waitangi Tribunal, 2019), it seemed timely to review disability policy. In this paper, the authors use a novel methodology Critical Tiriti Analysis to review the NZDS to test its compliance with Te Tiriti. We expect such an

examination will be of interest to others working in settler-colonial contexts interested in strengthening engagement and commitment to Indigenous health.

Method

We have selected the NZDS to review as it is the current peak disability strategy in Aotearoa. The Strategy was developed in 2016 under a conservative coalition government. There was inconsistent engagement with te Tiriti and Māori health within public policy at that time (Came et al., 2018; Came et al., 2019). We acknowledged the mana (prestige and authority) of those that contributed to, authored and signed-off the New Zealand Disability Strategy (NZDS) (Office for Disability Issues, 2016). We recognize that this critique only addresses what is written on the page and does not capture the complex dynamics of good will and good intentions. The authors are Māori and non-Māori critical scholars and temporarily able-bodied allies interested in strengthening health policy, enhancing equity and te Tiriti compliance.

We choose to use Critical Tiriti Analysis (CTA) developed by Came, O'Sullivan and McCreanor (2020) as a critical policy analysis tool to determine whether NZDS is compliant with Te Tiriti o Waitangi. It was developed in response to the experience of giving evidence before the Waitangi Tribunal. As per other completed CTAs (Came & Kidd, 2020; Came, Kidd, et al., 2020; Came et al., 2021; Goza et al., 2021; Kidd et al., 2021; O'Sullivan et al., 2021; Rae et al., 2022), we used a five-phase system.

In the initial orientation phase, we conducted a high-level review of the NZDS in relation to language, cultural epistemology, priorities and how the policy engages with Te Tiriti o Waitangi, the Treaty of Waitangi and the Treaty principles. In the second close examination phase, we reviewed evidence of how the Strategy engaged with the elements of the Māori text, preamble, kāwanatanga, tino rangatiratanga, ōritetanga, wairuatanga. This involved looking at statements of values, intent and the detail available about the process of the Strategy's

development.

In the third phase, we made a determination of whether the policy aligned to a set of *Te Tiriti* indicators. We applied the CTA assessing criteria consistently with previous CTAs:

- Poor – The policy substantially failed to transparently address the indicator.

- Fair – The policy had vague engagement with the indicator.

- Good – The policy deliberately and consciously addressed the criteria.

- Excellent – The policy clearly achieved the indicator.

The fourth phase focuses on what could be strengthened in the reviewed policy and the fifth phase is a final Māori assessment of the overall policy. The CTA was undertaken by several authors who negotiated a consensus interpretation and assessment. This collaboration enabled assumptions and biases to be challenged and new understandings reached.

Results

Phase One: Orientation

Our phase one review found NZDS strongly reflected a Western epistemologies and world view in its structure. There is however a stated commitment to weaving Māori world views through the implementation of the Strategy. The importance of Te Reo (Māori language) is affirmed and Māori terms such as whānau (meaning extended family) are used throughout the Strategy. A whakataukī (Māori proverbs) is included within the strategy, and there is solitary reference to kōhanga reo and kura kaupapa Māori (types of Māori immersion schools).
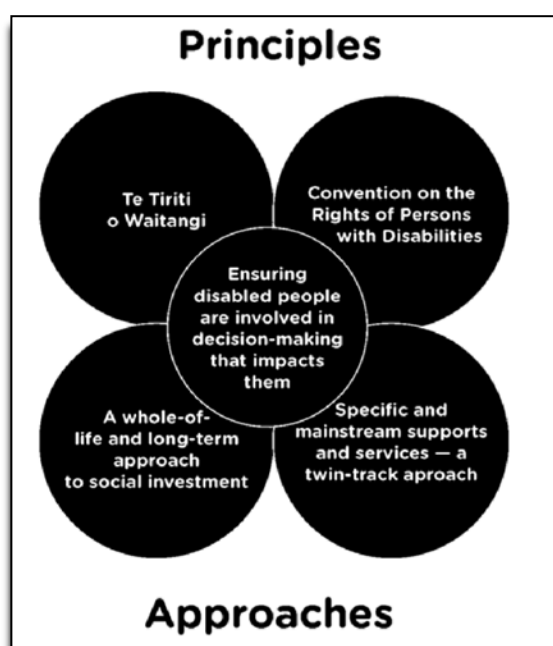
The NZDS (Office for Disability Issues, 2016) has a strong inclusive universal orientation focusing on achieving equal opportunity for all New Zealanders. It states "…all of our community is visible, acknowledged and respected on an equal basis…" Neither the overall framework for the strategy nor the priority eight-outcome areas therefore make explicit mention of prioritizing Māori health.

The Strategy consistently refers to Te Tiriti o Waitangi the Māori text as the founding

document of New Zealand. Te Tiriti is explicitly identified as one of three principles of the Strategy (see figure 1). But when te Tiriti is addressed in more detail it refers to the Royal Commission on Social Policy (1987) Treaty principles of partnership, participation and protection.

Figure 1

NZDS principles & approaches

(Office for Disability Issues, 2016, p.16).

Phase Two: Close examination

The second reading involves seeking evidence of engagements with the element of Te Tiriti.

Preamble

Within the diversity section Māori are recognized as tangata whenua, as the Indigenous people, the first people of this land. The special relationship between Māori and the Crown is reinforced through a reference to Te Tiriti o Waitangi as our founding document. The Strategy emphasize the importance of a relationship between Māori and the Crown characterized by

"…good faith, mutual respect and understanding and shared decision-making" (p. 18).

Kāwanatanga

There is a commitment in the Strategy to include whānau, hapū (sub-tribes), iwi (tribes) and Māori communities "at all levels of decision-making" (p. 18). The NZDS was developed through a significant consultation process involving face to face workshops on-line submissions and an expert reference group. It is not clear to what extent Māori engaged in these processes, but the reference group included the perspective of two Māori disabled people. We understand from an insider involved in the development of the Strategy that a bicultural co-governance model was proposed and rejected (Anon personal correspondence, 28 April 2020). In addition, the draft signed off by the expert reference group through a consensus process was later considerably changed by officials after subsequent consultation among Government agencies.

Figure 2

NZDS Governance & monitoring
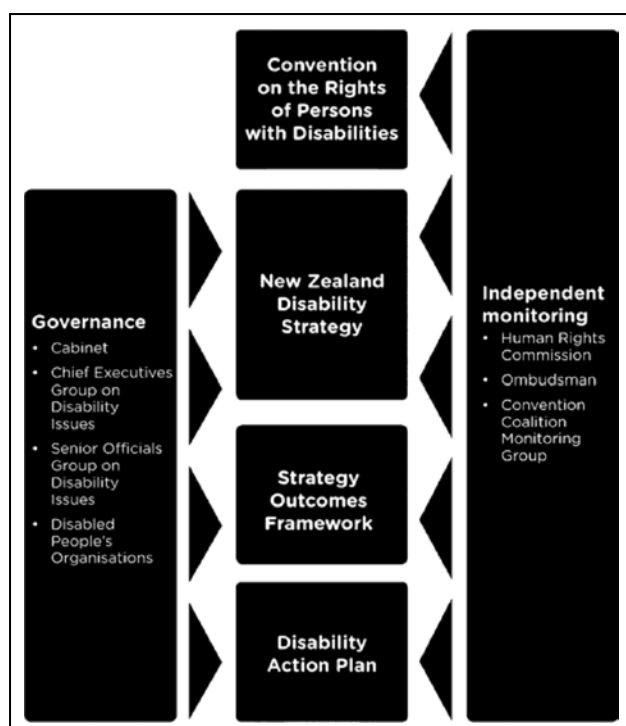
(Office for Disability Issues, 2016, p.40).

Figure 2 shows the governance and monitoring schematic for the NZDS; which renders tāngata whaikaha, whānau, hapū and iwi voice invisible. It is unclear how Māori are involved in the Independent Monitoring Mechanism the government established to review the implementation of the NZDS. The Office of Disability Issues has planned ongoing consultation around updating the national disability action plan and associated outcomes framework. The Strategy states that the consultation process will consider the principles of Te Tiriti. Tāngata whaikaha or more broadly Māori are not however identified as stakeholders for achieving the vision of implementing the NZDS.

Rangatiratanga

The Strategy mentions Māori seeking self-determination but does not directly address the dynamics of rangatiratanga within the Te Tiriti partnership. Kaupapa Māori disability providers, who work from a Māori philosophical worldview delivering health and social services by Māori for tāngata whaikaha are invisible within the NZDS. The Strategy incorporates a handful of references to government reports and one non-governmental organization report. There is no evidence that engagement with the scholarly work of Māori academics as informed this Strategy.

The Strategy priorities eight key aspirational outcome areas to build a shared understanding of the future for disabled people. The need for a uniformed approach is strongly emphasized to: "…make sure that everyone has the same understanding about what the future should look like and that all actions are consistent with this" (p. 23).

Ōritetanga

The NZDS outlines a "twin-track approach" to health services where there are

"mainstream" services and specific services for disabled people. Kaupapa Māori and/or iwi disability, health and social service providers are all invisible within the Strategy. The pursuit of equity is acknowledged in the Strategy without detail of how this might be achieved.

Wairuatanga

The importance of Māori values and world views is briefly identified within the Strategy. The need for culturally appropriate health services is stated as is the importance of being able to contribute to cultural activities. Rongoā Māori (Māori medicine) and wairua are not mentioned in the Strategy.

Phase Three: Determination

If *te Tiriti o Waitangi* was upheld within the NZDS, it would score good and excellent assessments in table one against the CTA indicators. The NZDS consistently scored poor and fair assessments. In relation to indicator one, the Strategy mentions the special relationship with Māori but this is not reflected elsewhere in the document. For Indicator two, there were two Māori on the expert reference group, but no further mechanism appeared to be in place to elevate Māori leadership. Research by Came, McCreanor, Haenga-Collins and Cornes (2019) suggests inequities in the health system also reproduced in advisory groups. There was a whakataukī included within the Strategy but limited or no engagement with Māori values, epistemologies, or approaches. Māori are listed as a special group in the diversity section of the Strategy but consideration to Māori aspirations is not visible. Wairua, rongoā and tikanga (cultural protocols) are not recognized within the Strategy.

Table 1

Assessment of NZDS against CTA indicators

Assessment of NZDS Against CTA Indicators

Indicators	Poor	Fair	Good	Excellent
1. Māori equal or lead partners in policy development		✓		
2. Mechanisms to ensure equitable Māori participation/ leadership	✓			
3. Evidence of inclusion of Māori values epistemologies, approaches and authority		✓		
4. Māori exercising their citizenship as Māori	✓			
5. Acknowledging importance wairua and rongoā	✓			

Discussion

Phase Four: Strengthening practice

Reviewing the NZDS, we identified four areas that we believe could be strengthened. These were: i) centering Māori world views, ii) addressing the determinants of Māori health, iii) embracing intersectionality and human rights and iv) deeper engagement with Te Tiriti o Waitangi responsibilities.

Centering Māori world views

Within the NZDS, the Office for Disability Issues (2016) recognized that:

Most Māori disabled people identify as Māori first. The importance of their cultural identify, which encompasses language, whānau, cultural principles, practices and linkages to the land through genealogy, is paramount to how they live their day to day lives in both Te Ao Māori [the Māori world] and Te Ao Pākehā [the settler world].

An initial review confirmed that the NZDS has privileged Te Ao Pākehā rather than Te Ao Māori. One way of centring tāngata whaikaha world views would have been to frame the strategy using *Te Pae Mahutonga* (Durie, 1999) or another Māori health model. With Te Pae, Durie uses the Southern Cross to represent the elements of a Māori health promotion approach

to wellbeing. Most critical are the two pointers – that is ngā manukura (community leadership), and mana whakahaere (autonomy), which is about Māori control. The other elements include mauriora (cultural identity), waiora (physical environment), toiora (healthy lifestyles) and te oranga (participation in society). All elements need to be incorporated and addressed.

Tāngata whaikaha is a term gifted by a prominent elder Maaka Tibble to the disability community in 2015 (Opai, 2017). Tāngata whaikaha is a strength-based description to strive for enlightenment and enablement. It captures Tāngata whaikaha taking rangatiratanga (absolute control) over how they wish their impairments/disabilities to be described in Te Reo Māori (Māori language). The term tāngata whaikaha encapsulates all disabled people and also includes tāngata whaiora, a term that is used to mean a person who is subject of care, assessment and treatment in mental health. The Office for Disability Issues did not use this Māori term within the Strategy.

Māori and/or iwi health, disability and social service providers and services are an important expression of tino rangatiratanga (sovereignty) within Aotearoa. They are services developed from a Māori philosophical perspective by Māori for Māori. The twin-track approach outlined within the NZDS recognizes "mainstream" services and specific disability services but renders invisible the option of kaupapa Māori providers.

There is considerable evidence that kaupapa Māori services are effective in delivering quality holistic care to Māori whānau (Forrest et al., 2016; Gould et al., 2013; Te Puni Kōkiri, 2013). This effectiveness in part comes from the employment of Māori practitioners that are both clinically and culturally competent (Hunter, 2019; Wilson, 2018). Māori nurses for instance are often immersed in tikanga (Māori protocol), whakapapa (genealogy), and are fierce advocates for Māori whānau (Simon, 2006).

Determinants of Māori health

The Strategy failed to address the historical, cultural, political and social determinants of

tāngata whaikaha health and well-being (Kiro, 2000; Robson, 2007). The inter-generational impact of the trauma of colonization on Māori whānau is well documented but rarely considered in public policy (Pihama et al., 2014). This historic legacy is compounded by contemporary manifestations of racism across the administration of the public sector (Came, 2014; Came et al., 2017). Within the health sector, racism can also be traced back to the quality and quantity of health care Māori whānau can access (Crengle et al., 2005; Harris et al., 2019).

Health inequities are fueled by the socio-economic circumstances in which people work, live and play (Marriott & Sim, 2014). The average Māori household income in 2013 was $22,500 (Statistics New Zealand, 2013), while the living wage in New Zealand was $46,500 (Living Wage Aotearoa New Zealand, 2017). The living wage is calculated to determine the real costs of essential family needs as well as energy, health, communication and education costs. These economic realities are different for Māori and non-Māori. Public policy needs to address the determinants of health and recognize the impact of the normalization of racism and privilege within settler colonialism.

Intersectionality and human rights

The NZDS would be strengthened by engagement with additional human rights instruments such as the Convention on the Rights of Indigenous Peoples (UN, 2007). There is strong evidence of systemic discrimination and disparities of outcomes disadvantaging Māori within the education and health sectors, the criminal justice system and elsewhere (Harris et al., 2019; MacDonald, 2019; McAllister et al., 2019; Workman, 2011). To achieve equitable access for all disabled people requires engagement with what Crenshaw (1991) calls intersectionality. Disabled people experience discrimination due to disability, but many also experience racism, sexism, homophobia and other forms of discrimination. All of these factors need nuanced consideration, especially racism, given it is importance as modifiable determinant of Indigenous health and wellbeing (Paradies, 2016).

Proportional universalism

Universal access to health services is widely accepted as part of the social contract in Western liberal social democracies. In the context of significant ethnic inequities in social and economic outcomes (Marriott & Sim, 2014), such as in New Zealand, the application of universal provision serves to maintain pre-existing inequities. Marmot (2010) maintains if a health service is committed to health equity, as claimed in the NZDS, it needs to engage with what he calls proportional universalism. That is "…actions must be universal but with a scale and intensity that is proportional to the level of disadvantage."

Te Tiriti o Waitangi

Although the Strategy mentions Te Tiriti and emphasizes the special relationship between Māori and the Crown, this specialness is not reflected in the substance of the document. To uphold Te Tiriti, the NZDS needed to be much more explicit about how they proposed to engage with their te Tiriti responsibilities. It is not explicit how Māori have been involved in the development of the Strategy, or how they will be involved in implementation, monitoring and evaluation. It is unclear how this document advances tāngata whaikaha aspirations.

From a technical viewpoint, it is something of a polemic to refer to te Tiriti o Waitangi (the Māori text) which affirms Māori tino rangatiratanga (absolute sovereignty) and the Treaty principles interchangeably (Berghan et al., 2017). Scholars such as Durie (1998) have long maintained that Māori place greater emphasis on the actual words of te Tiriti rather than the Treaty principles because the definition of these has been left to the Crown acting on their own. It would therefore be more tika (correct) if the NZDS referred to the Articles of the Māori text of te Tiriti rather than the Crown-defined Treaty principles.

From the international experience in the field of disability among indigenous peoples, particularly those in anglophone colonial settings raised in the introduction, many of the issues with colonization, racism and other intersectional oppressions evident in the setting of Aotearoa apply. We can add to Stienstra's (2018) view that indigenous, local, community perspectives are of critical importance to the constructive inclusion of indigenous disability, to argue that even a foundational document like Te Tiriti cannot prevent inequities unless the society is decolonised and transformed toward systems of natural justice for indigenous peoples. What Te Tiriti can do along with international human rights instruments such as the Declaration of the Rights of Indigenous Peoples (UN, 2007), is set in place alternative philosophies of society that allow the development and enactment of Indigenous-centered policy and practice for the elimination of this and other critical disparities.

Conclusion

Phase Five: Māori final word

It is sense of pōuritanga (sadness of heart) to review another health strategy centered in a western paradigm, tokenistic and hollow in its intent. It signals, another failed and lackluster opportunity to address and support Māori, who are overrepresented in disability statistics.

The uses of a whānau centered and well known whakatauakī, *He aha te mea nui o te ao*, must in principle be acknowledged as an attempt to weave a Māori worldview into the NZDS. It is an attempt to uphold the integrity and cultural important of people and whānau centred approaches. However, in my perspective, this whakatauakī has its own mana, mauri (life essence) and wairua (spiritual essence). Anyone using this whakatauakī must act with integrity, practice cultural authentic engagement, whānau centred approach, and a true commitment to Te Tiriti o Waitangi.

Unfortunately, the strategy does not actively demonstrate true commitment to the mana of the whakatauakī. It disappointingly does not implement any values of collectivism, whānau

centred or whānau empowerment. There is little added value in the NZDS to understand the burden of disability for Māori, both from an individual and collective view. This should include essential dimensions of cultural appropriate health care, resourcing to support the life, work or play environments of tāngata whaikaha.

The CTA clearly highlights ways in which the strategy could be strengthened from a Māori worldview, at the center within the structure and content. How the NZDS engages with Māori as a collective of whānau, hapū and iwi, and/or as individuals, is unclear. Including only two perspectives of Māori disabled people on a reference group is inadequate. The NZDS fails to commit to tāngata whaikaha on many levels. This including failing to demonstrate a true or meaningful Te Tiriti o Waitangi relationship or partnership, bicultural governance, monitoring and decision making. This strategy has failed Māori and Tāngata Whaikaha.

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"Listen to the Parents, Just Listen to Them": Exploring the Beliefs and Actions of Mothers Advocating for their Children with Disabilities

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Abstract

Through the analysis of 13 interviews of mothers who self-identify as advocates or activists, the author describes how mothers' experiences with and understandings of disability impact the narratives they tell and the actions they take when advocating for their children. While participants identified positive results of advocacy, many mothers recognize the limits of their advocacy. This work is significant because parental narratives and counter-narratives are powerful in that they may challenge existing notions of disability.

Keywords: disability studies, parenting, counter-narratives

"Listen to the Parents, Just Listen to Them": Exploring the Beliefs and Actions of Mothers Advocating for their Children with Disabilities

> Listen to the parents, just listen to them. Know that they know who their child is. They have been doing this for a long time, struggling for a long time. You need to listen to them, to understand them, to understand their child- not in the way that you view them, but in the way that the parents view them. ~ Mariela[1]

While 14% of elementary and high school students in the United States have disabilities (National Center for Education Statistics, 2019), many schools have failed to create inclusive spaces to serve all children (Danforth & Gabel, 2006). Within this context, parents have a unique role in advocating for their children. This article explores caregivers' perspectives of children with disabilities as they advocate for their children. I have centered caregivers' experiences because they are often the first to frame disability for their children and advocate for their children within medical and educational systems (see Valle, 2009). I have specifically focused on the stories of mothers because only mothers responded to my research call, which is consistent with the literature that describes mothers' central role in caring for and advocating for their children with disabilities (Fisher & Goodley, 2007; Valle, 2009). However, many of the lessons learned from interviewing mothers would also extend to other caretakers (Rogers 2007a).

Mothers' understandings, frameworks, and advocacy efforts can impact their children's early experiences in school and society. As such, I assert the need to heed Mariela's call to "listen to parents," listening to mothers and caregivers' experiences can provide a perspective from those simultaneously navigating and critiquing education systems. In this context, listening can also offer insights about places where parents, including those who self-identify as advocates or activists, could benefit from connections to larger disability rights and disability

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[1] The names of all mothers in the study are pseudonyms.

justice movements.

In this article, I explore what disability means to mothers and how understandings of disability impact actions. While many of the parents in my study do not identify as having disabilities, *"[e]veryone, disabled or not, who interacts with disability is engaged in producing its meaning and its social identity" (Titchkowsky, 2003, p. 4; see also Rogers, 2007b). As such, caretakers have experiences and knowledge that have value in discussions about school-based practices for children with disabilities.* Specifically, I explore the following questions through both parent narratives and a review of the literature:

• How do mothers understand disability?

• How do mothers advocate for their children, other specific children, and children with disabilities in general? How do they understand the use of cultural, economic, and social capital to influence advocacy efforts?

• What do mothers hope for their children and children with disabilities in general?

Theoretical Frameworks

This article utilizes Critical Disability Studies (CDS) and Disability Studies in Education (DSE) frameworks to explore mothers' understandings of their own beliefs and actions.

Critical Disability Studies

Disability Studies (DS) is an interdisciplinary field that, according to Dan Goodley (2011), provides a *counter-view* to medical (or deficit) models of disability and focuses on "cultural, historical, and socioeconomic conditions" that impact individuals with disabilities (p. 9). Many DS scholars have illustrated ways that our school policies operate within the medical/deficit model that seeks to "diagnose" and "treat" students with disabilities to help them become more like their nondisabled peers (Valle, 2009). There are many alternatives to the medical model, including the social model, popularized by Oliver in the 1980s, which positions "disability as a political category and provide[s] a vocabulary for contesting the processes of disablement: social, economic and cultural barriers that prevent people with impairments from living a life like their non-impaired brothers and sisters" (Goodley, 2014, p. 7).

Within the larger field of Disability Studies, I specifically draw upon the ideas of Critical Disability Studies (CDS) scholars. While CDS does not ignore experiences of the body (Goodly, 2014, p. 84) or physical or physiological differences that have meaning in people's lives, it provides a framework to examine "the interaction between ideas, the body, and society" (Robinson, 2017, par. 2). This informs my work in two ways. First, in this work I seek to explore the impacts of ableism, a system of beliefs that centers and normalizes the experience of nondisabled people, and disableism, which includes active "oppressive practices" that discriminate against individuals with disabilities (Goodley, 2014, xi). Second, critical disability studies, according to Goodley 2013, "starts with a disability but never ends with it" (Goodley, 2013, p. 632). As Annamma et al. (2016) document, there are "qualitatively different experiences of students of color labeled with the same dis/ability in comparison to White peers" (p. 15; also see Voulgarides et al., 2021). Further, racism and differing conceptualizations of independence can create barriers for families of culturally and linguistically diverse students (Harry and Ocasio-Stoutenburg, 2020, p. 116). The mothers interviewed are engaging in larger systems, and such engagement is influenced not just by disability but also by race, class, gender, and other identities.

Disability Studies in Education

Disability Studies in Education (DSE) scholars use similar theoretical frameworks as DS scholars; however, DSE emerged in the late 1990s when "scholars and educators began to move away from positivist inquiry and problematized conceptualizations of disability as deficit" within education systems (Buffington-Adams & Vaughan, 2019, p. 4). Focused on the ways that disability is understood and acted on within schooling, I embrace DSE's focus "on *what disability means*; how it is interpreted, enacted, and resisted in the social practices of individuals, organizations, and cultures" (Danforth & Gabel, 2006, p. 5). In addition, DSE provides a framework to explore parents' understanding of disabilities and even parents' hopes for their children.

Literature Review

I seek to contribute to an ongoing conversation about parent advocacy and disability. Multiple scholars have documented how parents of children with disabilities navigate school and social systems (Valle & Gabel, 2010; Ware, 2002), retheorize experiences through counternarrative (Ferguson & Ferguson, 1995; Kitty, 1999; Ryan & Runswick-Cole, 2008; and Vaughan & Super, 2019), critique existing curricular, pedagogical practices in schools (Gabel, 2002), and advocate for children in schools (Lalvani & Hale, 2015; Leitner, 2004; Kliewer, 2006; and Rogers, 2007a). I am influenced by scholars who have documented how varying degrees of social, economic and cultural capital affect the efficacy of advocacy work (Harry, 2008; Harry & Ocasio-Stoutenburg, 2020; Ong-Dean, 2009; Ryan & Runswick-Cole, 2008; Sauer & Lalvani, 2017). Finally, I am influenced by typologies of narratives, including a study by Fisher and Goodley (2007) that describes three types of narratives that parents of young children with dis/abilities tell about their experience of motherhood, including a narrative of "challenge," which aligns with a social model of dis/ability. Within this narrative, mothers are more critical of professional or expert opinions and more likely to engage in "resistance against oppressive and normative values" (p. 73). In the "narrative of challenge," which is similar to the narrative of resistance (Valle & Gable, 2010) or the "quest narrative" (Frank, 2013), parents resist unjust structures within schools and society.

In crafting my call for parents who self-identified as advocates or activists, I anticipated having multiple parents engaged in "narratives of challenge." In my work, I seek to expand upon these bodies of literature by discussing parental understanding of disability, advocacy efforts, recognition of privilege within such advocacy efforts, and hopes and desires. In so doing, I hope to offer counternarratives of disability and schooling.

Methods and Positionality

I utilized an interpretive framework in this small qualitative study, designed as an exploratory

project (Glesne, 2011). As an interpretivist, I seek to understand how mothers' lived experiences influence their understandings of disability. I also seek to understand how mothers interpret their actions. I am also influenced by critical frameworks in that I am centering the knowledge and agency of those being interviewed with a focus on impacting future practices. As Ferguson and Ferguson (1995) explain, counternarratives can transform the field of disability and special education research by providing a forum for those impacted by disability to share their own stories and expose conditions that need to be changed (pp. 118-119).

Focus on narratives

 I asked mothers to share their own stories of mothering and advocating with me in this work. I did not verify the stories they were sharing, nor did I ask their children or educators for their own stories of the same events. As such, my article seeks to amplify the experiences and stories of mothers, focusing on sharing stories so that mothers could learn from each other, and educators and researchers could consider the experiences and wisdom of parents. Because the act of mothering is often private and because I was asking parents to share stories about mothering (which is, of course, relational), I made sure that participants were aware of the purpose and process of the interview, as well as their rights to skip questions and/or withdraw consent at any time.

Author's Positionality

While this work is not auto-ethnographical, I acknowledge that this work is a standpoint project in that my own experiences as a member of the community I am studying (Harding, 2009, p. 149-150) inform the questions I ask and my understanding of the context of schooling. As a researcher, I also disclosed my experience as a mother of a child with disabilities to research participants, which may have provided a level of familiarity with the experiences mothers shared. However, I sought to ask questions clearly and interpret parents' experiences without

bias. Within these tensions, I sought to "work the hyphen" to make transparent my relationship with those researched (Fine, 1994, p. 72).

Qualitative interviews

In designing this research project, I worked with representatives from three organizations that work with families of children with disabilities to distribute information about the study to potential participants. In determining eligibility, I focused on mothers who met three criteria: each has a child or children with a disability eligible for school-based services; the child had experience in public or private schools; the mother self-identifies as an advocate or activist. *In formulating my research questions, I looked at academic research and publicly documented parental narratives, including newspaper and media articles. My central questions focused on participants' early experiences with and understandings of disability; knowledge of and actions taken regarding their child's schooling and community activities; experiences with schooling and special education services; and advocacy or activism related to dis/ability. Inspired by Eve Tuck's (2009)* calls for researchers to move toward "desire-based" research in which participants share not only pain but also "wisdom and hope" (p. 416), I also asked parents about their hopes or desires.

Interviews were semi-structured. I recorded each interview using a digital audio recorder and transcribed and coded each interview. Many of the codes were "in vivo" codes, coming directly from participants' words (Glesne, 2011, p. 195). Codes evolved and changed through analysis (Glesne, 2011, p. 197). I analyzed transcripts using AtlasTI qualitative data analysis software for common themes. After the analysis was concluded, I shared my findings with colleagues and conference audiences. I also sought to identify connections between what I had observed and themes presented in the existing literature.

Table 1

Name	Advocacy/ Activism Efforts (not a complete list)

Adeline	- School-based advocacy for her child, including providing education for teachers and community members - Community and state advocacy through organizations or nonprofit organizations focused on both special education and disability-specific initiatives - Leadership roles in a community organization or nonprofit organization
Betty	- School-based advocacy for her child - Advocacy through professional activities in her role as an educator
Carmen	- School and community-based advocacy for her child and children of friends or community members - School and organizational volunteer and leadership activities - Advocacy at the community level for special education
Helena	- School, community, and church-based advocacy for her children - Advocacy for children of friends or community members
Isabel	- School-based advocacy for her child, including providing education for teachers - Advocacy for children of friends or community members - Participation in an informal group for mothers of children with disabilities
Elaine	- School-based advocacy for her children, including providing education for teachers and community members - Advocacy through professional activities as an educator - Advocacy for other individuals with disabilities
Frida	- School-based advocacy for her child, including providing education for teachers and community members - Advocacy for other individuals with disabilities, - Volunteer work with a disability-specific organization, including meeting with other families
Julia	- School-based advocacy for her child - School-based advocacy for children throughout the community and city - Community advocacy through a community organization or nonprofit
Katrina	- School-based advocacy for her child, including providing education for teachers and community members - School, community, and statewide advocacy for children with a specific disability
Mariela	- School-based advocacy for her child - Advocacy with community organizations or nonprofits, including speaking with the press and attending district meetings
Nancy	- School-based advocacy for her child - District-wide advocacy for children with the same disability as her child - Volunteer activity and leadership within organizations for children with same disabilities as her child
Olivia	-School-based advocacy for her child, including providing education for teachers and community members - Advocacy for children of community members - Advocacy through professional activities as an educator - Work with community organizations or nonprofits, including legislative advocacy and media advocacy
Reina	- School-based advocacy for her child, including education for teachers/ schools/community - Online education and advocacy about a specific disability

Mothers interviewed

I interviewed 13 participants, including nine White women, one African American

woman, and three Latina women. Three mothers either discussed having a disability/ chronic

health condition or recounted their personal experiences in special education classrooms. Three additional mothers grew up with family members with disabilities. All participants lived in the Midwest region of the United States, with participants from large urban areas, suburbs, and towns. Four participants discussed professional experience working with people with disabilities in schools or health care settings.

Multiple disabilities/disability labels represented

Each mother interviewed had at least one child who had received special education services, and four mothers had more than one child with a disability label. Participants shared that their children had a wide range of disabilities/ disability labels, including epilepsy, Tourette's syndrome, Attention Deficit Hyperactivity Disorder, autism, speech apraxia, hearing impairment, anxiety, cerebral palsy, learning disabilities, and cognitive impairments. Children were in various school-based placements, including public and private schools. Within those schools, children were educated in general education classrooms for children with and without disabilities, co-taught classrooms with general education and special education teachers, special education classrooms that included only children with disabilities, and special education schools for only children with disabilities. Because I only interviewed 13 mothers, additional research that included a more diverse representation of parents would be beneficial to see if the themes identified below were more widespread.

Findings and Themes

Instead of presenting results, I offer four themes gleaned from in-depth interviews. Within these themes, I assert that mothers' understanding of and experiences with disability and their social, economic, and cultural capital influenced their advocacy efforts. While most participants found that individual advocacy efforts were successful, many mothers acknowledged the limitations of individual advocacy

Theme one: Mothers had a wide range of understandings about disability informed by various information-gathering processes

> I always said God doesn't make abnormal people; people make abnormal people, . . . their ability might not be like the majority, but they have ability. ~ Helena

Language of disability

The women in the study described their children's disabilities in various ways. Some used the term disability, while others preferred "differences" or "special needs." About half of the mothers in the study talked about disability as needing *extra* help to accomplish tasks (academic, professional, independent living). While this can be understood as a conservative or "deficit" perspective in that it compares a person with disabilities to a peer without disabilities, many participants mentioned that all people have strengths and challenges (Broderick & Lalvani, 2017). In addition, a few mothers interviewed expressly rejected words like "typical" or "normal." For example, in the quote above, Helena rejects the labels of normal/abnormal and asserts that it is not her children's impairments but how society interacts with her children, creating the concept of "abnormal." Thus, even though parents did not reference Disability Studies literature, many parents shared a rejection of definitions that reified deficit perspectives. This is important because some participants critiqued schools for focusing too heavily on deficit perspectives.

Sources of information

Many participants identified their personal experiences with disability as essential to their understanding and advocacy. For example, one mother explained that she knew:

> exactly what kinds of things, like situations, I want for my daughter because I know that growing up with an IEP [Individualized Education Program], I would get taken out for periods at a time, and I would miss out on that education, and I actually thought the people [educators] for the IEP, they didn't know what they were doing.

Another mother recounted: "I don't think I ever really thought of anyone as having a disability, because I grew up with my mother who had severe seizures and um, you know, I don't think I really viewed it as anything because it was something I was born into." For mothers who had personal experience navigating medical and education systems, advocacy often focused on removing barriers or challenging systems that harmed their children. However, the concept of disability was "not on [their] radar" for many of the other mothers. Even though most participants attended public schools as children, many mothers did not remember children with disabilities included in their classrooms, and most did not have significant relationships with peers with disabilities in school. Multiple caregivers shared that they only began to learn about disability after the birth of their children. As such, some participants "c[ame] to the experience as 'others'" and initially viewed disability as "unexpected," "undesirable," or something to be feared (Ryan & Runswick-Cole, 2008, p. 203).

Many participants expressed frustration about the lack of information about their children's disabilities and education processes and practices. Mothers gathered information about their children's disabilities through their doctors, therapists, educators, community organizations, books, Internet sources, and formal and informal networks of families of children with disabilities. Nine mothers identified friends as an essential source of information. Others reported that they researched their children's disabilities directly or to find disability-specific support groups. Many parents, even those who independently found resources, expressed a desire for more information about their children's disabilities and education services.

Information gathering and advocacy

The process by which mothers came to understand disability is crucial as it also has implications for advocacy efforts. In 1975, the Education for All Handicapped Children Act was passed, now known as the Individuals with Disabilities Education Act (IDEA). This legislation guaranteed free and appropriate education for all children and increased parents' rights to

participate in their children's education. However, as Ong-Dean (2009) documents, while this legislative victory emerged from the civil rights struggles, parents were often left advocating for individual children instead of a collective good (p. 2). In this context, those parents who had access to the most information through their networks, experiences, and research skills were often better able to navigate medical and educational systems.

The mothers in this study generally researched their children's particular disabilities – not disability in general. As such, understandings of disability culture were secondary to insights into their children's specific impairments. Also, while many mothers sought out other parents, the only mothers who explicitly mentioned drawing upon the experience of adults with similar disabilities were those who shared a disability/chronic health diagnosis with their children or those with close family members with disabilities. Finally, while some parents sought out disability-specific organizations, many of these organizations appeared to be led by parents and not people with disabilities (see Carey, Block, & Scotch, 2019).

Theme 2: Mothers used varying degrees of social, cultural, and economic capital to advocate for their children and other children with disabilities.

One of the things that I think is depressing about the special education piece is that ... what you get for your child really depends on what parents advocate for. I don't feel that the system is set up necessary well to work in terms of equality of service delivery and for equity. ~ Elaine

In my interviews, mothers attended IEP (Individual Education Program) meetings for their children and other children, volunteered at extracurricular events so that children with disabilities could participate, encouraged pedagogical and curricular changes in their children's districts, worked with community groups to advocate for legislation changes, organized parents around specific issues impacting children with disabilities, spoke to the press, attended and spoke at Board of Education meetings, filed legal challenges to their children's placements or

services, and served as parent representatives on medical and educational boards and committees. Many mothers expressed their desire to support their children and others in their schools and communities. Yet, as Ong-Dean (2009) argued that parents "who have the most cultural and economic resources at their disposal" are often able to "make the strongest claim to distinguish their children's particular disabilities and needs in an objective, scientifically and legally justified way," which can equate to more services (p. 3).

Some participants utilized their cultural and professional knowledge, as well as what Lareau and Weininger (2003) describe as "interactional strategies" and "cultural resources" to intervene in education settings (pp. 589-590). Many mothers recounted how personal connections with education, social work, or legal experts helped their families with school selection, placement, extracurricular activities, and legal advice. For example, Carmen shared when she sought out a knowledgeable friend's advice because she was overwhelmed when reading the specialized language ("jargon") in IEPs and 504 plans. Olivia, a teacher, described a moment in an IEP meeting when there was a disagreement. She stated:

> Ahhh, I said this is, I am going to change my role a little bit. I said, if I were an advocate for families with children who have special needs, this is where I would say that you don't have the data, that this child did not get a free and appropriate public education, and that this would lead, could lead the family to go due process.

The parent challenged the school on their lack of data, and "in the end, [the woman running the meeting] said, you sold me. She said, I see your point and I will go with the IEP." This parent had to step into the role of a teacher and advocate to get her child's needs met.

In addition to cultural capital and networking, many parents used their economic capital to secure additional tutoring, services, and expert opinions. Others recognized the differing levels of service provided in school districts. Of the 13 mothers interviewed, five mothers reported that they moved at least in part to find a school that they thought would better serve their children. Finally, mothers credited time spent in schools as helpful in their advocacy. For example, Julia noticed problems with the staff-to-student ratio because she was often at the school. Elaine began preparing for the IEP re-evaluation meeting months before it occurred

through incremental conversations with teachers and service providers while in her children's school. A few mothers also noted that parents had facilitated inclusion at extracurricular events, like school dances and sports. For example, Isabel shared the following experience:

> [my child] is an excellent athlete. . . My agreement with them, with the coaches, was that I would be available to pick him up when he goes down [because of his disability]. So I get the phone call, 'Runner down.' We are at this location. The coach would call, I would go there.

Racism

Within the Midwest of the United States, there is significant racial diversity. There has been considerable research about t*he intertwined "legacy of historical beliefs about race and ability"* (Annamma et al., 2016, p. 10), impacting parents' experiences and advocacy efforts. In my study, some parents identified discrimination within special education services. For example, Helena, an African American mother, explained that despite her advocacy, "I felt like I was being discriminated against or they had never seen a child in their school with [a particular medical condition]. I just didn't understand what was going on." Helena thought that she and her daughter experienced discrimination based on her race and her daughter's disability.

Another parent explained that she had witnessed discrimination in schools where she had done advocacy work. She recounted that "there is a pattern of obfuscation, of misrepresentation of the law, of emotional manipulation, perpetrated by case managers and some service providers are in collusion with this." For example, she commented that she had observed service providers trying to talk mothers of African American boys out of services by convincing them that they don't want to have the child "labeled with a disability." Thus, while there is a powerful critique of the overrepresentation of African American and Latino children in special education (see, for example, Annamma et al., 2016, p. 10), This narrative also illustrates how children's access to services is limited.

Benefits and limitations to individual advocacy

My study adds to scholars' growing documentation about how parents use their privileges to get services for their children. In their narratives about advocacy, many participants simultaneously discussed successes in their advocacy and offered a critique of a system that relied on parents' advocacy to support students. Many mothers, including Helen, Frida, and Nancy, discussed providing information and support to other mothers navigating school and medical systems. Julia recounts a story about her daughter, who used assistive technology in the classroom. When the technology was lost, a service provider told her that the school district had prohibited purchasing additional technological devices. Knowing her rights, Julia said she would give them a week before filing a formal complaint. The provider "found" the device by taking it from a child refusing to use it. She reflected:

> So, instead of trying to find a way to make sure the kid would comply through counseling or other systems, she took it and gave it to my kid. And it's horrible, right, it's horrible, but I'm not going to fight other's battles. I took the thing. I took it for my kid because it is my kid. . . That's what it is [in] Special Ed. It is clawing and scratching.

Yet, many mothers (including Julia) tried to use their knowledge and capital to change education practices and systems and not just change their children.

Theme three: While most mothers in the study were able to advocate for their children successfully, many critiqued special education and education in general

> [The IEP team] still needs to fit within the school district culture, and it wasn't always in the best interest of my child. The metrics are somewhat arbitrary. Um, the goals still have to fit within the classroom and the goals of the particular class in that particular year. And sometimes, it is just silly, and it doesn't make a lot of sense. ~Isabel

Many mothers described their children's schools as places of learning and community. For these mothers, advocacy efforts can help improve particular problems or instances when the

system was not working as it should. Carmen discusses how the teachers helped her learn to embrace social and academic goals for her child. She worked with other parents to create more accessible extracurricular activities and support parents in advocating for their children. Helena, unhappy with her children's first school experience, found her children's new schools to be places of inclusion, belonging, and learning. Julia offers multiple critiques of the school system and IEP process; however, she stated: "it is not a perfect structure, but if they [the school systems] followed the mandates and the statutes in the way they're intended to be used, yes it could totally help the situation." However, for some mothers, their advocacy efforts were designed to change systems.

Each mother I interviewed could describe specific ways in which her advocacy benefited her child/children; however, many participants reflected on the limitations of individual advocacy. For example, some mentioned that accommodations were too narrowly defined. Others lamented that some educators and service providers working within the special education department focused on offering services instead of helping children succeed. These critiques extended far beyond concerns about the lack of services for children. Mothers critiqued the process of identifying children with disabilities and the process of labeling. Isabel, for example, stated:

> the labeling requirements give us services. You get a label; you get a service. Why do you need a label to get a service? How is that any longer helpful? The model is now outdated because we are finding that there are so many labeled and unlabeled unmet needs.

Multiple mothers also noted that our current model of special education focuses too heavily on student failures. Mariela argued against:

> the mentality where a child has to fail to get services. Your child should be able to thrive and succeed, and if something is working, then it is working, let's keep it going for a

little while longer and then slowly remove things and when they are able to do it, instead of just taking everything away.

Katrina provides an explicit example of this. She recounts that because her child entered school at grade level, she was ineligible for placement in the class "for kids who were struggling," even though she was not learning. She recounts:

> What I had to do, which the teacher and I came up with this together, was to let her fail- and she had to fail miserably. I had to stop working with her at home. So, against my nature. It only took two months . . . and [the administrator] took her reading and word test and she did so poorly that he . . . had to put her in the class.

Some mothers in the study critiqued the rigidity of services for children with disabilities. Betty called for increased "flexibility" for all students, and Adeline called for "creativity" to find things that work for the individual students. Betty, speaking as both a special education teacher and a mother of a child with a disability, noted that teachers "try to make our goals tied to the [general] curriculum as best we can, because in my school we don't even have a resource period with the kids." Betty acknowledged that "it is the best-case scenario for what we are given, but it is not the best-case scenario for the kids." Betty also noted that increased flexibility "either with the age range in the classroom or the curriculum you could access" would benefit all children.

Adeline noted that her daughter previously attended a public school that had a "pity model." While the school was less restrictive because it had children with and without disabilities, Adeline did not find the school a place of learning for her child. She believed that the teachers saw their roles as caretakers instead of educators and did not provide meaningful experiences. Describing her experience at her child's special education school, she explains that the teachers now "think that she is capable of learning." She further states that the teachers realize that her daughter "is a person with interests and ideas and is a fully-fledged human

being. She's not her deficits."

Many mothers discussed the over-emphasis on assessments, especially standardized assessments, to determine instruction. Others said that the skills and knowledge tested by standardized exams were not aligned with mothers' ideas of success for their children. Some mothers emphasized different goals for their children – including engagement with interesting work, development as productive members of society, and opportunities to grow academically and socially.

Theme four: Mothers in the study expressed hopes for their children and changes in how schools and social institutions understood and responded to disability

> I thought, you know what, why do we assume that because you cannot move your body in a [typical] way, [that] you cannot verbalize in a typical way, that you do not have an interior life? That you do not crave beautiful words and beautiful music and interesting problems and that thing that we love, stories, [which are] at the root of so many of our interests.......And people are like, OK lady, you think [your child] is smart, whatever. It is not that I think she is smart or not smart; I am not using those words. She is a human being, and she has an interior life. We don't get access to it, which is our great loss, but that is not her fault. We shouldn't assume that because her expression isn't on our wavelength that it is not happening, you know? ~ Adeline

Participants expressed many hopes for their children, schools, and society. While some mothers wanted a "cure" (medically or educationally), many also said they desired for more systemic changes. Many articulated a desire for enriching, holistic education for their children and more acceptance from educators, students, and society. Others wanted schools to provide their children with multiple opportunities to learn information and express understanding. Still, others wanted appropriate academic and social systems for their children and better supports for young adults. Some discussed their desires for their children to learn to be self-advocates. Many mothers spoke about their desire for teachers to reframe what it meant to be successful and embrace their children's multiple dimensions. Another

recurring desire was for more significant partnerships between educators and families and for educating all children about inclusion with and without disabilities. For example, Reina expressed a wish that schools would work to expand understanding of disability:

> Most schools, um, they don't hear about disability, and they might think they are doing everything they can, but there is always more that can be done. For instance, if there is a kid with disabilities in the classroom, talk about it. Get the other kids involved. Explain to them what is going on with this child.

For many mothers, their desires for their children share many similarities with the work of educators advocating a move beyond inclusion and toward "inclusive education," which includes a focus on "quality opportunities to learn" and "valuing of all student differences as reflected in content, pedagogy, and assessment tools" (Waitoller & Artiles, 2013, p. 322).

Discussion

In this study, many mothers discussed ways that they both participated in and critiqued systems of special education. While some participants talked about ways they were making changes in a system that they thought mainly was working effectively, other participants discussed examples of societal and school-based practices that harmed their children, including lack of accessible spaces, a failure to allow multiple expressions of knowledge, an absence of awareness about specific disabilities, a deficit view of children, and curricular decisions made to meet school or district policies, instead of addressing the needs of the child. In addition, some mothers identified when schools were creating initiatives/ policies to support students with disabilities, they often reinforced ableist and disablist practices.

Despite the many valid critiques of schooling and education practices, many mothers described the importance of schools as academic and social spaces of learning. Many mothers in the study would likely agree with the comments of critical educators, such as Pedro Noguera (2003), who argued that while there are many pervasive problems in systems of public education, public schools are "indispensable to those they serve" (p. 4). Noguera (2003) wrote

that "[w]ithout any viable alternative available, urban public schools cannot be written off as rotten structures in need of demolition" (p. 4). This idea was echoed by Adeline, who stated that schools "are the only resource for so many people, and so if you do not do the school well, then these families are just whacked on the head and then of course what happens when the school is gone?"

Many mothers found that their critiques of special education also applied to larger systems. For example, Adeline argued that increased accountability efforts in schools have created "less enriching academic experiences" for all students; however, she noted:

> in special ed[ucation], there is a horrible siren song which is, oh, we are doing right by kids with disabilities because we are going to measure them, we are going to include them in assessments, and you are one of us. Do we really want to be included in that club? I am not sure we do.

In this case, Adeline discusses how the impact of testing and narrowing the curriculum can be the "siren song" for all parents. Multiple mothers in the study addressed the need to change our education system while creating inclusive spaces for their children. The "offering of disability," as described by Goodley (2014), invites us to rethink neoliberal education reforms, to "deman[d] humility on the part of educators in terms of what they are trying to achieve in educational settings," and to disrupt "[e]ducation's obsessive academic standards and school performativity" (p.104). Goodley (2014) further argues that "[d]isabled children offer an olive branch to educators: to embrace a 'dialogic ethic' of collaboratively working together to develop ideas in local contextual environments" (p. 103). I would argue that mothers, too, could offer a proverbial olive branch to schools by challenging commonly accepted notions of disability and opposing structural barriers for those with disabilities and all students.

While many mothers critiqued ableist societal norms, very few connected with networks or resources offering alternative frameworks to deficit-based perspectives. As mentioned in the

finding above, most mothers relied on personal or familial experiences with disability or sought out information from doctors, parents, disability-specific (and often parent-led) organizations, or independent research. Few of the parents identified disability justice organizations – this deserves further study about why parents are not turning to disability justice organizations and how access to such information could impact parental perspectives. *As mothers both* mediate the "cultural assumptions regarding disability" (Valle, 2009, p. 219) and help their children make meaning of such assumptions, it becomes increasingly essential for mothers of children with dis/abilities to share stories that reject narratives that pathologize children with dis/abilities and to call into questions policies and systems of oppression that disable students (see Vaughan & Super, 2019).

The themes in this article are not new; however, listening to parents who are actively navigating systems continue to be necessary. When narratives of disability in schools are often focused on technical provisions of services, personal stories can empower the storyteller and be transformative for the reader. Narratives of parental advocacy are needed because they can challenge commonly accepted notions of disability and emphasize structural barriers and the need for more just policies and schools. The narratives in this study also suggest that, as parents seek out sources of information and critique existing ways to participate in advocacy, there may be opportunities for Disability Studies scholars to provide information and connections to parents.

Disclosure statement

No potential conflict of interest was reported by the author.

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Counseling Persons with Learning Disabilities: Counselor Perceived Competencies

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Abstract

Persons with learning disabilities[2] (PWLD) have the second most prevalent disability yet there is limited counseling literature on the population. This study examined counselors' perceived beliefs and knowledge serving PWLD and their self-reported multicultural competency. Findings suggest a need for additional training and educational experiences focusing on serving PWLD.

Keywords: learning disability, multiculturalism, competency, counselor, counselor preparation

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[2] The first author uses a person first approach to disability to emphasize the individual first and disability second. Some authors in the field may use the approach that emphasizes disability as a valued identity (i.e., disabled person). Both approaches are represented in the literature, however, the first author, who identifies as able-bodied, uses the person first approach when discussing disability related issues in the literature.

Counseling Persons with Learning Disabilities:
Counselor Perceived Competencies

Persons with disabilities (PWD) constitute the largest marginalized group in the United States; it is also a group that any person can become a member of at any point in time across their lifespan (Barton, 2009; Forber-Pratt & Zape, 2017; Rawlings & Longhurst, 2011). Like other marginalized groups, PWD experience barriers and challenges in employment, housing, and healthcare due to discrimination and biases (Olkin, 2017; Polo Sanchez et al., 2018; Smart & Smart, 2006). These daily barriers can have an impact on the mental health of PWD, yet the dearth of recommendations from the scholarly literature in the counseling field continues to create disparities on how counseling professionals can effectively provide services to this population (Foley-Nicpon & Lee, 2012; Woo Goo, & Lee, 2016).

Furthering this concern, persons with learning disabilities (PWLD) constitute one in every five people within the U.S. population (National Center for Learning Disabilities [NCLD], 2017; U.S. Census Bureau, 2016). According to NCLD (2017), a learning disability is defined as "brain-based difficulties in reading, writing, math, organization, focus, listening comprehension, social skills, motor skills, or a combination of these" (p. 1). PWLDs face discrimination and oppression because of their disability identity (American Psychological Association, 2012; Chapin et al., 2018). Discrimination experiences can cause stress and frustration beyond that of their non-disabled counterparts. There is an assumption that rehabilitation counselors and psychologists are the only professionals trained to serve PWD (Olkin, 2017; Smart & Smart, 2006). This misconception has become so imbedded that counselors outside the rehabilitation counseling and psychology realm may not believe they need to be trained and skilled in counseling PWLD (American Psychological Association, 2012; Chapin et al., 2018). Mental health professionals should utilize a holistic approach for PWLD by assessing level of functioning and personal and environmental factors together (Chapin et al., 2018; Smart & Smart, 2006). Failure to integrate a holistic approach can result in a host of issues, including marginalization of clients, health disparities, and premature termination of treatment.

Identity of Persons with Learning Disabilities

As it relates to learning disabilities, Higgins, Raskind, Goldberg, and Herman (2002) outline identity development specific to individuals with learning disabilities over a 20-year period. Five stages emerged from their ethnographic, qualitative study; (a) awareness of a difference, (b) the labeling event, (c) understanding/negotiating the label, (d) compartmentalization, and (e) transformation (Higgins et al., 2002). According to Higgins et al. (2002), awareness of a difference involved a time where participants reported having difficulties and problems (i.e., academic and non-academic difficulties and judgements) but were not able to determine the personal changes in the emergence of a disability. In the same study, the labeling event occurs when other stakeholders (e.g., doctors, teachers, parents) labeled them as having a learning disability. To differentiate from the labeling event, understanding/negotiating the label indicated the time when the participant struggled with making sense of the label, what the label meant, and what was needed to be successful in various settings. Compartmentalization focused on the period of time when participants attempted to downplay the potential importance of the label. In the final stage, transformation, participants reached acceptance of the label and identified the label as positive (Higgins et al., 2002). Integration of the model postulated by Higgins and colleagues (2002) provides a better understanding of the impact of learning disabilities on clients to allow for treatment that uses developmental approaches, contextual factors, and holistic perspectives.

Sociopolitical Model of Disability and Multicultural and Social Justice Counseling Competency

Smart and Smart (2006) and Rawlings and Longhurst (2011) discussed three models which serve to define disability: the biomedical model, the functional and environmental model, and the sociopolitical model. The biomedical and functional and environmental models tend to define disability from an abnormal aspect and environmental or functional factors of disability, respectively. The sociopolitical model, however, defines disability as a social construct developed by the dominant, non-disabled society. To expand, from the sociopolitical model, when the dominate culture stigmatizes, discriminates against, and prejudges an individual (or in this case group) with a disability, the problem is with the thinking of the non-disabled dominate culture, not that of PWD (Rawlings & Longhurst, 2011; Smart & Smart, 2006). Therefore, the non-disabled group who created the social construct is charged with fixing and dismantling the social construct. When conceptualizing disability and disability culture

from a sociopolitical framework, professionals are able to view the environment as oppressive and see how the environment needs to be fixed, not PWD. Conceptualizing disability from the sociopolitical model, professionals are also able to engage in advocacy and social justice initiatives to eradicate the systems of oppression that prevent PWD from reaching their full potential.

When understanding disability from a sociopolitical model, the multicultural and social justice counseling competencies can serve as a model to assess a counselor's capability in working with PWLD. In 1992, an influential article by Sue, Arredondo, and McDavis addressed multicultural counseling competencies and standards that should be implemented in counselor preparation programs to produce culturally competent counselors. These counseling competencies and standards focused on beliefs and attitudes, knowledge, and skills of counselors working with clients from different racial and ethnic backgrounds (Sue, Arredondo, & McDavis, 1992). Multiculturally competent counselors are consistently aware of their biases, assumptions, and prejudices as related to underrepresented groups, continue to understand the worldview of their underrepresented clients, and practice appropriate techniques and interventions when working with clients from underrepresented groups (Sue et al., 1992). This document set the groundwork for counseling accreditation bodies to charge counselor preparation programs with including courses and educational experiences that teach counselors-in-training (CIT) how to become culturally competent counselors (Castillo et al., 2007). Sue et al. (1992) identified racial and ethnic groups that were the most visible in society, such as African Americans, Asian Americans, Hispanic and Latino/as, and Native Americans. Eventually, the multicultural standards were used as a model of competency standards for additional cultural traits such as disability, sexual orientation, and gender (Sciarra, Chang, McLean, & Wong, 2005).

Related to disability, Strike, Skovholt, and Hummel (2004) defined the term disability competency utilizing 1992 multicultural standards and competencies, disability literature, and counseling literature. Disability competency was defined as "self-awareness/beliefs/attitudes toward disability, perceived knowledge of disability and disability related issues, and perceived skills/behaviors in working with clients with disabilities" (Strike et al., 2004, p. 322). From these three areas, the researchers developed an instrument, Counseling Clients with Disability Survey (CCDS), which assessed the self-reported disability competency of mental health professionals (Strike et al., 2004).

Results from the study revealed a significant difference between experienced and inexperienced counselors among all three subscales (Strike et al., 2004). Results also revealed that mental health professionals in this study rated themselves high in awareness and low in knowledge and skills in working with PWD (Strike et al., 2004).

Sue et al. (1992) multicultural counseling competencies were expanded to focus on the intersection of identities, the impact of this intersection on the counseling relationship, and the need for advocacy at all levels (Ratts, Singh, Nassar-McMillan, Butler, & McCullough, 2015). The MSJCC describes several domains (i.e., counselor self-awareness, client worldview, counseling relationship, and counseling advocacy and interventions) and how counselors can become more competent in those areas (i.e., developing attitudes, knowledge, skills, and action; Ratts et al., 2015). These competencies provide a framework for counselors to expand their definition of multicultural competency outside of race/ethnicity and expands it to be inclusive of additional social identities of clients while also providing areas for counselors to engage in action and advocacy efforts for and with PWLD.

The Counseling Profession

The counseling profession is a recent field to emerge from psychology (Mellin, Hunt, Nichols, 2011). Only recently has the profession developed a unified definition of what counseling is and what counselors do: "counseling is a professional relationship that empowers diverse individuals, families, and groups to accomplish mental health, wellness, education, and career goals" (Kaplan, Tarvydas, Gladding, 2014, p. 366). Counselors emphasize a wellness approach to their work with clients. More recently, there has been a call for the profession to integrate not only a wellness and preventative approach with clients but to also integrate social justice and advocacy (Ratts et al., 2015). Counselors are charged with viewing clients as part of the systems in which clients live and to consider how those systems impact clients' ability to navigate their lives. For example, when working with PWLD, counselors are charged with viewing clients as unique individuals and as part of a system or systems that may impede their abilities to navigate their worlds. However, the counseling literature providing counselors with resources and support for working with PWLD is lacking (Foley-Nicpon & Lee, 2012; Woo et al., 2016).

Counselors' Role in Counseling Clients with Learning Disabilities

Research, Counselor Preparation, and Curriculum

The amount of counseling literature focusing on disability related issues, specifically learning disabilities, is scarce (Foley-Nicpon & Lee, 2012; Woo et al., 2016). The limited counseling literature that does exist focuses on disabilities as a whole, and more often than not, on physical disabilities ((Foley-Nicpon & Lee, 2012; Woo et al., 2016). To eradicate systems of oppression for PWLD, it is necessary for mental health professionals to increase their competency with this cultural group. Considering the prevalence of disability, specifically learning disability (Hussar et al., 2020), it is concerning that less than 10% of articles focus on disability-related issues. Furthermore, most disability-related literature focused more on literature reviews or empirical pieces about strategies for generally working with PWDs (Foley-Nicpon & Lee, 2012; Woo et al., 2016).

To help counselors increase their competency in working with PWLD, training programs should integrate disability related concepts in program curriculum. In July 2017, two of the largest counseling accrediting bodies, Council on Rehabilitation Education (CORE) and Council for the Accreditation of Counseling and Related Educational Programs (CACREP), officially merged (CACREP, 2017). CORE and CACREP were both established in the 70s and 80s to provide educational standards for the preparation of professional counselors (Patterson, 2009; Sweeney, 1992). With the decision to merge, the CORE standards will be infused into the updated 2024 CACREP standards (CACREP, 2016). These new standards will further solidify the call for programs to train students to be ethically and culturally competent in providing services for PWLD.

In addition to the upcoming revisions to the CACREP standards, the American Rehabilitation Counseling Association (ARCA) Task Force developed the Disability Related Counseling Competencies (Chapin et al., 2018), which provides guidelines for work with PWD, including learning disabilities, across various settings. These competencies were approved by the ARCA in May 2018 and endorsed by the American Counseling Association (ACA) in March 2019. The purpose of these competencies is "to serve as a resource and provide aspirational guidelines to help shape best practice in counseling by

expanding meaningful understanding and support of PWD in contemporary American society" (Chapin et al., 2018, p. 1). These competencies can provide a framework for counseling professionals and students to provide competent and ethical services for PWLDs.

With the CACREP standards in the works and the Disability Related Counseling Competencies, literature also highlights the limited or lack of training students receive on PWD, including those with learning disabilities. For example, Alvarez, Bhat, and Landmark (2020), Feather and Carlson (2019), Rivas and Hill (2018) investigated the inclusion of disability-related concepts in curriculum, overall disability competency, and clinical training experiences of counselors in training (CIT). Authors from studies revealed that disability-related concepts were either absent or rarely incorporated into the curriculum and CIT were not prepared to work effectively with PWD (Alvarez et al., 2020; Feather & Carlson, 2019; Rivas & Hill, 2018). Furthermore, Rivas and Hill (2018) revealed that CITs who are engaged in their clinical experiences reported feeling unprepared and incompetent in providing services for PWD. Alvarez et al. (2020) and Feather and Carlson (2019) identified that programs were ineffective in addressing the needs of PWD. These studies further indicated a critical need for more disability-related concepts in all curriculum, classroom, and clinical counseling experiences to further support PWLD and PWD as a whole.

Finally, with the limited counseling literature on supporting and advocating for PWLDs and lack of curriculum surrounding PWLD, Dolmage (2017) indicated how these components reinforce ableism in higher education. Counselor education programs should work to analyze their curriculum, policies, and procedures regarding the inclusivity, or lack thereof, for PWLD. Dolmage further challenges those in higher education institutions to reflect on the following question:

> What is it about the history or philosophical foundations, or the map or the architecture, or the current mission or set of budgetary priorities of your own school that makes it particularly ableist, or more accommodation, or that allows the ineffectiveness of these accommodations to be obscured or hidden, or that leads to celebrations of inclusion and diversity that don't ring true or effect change? (Dolmage, 2017, p. 31)

Reflecting and analyzing these questions helps those who work in counselor education training programs to acknowledge how they unintentionally or intentionally reinforce ableism in the daily operations of

their training program. Furthermore, it challenges those to take action to dismantle the barriers that exist in training programs for not only the clients with learning disabilities that will be served, but the students, faculty, and staff with learning disabilities. When decolonizing our programs, there is an opportunity for regrowth and inclusivity of not only PWLD, but all underrepresented marginalized groups.

Professional Counselors in Practice

Furthering the limited training surrounding work with PWD, including those with learning disabilities, practitioners are also reporting limited training and familiarity regarding this cultural group in their practice (Beecher, Rabe, & Wilder, 2004; Corrigan, 1998; Dunn & Baker, 2002; Hatch, Shelton, & Monk, 2009; Milsom & Hartley, 2005; Milsom, 2006; Mitcham, Portman, & Dean, 2009; Smart & Smart, 2006; Smith, Foley, & Chaney, 2008). For example, school counselors, like rehabilitation counselors, often provide counseling services to PWD (Dunn & Baker, 2002; Frye, 2005; Milsom, & Akos, 2003; Scarborough & Gilbride, 2006). Milsom & Akos (2003) found that school counselors do receive some formal training related to PWD. However, in other studies, school counselors and school counseling trainees reported feeling inadequately prepared to provide services to PWD and reported the need for additional training (Dunn & Baker, 2002; Helms & Katslyannis, 1992; Milsom, 2002; Romano, Paradise, & Green, 2009). The inconsistency in the literature indicates clear lack of perceived competency when working with PWD. As it relates specifically to PWLD, the literature focuses on postsecondary transitions and college readiness (Durodoye, Combes, & Bryant, 2004; Milsom & Dietz, 2009; Milsom & Hartley, 2005) with little attention given to counselor competency in working with PWLD.

Counseling literature has indicated that disability-related topics are missing or lacking in curriculum and training programs (Alvarez et al., 2020; Feather & Carlson, 2019; Rivas & Hill, 2018); however, there is very little literature in the counseling field that focuses on practitioners' competency with PWDs, especially those with learning disabilities. Furthermore, the counseling literature lacks a conceptualization of disability as a social construct and its importance in curriculum focused on surrounding diversity, equity, and inclusion (Feather & Carlson, 2019; Rivas & Hill, 2018). Finally, the

focus of much of the literature has been on disability broadly with little attention given to learning disabilities and counselors' competency regarding work with PWLD. The purpose of this study was to investigate how counselors (college, mental health, and school counselors) expressed their beliefs and perceived knowledge regarding PWLD and what differences, if any, existed between the group of counselors. We sought to investigate the relationship between counselors perceived beliefs and knowledge and perceived multicultural competence.

Method

We used a cross-sectional, non-experimental survey design for this research study. Invitational emails were sent out to members of professional counseling organizations outlining the purpose of the study and the link to the website to complete the instruments and demographic questionnaire. Assuming a moderate effect size at $P = .80$ and $\alpha = .05$, a minimum of 156 participants (52 participants per group; Cohen, 1992) were needed for this study. Potential respondents included college, mental health, and school counselors.

Participants

The majority of the sample identified as female (76.6%, $n = 183$) and White/European American (87.4%, $n = 209$), which is consistent with the demographics of other research studies involving counseling professionals and students (see Bardhoshi et al., 2019; Field et al., 2019; Fye et al., 2020; Jodoin & Ayers, 2017; Lent & Schwartz, 2012; Ober et al., 2012; Simons & Bahr, 2020; Smith et al., 2019; Wambu & Myers, 2019). Most participants (68.6%, n = 164) also indicated having a loved one, close friend, or relative with a disability, reported their highest degree as a master's degree (66.9%, n = 160), and disclosed having more than five years of post-master's counseling experience (79.9%, n = 191).

Instrumentation

Counselors' Beliefs and Perceived Knowledge regarding Learning Disabilities Instrument (CBPKLDI)

Because there is no instrument that assesses counselors' beliefs and perceived knowledge related to clients with learning disabilities, a 16-item instrument was developed utilizing the *Counseling Clients*

with Disabilities Survey (Strike et al., 2004) as a guide. A thorough review of the literature was conducted to determine the common learning disability knowledge counselors should have in the counseling relationship. An initial list of items was generated and later revised by the primary researcher, a research team including experts in survey and disability research, a methodologist, and a statistical consultant.

To establish validity, a content analysis performed by an expert panel of professionals specializing in disabilities and learning disabilities, a format evaluation performed by a methodologist and a statistical consultant, and a peer review of item readability and response option review were conducted. Once feedback was received, instrument revisions were completed. A pilot study was conducted to determine psychometric properties of the instrument. Results were analyzed and the instrument was determined to appear unidimensional and reliable with two subscales (Beliefs and Perceived Knowledge). Final reliability analysis revealed a Cronbach's α of .66, which is fair for an instrument (Sheperis, Drummond, & Jones, 2020).

Multicultural Counseling Knowledge and Awareness Scale (MCKAS)

The MCKAS (originally the *Multicultural Counseling Awareness Scale* and *Multicultural Counseling Awareness Scale– Form B: Revised Self Assessment*) was developed in 1991 by Ponterotto and colleagues and assesses the perceived multicultural knowledge and awareness of respondents using the multicultural counseling standards (Constantine & Ladany, 2000; Ponterotto et al., 1994, 2002). The MCKAS consists of 20 Knowledge and 12 Awareness items, where the Knowledge items are positively scored and 10 of the 12 Awareness items are negatively scored (Ponterotto et al., 2002). Convergent validity was established through significant moderate correlation with the Knowledge/Skills subscales when compared to other multicultural counseling instruments, such as the MCI (2002). There was a high correlation (r = . 74) between the Awareness subscale of the MCKAS and the Counseling Relationship subscale of the MCI, however, no correlation existed between the Awareness subscales of both the MCKAS and MCI (Ponterotto et al., 2002). Discriminant validity was also found within both the Awareness and Knowledge subscales. Both were significantly correlated when compared to the *Social Desirability Survey* (r = -.39; Ponterotto et al.). Alpha levels for the MCKAS were .85 on both the Knowledge and Awareness subscales.

Results

Data Analysis

Participants completed the CBPKLDI and the MCKAS. A test of homogeneity for dependent variables, total score on the MCKAS, Perceived Knowledge subscale, and Beliefs subscale, was conducted to indicate the relationship between MCKAS and CBPKLDI. The Pearson correlations, ranging from $r. = .153$ to $.225$, which indicated a weak, positive relationship among the Belief subscale, Perceived Knowledge subscale, and the MCKAS; therefore, the instruments are not identical. Normality of the sample was obtained, and a weak, positive correlation of the CBPKLDI subscales and MCKAS was found. A total score for the CBPKLDI was not computed because the focus on the research study was on counselors' scores on the two subscales, Beliefs and Perceived Knowledge. Therefore, further analysis of data was conducted.

When addressing the first research question, which addressed counselors' beliefs and perceived knowledge, descriptive statistics were utilized. The mean for counselors on the Beliefs and Perceived Knowledge were 2.62 and 2.88, respectively (See Table 1). This result indicates that the counselors reported moderate level of beliefs and perceived knowledge regarding PWLD. To answer if differences exist among counselors (college, mental health, school counselors) on the subscales, where those differences occurred, and if a difference exists between the scores on the CBPKLDI subscales (Beliefs and Perceived Knowledge) and MCKAS, a MANOVA was conducted. Using the Wilk's statistic, the MANOVA revealed a statistically significant difference between counselors' scores on the Beliefs and Perceived Knowledge subscales and the MCKAS, $\Lambda = .895$, $F(6, 420) = 3.99$, $p < .05$ (See Table 2). This result indicated that a difference was found among counselors on the CBPKLDI subscales and the MCKAS. To determine where the differences occurred among the groups of counselors on both the CBPKLDI subscales and the MCKAS, a discriminant analysis was conducted, which revealed two discriminant function where one was statistically significant (See Table 2). In Table Two, the first function accounted for 97.8% of the variance, canonical $R^2 = .10$, whereas the second explained only 2.2% of the variance, canonical $R^2 = .26$. On the first function, MCKAS loaded the lowest ($r = -.845$) whereas the Beliefs subscale loaded in the middle ($r = .380$), and Perceived Knowledge loaded the highest ($r = .634$) (See Table 3). As it relates to counseling groups on the first function, college

counselors and mental health counselors loaded the lowest (r = -.276 and r = -.310, respectively) and school counselors loaded the highest r = .388 (See Table 3). The result from the first function reveals that Perceived Knowledge subscale accounted for most of the function while MCKAS accounted for the least (See Table 3). As it relates to counseling groups, school counselors loaded the highest on the Perceived Knowledge and MCKAS (See Table 3). Overall, there was a statistically significant difference in how counselors reported their scores on the Beliefs subscale, Perceived Knowledge subscale, and MCKAS. However, school counselors scores were statistically significant from college and mental health counselors on both the Perceived Knowledge subscale and the MCKAS.

Discussion

The purpose of this study was to investigate the beliefs and perceived knowledge of college, mental health, and school counselors regarding counseling PWLD in addition to their self-reported multicultural competency. A statistically significant difference was found among the counselor groups on the Perceived Knowledge subscale and the MCKAS. This finding is consistent with the literature where counselors report a lack of knowledge in counseling PWD (see Costello & Stone, 2012; Foley, 2006; Jones, 2013; Milsom, 2007; Milsom & Dietz, 2009; Weis et al., 2016; Wilson et al., 2009). Results indicated that school counselors scored the highest on the Perceived Knowledge subscale. This is consistent with the literature about PWD, especially those with learning disabilities, as much of the literature is within the school counseling literature (Beecher et al., 2004; Costello & Stone, 2012; Corrigan, 1998; Dunn & Baker, 2002; Foley, 2006; Hatch et al., 2009; Milsom, 2006; Milsom & Dietz, 2009; Milsom & Hartley, 2005; Mitcham et al., 2009; Smart & Smart, 2006; Smith et al., 2008; Weis et al., 2016). College counselors and mental health counselors scored the lowest on the Perceived Knowledge subscale which could indicate a need for additional training that focuses on addressing PWLD in college and mental health settings (Jones, 2013; Wilson et al., 2009).

Regarding the MCKAS, school counselors' scores were statistically significantly different than college and mental health counselors. This finding is interesting as there has been a significant shift in multiculturalism, social justice, and advocacy over the past several decades in accreditation standards, various competencies, and professional development trainings. It should be noted that the MCKAS is

aligned with an earlier version of the multicultural counseling competence (Ponterotto et al., 1994, 2002). Additional research is needed to assess the multicultural competency, social justice, and advocacy among counselors using instruments that align with the multicultural and social justice counseling competencies.

Implications for Practice

With the CACREP standards being revised to include disability-related concepts, and the adoption of the Disability Related Counseling Competencies (DRCC) by ACA in May 2018, knowledge surrounding work with PWLD is likely to improve. Practitioners, CIT, and counselor educators have more explicit language and visibility on how to provide ethical and competent services for PWLD. These standards and competencies can provide counselor training programs specific ways to increase knowledge among students in working with PWLD. For example, the DRCC can aid program to expand curriculum, such as testing and assessment, to include PWD, including those with learning disabilities. According to the DRCC, mental health professionals should keep in mind how assessment tools may not be normed or inclusive for PWD and procced with caution when interpreting and utilizing assessment results. For example, the Beck Depression Inventory (BDI) is a popular and reliable and valid depression screening tool utilized by counselors (Peterson et al., 2014); however, the BDI was not originally normed with PWLD. Counselor educators can train students on how to evaluate the usefulness of various assessment and testing measures for PWLD. Furthermore, professional development opportunities should be provided to practitioners on the importance of inclusivity and appropriateness of assessment and testing practices for PWLD. The DRCC also addresses other areas such as understanding and advocating for PWLD, the counseling process and relationship, and working with and supervising PWLD. These other areas can be applicable to courses across the counselor education curriculum and/or development of professional development for practicing counselors (Chapin et al., 2018). Further research assessing the current trend of disability competency among various groups (e.g., clinical mental health, school) and CITs should be explored, both quantitatively and qualitatively. Future research should also focus on the implementation of the DRCC in counselor education curriculum. It is important to document the experiences of PWLDs in counseling to give voice to their experiences and to see how, if at all, practitioners and the current DRCC, speak to their lived experiences.

To increase the perceived knowledge among practitioners, research that focuses on disability-related content needs to be expanded. Two content analyses revealed that less than two percent of research articles in counseling and psychology journals focused on PWD (Foley-Nicpon & Lee, 2012; Woo et al., 2016). Given the prevalence of disability and the needs of PWLD, research that focuses on disability culture, the unique needs of disability, the diversity and intersection within disability culture is needed, along with applicable and inclusive interventions. Conceptual, theoretical, and empirical studies should be developed to provide practitioners and CIT resources and guidance in understanding disability culture and best practices for working with this population.

Findings suggested that school counselors self-reported higher knowledge in working with PWLD than college and mental health counselors. However, a statistically significant difference was not found on the Beliefs subscales among the counselor groups. Although the finding related to knowledge surrounding PWLD is consistent with literature on school counselors, when it comes to Beliefs, this finding needs further investigation. Additionally, this finding is concerning because it further reinforces Dolmage's claims about ableism in academia, specifically counselor education curriculum and training programs. Further research focusing on counselors' attitudes, beliefs, and perception of PWLD should be explored. Without an understanding or awareness of PWLD and their experiences, how can counselor training program adequately provide services and advocate for and with PWLD?

Finally, the results of study suggested a statistically significant difference among school counselors as it relates to multicultural competency. Multicultural competency has been an area of focus in the literature, ethical standards, and curriculum and accreditation standards. There has been more of a focus not only understanding diverse cultures, but on the impact of the intersection of power, oppression, and privilege in the counseling relationship (Ratts et al., 2015). Further research related to multiculturalism, diversity, and social justice among practitioners is needed to determine practitioners' perceived competency in this area.

Limitations

Despite its strengths, this project had several limitations. The first limitation was the development of the CBPKLDI. This instrument was developed solely for the purposes of this research study. The alpha level for the scale was .66, which is fair (Sheperis et al., 2020). Before being used in

additional studies, further pilot tests and item and data analysis should be conducted to evaluate the reliability, validity, and item analysis of the CBPKLDI.

A second limitation was the composition of the sample which excluded student members of professional counseling organizations. Inclusion of student members could have provided more information about counselors' work with PWLD, and therefore, might have impacted the results. Future research should incorporate additional methods of recruiting participants, such as soliciting local mental health agencies, vocational rehabilitation centers, family therapy centers, student members within professional counseling associations, and other counseling professional associations.

Additionally, the majority of participants in the study indicated a connection with someone with a disability. Because there was an interest in this topic, results may not be generalizable to all counselors. Further research should ensure sample is representative of both those with and without connections to PWLD. Furthermore, research could control for extraneous variables, such as personal connection with disability, to obtain a clear picture of counselor' perceived knowledge and beliefs regarding PWLDs.

Conclusion

This research study sought to determine counselors' beliefs and perceived knowledge regarding counseling PWLD. Results revealed statistically significant results on the Perceived Knowledge subscale and the MCKAS, specifically among school counselors, which indicates a need for additional education in programs and continuing education opportunities centered on working with PWLD and multicultural competency among college and mental health counselors. The future 2024 CACREP standards and the Disability Related Counseling Competencies will provide opportunities for programs to include disability-related concepts in curriculum and continuing education opportunities for practitioners, however, programs and practitioners need to work to ensure they are knowledgeable in working with PWLD to ensure they are providing the most ethical and competent services for PWLD. Furthermore, counselor training programs and counselor educators should collaborate with and integrate the work of disability studies texts and disability studies scholars in the curriculum to ensure counselors are engaging in socially just work for and with PWLD.

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Table 1

Participants' Mean Scores on the Perceived Knowledge and Beliefs Subscales

	Perceived Knowledge	Beliefs
N	239	239
M	2.88	2.62
SD	0.48	0.25
Range[a]	1.43-4.00	1.88-3.38

Table 2

Wilks' Lambda and Discriminant Analysis Results

	Value	F	Hypothesis df	Error df	Sig
Wilks' lambda	.895	3.99	6	420	.001

Function	Wilks' Lambda	Chi-square	α
1 through 2	0.895	23.401	0.001
2	0.997	0.551	0.759

	Eigenvalue	Percentage of Variance	Cumulative Percentage	Canonical Correlation
1	0.114	97.8	97.8	0.320
2	0.003	2.2	100.0	0.051

Table 3

Discriminant Function Coefficients and Group Centroids

Scale	Function	
	1	2
Perceived Knowledge	0.634	0.789
Beliefs	0.380	-0.235
MCKAS	-0.845	0.483
Counselor		
College Counselors	-0.276	0.059
Mental Health Counselors	-0.310	-0.077
School Counselors	0.388	-0.002