

CYC-Online

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A Journal for those who live or work
with Children and Young People

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Contents

Editorial: Child and Youth Care: Disability Matters	3
<i>Janet Newbury, PhD</i>	
Do Not Doubt the Worth of Your Work	10
<i>Dr. Jaiya John</i>	
Nurturing Belonging: (Re)centering Indigenous Perspectives on Disability	12
<i>Chantal Adams</i>	
Inclusion in Sport: Supporting the Complimentary Use of Assistive Technologies	35
<i>Becki Steel</i>	
From Blaming to Belonging: Re-examining Our Approach to Fetal Alcohol Spectrum Disorder	51
<i>Emily Hellard</i>	
Speech and Language Delay/Disorder in Early Childhood	66
<i>Xinwen Liao</i>	
Universal Design for Learning: Background and Applications in North America	78
<i>Ari Saunders</i>	
Online Accessibility for Post-Secondary Students with Disabilities	94
<i>Kelsey Kotzian</i>	
The Crack in Everything	109
<i>Hans Skott-Myhre</i>	
Child and Youth Care, Disability and Some Cautions	118
<i>Kiaras Gharabaghi</i>	
Postcard from Leon Fulcher	124
Information	129



November 2018

ISSN 1605-7406

Child and Youth Care: Disability Matters

Janet Newbury, PhD

It is my great pleasure to introduce this Special Issue of *CYC-Online*. Just a couple of years ago there was some online discussion on a CYC-Net forum about disability within the field of Child and Youth Care (CYC). While there was great interest in the discussion, there also seemed to be a recognition that in practice and policy, disability seems not to be as deeply considered in our field (see <http://www.cyc-net.org/threads/view.html>). Acknowledging where our expertise does and does not lie (as individuals and as a field) is indeed important and can help us to build meaningful and useful partnerships with allies in a range of disciplines. Learning how to connect meaningfully across differences, how to speak to and inquire about that with which we may not (yet) have personal experience, and how to center dignity in our work with diverse populations is vital to CYC practice (Richardson & Wade, 2010; Skott-Myhre & Skott-Myhre, 2007). So to be clear, this focus of this special issue is not disability per se, but Child and Youth Care itself. How can we continue to have these conversations, and learn from those whose lived experience and expertise can guide our practice with children, youth, and families in a range of settings? What responsibilities do we have in our practice settings to alter structures in



November 2018

ISSN 1605-7406

ways that center dignity and belonging? How can we continue moving towards justice in our field?

In the winter of 2018 I taught two cohorts of students (at the University of Victoria) in a third-year undergraduate course that explores disability in CYC practice. As always, students started the semester with a range of personal and professional experiences related to the content we would be exploring. Many expressed some concerns around language and how to engage and speak with respect in relation to disability. The word ‘disability’ itself was – and remains – a contested one (Berger, 2013). Given that dominant ideas about ‘best practices’ within this sector continue to shift and change, I knew I could not offer any certainty in relation to these questions, but still hoped to build curiosity, confidence, and competence throughout the course. So, we began by locating our current moment historically, and learning some about what has brought us to it:

In an article entitled *No Time for Nostalgia*, Roman, Brown, Noble, Wainer, and Young (2015) offer up a comprehensive “relational genealogy”, with a focus on some of the convergent histories of Victoria BC Canada – the city where our university is located (p. 18). Through their analysis, these authors track the simultaneous containment and control of disparate groups of people on unceded Coast Salish territory through a range of tactics that advanced the colonial nation-building project. First Nations, certain immigrant groups, and people with intellectual disabilities were systematically targeted in various ways by legal, political, and medical practices. The forced removal of the Songhees First Nation people to a small reserve of land, and then the “institutional confinement of the so-called ‘medically unfit’ ... [in an Asylum] on stolen land” clearly challenges the narrative of western development as equitable and just (p. 20).

By foregrounding the historical memory of those people most deeply impacted by such policies and practices, stories of resistance were



November 2018

ISSN 1605-7406

explored, and from there the advocacy movement – beginning most publicly with parent advocates and then self-advocates – was highlighted.

We then panned out and took a more global perspective on disability, observing how discourses and practices develop *in response* to such local and global dynamics. Looking today, for instance, at the United Nations Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities, we can see our current moment marked with discourses of inclusion, rights, and individual capacity building (UNICEF, 2007). The notion of inclusion is now front and center in the names and mandates of many non-profit and government organizations that relate to disability today. Two specific examples are *Inclusion BC* (which was previously called *BC Association for Community Living*) and *Humanity and Inclusion* (which was previously called *Handicap International*). With this we can see this discourse of inclusion emerging both locally and globally – and Roman et al's (2015) 'relational genealogy' reminds us that this is no coincidence. We can also already see important critiques of inclusion discourses coming to the fore.

As the class heard more and more specific and unique voices of people with disabilities, their families, and their allies (with guest speakers, videos, and other resources), we were able to better understand that all concepts and commitments implicate people's lived experiences in different ways, in different times and places. Within the disability sector there is currently great debate, for instance, over people-first and identity-first language (which was also highlighted in a CYC-Net online discussion: <http://www.cyc-net.org/threads/identityfirst.html>). Given the power dynamics in which language is embedded (and which it informs) and the ever-changing political and cultural dynamics in which we are all participating, it makes sense that choices involving language are not simple (Kunc, Reynolds, Munro, & Van der Klift, 2015).



November 2018

ISSN 1605-7406

We were able to recognize that ethical engagement does not necessarily require clarity or consensus over definitions, or certainty in terms of language (Berger, 2013). It does, however, require a willingness to enter the conversation, learn, show up, reflect on *how* we show up, hear and respect diverse experiences and perspectives, and be responsive to them (White, 2007). Just as we began our semester with an acknowledgement that our current moment is informed by the histories that preceded it, we ended it with a recognition that this flow of practices, policies, ideas, and experiences continues to unfold ahead of us, and we are part of that trajectory. As history marches forward, language and ideas that are new to us and challenge current practices of inclusion are already informing new directions.

All of this makes the idea of publishing anything at all a particularly daunting undertaking! Most of the articles that comprise this Special Issue were all written by authors who were students in the course to which I have referred. Their topics are wide ranging, and their perspectives are not uniform. In these articles you will see them grappling with some of the ideas I have laid out here – and many others – in a range of contexts. These authors have taken as their starting place their own commitments as they relate to CYC practice. Speaking from that place – *their* place – they each bring forward important considerations for all of us in the field of Child and Youth Care.

As you read, you will see how they consider the implications of some of these ideas for their CYC practice in various settings. And while they each offer something unique, you will notice a commonality among their approaches: First, they resist viewing ‘disability’ as a problem. Norman Kunc speaks from a personal and professional perspective about the value he places on “the right to be disabled” in a brilliant interview with his colleagues (Kunc, Reynolds, Munro, & Van der Klift, 2015). This is a



November 2018

ISSN 1605-7406

commitment that I believe can be read through all of the articles in this Special Issue. Second, and following from this, these authors – Adams, Steel, Hellard, Liao, Saunders, and Kotzian – provide insights into how we all, as CYC practitioners, community members, policy makers, and individuals (whatever our positionality or relationships) can play a role in cultivating spaces, relationships, practices, structures, and ways of thinking and being by which this “right to be disabled” can be respected.

Beyond inclusion, my sense is that this approach nudges us ever so tentatively in the direction of decolonization. The articles encourage us to ask the question: rather than ‘inviting in’ those who have been marginalized by existing systems and practices, how might we *alter those very structures* to be less oppressive to begin with (see de Finney, Dean, Loiselle, & Saraceno, 2011, and the entire September 2018 issue of *CYC-Online*)? I believe there are seeds of hope and possibility in the collection of articles that follows and am very grateful to the authors for engaging in this important ongoing conversation. And I look forward to upcoming issues in this journal in which these conversations continue, with more perspectives being shared. If you are someone for whom these matters are of particular personal or professional significance, we hope you will consider submitting something for future publication in *CYC-Online*.

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November 2018

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November 2018
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November 2018

ISSN 1605-7406

Do Not Doubt the Worth of Your Work

Dr. Jaiya John

Do not doubt the worth of your work.
You are the memory of humankind.
From the time when sky touched earth
and caring was born, placental and wailing.
You are the echo in a child's emptiness
that promises rain and what grows after.
You are the fierce growl of decency.
The reprimand to retreat.
You are the Love letter,
the bottle that carries it,
the hands that wrote HOPE,
the sea, the shore, the finding.
You are the bringer of tomorrow,
the caresser of yesterdays.
Every angel mantras your name.

***DR. JAIYA JOHN** was a plenary speaker at the 3rd Child and Youth Care World Conference in Ventura, California USA. Jaiya has written 14 books addressing healing and wellness within the human experience. See his full bio and more at www.jaiyajohn.com*



November 2018

ISSN 1605-7406

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Nurturing Belonging: (Re)centering Indigenous Perspectives on Disability

Chantal Adams

Abstract

Colonization has occurred in many ways, one of which is the bio-medical colonization of Indigenous people and people with 'impairments' or 'disabilities.' Colonial processes of dehumanization and enforced institutionalization are not only historical, they are perpetuated through ongoing pathologizing perspectives of Indigenous bodies and minds. Diagnostic and assessment criteria have been used to justify disconnecting families, communities, and society. This has created a pathologizing perception that people who are diagnosed with impairments and/or disabilities have something that they lack or that needs to be fixed. To do good work, especially with Indigenous children, youth, and families, front line practitioners need to decolonize our thoughts and practices by (re)centering Indigenous ways of being, which includes Indigenous perspectives on 'disability.'

In many Indigenous worldviews across the world, ethics of belonging, dignity, and inclusions of people of all abilities were upheld and the concept of disability did not exist. Indigenous perspectives explored in this article offer a more wholistic perspective to the topic of disability. This article intends to evoke possibilities for change in the way CYC workers practice with children, youth, and families – especially with Indigenous people.

Key Words

Indigenous, Disability, Indigenous Perspectives, Colonization, Belonging



November 2018

ISSN 1605-7406

There is a scarcity of research on the topic of Indigenous peoples with disabilities and a limited number of academic articles written about different Indigenous perspectives on dignity and belonging in how we include diverse children in society. Gerlach (2018) states that the absence of reliable data and research on disabilities in Indigenous contexts “has been identified as a serious concern for many years” (p. 8). In response to the scarcity of written Indigenous perspectives on disability, I decided to gather stories from across the globe that were written on the topic and offer my findings to others. I am taking a stand to say “we exist and we are here. Our knowledge is valid, real and concrete” (Absolon, 2011, p. 12). It is also important to note that Indigenous peoples are part of diverse communities and Nations, who differ in beliefs, values, degree of acculturation, knowledge, and cultural practices. Therefore, there is no singular perception of disability, and there is ongoing debate about the relevance of the very concept of disability in Indigenous contexts. Given the breadth of perspectives and ways of being across the world, the construct of disability is perceived differently by various groups globally (Bevan-Brown, 2013). As a young Haida woman who has European ancestry, I am transparent about my limited knowledge and understanding of cultures other than my own. In this article, I have carefully and intentionally woven in perspectives from other writers, to highlight the rich and nuanced scholarship that exists across academic disciplines on disability and belonging. I raise my hands in gratitude for the Indigenous people in Canada, the United States of America, Aotearoa (New Zealand), and Australia who have written and/or spoke about disability from either their own Indigenous perspectives or have captured Indigenous perspectives in their research and writing. They have enabled me to be true to my ways of being and in challenging western narratives of disability.



November 2018
ISSN 1605-7406

It is essential to understand the socio-historical contexts of colonization of Indigenous lands and people before trying to comprehend the complexities of 'disability' and how disability is perceived by Indigenous people across the globe and how we can promote belonging in children, youth, families, and communities. The predominant perspectives on disability "largely fail to recognize the multifaceted disabling impacts of colonization on the health and well-being of Indigenous families and children" (Gerlach, 2018, p. 11). The term 'disability' does not exist for some cultural groups, and therefore they do not consider attributing this identity to a group of people (Hickey, 2008, p. 64). In the Canadian context, rather than "focusing on illness or disability language and concepts, First Nations, Inuit and Metis communities and health organizations have advocated for distinct perspectives of health that often share a focus on well-being, balance, harmony, and healing" (Gerlach, 2018, p. 10).

It is essential for Child and Youth Care practitioners to learn about personal and communal beliefs, values, and perspectives when working with Indigenous peoples with disabilities and seek to understand Indigenous views on 'disability.' Winona La Duke (who is Anishinaabeg of the White Earth Reservation in northern Minnesota) states,

And the question, I think, that should be asked and needs to be asked of each of us is how much and how brave we are in our ability to deconstruct some of the paradigms which we have perhaps embraced. If we are able to liberate our minds to be the people that are going to be here on this land. The people who are going to protect our mother, and care for ourselves. (as cited in Clark, 2015, p. 11)



November 2018

ISSN 1605-7406

Colonial thought processes are deeply embedded in western schools of thought and theory. Are we brave enough to challenge these paradigms?

Colonial Policies and Practices

In Canada, disability definitions, assessments, and funding have been embedded in Eurowestern-centric definitions that have always positioned Indigenous knowledges as inferior. Government assessments and policies have worked to erode Indigenous families' control over their children's wellbeing. Colonial policy and policy processes "have been, and continue to be, central to the colonization of Indigenous peoples, locally and globally" (Clark, 2015, p. 3). People in governmental positions have imposed the *Indian Act* (1867, 1985) on Indigenous peoples throughout Canada to gain access and control over Indigenous homelands. Reservations were created, the government restricted and/or prohibited cultural practices and protocols, and so much more. Thus, the *Indian Act* (1985) served to take away Indigenous peoples' dignity and sense of belonging.

The process of colonization "required the silencing of Indigenous women, as the matrilineal and co-operative societies did not fit within the individualistic and patriarchal ways of the colonizer. To get to the land, they had to remove the women and children" (Clark, 2015, p. 3). Sarah Deer (2009) explains how rape and sexual violence "are deeply embedded in the colonial mindset. Rape is more than a metaphor for colonization – it is part and parcel of colonization" (p. 150). Colonizers portrayed Indigenous women as objects. Throughout colonization, government agents have abused their authority by withholding food supplies "unless Aboriginal women were made available to them" (Razack, 2002, p. 131). Colonizers not only portrayed women as objects, they also took children away to prison-like residential schools, thus disconnecting, disempowering, de-dignifying, and assimilating children into western ways. This practice of disconnection



November 2018

ISSN 1605-7406

continued through the Sixties Scoop. Social workers removed or ‘scooped up’ Indigenous children from their families and communities and placed them into foster homes or adopted them into predominantly non-Indigenous families (McDaniel & Tepperman, 2015). This included a large scale of home invasions, apprehensions, and adoptions of Indigenous children out of their communities, justified as ‘the best interest’ of the child (Barker, Alfred, & Kerr, 2014; Brown, Ivanova, Mehta, Skrodzki, & Rodgers, 2014). The multigenerational government policy of cultural assimilation is reflected by the overrepresentation of Indigenous children in the current child welfare system (Brown, Ivanova, Mehta, Skrodzki, & Rodgers, 2014; Palmer & Cooke, 1996). As Blackstock (2010) explains, many of the federal government policies undermining Indigenous children continue to flourish. Residential schools and the Sixties Scoop, Blackstock (2011) states, were just “warm-up runs” for what is happening today. The best estimate determines that there are more Indigenous children in the Canadian child welfare system than there were in the height of the residential school era by a factor of three (Blackstock, 2011; Barker, Alfred, & Kerr, 2014).

During the time of residential schools and Indian day schools, Woodlands school, which was “formerly the Victoria Lunatic Asylum, the Provincial Asylum for the Insane in Victoria, BC 1859–72 and the Public Hospital for the Insane, . . . and most recently, the Woodlands School in New Westminster, British Columbia [Canada] (1878–1996) was also running (Roman, Brown, Noble, Wainer, & Young, 2015, p. 17).

Colonial administrators and medical authorities established Woodlands, initially as an asylum (it began as an asylum for those quarantined for small pox, other infectious diseases, and for those diagnosed as ‘insane.’ Roman et al. explore “the conjunct processes of colonialization, racial, gender, class, and ableist oppression as expressions of empire its fledgling settler colony part of which was the city of Victoria, British Columbia as part of the



November 2018

ISSN 1605-7406

process of expansion” (p. 19). Like the reserve systems, Woodlands was another way to keep Indigenous and ‘disabled’ people out of sight from the new white settler colonial metropolis as well as ‘civilize’ people into Euro-colonial ideals. Incidentally, Woodlands closed in 1996, the same year that the last residential school closed. The building itself was built on the Songhees’ reserve (Roman et al.). The medicalization of Indigenous people and asylum-making is “a hidden history only now being unearthed of the interrelations between the making of residential schools for indigenous peoples and asylum-building as part of medicalized colonial practices” (p. 22). Medical authorities and colonial administrators medically colonized lands, people, bodies, and minds (Roman et al.).

Roman et al. describe these processes through relational genealogy, which is “the effort to analyze unequal power relations within and across different temporal and spatial zones so as to discern whether and how seemingly discrete or disparate social and institutional practices connect” (p. 18). In this instance, the relational genealogy is the simultaneous institutionalization of disabled people and Indigenous people in both prisons and asylums by a dominant political structure that deemed both to be physically, mentally, or otherwise ‘unfit.’

These were part of colonial tactics to disconnect Indigenous peoples from their identities, cultures, communities, and land. Absolon (2011) critically states, “colonization has attempted to make our realities invisible and has tried to turn us into the disappearing race” (p. 12). Throughout colonial processes, colonial administrators categorized land and people into ‘fit’ and ‘unfit’. Colonizers stole land and allocated the ‘desirable’ land to the white settlers and forced Indigenous people onto reserves outside of the white metropolis. Colonizers further categorized by assigning labels and diagnoses, which dictated who was ‘fit’ to be considered able to live in their constructed society, or who was ‘unfit.’



November 2018

ISSN 1605-7406

Western Worldviews and Interventions

Government funded programs, policies, and interventions are typically based on western values and “serve to further colonize and pathologize Indigenous children and youth’s health and their bodies” (Clark, 2015, p. 3). Indigenous healing practices and approaches have been ignored and/or erased within western health care systems (Clark). In Sarah Hunt’s (2018) presentation on ‘Justice at the Shoreline: Rethinking Sovereignty through Coastal Wisdom’ she stated that there is a perception that Indigenous people are not able to care for themselves, which directly links to reserve systems and their containment and governmental ‘need’ to help ‘civilize’ them (personal communication, March 8). To expand Hunt’s statement, Indigenous people were able to take care of themselves prior to European contact, then populations were decimated by diseases introduced by colonizers who forced survivors off the land and onto reserves, thus preventing Indigenous people from being self-sufficient. The colonizers then portrayed Indigenous people as being unable to care for themselves. The ‘need’ to civilize is apparent and deeply embedded policies and practices throughout Canada, including the disability sector. For example, through exploring Woodlands, Roman et al. (2015) explain how the “workings of asylums in the new metropolis of white settler colonial formations as part of the larger empire, which sought to ‘civilize’ and make its new ‘dependents’ . . . wards of the state” (p. 23). Roman et al. further state that the “colonization and segregation of First Nations people in residential schools also involved judges, doctors, and psychiatrists confining those deemed as medically or psychiatrically ‘unfit’ – whether First Nations or not – to asylums and hospitals (p.18).” Overall, the medical model of disability views there being a problem within the person, caused by a disease or other health concern which needs to be ‘fixed’ or ‘cured’ by medical professionals (Wilson, 2014).



November 2018

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RESIDENTIAL CHILD AND YOUTH CARE IN A DEVELOPING WORLD

Tuhinul Islam and Leon Fulcher
Editors



Residential Child and Youth Care in a Developing World builds from a critique of Courtney, M. E. & Iwaniec, D. (Eds). (2009). *Residential Care of Children: Comparative Perspectives* (Oxford University Press) which evaluated de-institutionalisation policies in the residential care of children in 11 countries.

It also builds on the comparative efforts of Whittaker, del Valle & Holmes (2015) *Therapeutic Residential Care for Children and Youth: Developing Evidence-Based International Practice*. We started from an intellectual claim that residential child and youth care “places” exist everywhere – whether called homes, orphanages, schools, centres or institutions. Unlike Courtney & Iwaniec or Whittaker et al, we include private boarding schools, madrassa and other religious learning centres in our definition of residential child and youth care. Residential establishments involve any building(s) (and sometimes tents) where children or young people are brought together to live in shared community life spaces for given periods of time, whether as refugees of war, poverty, disease, abuse, famine or natural disaster.

Residential Child and Youth Care in a Developing World captures some of the challenges and changes faced by residential child and youth care workers in 83 countries – places that rarely feature in the international literature. Each contributor has highlighted challenges and opportunities facing residential child and youth care in their own country’s.

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Indigenous People with Disability in Western Contexts

There is currently a lack of culturally appropriate resources for Indigenous children, youth, and families across the world regarding disability. Clark (2015) speaks to the ongoing challenges that exist on a policy level regarding Indigenous peoples' health and well-being. Clark highlights how focusing on trauma as an embodied and individual problem prevents a critical analysis of the underlying issue: historically-situated (neo)colonialism. She states that colonialism disrupts the inextricable connection between Indigenous people and the land they and their ancestors belong to. The protocol within many Indigenous communities and nations requires us to honour the relationships and accountability we have to the people and the land. The current 'health care' systems are inherently 'western' and based on colonial worldviews, not Indigenous worldviews (Clark, 2015). These systems continue to further colonize and pathologize us as Indigenous people. As Clark highlights, policies have and continue to be the center of colonization of Indigenous people and our lands. To deconstruct western constructs of disability, we must first explore the different aspects of disability from different modalities.

Within the field of disability studies, disability has been defined in numerous ways. Gronvik (2009) states that "the problem with disability as a concept, as with many other concepts in social sciences, is its contingency. Like the operational definition of 'ethnicity' disability can be defined in several ways, sometimes with contradictory meanings" (p. 1).

The social model, the medical model, and the cultural model are three dominant models used in studies of disability (Berger, 2013). These models acknowledge an 'inherent' need to categorize, label, or bring to existence people with disabilities as an issue needing to be addressed. The medical model is grounded in disabilities being rooted within the individual, while



November 2018

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the social model contrasts the medical model by positing that disability is not situated within an individual, but rather is produced by socially-imposed barriers (Berger, 2013; UNICEF, 2007). The cultural model of disability focuses on celebrating, embracing, and creating group identity and belonging related to disability (Berger, 2013). The prevalence of these models suggests that disability is something that is, in one way or another, an issue that needs to be fixed.

Another aspect of the disability field is the differentiation between impairment and disability. Berger (2013) states that impairment is a “biological or physiological condition that entails the loss of physical, sensory, or cognitive function” whereas disability is “an inability to perform a personal or socially necessary task because of that impairment or the societal reaction to it” (p. 6). Someone may have an impairment, but not necessarily a disability. For example, an individual’s ability to compensate for the impairment and social willingness to accommodate the impairment may help them to perform those necessary tasks. If we focus on individual disability, we can divert attention away from the social context that creates and perpetuates disability.

How do Indigenous people with disabilities respond to and resist Eurocentric ‘services?’ How do Indigenous people perceive the colonial construct of ‘disability?’ What do people want instead?

In global settler-colonial contexts, individual and social models and human rights have been critiqued for privileging Western Eurocentric, individualistic, and deficit-oriented language and concepts, and failing to be inclusive or representative of the enormous diversity of Indigenous perspectives and experiences of disability. (Gerlach, 2018, p. 10)



November 2018

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Disability, as a subject being applied to Indigenous peoples with disabilities, has been noted to be problematic (Hickey, 2008). Hickey states that the perception of 'disability' by many Indigenous peoples with disabilities differs from that of non-Indigenous peoples. Services, policies, and practices therefore need to reflect these differences. The process of naming disability and labelling people as disabled primarily serves the government through service provision, planning, and welfare, as well as economically through insurance companies and pharmaceutical companies, and for-profit corporations that thrive from capitalizing on disabilities (Hickey, 2008). As UNICEF (2007) states, the history of 'disability' is "for the most part one of exclusion, discrimination, and stigmatization. Often segregated from society, persons with disabilities – and in particular, children with disabilities – have been regarded as objects of charity and passive recipients of welfare" (p. 5). Instead of creating contexts where people can contribute, society excludes people who must work through multiple barriers set up by society, and instead 'give them charity.'

Gerlach (2018) states that "individualistic and biomedical perspectives of disability are reinforced by, and reproduced through, research, education, funding, organizational, and professional policies and structures, and therapeutic interventions that are primarily focused at the level of an individual child and family unit" (p. 9). Participants in Milner and Kelly's (2009) research reported mainstream western settings "tended to include the normality of discrimination, intolerance, and more subtle forms of personal exclusion" (p. 59). These participants further brought up issues of their involvement in community being dependent on the service providers, and within these settings there were many limitations (Milner & Kelly, 2009). Such limitations included the duration and range of activities was controlled by the service, they were in a passive role of service consumer, and people with disabilities were the foci of the services (Milner & Kelly).



November 2018

ISSN 1605-7406

Gerlach (2018) also states that accessing specific funding and/or specific services or resources is typically

dependent on an individualized and biomedical process of identifying and assigning a diagnostic label or condition to a child. This structure maintains the focus on 'children's bodies' regardless of how their families' daily lives are differentially shaped by social and structural determinants.
(p. 10)

This western obsession with diagnosing, assessing, treating, and categorizing sustains damaging colonial interventions in Indigenous families. Even when there are services specifically for people with disabilities, it does not necessarily result in a sense of dignity and belonging because although these programs aim to be inclusive, they often result in isolating people with disabilities from their larger community. For instance, Duran (2006) explains how receiving a name as an Indigenous person is part of ceremony and it is very sacred as it recognizes your spiritual gifts and identity. Duran further explains how if a practitioner labels (names) an Indigenous person, through a diagnosis, it could have negative implications for that person's identity. That individual now takes on the identity of being sick and carries the illness that is being projected by the person diagnosing/labelling them.

Pre-Contact Indigenous Ways of Being in Current Contexts

Indigenous perceptions of disability can differ substantially from Eurowestern definitions and constructs of disability, and these differences can create significant gaps in service provision. Western society typically



November 2018

ISSN 1605-7406

sees Indigenous people with disabilities as having a disability, whereas Indigenous peoples may not see themselves as having these disabilities (Hickey, 2008). In Australia, for instance, “the concept of ‘disability’ as a category for classifying people was not part of the Indigenous culture or language” (King, 2010, p. 183).

King’s research explores Indigenous social and cultural constructs of disability through the lived experiences of urban Indigenous people with adult-onset disability. King emphasizes that it “was not until doctors came in and started putting names to things and acting like something was wrong that they started to think maybe there was” (p. 184). According to King’s research, the participants stated that in Australia many Indigenous people did not have a construction of an overarching concept of ‘disability.’ A strong theme in the participants’ stories, in this research, was that people with disabilities were looked after by people in the community, and the “conceptualisation of individuals appeared to be in terms of their participation in the family and community . . . rather than in terms of physical appearance or functioning” (p. 191).

Māori core values also support that of inclusion (Bevan-Brown, 2013). Bevan-Brown studied Māori perspectives on intellectual disability, blindness and vision impairment, and autism spectrum disorder (ASD). The study “examined for evidence of inclusive and exclusive attitudes and practices. Findings show that while Māori participants’ opinions varied, people with intellectual disabilities, ASD, blindness and vision impairment were generally valued family members and many examples of inclusive attitudes and practices were shared” (p. 571).

Bevan-Brown speaks about how “for Māori, disability relates to the loss of land, culture, identity, knowledge base, values and language rather than to a concept centered around individual pathology” (p. 573). In this sense, colonialism creates harm and is what ‘disables’ people. The most frequent



November 2018

ISSN 1605-7406

24

themes to emerge from participants in the study were “those of whānau [extended family] support, aroha [love in the broadest sense] and total acceptance” of the person with an intellectual disability by a person and the Māori community (p. 573). Bevan-Brown describes how the participants had “positive schooling experiences when they were in schools that made an effort to take into account the whole child, and accommodated both their cultural identity and their impairment” (p. 576-577). For Māori people, well-being involves the interaction of the spirit world, thoughts and feelings, the physical world, and family (Bevan-Brown, 2013). Further, Bevan-Brown states, participants shared a holistic view of belonging, arguing that “excluding family members because they have a disability would be counterproductive to one’s own well-being” (p. 580). Māori teachings emphasize respect for the whole person and for all living beings, including teachings that uphold dignity and promote values such as, nurturance, hospitality, and inclusivity (Bevan-Brown, 2013). Māori

in the ancient world who had a vision impairment were people with the power and status of deities. They were known for the talents that they possessed, not for what they didn't have. They also held great knowledge and shared that knowledge with others. As time has progressed, though, this notion appears to have changed. (p. 577)

Another Māori belief is that everybody in the family has a role to play in children’s lives, and a child is made to “feel secure no matter where he goes, and he’s included in everything” (Bevan-Brown, 2013, p. 578). As I write this I think of an Elder, Dr. Skip Dick, of the Songhees First Nation (Victoria, British Columbia in Canada) who spoke at a welcoming held at the University of Victoria where I attended my undergraduate degree in



November 2018

ISSN 1605-7406

Child and Youth Care. He said, no matter where he is in the world he holds deep knowledge that he belongs to a family, community, and culture where he is an active member (personal communication, March 8, 2018). King, Bevan-Brown, and Dick all speak of essential aspects of belonging and inclusion. They prompted me to think about ways Indigenous people fostered belonging as well as dignity in children, youth, and families and how this can transfer to the concept of disability.

Indigenous Worldviews of Dignity and Belonging

Preceding colonization, Indigenous communities and families in Canada raised, nurtured, and educated their children. Concepts of family, in many Indigenous communities, extend to clans, kinship, community, and the non-human world (Neckoway, Brownlee, & Castellan, 2007). Little Bear (2000) describes these relationships as "a spider-web of relations" (p. 79). Extended families are interconnected circles based on wholeness with the strength of providing balance. They include social and religious functions and "from the moment of birth, children are the objects of love and kindness from a large circle of relatives and friends" (p. 81). All members of the family systems cared for the children. They were not the sole responsibility of the biological mother and father, but rather a community contribution of parenting (Neckoway, et al., 2007). Having multiple caregivers can create a sense of community and belonging for children. In many Indigenous cultures, children are seen as 'gifts from the Creator' and are held with dignity.

I do not want to romanticize Indigenous child raising systems, but rather I want to provide a foundation for how dignity and belonging has been traditionally and culturally upheld within various Indigenous communities.



November 2018

ISSN 1605-7406

As philosopher Vartan Gregoria (in Derrida, 1988) reminds us: "Dignity is not negotiable." Without dignity, people experience what can be called a "social wound," which may or may not be addressed or restored later in life. Treatment such as neglect, dismissal, humiliation, or abuse constitutes a social wounding, while care, attention, love, and respect (positive social responses) assist people of all ages in filling their being with a sense of worth. (Carriere & Richardson, 2009, p. 59)

In early childhood, the dignity of children is supported “by responding, in culturally appropriate ways, to calls for love through the offering of physical contact, food, familiarity of voices and scents, cleanliness, and a safe family and community environment” (Carriere & Richardson, 2009, p. 59). A sense of security built by extended family, community and culture ensures a sense of belonging and feeling of being part of a larger whole (Carriere & Richardson, 2009). Carriere and Richardson (2009) use the term connectedness to refer to belonging, which they define as “a feeling of belonging, of being an important and integral part of the world” (p. 52). Connectedness may be described as a form of attachment that implies a broader grounding in a person's total environment, which is different from attachment to only one or two central figures (Carriere & Richardson, 2009, p. 57). By supporting connectedness and cultural identity for Indigenous children and families, practitioners and service providers may help turn a sense of longing into belonging (Carriere & Richardson, 2009). Children with diverse needs were held as sacred and treated with dignity. There are endless lessons here for Child and Youth Care practitioners, especially in the realm of disability. The above narratives move beyond inclusion to belonging. Indigenous people are not simply ‘including’ people with



November 2018

ISSN 1605-7406

'disability' in community, rather each member of the community is nurtured to *belong* in community.

Paradigm Shift

Grosfoguel (as cited in Segalo et al. 2015) urges researchers to “turn away from imported and borrowed knowledges” and instead engage “rooted, site-specific inquiries into contexts that bear the scar tissue of colonialism, dispossession and occupation” (p. 343). Research and practice with and about Indigenous peoples and communities needs to be rooted in those communities’ worldviews, beliefs, values, and need. Therefore, western worldviews should not be imposed onto people or communities where they do not belong. Altering social practices within service settings to “approximate the ways people with disabilities daily seek out and nurture common community is an obvious way to advance the policy aspirations to move from a disabling to an inclusive society” (Milner & Kelly, 2009, p. 58). We can move even further than an ‘inclusive society’ to a society where people belong if we are willing to shift our perspectives and open our hearts and minds.



November 2018

ISSN 1605-7406

What if we also viewed impairment as a growth opportunity for all involved? For those with the impairment, it may be an opportunity to face adversity and develop skills, strengths, perseverance, self-acceptance, knowledge, and wisdom. For those around a person with an impairment, it may be an opportunity to develop patience, tolerance, consideration, and compassion. Thus, impairment may be seen as something to embrace and work with rather than as a lack of ability which focuses on the negative (i.e. what is not there instead of what is).

de Finney et al. (in press) express their hopes for the future of Indigenous and racialized youth, stating they hope

that they can continue to be held in dignity and capacity by the communities they are born into and the ones they intentionally create. That their communities accept them without judgment, honouring their spirits and holding them close as sacred gifts . . . that youth are deeply connected to their ancestral lands and the lands where they have chosen to build their futures. That through their relationships with the land they are able to feel more wholly connected to all things and all beings. And ultimately, that through these connections, the healing power of decolonial love is able to take root and grow in their minds, bodies, and spirits. (p. 15)

For services to be responsive to the lived realities of Indigenous peoples, families, and communities, they need to be grounded in the communities and cultures that they serve. DiGiacomo et al. (2013) found that “despite a high prevalence of disability, Aboriginal Australian access disability services in Australia less than non-Aboriginal Australians with disability” (p. 1). This study sought to determine the factors as to why services were not being



November 2018

ISSN 1605-7406

accessed by Aboriginal Australians, and results indicate that there is a “lack of awareness of services and inadequate availability. . . racism, insufficient or non-existent services” (p. 1). Even though there are services available, Indigenous people are not accessing them as they are not culturally relevant or appropriate.

Conclusion

Diverse Indigenous perspectives tend to add a more wholistic perspective to the topic of disability. It is also important that the inclusion of Indigenous knowledges and practices in all programs with Indigenous families and children is increasingly recognized as being essential to improving children’s health and well-being across their life course and the future collective health and well-being of their communities and Nations. (Gerlach, 2018, p. 21)

This article does not provide concrete ways to integrate culture but evokes ideas about things we can do to change the way we work with Indigenous children, youth, and families with disabilities. Promoting the person’s whole self – including their personal and cultural values – will lead to more culturally appropriate provisions and “contribute to the greater inclusion of all disabled people” (Bevan-Brown, 2013, p. 580). Service delivery needs to be grounded in Indigenous self-determination and human rights (Gerlach, 2018). Child and Youth Care practitioners should actively and critically engage in decolonizing and anti-oppressive practices. To differentiate between decolonizing and anti-oppressive practices, Sandrina de Finney eloquently describes decolonization as “physically, socially, politically, spiritually and symbolically re-occupying the places that hold our ancestral connections as First Peoples” (personal communication, May 17, 2017) and Thomas and Green (2007) state that at its core, anti-oppressive practice must include a power analysis and must strive to work



November 2018

ISSN 1605-7406

across differences. Anti-oppressive practice critically examines how we know what we know, explores our assumptions, and connects subjective lived experiences to our knowledge (Thomas & Green, 2007). Decolonization and transformation requires us to note sites of struggle between western and Indigenous worldviews and the need to reclaim the knowledge of Indigenous healers and communities and healers, thereby reasserting and upholding Indigenous epistemologies and ontologies (Clark, 2015). I urge practitioners to engage with perspectives and frameworks that are outside western colonial constructs and that are grounded the specific cultural location of those they work with. By shifting perspectives, we shift the way we practice, and by shifting practices we become active participants in change. My hope is for the people we work with to be held in dignity, love, and respect through meaningful and wholistic practices.

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November 2018

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Inclusion in Sport: Supporting the Complimentary Use of Assistive Technologies

Becki Steel

Abstract

This paper explores the use of assistive technologies (AT) in facilitating sports inclusion and the role it plays in reinforcing problematic discourses of disability. Through a critical analysis of relevant literature and perspectives of children using AT it is argued that while AT have the capacity to mediate some physical barriers to inclusion, giving children the ability to achieve socioemotional benefits of sport, AT are quite inaccessible and the method in which they are used carries troubling social messages about disability. A universal design approach to the practice and policy of AT is then advocated for.

Keywords

assistive technology, sports inclusion, universal design, disability studies

An exciting innovation in the field of sports inclusion is the addition of Assistive Technologies (AT). These are approaches that improve access to sports for people with disabilities. AT are often celebrated as tools which allow professional athletes with disabilities to be



November 2018

ISSN 1605-7406

35

represented and achieve success and which drastically improve quality of life of people with disabilities by enabling them to access the socioemotional benefits of sport. However, AT are not readily available, are often unfairly regulated in sports, and can be critiqued as reinforcing damaging societal misperceptions about disability (Baker, 2016; Smith & Thomas, 2012; Van Hilvoorde & Landeweerd, 2010). These misperceptions can more easily be seen via the concept of the 'supercrip', a term created by the disability community to describe how athletes with disabilities are often celebrated by the public as heroes and inspirations for overcoming their perceived physical limitations (Berger, 2008).

"[The] concept of 'supercrip' illustrates the disability community's grappling with the stereotype that disabled people should strive to 'overcome' disability (Saxon, 2018, p. 27). The celebration of 'supercrips' is often argued to be stereotypical attitudes framed as compliments, which have an underlying implication that there are societal low expectations of people with disabilities, that people with disabilities need to overcome their impairments, and that all people with disabilities need to do in order to overcome these impairments is try; therefore, ignoring the many social impairments imposed by society (Saxon, 2018; Van Hilvoorde & Landeweerd, 2010). Despite these concerns, 'supercrips' can be influential figures for children and all people with disabilities by creating representation of disability in sports on a global scale, and therefore create motivation for their own participation in these activities, allowing them to benefit from their involvement in sport (Ravneberg & Söderström, 2016). The 'supercrip' is commonly associated with athletes who use AT, as their technology is seen as giving them the edge needed to succeed in sporting contexts; their success is therefore dependant on their technology (Ravneberg & Söderström, 2016; Saxon, 2018). The 'supercrip' and other discourses of disability are discussed in this paper in order to understand



November 2018

ISSN 1605-7406

the benefits and drawbacks of AT, the ideas that accompany AT, and the practice implications for using AT with children and youth.

Understanding Sports Inclusion

The participation of children with disabilities in sports and physical activities has a wide range of physical and socioemotional benefits, so much so that their participation is a fundamental goal in international legislation such as the Convention on the Rights of Disabled People (CRDP), the Convention of the Rights of the Child (CRC) and is a key initiative of the World Health Organization (WHO) and the United Nations International Emergency Children's Fund ([UNICEF] Kooiman, Sheehan & Wesolek, 2016; Kiuppis, 2018; World Health Organization[WHO], 2015; UNICEF, 2013a; United Nations, 1989, United Nations, 2006). Children with disabilities who participate in physical activities experience improved strength and coordination. They also experience drastically improved self-esteem, self efficacy and both emotional and physical self-worth (Wickman, Nordlund, & Holm, 2018). Despite these benefits, there are a number of physical and social barriers to their access and participation in sport (Ravneberg & Söderström, 2016; Wickman et al., 2018). Where persons with disabilities are concerned, these barriers include: limited awareness about how to encourage their involvement, limited opportunities and programmes for training and competition, a lack of supportive equipment and accessible facilities, and limited information on and financial inaccessibility of resources (Cairns, 2015; Kiuppis, 2018; (Ravneberg & Söderström, 2016). Sports inclusion is a multidisciplinary field that attempts to mitigate the barriers to sport for people with disabilities by creating inclusive sporting practices through a variety of different sporting modalities from segregated to integrated. The goal is to create equitable access, ensuring that athletes with (and without) disabilities are able to



November 2018

ISSN 1605-7406

exercise their agency and choose how and if they want to participate (Kiuppis, 2018).

Assistive Technologies

Generally, AT in sport are understood to be dramatic high-tech devices, such as the cheetah running blades seen in the Paralympic Games (Smith, 2015). However, AT are a broad category that encompasses any device or method that applies knowledge to enable people with disabilities to participate in their chosen sport (Kooiman et al., 2016). Examples include: specialized wheelchairs and prosthetics, bright coloured equipment, weights that can be attached to limbs so that the wearer does not have to grip them, balls which have bells inside them to alert players of their location, and games with modified rules (Kooiman et al., 2016; Ravneberg & Söderström, 2016).

Benefits of Assistive Technologies

AT are recognized internationally by the CRPD, CRC, and WHO as tools that can improve the quality of life of people with disabilities in many areas, including in sports and recreation (WHO, 2015; UNICEF, 2013a; United Nations, 2006). AT are considered more effective and beneficial if introduced at a young age, as this allows children to access the physical, social and emotional benefits of AT over a longer duration, feel comfortable and confident with their AT, and can increase the acceptance and normalcy of AT (UNICEF, 2013b; Borg, Lindström & Larsson, 2009).

Physical activities and sports are significant sources of development for all children, but can be extremely beneficial for children with disabilities since they provide structured social, cultural and personal experiences that challenge children and create opportunities to develop confidence, self-esteem and physical self-worth (Berger, 2008; Hart et al., 2014; Wickman et



November 2018

ISSN 1605-7406

al., 2018). These experiences have rich impacts on children's mental health, academic performance, social relationships and family life (Borg et al., 2009; Hart et al., 2014). Additionally, involvement in certain modalities of sport such as wheelchair basketball can be empowering for people with disabilities, as these provide a context where one's 'impairment' is socially valued and embraced, rather than rejected (Berger 2008; Kiuppis, 2018). Despite these numerous benefits, children with disabilities are often excluded from or cannot access physical activity and sport (Ravneberg & Söderström, 2016; Wickman et al., 2018). AT can help improve access and create new opportunities for access, allowing children with disabilities to achieve the socioemotional and physical benefits of sport (Ravneberg & Söderström, 2016; UNICEF, 2013b). These benefits extend beyond individual children. When children have access to AT it can significantly reduce the stress of their families (Borg et al., 2009; UNICEF, 2013b).

Being involved in activities in which some or all children use AT can also allow children without disabilities to gain a greater understanding and appreciation of the quality and legitimacy of disability sports and the challenges that people with disabilities experience, leading to improved social connections to peers with disabilities and an overall change in attitudes toward people with disabilities (Evans, Bright & Brown, 2015; Kooiman et al., 2016). Additionally, AT can provide people with disabilities with the capacity to participate in global sporting events in either segregated or integrated modalities, which promotes exposure and challenges prejudice towards people with disabilities by portraying them as elite athletes (Berger, 2008; Smith & Thomas, 2012).

The Drawbacks of Assistive Technologies

Despite having the capacity to enable people with disabilities to overcome physical barriers to access, AT have significant social barriers and



November 2018

ISSN 1605-7406

carry implicit social meanings. One of the more obvious factors is the affordability and availability of AT. While the CRPD promotes equal access and affordable AT opportunities for all, the actual availability and affordability of AT is largely dependent on one's socioeconomic status and location, for example, living close to a research facility or having the ability to travel to rehabilitation centres (Ravneberg & Söderström, 2016). Additional barriers to AT include a lack of awareness, lack of human resources knowledgeable in AT, lack of legislation, policies and national programmes relating to the provision of AT, and inaccessible environments in which to use AT (WHO, 2016; UNICEF 2013b). Furthermore, simply providing AT is not enough, as children and their must learn how use AT and therefore need regular support, and as children develop AT will have to be adjusted and modified to meet their changing needs (Borg et al., 2009; UNICEF, 2013b).

The provision of AT is uneven and lacking, especially in under resourced areas and developing countries. While AT have sometimes been provided to select communities in developing countries through charitable efforts, the infrastructure to support families in benefiting from AT (such as technicians who can provide adjustments as children develop; practitioners who can help to teach families how to use AT) is not sufficient (Borg et al., 2009). Therefore, there is limited data and research that supports AT, especially where children are concerned (Borg et al., 2009; WHO, 2016). This demonstrates the ongoing link between poverty, exclusion and disability and how social structures shape health disparities, including those for people with disabilities (Raphael, 2015; Hart et al., 2015). In a 2016 WHO report entitled *Assistive Technologies for Children with Disabilities* several recommendations were made with a view to mediate these obstacles. These recommendations spoke to legislation and policy strategies that address funding and equitable access concerns, and noted



November 2018

ISSN 1605-7406

that these strategies would need to involve a great deal of local, national and international cooperation between governments and organizations. In order for AT to be considered a legitimate and effective tool for accessibility, these changes must occur.

With further analysis AT become increasing problematic. At elite levels, AT are often regulated unfairly as they are seen as giving athletes with disabilities an unfair advantage and violating the purity of the sport (Corrigan, Paton, Holt & Hardin, 2008; Baker, 2016). AT are in fact present throughout sport, however some are normalized to the point that they are uncontested, such as running shoes or specialized clothing (Baker, 2016). This approach to AT reinforces the misperception that able bodies are normal, as it requires the athlete using AT to only achieve at or below a set of performance standards, standards able-bodies athletes are not made to conform to and actively encouraged to break (Corrigan et al, 2008; Baker, 2016; Smith, 2015). Elite sport is built upon supremacy, and privileges certain 'natural' advantages (i.e., a strong metabolism), but regulates others such as AT (Van Hilvoorde & Landeweerd, 2010). For example, prosthetic legs must not be able to give an athlete an 'unnatural' advantage and athletes are often penalized if they are judged as doing so, however an athlete who has larger than normal lungs is not subject to any regulations (Baker 2016). This is further reinforced by the framing of athletes with disabilities in media and popular culture, portraying them first by their disability, second by their athleticism, which challenges the authenticity of athletes with disabilities who use AT that are not available, or not appropriate for able bodies athletes (Berger 2008; Smith, 2015). For example, Paralympic athlete Oscar Pistorius' success was attributed to his Cheetah prosthetic legs, so much so that he was banned for competing against able-bodied athletes who could not use these pieces of equipment (Smith, 2015). The regulation and portrayal of AT demonstrates how non-



November 2018

ISSN 1605-7406

typical bodies are considered an afterthought in sports, and how fairness is correlated with the perception of a natural body type.

Additionally, AT can carry implicit social messages that reinforce dominant discourses of disability. For example, a common assumption is that by addressing a physical impairment AT level the playing field and treat a problem. This supports the medical model of disability which sees impairments as problems that need to be treated and therefore privileges a way of being that must be replicated (Foley & Ferri, 2012; Smith & Thomas, 2012). This, therefore, runs counter to the social model of disability, which sees impairments and inaccessibility as the result of a social environment full of physical, personal attitudes or feelings, and communication barriers (Berger, 2013; Kiuppis, 2018). Furthermore, AT can reinforce the 'supercrip' ideology by insinuating that if people with disabilities tried harder—or had the right technology—they could transcend the limitations of their disability (Smith, 2015; Smith & Thomas, 2012). These messages shift the responsibility for accessibility onto the technology rather than emphasising changes in society or personal attitudes and run counter to the idea that there are multiple healthy and legitimate ways of being (Foley & Ferri, 2012). Both the supercrip ideology and the very real barriers to accessing AT demonstrate ever-present societal views that work to invalidate the experiences of people with disabilities on multiple levels. AT cannot be considered outside of the societal discourse of disability and can play a role in reinforcing it. AT must therefore be used mindfully and not as a stand-alone solution.

Children's Perspectives of AT

Macro-level social barriers to and problematic narratives about AT aside, children's participation and use of AT is largely motivated by their perception of the technology itself and the benefits it can bring. If AT are



November 2018

ISSN 1605-7406

seen as enabling children to have fun and exciting experiences, creating social connections, and if they look like attractive, fun devices, then children with disabilities are more likely to use them (Cairns, 2015; Light, Page, Curran & Pitkin, 2007; Ravneberg & Söderström, 2016). Accessibility of equipment is also a key determinant of attendance and participation in community and social programs (Cairns, 2015). Conversely, if there is no perceived social benefit to using the device, if the device carries stigma or if the device makes them physically exhausted, children are less inclined to use it (Light et al., 2007; Ravneberg & Söderström, 2016).

Social experiences and representations of AT are integral to children's positive experiences with AT, and so can affect their ability to benefit from sport. Children with disabilities who have peers who use AT or who see their AT being used and celebrated on a global scale (such as in the Paralympics) have more positive experiences with AT and are more inclined to participate in a variety of different sporting and social events with their peers (Light et al. 2007; Ravneberg & Söderström, 2016). The benefits are mutual: when children without disabilities participate in modified activities (where children without disabilities play alongside children using AT) and reverse integration activities (where everyone uses AT regardless of ability) they are more able to connect with and understand their peers with disabilities, become more willing to engage with them and understand AT as a legitimate modality of sport (Berger, 2008; Evans et al., 2015;). Additional broader societal benefits come from diverse identities being represented and socially connected represented, such as reduced prejudice and richer and more expansive opportunities (Cairns, 2015; Limbach-Reich, 2015). Children's perceptions of AT, both by children and adults, are socially informed, which further complicates the 'supercrip' critique by demonstrating how the representation and celebration of athletes using AT can help to overcome social barriers to



November 2018

ISSN 1605-7406

accessing physical activity (Berger, 2008; Smith, 2015). This reflects how discourses of AT can be both empowering and disempowering.

Towards a Universal Design Approach of AT

While AT are in some ways problematic, they are a powerful tool that helps improve access to sports and physical activities. In an effort to mitigate the negative social discourses implied by AT, those in the field of sports inclusion are advocating for a universal design approach to using AT in sports. Universal design is used in a range of contexts from architectural design to structure of programs, and can be as simple as low-floor busses or Velcro fastenings (UNICEF, 2013b). This approach prioritizes diversity in the design of activities, spaces and environments which makes them accessible, usable, convenient, flexible and a pleasure to use, creating collective benefits across populations (Foley & Ferri, 2012; Kooiman et al., 2016).

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November 2018
ISSN 1605-7406

The universal design approach to AT in sports would create a shift away from seeing AT as specialized tools for people with disabilities to accessible technologies for all that enhance sport for all users by addressing a multitude of barriers to participation, such as geographic barriers (Foley & Ferri, 2012; Kooiman et al., 2016). AT can be used to augment accessibility proactively by considering the needs of all potential sport participants as sources of diversity and complexity necessary to include in the design of the activities, rather than as an after thought (Foley & Ferri, 2012). This would enable the inclusion of AT to be built into the activities and sports themselves and their regulations. The universal design approach to AT therefore values different identities and ways of being and participating in physical activities, rather than generalizing access across populations (Foley & Ferri, 2012). Additionally, the social benefits of sports inclusion extend to people without disabilities as they allow for discourses to be challenged and new social relationships to be created. When used to facilitate this process AT can also be a tool of social change (Evans et al., 2015; Kooiman et al., 2016). While there are many contextual (such as policy or funding) issues to consider in enacting this approach, AT has the potential to create individual and collective benefits and help move away from celebrating athletes with disabilities as extraordinary, and work to help establish a norm of inclusive practices (Foley & Ferri, 2012).

The universal design approach to AT is complimentary to a key component of the Inclusion Spectrum in sports. The Inclusion Spectrum situates various modalities of practicing sport along a spectrum, ranging from inclusion within mainstream settings to inclusion within disability-specific opportunities, with no implied hierarchy, allowing all users to act autonomously and choose whichever (equally legitimate) modality of sport they prefer (Black & Stevenson, 2011 as cited in Kiuppis, 2018). The Inclusion Spectrum works to build in access from the beginning—a goal of the



November 2018

ISSN 1605-7406

universal design process (Foley & Ferri, 2012)—by focusing on “different development potentialities, abilities, characteristics and expectations as a prerequisite of inclusive approaches in any heterogeneous group of people doing sport together” (Kiuppis, 2018, p. 14). While there is often debate as to whether segregated activities can be truly inclusive, differentiation is often required in order to support diversity (Kiuppis, 2018; Limbach-Reich, 2015) as demonstrated by the continuum approach to inclusive sports (Kiuppis, 2018; Berger 2008). A study by Berger (2008) found that people with disabilities want a broad spectrum of opportunities to be involved in sports—from elite to recreational, and segregated to integrated—and concluded that the best way to achieve this is to provide a continuum of options and opportunities. A universal design approach to AT in sport would augment accessibility across sporting modalities, thus complimenting the inclusion spectrum and providing these opportunities. When seen as complimentary to inclusive practices in sport, instead of a replacement, AT can work to increase accessibility and challenge social norms, rather than reinforce societal misperceptions around disability.

Implications for Practice

An important caution to consider when working to create inclusive programs and opportunities with children, youth and their families is that simply providing opportunities is not inclusive. For programs to be truly inclusive they must be organized and implemented clearly and effectively and must be represented as legitimate in order to be valued by the communities they serve, and the broader public (Limbach-Reich, 2015). This reflects the need for initiatives to provide AT to be holistic, meaning that they do not just provide the technology, but provide instruction to families and the community in how to use and accommodate AT, continued support and resources for children and families in the maintenance,



November 2018

ISSN 1605-7406

adjustment and personalization of their AT, and programs and activities in which diverse AT can be used (Berger, 2008; UNICEF, 2013b). This approach will help eliminate barriers, create sustainable programs which communities can benefit from and contribute to changing social discourse by representing the use of AT as a legitimate way of being (Berger, 2008; Smith, 2015). While this is certainly important on a large scale, it can be applied on a smaller scale. By striving to universally design our practice settings, we can increase this legitimacy on an interpersonal level, and in turn, add social pressure for policy change.

A critical element of sports inclusion is providing the means for people with disabilities to choose their method and level of participation (Kiuppis, 2018). This extends to the use of AT. Children must be able to choose based on their personal preference how and if they want to use AT, rather than feel that they are expected to use it because of their perceived impairment (Ravneberg & Söderström, 2016). Personal choice and agency of people with disabilities is also being advocated for on an international scale. The WHO (2016) states that one of the key considerations in the provision of AT is making them responsive to each individual's context and adaptable to personal preference. Considering the multiple social and societal influences that impact children's understanding of, reaction to, and motivation to use AT, children must be supported to explore and enact their personal preferences in regards to their AT.

To enable this choice, families need to be supported in making informed decisions. To fulfill this responsibility, practitioners must be literate in AT, do research, and be resourceful, in order to increase children's and families' awareness of what AT are available, how they may be suitable to their unique needs, and how they can access these technologies, both financially and physically (WHO, 2016; UNICEF 2013b). Agency for people with disabilities on an individual level is vital, but it is also critical to enable



November 2018

ISSN 1605-7406

and value the knowledge of people with disabilities on a larger scale, through the design of and policy for AT (Foley & Ferri, 2012; Kooiman et al., 2016). Efforts that aim to support youth with disabilities must involve and be directed by the youth themselves, or else they work to contribute to exclusion (Cairns, 2015). Practitioners must therefore work to advocate with people with disabilities to have authority in legislation and implementation of AT. Only in this way can AT be designed and regulated in ways that is responsive to social context and therefore facilitates inclusion (Foley & Ferri, 2012). This advocacy can be done at all levels, and work to increase access to AT at local municipal levels to larger global policy and is not specific to adults. The voices of children with disabilities must be included and responded to in research and policy (Ravneberg & Söderström, 2016).

Conclusion

AT can be discussed in purely positive terms, reinforcing common discourses of disability and therefore limiting inclusion in sport for children youth and families. AT hold power and the informed and balance use of AT is critical to this power facilitating inclusion. AT can be a tool that supports the inclusion of people with disabilities in sports, but it can also invalidate the experiences of, and perpetuate the exclusion of, the majority of people with disabilities. AT cannot be regarded as a comprehensive solution to the exclusion of people with disabilities in sports, however, people with disabilities are advocating for a universal design approach to AT, an approach that creates a context of inclusive and accessible sporting practices of which AT are a part. CYC practitioners are well-positioned to help overcome the stigma rather than the disability by using creative, accessible, supportive and innovative approaches to sport, such as AT, that welcome people with disabilities to join, excel and lead.



November 2018

ISSN 1605-7406

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November 2018

ISSN 1605-7406

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November 2018

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From Blaming to Belonging: Re-examining Our Approach to Fetal Alcohol Spectrum Disorder

Emily Hellard

Abstract

Canada's current approach to Fetal Alcohol Spectrum Disorder (FASD) is informed by discourses that frame FASD as a 100% preventable childhood disability that is most prevalent in Indigenous communities. This article advocates for a more nuanced understanding of FASD that acknowledges the inaccuracies or oversimplifications behind these notions and examines how they may cause harm to mothers and children. Drawing from ongoing conversations in postcolonial feminist literature and critical disability theory, I highlight an alternative view of FASD that upholds dignity and belonging by relocating the problem from mothers or children with FASD to societal barriers and structural processes such as racism, colonisation, and ableism. Above all, I ground my thinking in the strengths-based and relational frameworks that are integral to Child and Youth Care practice.

Keywords

Fetal Alcohol Spectrum Disorder, FASD, Child and Youth Care, prevention, colonialism, dignity, belonging



November 2018

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Canada's approach to Fetal Alcohol Spectrum Disorder (FASD) exemplifies how our understanding of a situation informs our engagement with it. Current discourses surrounding FASD frame it as a 100% preventable childhood disability that primarily affects Indigenous communities (Salmon, 2011; Shankar, 2015; Temple, Ives, & Lindsay, 2015). However, these themes are not as accurate as they are pervasive and actually have harmful implications for women and children. Drawing from ongoing conversations in postcolonial feminist literature and critical disability theory, I will highlight an alternative view of FASD that upholds dignity and belonging by relocating the problem from mothers or children with FASD to societal barriers and structural processes such as racism, colonisation, and ableism. This transdisciplinary approach aims to spark active, open dialogue between diverse perspectives, creating new possibilities and promoting socially just actions (Moore, 2011). Above all, I ground my thinking in the strengths-based and relational frameworks that are integral to Child and Youth Care practice.

Troubling Our Current Framework

In 1973, Jones and Smith published the first clinical description of Fetal Alcohol Syndrome in North America (Burd, Martsof, Klug & Kerbeshian, 2003). The condition came to public attention in the late 1980s, primarily through the work of child welfare advocates and professionals, and is now seen as a public health priority in Canada with national prevention and action strategies that have been developed in recent years (Pei, Tremblay, McNeil, Poole, & McFarlane, 2017; Poole, 2008; Public Health Agency of Canada, 2005; Shankar, 2015). As a relatively new diagnosis, research on FASD continues in an effort to determine what amounts of alcohol at which stages of pregnancy cause the varying effects on physical, cognitive, and behavioural functioning (Meurk, Lucke, & Hall, 2014).



November 2018

ISSN 1605-7406

FASD as an ‘Indigenous Problem’

While the medical understanding of this condition has changed over the years, as represented by the shift in terminology from Fetal Alcohol Syndrome to the more inclusive umbrella term Fetal Alcohol Spectrum Disorders (Public Health Agency of Canada, 2005), one key perception has stayed the same: FASD is primarily an Indigenous problem (Hunting & Browne, 2012; Salmon, 2011; Stewart, 2016). This notion persists in spite of growing challenges due to longstanding misconceptions regarding Indigenous peoples and alcohol. To be honest, I personally was drawn to this topic because I believed it would be particularly relevant to my future practice with Indigenous communities. However, a review of the literature thus far has demonstrated that this association between Indigenous peoples and FASD deserves a critical re-examination.

Until very recently, the prevalence of FASD in the general Canadian population has typically been estimated at 9 births per 1000, or about 1% (Public Health Agency of Canada, 2005, p.8). A publication from the Canada FASD Research Network has increased this estimate to 4% based on two new studies published in 2014 and 2018 (Flannigan, Unsworth, & Harding, 2018, p.2). However, even these two studies were conducted on specific populations, one in Alberta and one in the Greater Toronto Area, such that definitive, accurate prevalence rates of FASD in Canada still do not exist (Pei et al., 2017; Salmon, 2011). Popova, Lange, Probst, and Parunashvili (2017) conducted a comprehensive literature review on all Canadian and United States studies related to the prevalence of alcohol use during pregnancy in the general or Indigenous populations published between 1984 and 2014, aiming to establish prevalence rates through meta-analysis. Of the 125 articles found to have relevant data, only two contained research on FASD rates in the general Canadian population and five on FASD rates in Canadian Indigenous populations.



November 2018

ISSN 1605-7406

These seven studies represent the extent of Canadian research on the prevalence of FASD, and the variation in methodology, sample characteristics, geography, and diagnostic criteria led the authors of the review to conclude that “these estimates are not only out of date, but... as a result of the limitations listed above, are not generalizable to the Canadian population or applicable for decision-making purposes.” (Pei, et al., 2017, p. 40). If anything, the authors acknowledged that current estimates of FASD prevalence are likely too low due to underreporting and misdiagnosis, which can be linked to the racialized discourse surrounding FASD (Pei et al., 2017). Though difficult to prove, some have suggested that non-Indigenous children are more likely to be diagnosed with related conditions such as Attention Deficit Hyperactivity Disorder (ADHD) or autism rather than FASD due to racial bias and stigma in the diagnostic process (Dej, 2011; Meurk, Lucke, & Hall, 2014; Stewart, 2016). This conclusion is supported by studies reporting that 40 to 75% of children with FASD were initially misdiagnosed with another condition, the most common being ADHD, before ultimately being diagnosed with FASD, potentially representing a hesitation to assign such a stigmatized label to non-Indigenous children (Popova et al., 2017, p.41).

Racial bias is also reflected in the literature as there is significantly more research on Indigenous children with FASD than any other common neurodevelopmental condition such as autism or cerebral palsy (Di Pietro & Illes, 2016). In an analysis of research on Indigenous children’s health particularly related to neurodevelopmental disabilities, 51 of the 52 relevant articles found discussed FASD. This skewed focus perpetuates stigma and ignorance while denying Indigenous children and communities the benefit of research and support related to other disabilities (Di Pietro & Illes, 2016). Research about the drinking patterns of Indigenous women during pregnancy and how they may differ from non-Indigenous mothers or may



November 2018

ISSN 1605-7406

be influenced by factors such as age, employment status, education level, or cultural affiliation that have been seen to affect alcohol use in other populations is also lacking (Salmon, 2011).

The statistics that do point to higher prevalence rates among Indigenous communities are misleading. Some reports of prevalence are four to five times higher than the national average, but this data was gathered from communities that had already identified FASD as a specific concern and were seeking to highlight and document unmet need in order to receive support (Salmon, 2011). In other words, the statistics cannot be considered representative of the diverse Indigenous communities across Canada who have widely differing experiences and relationships with alcohol. In communities where intergenerational patterns of FASD and alcohol misuse do exist, “the root causes are undoubtedly related to the historical and collective emotional injury Aboriginal peoples have experienced as a result of colonialism” (Johnston & Boyle, 2013, p.6). Thus, even if FASD may be more prevalent in *certain* Indigenous communities than in the general population, the notion of FASD as an Indigenous problem must be reconsidered.

FASD as a ‘Children’s Disability’

Another problematic trend in the literature is the focus on mothers and babies or school children in classrooms, representing a seeming lack of recognition that those babies and children grow into adults who continue to need support but often cannot draw on the resources that were available to them in childhood (or not). Challenges facing adults with FASD include homelessness, mental health issues, substance use, unplanned parenthood, or involvement with the justice system (Temple, Ives, & Lindsay, 2015). Unfortunately, adults with FASD are highly overrepresented in the criminal justice system – in practice and in the literature. DeJ (2011)



November 2018

ISSN 1605-7406

argues that the change in conceptualization between a child with FASD and an adult with FASD impacts how these individuals are governed, with “sick” children targeted by the public health or welfare systems and “bad” adults recognized in the criminal justice system. Adults with FASD are seen as “deviant, dangerous, and irredeemable” (Dej, 2011, p.138) after failing to “cure” or effectively manage their condition with the supports available in childhood.

Not surprisingly, no official prevalence rates of FASD in Canadian prisons have been determined, but some studies in specific inmate populations across the country estimate the occurrence of FASD in their institutions to be between 10% and 55%, significantly higher than the most commonly cited national prevalence rates (Green, Cook, Stewart, & Salmon, 2016; MacPherson, Chudley, & Grant, 2011). It is difficult to determine exact numbers due to the general trend of under-diagnosis as well as a lack of screening of inmates, but simply put, “there is a population of offenders within Correctional Service Canada who are affected by FASD who are currently not being recognized upon intake, and are not being offered the types of services or programs that meet their unique needs” (MacPherson, Chudley, & Grant, 2011). Clearly, they are not being offered the services or programs to meet their needs outside of the prison system either. While adults with disabilities may not be the primary focus of a Child and Youth Care practitioner, understanding the outcomes of a condition such as FASD across the lifespan is essential to supporting and preparing a child and their family for adulthood.

FASD as ‘100% Preventable’

A final misconception to re-examine is the popular slogan that FASD is “100% preventable”, which fortunately is beginning to fall out of use. While the claim is technically accurate, since women who abstain from alcohol



November 2018

ISSN 1605-7406

will not have children with FASD, it is an oversimplification (perhaps purposefully so) that places the onus for change on the individual rather than on the systems surrounding them (Salmon, 2011; Stewart, 2016). This discourse erases important contributing factors such as the woman's life circumstances, available supports, and awareness of pregnancy, resulting in "fictions of prevention" and mother-blaming (Stewart, 2016, p.55). It is implied that good, responsible mothers will stop drinking as soon as they know they are pregnant, while bad, irresponsible mothers will continue to drink and knowingly harm their child.

Federal and provincial governments have funded countless prevention campaigns on this premise, and while they may have elevated the country's awareness of FASD, "research examining the histories of birth mothers of children diagnosed with FASD strongly suggests that the women most likely to have a child with FASD are those least likely to be able to reduce their alcohol use on their own in response to public health messages" (Salmon, 2011, p.168). The Public Health Agency of Canada's (2005) *Framework for Action*, primarily focused on health education, does not do enough to support women with histories of trauma or challenging life circumstances and especially does not acknowledge the underlying colonial context and long history of state intervention that has created the structural inequities in which many Indigenous women and children live today.

Conceptualizing FASD as 100% preventable is not only misleading, but harmful. Thus, many critical feminist and postcolonial scholars have offered critiques of the current approach and reframe the 'problem' of FASD through an intersectional, woman-centred perspective (see Hunting & Browne, 2012; Salmon, 2011; Stewart, 2016). For instance, the belief that "women just need to stop drinking" implies that FASD is an issue of personal moral failure without recognizing systemic causes, positioning



November 2018

ISSN 1605-7406

57

women's lives and bodies as the site of intervention and thus infringing on their rights (up to and including "detention-for-treatment" (see Stewart, 2016). It is especially harmful because it is most often Indigenous women's bodies that are targeted, perpetuating a colonial legacy by punishing them for not conforming to liberal constructions of "good mothering", a dynamic that is also exemplified in the alarming rates of Indigenous children being taken into government care (Hunting & Browne, 2012; Salmon, 2011). The emphasis is on how (Indigenous) women may put their children at risk, with no acknowledgement of the many government policies and practices that harm or fail to protect (Indigenous) children. In direct contrast to the stereotype that Indigenous mothers are not good mothers, Johnston and Boyle's (2013) ethnographic study of Indigenous mothers in northern British Columbia highlights how mothers of children with FASD respond with remarkable adaptability and strength to do the best they can for their children in the face of difficult circumstances and limited resources.

Asserting that FASD is 100% preventable also has negative, dehumanizing consequences for children, as was seen in 2014 when the Alaskan Senate was passing resolutions related to FASD funding. Media discussions at the time used language that described FASD as a "plague" that they aimed to "eradicate" through a "war on FASD" (Kelly, 2014, as cited by Stewart, 2016, p.59). While this harsh language is drawn from a particular context in the United States, the underlying sentiment is not unheard of in Canada. For instance, common arguments used to secure funding for prevention or early intervention focus on avoiding future costs to the system, such as the millions of dollars in health care and criminal justice spending, assuming that a child with FASD will inevitably be a drain on society's resources (see Pei et al., 2017). Salmon (2011) explains:



November 2018

ISSN 1605-7406

Moreover, it is suggested that these 'extra lifetimes costs' cannot be met, nor should they be expected to be met, through state resources. Given the neoliberalist orientation of the contemporary Canadian welfare state, the needs and interests, and indeed the existence, of persons with FASD are therefore seen as being at odds with the needs, interests and expectations of 'Canadian society' (p.172).

These metaphors related to violence, disease, and economic burden do not recognize the humanity or promote the dignity of children with FASD while denying their right to belong in and offer their gifts to society. A person with FASD becomes “a person who should not exist because FASD is 100% preventable” (Stewart, 2016, p.163).

Addressing the “causes of causes”

If our current understanding of and approach to FASD does not stand up to this critical examination, where do we go from here? Based on my current understanding of FASD through my analysis of the literature thus far, and an understanding of the complexities of people’s lives, I believe a first step is to move beyond responses that are simple and inexpensive such as health education campaigns to a response that is comprehensive, holistic, and addresses the systemic root issues of maternal drinking. Recognizing that substance use stems from an already “complex web of mutually reinforcing influences” (Pei et al., 2017, p.26) ranging from interpersonal violence to socioeconomic status to mental health challenges, I argue that an effective, ethical approach to FASD prevention must also consider the “causes of causes” (de Leeuw, Greenwood, & Cameron, 2009, p.293) including racism and colonialism. In this way, our work with children and families is inherently politicized. Care must be



November 2018

ISSN 1605-7406

taken to interrogate our complicity in structural inequalities and to resist assimilative practices that reinforce existing power dynamics rather than inciting social change (de Finney, Dean, Loiselle, & Saraceno, 2011).

In relation to FASD, Canada's colonial legacy includes ongoing impacts on structural determinants of health such as poverty, housing, education, and intergenerational trauma, which in turn have links to rates of substance use (de Leeuw, Greenwood, & Cameron, 2009; Hunting & Browne, 2012). Salmon (2011) notes that Indigenous communities are committed to FASD prevention within a broader decolonisation movement that views alcohol-related challenges as a result of colonisation. However, the motives and approaches advocated for by Indigenous communities are usually quite different from those employed by the colonial government, which prioritizes neoliberal politics and economics. A new approach to FASD should include increasing Indigenous access to and control over social determinants of health in a way that makes sense for each community, along with the necessary supports and resources, so that the government is not simply relinquishing accountability and saving money (Salmon, 2011).

New approaches to FASD should also involve community-based research to identify existing needs and opportunities, along with asset-based community development that recognizes and mobilizes the gifts of community members to improve the wellbeing of all (Kretzmann & McKnight, 1997; Wilson & Martell, 2003). Creating partnerships between organizations, communities, and all levels of government, will help ensure that the needs of women, children, and their communities are met in a way that is coordinated, holistic, and culturally relevant (Pei et al., 2017). This combination of supports will provide "in-depth care that is more likely to result in comprehensive healing (spiritual, physical, and emotional)" (Poole, 2011, as cited by Stewart, 2016, p. 63). Supports must also be available for



November 2018

ISSN 1605-7406

adults with FASD, rather than disappearing as soon as a child turns 18 (Dej, 2011).

Dignity and Belonging

Above all, it must be remembered that the women and children at the centre of discussions around FASD are human beings with inherent dignity and worth. Rather than seeing a life with FASD as something to be avoided at all costs, Child and Youth Care practitioners must recognize that everyone has gifts to offer and has the right to a quality of life with plenty of opportunities for being, belonging, and becoming (Quality of Life Model, n.d.). While numerous models and frameworks to describe quality of life have been developed, the general consensus is that quality of life is measured both objectively and subjectively and refers to a holistic sense of wellbeing in physical, emotional, social, and spiritual domains (Albrecht & Devlieger, 1999; Post, 2014). It is also worth noting that people with disabilities tend to report a higher quality of life than the friends, family, and professionals in their life might expect (Albrecht & Devlieger, 1999; Berger, 2013).

Furthermore, disability is an inescapable part of the human condition, as almost everyone will experience temporary or permanent impairment at some point (World Health Organization & World Bank, 2011). Critical disability theory invites us to move away from the idea that people should not be disabled and must change the way they are to fit into society towards an understanding that we all have a right to exist, to belong, and to access services just the way we are (Kunc, Reynolds, Munro, & Van der Klift, 2015). As Child and Youth Care practitioners we must be dedicated to supporting children and families and to creating conditions where all can thrive, resisting society's tendency of framing the needs of certain groups of people as pathological, competitive, or mutually exclusive.



November 2018

ISSN 1605-7406

On that note, rather than perceiving the needs of certain children or people as too complex, we must consider that our systems are too simple (Gharabaghi & Anderson-Nathe, 2017). In particular, our approach to working with children with FASD must shift from managing behaviours in a way that is convenient for the adults around them to truly striving to help young people flourish. Research in schools confirms the value of a holistic, relational, strengths-based approach that adapts to the diverse learning styles and abilities of each child (Millar et al., 2017; Pei et al., 2017). However, schools and other institutions may not currently hold space for this type of approach, and therefore must be adapted. The principles of universal design, most notably the principle of flexibility, would be useful to inform this shift (Steinfeld & Maisel, 2012).

Conclusion

As Child and Youth Care practitioners, helping professionals, and responsible citizens, we must be critically aware of the theories, perceptions, and dominant discourses that inform our practice in helpful or harmful ways. By examining these assumptions and their implications, we can identify gaps or problematic thinking that may negatively impact the people we work and live with. In the case of FASD, this includes the need for more research on prevalence rates of maternal drinking and FASD, the specific effects of alcohol on a developing fetus, and a broader scope of research on disabilities in Indigenous communities. Together, these new understandings can dispel stereotypes and harmful assumptions and provide guidance for moving forward. While the current social and political environment presents certain challenges to overcome in the journey towards wellbeing for mothers and their children, there are also many opportunities to learn and improve.



November 2018

ISSN 1605-7406

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November 2018

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Speech and Language Delay/Disorder in Early Childhood

Xinwen Liao

Abstract

This article introduces the social innovations of speech and language delay/disorder - moving from using unstandardized and subjective assessment tools to considering potential risk factors. The importance of working collaboratively with families, teachers, and Child and Youth Care workers is discussed. However, it is important to raise everyone's awareness on not only the negative impacts of social stigmas on children with speech and language delay/disorders and their families, but also explore ways to approach children who speak more than one language with potential speech challenges since they may face more challenging situations.

Keywords

Child and Youth Care, speech and language delay/disorder

Approximately 6% of children experience speech and language delay/disorder (SLD) in early childhood (Law, Boyle, Harris, Harkness, & Nye, 2000; Nayeb, Wallby, Westerlund, Salameh, & Sarkadi, 2015). On the one hand, many researchers have proven that early interventions and speech and language therapy (SLT) are effective,



November 2018

ISSN 1605-7406

especially for children with expressive language delay (Garrett, Law, & Nye, 2004). On the other hand, unfortunately, the assessment, evaluation, and referral processes for SLD can be unclear and disorganized, with the situation becoming even worse for bilingual children.

According to various sources, different terminologies are used to describe and define SLD. According to *Talking Point*, an organization devoted to helping children with SLD, language delay and language disorder are opposite. To be more specific, this organization defines “language delay” as children who follow the usual pattern but experience slower pace on language development while “language disorder” indicates children who do not follow the usual pattern, have trouble with pronunciation, and experience different pace on language development. In contrast, speech and language delay and disorder are interchangeable according to several peer-reviewed articles (Blackburn, & Aubrey, 2016; Situmorang, Hariyono, & Gultom, 2017; Stock, & Fisher, 2006; Singh, Chan, & Rusli, 2016).

In this article, I will use the term speech and language delay/disorder (SLD). I will first clarify each term separately— Speech refers to the verbal production of language while language represents a way of conveying ideas, feelings, and thoughts. Also included sign language and visual form of communication (McLaughlin, 2011). Delay represents children who “scored the lowest 5% of the distribution on the language scales” (Silva, McGee, & Williams, 1983. p3).

Regardless of using the term delay or disorder, SLD can result in negative long-term impacts on children’s later development in different areas. Generally, according to Cohen, Davine, Horodezsky, Lipsett, and Isaacson (1993), SLD resulted in negative outcomes on children’s mental health and social competencies. To expand on that, they suggest that children with SLD might experience: higher likelihood of difficulty



November 2018

ISSN 1605-7406

communicating; reading, spelling, and writing difficulties that lower the level of school readiness; attention deficits; bullying by other peers; feeling isolated and lonely; lower self-esteem, depression, and anxiety; and withdrawal from social interactions (Blackburn, & Aubrey, 2016; Hart & Risley, 1995; Law et al., 2000; Macharey, & Suchodoletz, 2008; McLaughlin, 2011; Nayeb et al., 2015; Silva et al., 1983). SLD is also a predictor of other serious mental disorders in later development since 60% children with SLD are later diagnosed with other neuropsychiatric disorders (Silva et al., 1983). Therefore, for the purpose of this article, I will combine delay and disorder.

Current Social Innovations

In Canada, the first clinical services for SLD can be traced back to the 1930s when Ruth Lewis, a clinical psychologist, became aware of the lack of services and support for children with SLD during her work. She went to England for professional and systemic speech therapy training and established a program for children with SLD after her return to Canada in 1937 (Martin, 2007). Between the 1950s and 1960s, the clinical services in Canada expanded while educational programs in this profession were also introduced. Moving into the 1970s and 1980s, the notion of “language disorders” was introduced and the federal government policy was published to unify the professions (p. 34).

In the historical context, subjective screening and assessment tools have often been applied when diagnosing children. Because of the fact that these tools can be unstandardized and subjective, the misdiagnosis often results in inaccurate labels on children. Children who are misdiagnosed with SLD are often be placed in inappropriate speech education settings which can lead to poor development and lower expectations of their development (Damico, Müller, & Ball, 2013). Besides the subjective screening tools, people often individualize the problems



November 2018

ISSN 1605-7406

within each child and ignore the ecological system when working with children who are diagnosed with SLD (Damico et al., 2013). This runs the risk of supports that are deficit-based, incomplete, decontextualized, and which can in turn lead to social exclusion of people with SLD.

There have also been other challenges to providing adequate care in relation to SLD, beyond diagnosis. For example, the inequalities in health services; the family's social-economic status (SES), the parenting style, parents' education level, the age of parents, parents' mental health status, family history of SLD or other mental illnesses, premature birth, low birth weight, a larger family size, and the level and quality of parents' interaction with the baby have all been identified as potential factors that can contribute to children's speech and language development. (Amster, 1999; Blackburn, & Aubrey, 2016; Law et al., 2000; Lee et al., 2017; Mclaughlin, 2011). This means these factors must also be taken into consideration when supporting children and families.

Contextualizing Care

It is fundamental to understand that SLD can be present either as a primary condition which cannot be accounted for by any known etiology (Singh, Chan, & Rusli, 2016) or as a secondary condition since SLD might also be the direct cause of other primary conditions such as autism, hearing impairment, behavioural difficulties, emotional difficulties, or neurological impairment (Mclaughlin, 2011; Silva et al., 1983; Singh et al., 2016). Therefore, it is necessary to refer children with indicators of SLD to a doctor who could test children's speech, language, physical, cognitive development as well as the possibility of hearing problems (Mclaughlin, 2011). We should also be aware of the fact that research shows that 35% of children with SLD have had experienced maltreatment (Sullivan & Knutson, 2000).



November 2018

ISSN 1605-7406

As mentioned above, various risk factors have been identified when working with children with potential SLD, which indicates the need of a team when working with children with SLD. In this team, speech and language pathologists (SLPs), families, schools, teachers, and CYC workers should work collaboratively. Based on a Malaysian study (Singh et al., 2016), parents were involved in almost every aspect of their child's care. Parents were involved in the assessment session to ensure that children presented their common and typical behaviours. The family's capability and dynamics were considered during the planning session and the treatments mostly aimed to meet children and families' communication needs (Mclaughlin, 2011). Involving parents in the decision-making process and sharing goals with them is also a form of empowerment (Singh et al., 2016). Moreover, several sources showed that parents are more sensitive to children's semantic performance since most conversations occur in everyday settings (Lee et al., 2017).

Parents are also helpful in promoting interpersonal communication by encouraging their children with SLD to interact with them, to respond to other people to talking, and exchange meanings through communications (Situmorang et al., 2017). Parents can also work on creating supportive environments in the family for children in five distinct ways: "openness, empathy, supportiveness, positivity, and equality" (Situmorang et al, 2017, p4). This is where CYC workers can be of great support for the whole family. Supporting parents to know how their early interventions are often effective would be very empowering and useful (Mclaughlin, 2011).

Teachers and those caring for preschool age children are other important sources of support, when the child's life is understood in context. Research show that teachers can have very positive impacts on children's speech and language development (Singh et al., 2016). Since teachers are more focused on the use of academic language, they are more sensitive to



November 2018

ISSN 1605-7406

70

children's morphosyntactic performance (Lee et al., 2017). In a survey that was conducted towards child healthcare nurses in Sweden, 68% workers reported that before referring the children with suspicious of SLD to SLPs, they would contact "the children's preschool to obtain additional information about their language abilities" (Nayeb et al., 2015, p2).

Ongoing Challenges and Opportunities

For monolingual children, 96% of workers reported receiving instruction on how to carry on language screening and assessment. However, when it comes to children who speak two or more languages, 66% of the workers stated that they did not receive instruction on how to apply screening and evaluation tools for bilingual children (Nayeb et al., 2015). In Sweden, a country where approximately 50% of children have at least one foreign-born parent, only 8% of the healthcare workers reported receiving instructions on screening a bilingual child. Without proper training, 95% of the healthcare workers hold a stereotype that bilingual children experience a slower pace of language development. Therefore, they intentionally simplified the language screening process or delayed referrals to Speech and Language Pathologists (SLP) which resulted in late interventions and under-representation of bilingual children in the Speech and Language Disorder/Delay (SLD) (Nayeb et al., 2015). In fact, bilingual children who share a similar SES with their peers who only speak one language develop core vocabularies and reach milestones in language development at the same age (Kohnert, 2013).

In Singapore, a country that uses English as the main language while requiring children to also have either Mandarin, Malay, or Tamil as another medium of communication, the screening and assessment tools are still English-based even for the children who identified Mandarin as their first language (Lee et al., 2017). In Malaysia, the SLPs did not start to develop



November 2018

ISSN 1605-7406

until the late 1980s and this field is heavily influenced by Western literature and practices. Due to the lack of cultural context in the screening methods, most SLPs reported using behavioural observations and their own clinical experiences when assessing the children and only 10.2% of them usually or always applied standardized tests during assessments (Singh et al., 2016). Because of (1) the lack of valid screening tools based on children's first language; (2) insufficient empirical data and research; (3) the lack of SLPs who speak both languages; (4) inadequate special and in-depth trainings; (5) the ambiguity between actual language impairment and linguistic features displayed while learning a second language; and (6) the fact that children can only be diagnosed when they present a delay in both languages, bilingual children are at risk for both over-representation and under-representation (Damico et al, 2013; Lee et al, 2017; Singh et al., 2016).

To improve the situation for bilingual children, several sources emphasized the importance of considering cultural diversity when working with bilingual children with suspicion of SLD (Goldstein & Ikard, 2013). Working with parents and teachers together becomes even more important in this context since parents have most interactions with the children while teachers can use other bilingual classmates as a reference point to identify whether the children are experiencing SLD (McKinnon, McLeod, & Reilly, 2007).

Implications For Children, Youth, and Families

Like other types of disabilities, children with SLD and their families also struggle with the stigma that comes with this impairment. The concept of stigmatization is the result of social processes (Link & Phelan, 2001). First, a label is used to distinguish differences among humans. However, labelling becomes a way of excluding and constructing biases and assumptions. Secondly, negative stereotypes are often placed on labeled people when



November 2018

ISSN 1605-7406

considering their differences from the social norm. However, from a postmodern perspective, the social norm is originated from what most people will do and perform. Thus, these labeled people are placed in different categories which increases the gap between “us” and “them”. In terms of SLD, these children were placed in special education with lower expectations. And finally, people labelled in this way will often experience discrimination and loss (Link & Phelan, 2001). According to a survey conducted by Macharey and Suchodoletz (2008), around 50% of parents reported that their children had experienced rejection and exclusion by other children and 36% of them experienced bullying at school. Even within their own families, approximately 20% of parents indicated the lack of acceptance and understanding by other family members. Because of the judgement and avoidance parents received from other adults and family members, some of these parents reported avoiding contact with others and playing down their children’s developmental problems. Most of the time, the concept of stigmatization caused more negative impacts than the actual disabilities. Therefore, as CYC workers, it is important to recognize the various factors and social norms that underlie such labels and how labelling has excluded children with disabilities and their families from the society (Goldstein, & Ikard, 2013).

Combining all challenges that have been discussed above, a comprehensive approach to SLD is necessary. Since research indicates that SLD can be identified as early as 2-years-old and therapies lasting more than eight weeks are very effective, timely and efficient diagnosis and early interventions are essential. Furthermore, a precise and universal classification of SLD will help on building standardized screening and assessment tools. Moreover, regular trainings and more SLPs working in this field, especially when working with bilingual children, may reduce caseloads for each worker. This training needs to extend beyond



individualized understandings of SLD to also include social contexts and the potential for social exclusion. Finally, screening methods based on bilingual children's first language will make the assessment more valid and reliable (Blackburn, & Aubrey, 2016; Stock & Fisher, 2006; Nayeb et al., 2015; Lee et al., 2017).

Conclusion

Increasing numbers of workers and researchers in different fields have realized the importance of speech and language development in children. Although the work in the field is becoming more organized than before, more effort should be made to promote a standardized definition of SLD; screening tools that are based on children's first language while considering cultural diversity; SLPs that are well trained to work with bilingual children, and more responsiveness to the child's experience in the context of their home, school and community life. CYC workers are positioned to work on deconstructing the stigma and stereotypes that negatively impact children with SLD, ensuring parents or caregivers' status and provide counselling or other forms of support; be aware of the possibility of trauma responses and bullying; and empower family members by using a strength-based perspective.

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November 2018

ISSN 1605-7406

75

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November 2018

ISSN 1605-7406

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Universal Design for Learning: Background and Applications in North America

Ari Saunders

Abstract

This article begins by presenting Universal Design for Learning (UDL) in its historical and political context along with some of its defining features and the research behind it. It then moves into some specific examples of how people are implementing UDL in North America. These specific case studies serve to explore the latest developments in the application of UDL in the general education system. Research from the second case study specifically addresses some of the challenges faced by teachers and schools in addressing the gap between policy and practice. It also presents findings on positive outcomes for teachers and students related to the implementation of UDL using the Three Block Model (TBM) for UDL. Child and Youth Care (CYC) workers are implicated in these findings, because of the significant potential that widespread uptake of UDL has for positively impacting children, youth and families.

Keywords

Universal Design for Learning, Inclusive Education, Child and Youth Care, Accessible to all, Education, School Reform, Salamanca Statement, Education for all



November 2018

ISSN 1605-7406

78

Universal Design for Learning (UDL) is an educational approach which aims to create environments where all students can thrive. It could be said that UDL takes its origins from two different sources. One source is the Universal Design (UD) movement which developed in the middle of the twentieth century as part of the Disability Rights Movement (Robinson, 2017). UD considered building design from the perspective of accessibility, recognizing the value of designing buildings which could be accessed by people with many different abilities. The dropped curb is the most well cited example of how UD has become common place in today's world. UDL applies the principles of Universal Design to education. The Centre for Excellence in Universal Design identifies seven principles which should guide all universally designed spaces and objects (Centre for Excellence in Universal Design, 2018). These include: equitable use, flexible use, simple and intuitive use, perceptible information, tolerance for error, low physical effort (not requiring strenuous activity), and appropriate space for approach and use. These principles are specifically geared towards building and product development, but many of them apply to education as well.

The other important source of development of UDL comes from the United Nations World Conference on Special Needs Education of 1994 (UNESCO, 1994). At this conference, the United Nations adopted the Salamanca Statement, confirming the "necessity and urgency of providing education for children, youth and adults with special educational needs within the regular education system" (Katz & Sugden, 2013, p. 1; Curcic, 2009). The nations who participated in this conference and took these recommendations to heart were thus compelled to integrate students with special educational needs into their general education classrooms (Ainscow & César, 2006). In Canada and the USA, policies were created reflecting this resolution and the diversity of students in general education



November 2018

ISSN 1605-7406

79

classrooms increased (Katz & Sugden, 2013). This led to a further question: how could a general education classroom be organized to meet the needs of diverse learners?

UDL began to be specifically articulated and defined around the turn of the twentieth century following the 1997 reauthorization of the Individuals with Disabilities Education Act (IDEA) in the United States of America (Edyburn, 2005). The reauthorization of this act sought to address an important question: How can we meet the needs of the growing numbers of students with disabilities in the mainstream classroom? It recommended careful consideration of students with disabilities' needs and capacities by creating Individual Education Plans (IEP) for each student. These plans were to be created by parents, teachers and support staff and were to include the student's current capacities, educational goals and any necessary supports or modifications (Edyburn, 2005).

Under Rose and Meyer's leadership, the Centre for Applied Social Technology (CAST) worked to develop the idea of UDL into an educational approach that was grounded in research about how people learn (Edyburn, 2005). They encouraged an approach to education that provided learners multiple ways of experiencing information, demonstrating their learning and becoming engaged with the material. The goal was to give access to the material being studied to the broadest possible range of learning styles. In 2008, UDL was publicly recognized and legally defined within the Higher Education Opportunity Act (HEOA; Public Law 110-315, August 14, 2008). It is defined as:

A scientifically valid framework for guiding educational practice that:

- a) provides flexibility in the ways information is presented, in the ways students respond or demonstrate knowledge and skills, and in the ways students are engaged; and



November 2018

ISSN 1605-7406

- b) reduces barriers in instruction, provides appropriate accommodations, supports, and challenges, and maintains high achievement expectations for all students, including students with disabilities and students who are limited English proficient. (Hall, Meyer and Rose, 2012, p.3)

Miles & Singal's (2010) paper highlights how the international conversation around meeting the needs of diverse learners can be a bit fractured. They describe two different streams, Education for All (EFA) and inclusive education which could better serve the needs of all learners by aligning their work more closely. Inclusive education focuses on the importance of including students with disabilities into public school classrooms but does not always consider other student populations suffering in the public education classroom. EFA focuses on ensuring that everyone has access to education but does not always consider students with disabilities as being able to receive education. UDL has the potential to transcend this division entirely through its focus on meeting the diverse learning needs of all learners

Research Supporting UDL

Hall, Meyer and Rose (2012) explain the research which lies behind UDL. They note that “advances in neuroscience and education research over the past forty years have reshaped our understanding of the learning brain” (p.2). It is widely recognized today that there is no “regular student”. Everyone has a learning style which is “as unique to individuals as their fingerprints or DNA” (p.2). They emphasize the environment as a key factor in shaping how people learn, noting that “individual qualities are not static or fixed; rather, they are continually shifting, and they exist relative to the environment” (p.2).



Child & Youth Care Practice

Collected Wisdom for New Practitioners



Patricia Kostouros and Michelle Briegel

Editors

all students and the importance of moving beyond the idea of an “average” student. To form a model of how this could be done, the researchers looked at three different brain networks which work together during learning (Hall, Meyer & Rose, 2012). The three networks are:

- 1) Recognition networks, which allow us to understand what we are learning,
- 2) Strategic networks which allow us to demonstrate what we have learnt and
- 3) Affective networks which allows us to connect to what we are learning and give it meaning.

They emphasize that considering learning through the interrelationship of these three networks can be helpful in forming a basis for creating a suitably accessible educational environment. To do this, teachers are encouraged to consider providing multiple ways of engaging with learning in each of these areas. The examples of applications of UDL found below can be helpful in illustrating how this can be done.

Applications of UDL

This section presents two different examples of UDL in the general education system. The first example references the way that school libraries have historically played a role in meeting the needs of diverse learners and presents a specific case study as an example of this. This example helps make it clear that UDL is not a new phenomenon and allows the reader to recognize existing opportunities for UDL partnerships in schools. The second example presents a more ambitious picture of UDL. It describes a recently developed model, the Three Block Model (TBM) for UDL, whose goal is to support the wide spread implementation of UDL in



November 2018

ISSN 1605-7406

schools. This example demonstrates a different kind of opportunity which requires a greater level of vision and commitment and leads to a more impressive outcome.

Natural Partnerships between School Libraries and UDL

Robinson (2017) describes the important role that school librarians have traditionally played in supporting students who did not adapt easily to the traditional classroom environment. They serve as resource hubs, helping guide students towards materials that are well suited to the subjects they are exploring. From their place in the school library, librarians can develop relationships with individual students and consider what kinds of materials they will connect with easily. “These key roles of the school librarian, particularly the roles of instructional partner and information specialist, serve as a model for infusing UDL principles and strategies throughout the entire school curriculum” (p. 58). Robinson notes frequent success in working with these students to create individualized learning opportunities before the existence of UDL. This suggests a “natural partnership” between school libraries and UDL.

Robinson (2017) offers a specific case study from his own experience as a librarian to explain the application of UDL in school libraries in more detail. He describes working with “a group of five middle school students who collaborated on a research and multimedia project on the United States Civil War” (p. 58). Robinson worked with their teacher to identify a way that the students would be able to engage with the material, process the information and demonstrate their understanding in ways that suited them. Rather than ask them to write the traditional research essay, they were asked to “produce a video documentary in the spirit of Ken Burns’ *The Civil War*” (p. 60). They assigned each student a specific Civil War topic to research and had them take notes on it, helping as needed.



November 2018

ISSN 1605-7406

Students could select their preferred medium from which to retrieve the information they needed. Following completion of note-taking, students were supported by their teacher to write a script and create a storyboard and then tasked with finding images connected to the text. They had to record the narration, soundtrack and images and edit the final video. All of this was done in partnership with the teachers. The students were then given the opportunity to present their final product to the rest of the class. Through this process, students were given multiple means of learning about the Civil War, demonstrating their knowledge about it and finding meaning in the educational process. They also had the opportunity to learn valued technological skills. Both students and teachers described this as a satisfying process (Robinson, 2017).

The value of Robinson's (2017) work is that it identifies specific avenues through which UDL is already manifesting itself within the general education system. Educators are often faced with a gap between their appreciation for UDL and their understanding of how to manifest it in their work (Hall, Meyer and Rose, 2012). Describing situations where UDL is already present in people's experiences can help to demystify UDL, making it easier to relate to and realize in schools. This is an approach that celebrates small successes and cultivates readily existent opportunities to gradually increase the proliferation of UDL consciousness throughout schools. The next example offers a different approach to achieving the goals of UDL

The Three Block Model

Katz (2015) developed the Three Block Model (TBM) for UDL as a response to current challenges in the education system. She cites widespread student disengagement in schools and teachers with high stress levels leading to early retirement as two of these challenges. The



November 2018

ISSN 1605-7406

TBM for UDL provides a process for shifting classroom dynamics in three stages. The first block uses a programme called Respecting Diversity (RD), which supports the creation of a class culture that is supportive for all students. The second block engages teachers in developing educational resources which meet the needs of all their learners, including lesson plans, assessment tools, and peer to peer learning groups. The third block addresses the administrative resources needed to be successful. This program is very elaborately laid out in Katz's (2015) work and has been implemented with substantial documentation and study in five school divisions in Manitoba. The people studied included over 650 students, 50 teachers, and 15 administrators (Katz & Sokal, 2016). The research from these studies is documented separately in different articles. One of Katz's (2015) articles explores how teachers' self-efficacy and stress levels are affected by their use of the TBM for UDL. Another article explores Katz's (2013) findings of students' experiences of the TBM for UDL. Yet a third study (Katz & Sugden, 2013) provides a detailed case study of the implementation of TBM for UDL in a specific high school.

This paper focuses on the high school case study because it provides an in-depth exploration of how the TBM for UDL was implemented. In 2009, the school identified a need for a school wide approach to meeting the needs of diverse learners (Katz & Sugden, 2013). Through the leadership of their school principal, Katz was engaged to introduce the TBM for UDL to the school staff for them to consider. The staff agreed to implement this model and began to actively learn about it in the spring of 2010, in preparation for the 2010-11 school year.

Block One: Respecting Diversity

The first step of the TBM for UDL is Respecting Diversity. This is a term which is closely related to the idea of inclusion as discussed in Booth &



November 2018

ISSN 1605-7406

Ainscow's (2002) *Index for Inclusion*. The school introduced this term to their learners through several different strategies. The principal hosted an assembly with each grade of students to discuss what RD meant, introducing the idea of Multiple Intelligences and asking questions like: "What does smart mean?" and "Who is smarter, Einstein or Crosby?" (Katz & Sugden, 2013, p. 13). He invited students to consider their multiple intelligences and let them know that their teachers would be discussing this more with them. This set the tone for classroom discussions with teachers who took the exploration of multiple intelligences further. (For further discussion of multiple intelligences, please see Dolati and Tahiri's (2017) research into teacher's multiple intelligences and the effects on their teaching styles.) Using a variety of mediums, students were asked to consider their own intelligences and share these with the teachers. These were then used to create learning profiles for the students which teachers could use in creating their lesson plans. Another important part of this process involved helping the students to understand themselves as part of a learning team who could work together to support one another and thus achieve better outcomes than any one of them could achieve on their own. These efforts to shift the school culture around celebrating diverse learning styles were followed up over the school year with guest speakers who exemplified the idea of multiple intelligences. Katz and Sugden (2013) note that students who participated in the program showed improvements in self-concept and belonging.

Block Two: Instructional Practice

Instructional practice in the TBM for UDL is designed to foster the engagement of all students through attending to their individual intelligences and meaning centres (Katz & Sugden, 2013). This is done through presenting theme-based curriculum offerings which span all of



November 2018

ISSN 1605-7406

the student's courses. To implement this, teachers worked together within each grade to decide on a theme for the year and design curriculum in each course which related to this theme. They used the learner profiles developed through the RD block to design an educational approach in their classroom which worked for all of the learners. Working together, the teachers were able to design curriculum and problem solve in partnership to increase their chances of success. This required buy in from teachers and administration to work well. For this reason, Katz (2013) emphasizes the importance of distributed leadership in implementing the TBM for UDL.

Block Three: Systems and Structures

Successful delivery of this model requires a high level of coordination and reflection (Katz & Sugden, 2013). To achieve this, the teachers were invited to participate collaboratively in planning and implementing changes in the school. In this way, the teachers shared responsibility for the decisions that were made and helped set-up systems which would be supportive. They set out clear goals and timelines for how the different stages of the TBM for UDL would be rolled out. They made commitments to invite the principal into their classrooms to observe the classroom dynamics and offer feedback. The administration ensured that the teachers had opportunities to meet with each other during the school day to work collaboratively and share reflections. Staff meetings prioritized opportunities to reflect on new developments in the school. The principal shared pictures of what was occurring in the different classrooms and how the students were responding to it. This had an encouraging effect for teachers and helped them to recognize the value of the work that they were doing.



November 2018

ISSN 1605-7406

Review

Implementing the TBM for UDL yielded positive feedback from teachers and students (Katz & Sugden, 2013). Teachers described feeling better able to meet the needs of their students and students described feeling much more engaged. Observation of students in the classrooms showed that prior to the introduction of this model students were engaged for a total of fifteen minutes in each hour. Following its introduction, this number jumped to forty-five minutes per hour. Another article by Katz (2016) goes into more detail around the qualitative outcomes of implementing the TBM for UDL. This study found significant growth in student's levels of achievement, self-confidence and positive perception of the school environment. These self-identified experiences of the students contribute to a greater level of resiliency in the face of potential challenges (Brunnberg, Coombe et. Al., 2014).

Katz and Sugden's (2013) research provides a much different picture of how UDL can find its way into school communities. As stated at the outset, it requires a higher level of planning and participation from the whole school. Because of this, it requires schools to have these resources available to them. Dr. Katz's interest in this project and support for the different schools is clearly an important contributing factor to the success of this initiative. Lack of resources and support is often described by teachers as a significant barrier to the realization of UDL in classrooms (Katz & Sugden, 2013). This is where the more gradual, individualized approach which is described in the first example can be of value. Unfortunately, this approach means that only specific students benefit from access to diverse learning opportunities. The second approach, which could be called the school wide approach gives all students the opportunity to experience the benefits of UDL.



November 2018

ISSN 1605-7406

Implications for Child and Youth Care (CYC) Professionals

This paper describes a number of significant influences on the lives of children and youth in schools. CYC workers can recognize in these descriptions some important elements to consider in their interactions with families. For most families, the relationship to school is an integrally contributing factor to the health of the whole family system.

Bronfenbrenner describes the school as a part of the child's microsystem (Oswalt, 2008). CYC workers are often required to interface with schools when supporting children and families. Understanding of trends in schooling can help CYC workers recognize what is occurring within a given school and how that influences the families they support. This recognition can lead them to voice these observations and support families in seeking and/or advocating for change when they recognize potential improvements that can be made. Further to this, CYC workers can take inspiration from the applications of UDL in their work with children and families beyond the school context. There are many situations where CYCs play a role in helping children and families understand new ideas and develop new relationships with themselves and their surroundings. Instead of blaming clients for 'not getting' what is being shared with them, CYCs can consider the principles outlined in the UDL framework to see how they can more effectively engage the young people with whom they are working.

Conclusion

UDL has the potential to radically transform students' experiences in general education classrooms. It begins with reimagining the educational needs of human beings through applying the most current research into how people learn and develop. UDL advocates make these findings more accessible through models which simplify the research enough that it can



November 2018

ISSN 1605-7406

be worked with and applied in practical ways. Though UDL has clear benefits for students, it can still be challenging to apply it. In this interest, I have provided two different approaches to how UDL can be introduced in schools. Each of these has their strengths and liabilities. These examples can provide encouragement to educators who recognize the importance of transforming educational models to allow them to meet the needs of today students. CYC workers must acknowledge the positive impact that these changes in the education system can have for the families they support. This can strengthen their commitment to ensuring that families have access to an educational environment that is truly supportive.

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November 2018

ISSN 1605-7406

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November 2018

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Online Accessibility for Post-Secondary Students with Disabilities

Kelsey Kotzian

Abstract

Based on a review of literature about online resources for post-secondary students, this article presents an analysis of common barriers or gaps in online accessibility, which can hinder the educational, social, or physical experience of students. By exploring the concept of universal design as it applies to online learning and the post-secondary experience, the author offers a critical appraisal and theoretical explanation of current practices, and provides concrete recommendations for post-secondary institutions and Child and Youth Care professionals. These suggestions will support professionals in addressing or eliminating the barriers to online accessibility, including those with a disability, and promoting universal design to the benefit of all students.

Keywords

Accessibility, disability, online, post-secondary, universal design, website, W3C

An increasing number of people are undertaking post-secondary education (Statistics Canada, 2017a). One way that universities are responding to the influx in enrollees is by increasing their online services. This raises questions around the accessibility of online resources



November 2018

ISSN 1605-7406

for students with disabilities. It is essential that post-secondary institutions and the programs and resources they offer are accessible because they are essential to students' experiences and success.

This article explores barriers, supports, and guidelines for online accessibility in order to ascertain how students with disabilities are being impacted. It will explain what needs to be done to bring post-secondary institutional online resources up to universal design standards by using relevant theories on disability which impact this sector of accessibility. Finally, the implications for post-secondary institutions and child and youth care (CYC) workers are noted and recommendations for the improvement for online accessibility are given.

Statistical Relevancy

In 2012, there were 3.8 million persons over the age of fifteen in Canada who reported having a disability (Statistics Canada, 2016). A percentage of this demographic is not old enough or has chosen not to engage in some type of post-secondary education. However, of those aged twenty-five to sixty-four who attend a post-secondary institution, only 14% of people with disabilities graduate (Statistics Canada, 2016). This number is much lower than the 27% of students without a disability who graduate from a post-secondary school (Statistics Canada, 2016). Further, of those post-secondary students aged twenty-five to sixty-four with disabilities, 34% took fewer courses than the average, 30% took longer to graduate, and 30% discontinued their studies (Statistics Canada, 2016). These statistics can be particularly alarming as post-secondary education is becoming increasingly important in Canadian society due to employment requirements and the prospective job opportunities available (Statistics Canada, 2017b). The differences in the rates in which students with and without disabilities undertake or graduate from post-secondary cannot be



November 2018

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ignored and there must be both individualized and collective factors that are impacting persons with disabilities ability to begin or complete post-secondary education.

Universal Design

Universal design (UD) plays an integral role in general accessibility for all populations (Björk, 2009). UD is a set a principals and design characteristics that should be followed in order for people, no matter their ability, age, demographic, or other factors, to be able to utilize, access, and understand the services, resource, programs, and environment they are engaging with (Björk, 2009; Universal Design Project, n.d.). The seven guiding principals of UD as outlined by Story, Mueller, and Mace (1998) are: equitable use, flexibility in use; simple and intuitive use; perceptible information; tolerance for error; low physical effort; and size and space for approach and use. These UD principals and the ideas they embody are in many instances either missed or ignored in the creation and maintained of online materials (Fitchen et al., 2014). UD needs to be utilized to its fullest extent in the creation of websites, content, and resources provided online for the betterment of every demographic, including post-secondary students (Fitchen et al., 2014). UD is tightly intertwined with online accessibility and technology; therefore, this foundational concept will be further explored throughout this article.

Supports and Barriers to Post-Secondary Education

Research has linked students with disabilities' graduation rates in post-secondary institutions to online resources and accessibility, and identified factors which inhibit and support students with disabilities' post-secondary success (Cole & Cawthorn, 2015; Field, Sarver, & Shaw, 2003; Fichten, Asuncion, & Scapin, 2014; Fitchen et al., 2009; Fleming, Oertle, Plotner, &



November 2018

ISSN 1605-7406

Hakun, 2017; Lombardi, Murray, & Gerdes, 2012; McGregor et al., 2016; Ostrowski, 2016). Lack of socialization and social isolation was identified as greatly impacting student's mental health, as well as their willingness and ability to continue pursuing post-secondary education (Ostrowski, 2016). For online or distance students with disabilities, online class forums can provide socialization, however, the student's ability to either access or use the online forums creates barriers to social interaction. Further, being able to communicate with staff and professors, which in many cases occurs through email or online communication resources, has in certain cases made the post-secondary process more difficult for students with disabilities (Field et al., 2003). Asking for accommodations, supports, or resources, and the inability to access course and online resources can create major barriers to the learning or educational process for students with disabilities (Fitchen et al., 2014). Shame is also associated with having to ask for support or accommodations, limiting students with disabilities' ability to self-advocate (Fitchen et al., 2014).

Students with disabilities' ability, willingness, and comfort level with being self-advocates are directly correlated with their success in school (Fleming et al., 2017). Self-advocacy efforts could be further impacted by student's ability to access online resources, information, applications, and forms where they can learn about or apply for policies, programs, accommodations, and supports for their continued education. A study by Fitchen et al. (2014) found that access to accommodations and updated assistive technologies had a positive impact on graduation and post-secondary outcomes. This in part could be linked to students' economic status, as having access to more money, and therefore updated technology, was associated with better post-secondary outcomes for students with disabilities (McGregor et al., 2016). Finally, student's grade point average (GPA) was a major indicator in post-secondary continuation



November 2018

ISSN 1605-7406

and success for students with disabilities (Lombardi et al., 2012). If students struggle to access online course resources or class content, then their GPA may be affected. Additional barriers and supportive factors that impact student's post-secondary outcomes including familial support, age, bullying, and mental health (Field et al., 2014; Lombardi et al., 2012; McGregor et al., 2016; Ostrowski, 2016) but it is apparent that many factors can, in some way, be connected to online accessibility.

Accessibility Features for Online Resources

The accessibility features of online resources for post-secondary can be split into two separate categories: a) the design and content of websites built or used by post-secondary institutions and b) the online content such as documents, readings, videos, and forms used by staff of the school.

Website Design and Content

When it comes to designing website layouts, designs, and features, there are specific rules and regulations that need to be adhered to according to the World Wide Web Consortium's (W3C) accessibility guidelines, titled the Web Content Accessibility Guidelines (WCAG) 2.0/2.1, so that websites are accessible to all populations (Jaegar, 2012; Pun, 2016; University of California [UC] Berkley, n.d.; W3C, 2018). Websites should be built using Hypertext Markup Language 5 (HTML5) and the most current iteration of Cascading Style Sheet (CSS), as the formatting they create and coding language they use is the most easily read by screen readers and other assistive technologies (Pun, 2016). The typography, or the font size, style, weight, and colour need to be easily readable or, if it is necessary to have specialized text, there should be simple options for users to change the typography to a more accessible and readable option (Pun, 2016; Snell, 2016). The use of headers should be specific and properly formatted in



November 2018

ISSN 1605-7406

order clearly to denote different sections of webpages to both the user and assistive technologies (UC Berkley, 2016).

Additionally, the colours utilized in the design of a webpage should be kept to a minimum and be reasonably contrasting (Pun, 2016; Snell, 2016). For example, placing red text on a pink background may be difficult for someone with a visual impairment to see and having bright colours on a webpage can be distracting for some users (Pun, 2016). The images used should have an alternative description explaining what the image is in detail so that students with visual impairments are able to access all the content on a webpage; this feature is added in the coding of the image tag (UC Berkley; n.d.). Further, the spacing between images, links, text, buttons, and other content, or the white space, needs to be at a standard distance where users are able to discern clear breaks between content (Jaegar, 2012). While a screen reader will be able to recognize the spacing breaks, visually, it makes the content difficult to read or access. Tables should only be used to portray tabular data and the table tag, <table>, should not be used in the overall design of a website (UC Berkeley, n.d.). A screen reader's ability to portray webpage content in a reasonable amount of time is severely inhibited when tables are used (UC Berkley, n.d.). All of the content on a webpage should be easily accessible using only a keyboard and the way to do this is by adhering to all of the information provided above (UC Berkley, n.d.).

Finally, one of the important aspects of HTML5 and CSS is that all websites should be using adaptive website design (Jaeger, 2012; Snell, 2016; UC Berkley, n.d.) Making websites adaptive means designing websites so that the design and content can adjust to the size of the screen being used so that the content is accessible and readable (Jaegar, 2012). People with disabilities regularly use mobile and hand held devices to keep connected, access information, or as an assistive device (Abascal & Civit, 2000;



November 2018

ISSN 1605-7406

Manduchi, & Coughlan, 2008). Therefore, if a website does not use adaptive web design, the accessibility of the website by students with disabilities can become more difficult.

Extra features, not outlined by the WC3 guidelines for accessibility, that could be considered to create more accessible websites, are the addition to a style bar at the top of a webpage. The Victoria Disability Resource Center's website (<http://drcvictoria.com>) has created a menu bar where the user is able to change the contrast of the colours, the font size, and the font style on the webpage. The website also includes a feature where users are able to clearly tell when they are hovering over a link by outlining the link and creating spacing changes. Having small nuanced changes, such as a slight change in colour, font, or size when the mouse hovers over a link, may not be easy for a person with a vision impairment to see.

In regard to links and menu bars, the amount of menu bars used on a web page should be kept to a minimum (UC Berkley, n.d.). Too many menu bars can make navigating the website difficult for assistive technologies or for those peoples with limited mobility of their hands (UC Berkley, n.d.). Search bars should be placed near the top of the page and be relatively easy to use (Pun, 2016). This means that students using screen readers do not have to tab through a large amount of content before they can access the search function. The amount of information, including text, images, videos, and other content, on a webpage should not be excessive depending on the mission of the webpage (Pun, 2016). It can be overwhelming, distracting, or confusing for any person and trying to find information on webpages with too much content can be difficult for a person with or without disabilities and screen readers.



November 2018

ISSN 1605-7406

100

Additional Online and Technology Resources

The online resources provided by post-secondary institutions, including those in class, need to be screened for accessibility. Scans or copies of documents displayed online need to be clear and readable (Fitchen et al., 2009). If the documents are unclear, assistive devices or the students themselves will not be able to access the information in them (Fichten et al., 2009). Images, charts, and appendices should be provided in online documents as either text files, or have alternate text descriptions (Fitchen et al., 2009). Finally, videos should have closed captioned descriptions, written transcripts, and adhere to the same design principles described in the website accessibility guidelines (W3C, 2008).

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ISSN 1605-7406

Theoretical Impacts of Online Accessibility

In addition to Universal Design, described above, the issue of online accessibility for post-secondary students with disabilities is inherently based on the social model of disability. According to Berger (2013), the social model of disability centers around the idea that a person's disability is not caused by their physical impairments, but by society, its norms, and the barriers they create. Post-secondary students with disabilities are encountering problems with online accessibility due to the standards to which content is created and held. Similar to the utilitarian principle of "the greatest amount of good for the greatest number" (Driver, 2014, para. 2), most websites are created for the usability of the 'average' person, which in many cases does not consider diverse abilities. An example of this is documented in a study by Alahmadi and Drew (2017), where they tested one hundred and eighty of the world's top universities home, admission, and course description pages. The study found that there were 30944 W3C accessibility errors on the home page alone (Alahmadi & Drew, 2017). Therefore, some of the barriers that post-secondary students are facing with online accessibility are being created not because of their physical disability, but because how the institutions have created and utilized their online resources.

The medical model of disability also has an impact on post-secondary students with disabilities online experiences. The medical model understands disability as a purely physical problem, and focuses treatment internally (Berger, 2013). Many students need to have a diagnosis from a medical professional in order to access assistive technologies and supports (Lang et al., 2014). As explained previously, many of the accessibility design principals are created with assistive technologies in mind. If a student is not able to access these devices, then there will continue to be gaps in general accessibility for specific disability demographics. University



November 2018

ISSN 1605-7406

102

websites should be designed to consider all abilities, from physical to socioeconomic in order to avoid excluding anyone, based on disability or socioeconomic status.

Implications for Post-Secondary Institutions

There is much work that can and needs to be done by post-secondary institutions and their staff in order to make online resource more accessible for students with disabilities. Alahmadi and Drew's (2017) study found that the accessibility of university websites has barely improved between the years 2005 and 2015 (Alahmadi & Drew, 2017). Therefore, post-secondary institutions need to build their websites in accordance with the W3C accessibility guidelines so all students, regardless of ability, are able to easily access them and the content provided. There are monetary and time considerations with creating or updating websites so they adhere to the W3C; however, there is high potential to cover costs, bring in additional income, and build the reputation of the post-secondary institutions (W3C, 2012). By addressing these crucial parts of online accessibility, the accessibility for all students should improve.

Despite the general accessibility a universal design offers, there are still potential barriers that post-secondary institutions need to overcome and take into consideration when designing websites for accessibility. Universal design does not imply universal access. The needs of some demographics with specific disabilities may require accommodations that could make the usability of the website more difficult for another demographic. For example, in accordance to accessibility guidelines, bright contrasting colours should be used to increase web accessibility for people with vision (Pun, 2016). Conversely, bright contrasting colours can be over stimulating for some people with autism and it is suggested that more muted colours should be used (Pun, 2016). Therefore, there will still be potential for



November 2018

ISSN 1605-7406

103

accessibility issues to arise. As long as institutions are willing and open to creating universally accessible websites and resources, the overall usability of online resources should improve for students with disabilities.

Post-secondary institutions should also provide training for its staff on the diverse abilities of their students, what is considered accessible both online and offline, what assistive technologies are, and what they can do to support students with disabilities (Fitchen et al., 2014). With increased knowledge and understanding, inaccessible course or institutional content such as online forms, applications, images, readings, and videos may reduce (Fitchen et al., 2014), making the post-secondary experience easier for all demographics. Finally, post-secondary institutions need to consistently update their assistive technologies and keep them up to date (Fitchen et al., 2014). Technology is regularly advancing. Examples of this can be seen in the new virtual reality systems and cellphones that appear on the market every year. Therefore, post-secondary institutions must keep their assistive technologies updated to recent industry and technological standards to better support their students (Fitchen et al., 2014).

Implications for Child and Youth Care Practitioners

Unless a Child and Youth Care (CYC) practitioner has knowledge on how to create websites or access to change resources, there is not much they can do in the actual creation of the websites and other online resources provided by post-secondary institutions. However, CYC practitioners are able to be allies to students with disabilities, act as a support in students self-advocacy efforts, classes, and accessibility needs when requested, therefore enabling students with disabilities to achieve positive educational and social outcomes (Field et al., 2003; Mamiseishvili & Koch, 2011). They can also support students with disabilities in the transition process between secondary and post-secondary institutions by offering



November 2018

ISSN 1605-7406

104

one on one services or programs for groups (Banks, 2014). Further, those working in the CYC profession can advocate on behalf of all students with or without disabilities so that resources, programs, and classes are universally designed and accessible for all.

A key element of supporting students with disabilities attending post-secondary institutions with online accessibility issues is to be informed. CYC practitioners should educate themselves on the rights that peoples with disabilities have both in post-secondary institutions and in life. They should become aware of what types of roadblocks or issues students with disabilities may encounter during the post-secondary education process, including those related to online accessibility. CYC professionals should learn what assistive technologies are available, what they do, and have a basic understanding of how to utilize them (Mamiseishvili & Koch, 2011). Participants in a study conducted by Cairns (2015) expressed that equal opportunities for every person is key to programming and the inclusion of peoples with disabilities. Using the strategies listed, CYC practitioners can assist in addressing the barriers that lead to blocks in equality and inclusion, therefore facilitating in post-secondary students abilities to complete their schooling goals and make the most out of their experiences.

Conclusion

There is clear evidence that online accessibility should be made a priority for post-secondary institutions. Adherence to the W3C accessibility guidelines as well universal design principals is key to online accessibility. Institutions and CYC practitioners can and need to take concrete steps in order to support students with disabilities online accessibility by changing websites to adhere to the W3C guidelines, supporting and advocating students, educating themselves on matters pertaining to online



November 2018

ISSN 1605-7406

105

accessibility, and providing more resources for assistive technologies. Making online resources accessible to a more diverse population, including those people with disabilities, is only one step towards universal inclusivity. Universal design needs to be a priority for every country, industry, institution, and demographic, or else the barriers present in society now may one day become walls.

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November 2018

ISSN 1605-7406

106

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November 2018

ISSN 1605-7406

107

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November 2018

ISSN 1605-7406

108

Child & Youth Care Practice

Collected Wisdom for New Practitioners



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Editors

The Crack in Everything

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Ring the bells that still can ring
Forget your perfect offering
There is a crack in everything
That's how the light gets in

Leonard Cohen

I have been thinking about the question of difference as it relates to disability. I have been wondering about the ways in which difference is both celebrated and demonized in our current set of social discourses. It reminded me that when I was growing up, difference was definitely not celebrated. Indeed, to be different was to put oneself in harm's way. There were clear norms for behavior in the 1950s and early 60s based in the emerging culture of corporate conformity. The corporate vision of an ideal body was a narrow band of behavior built on masculinist ideals that valorized an impermeable body. Such a body was strong, heterosexually virile, and impervious to pain, physical and psychological. It was a body that could drink alcohol copiously, smoke packs of cigarettes a day, work endless hours and never flinch. Emotionally, this body had a very narrow range of emotions, none of which exceeded a certain degree of intensity, except for anger which was the only open prerogative. Such a configuration of physical and emotional aggressive armoring was the ideal



November 2018
ISSN 1605-7406

against which all other bodies were measured. This was the perfectly abled body. A body that could do anything asked of it without “breaking down”. This model of ability was distributed widely across our world in the form of movies and movie stars, the developing world of advertising, television programming, and school health initiatives. We were tough and we would stand up for truth, justice and the American way.

Of course, this left out an awful lot of bodies that were considered to varying degrees disabled in comparison to this paragon of the masculine warrior prototype. Of these bodies, only a few were allowed some degree of social access (at least as long as they took a properly subordinate position). These bodies included women, children and adolescents and people of color. Even though it was commonly thought that these bodies were inferior and subordinate to white male bodies, they served a social function that allowed them to participate in society with varying degrees of behavioral latitude.

I remember being very aware, as a child, of the penalties paid by those bodies who transgressed. I remember seeing women being scolded at public functions and in family homes by their husbands or boyfriends for threatening the dominant role of the “man of the house.” Any hint of violating the strict codes of monogamy and pre-marital chastity on the part of women was to risk becoming a social pariah as a “slut.” Of course, there was a whole other world that operated to the benefit of those who kept their sexual behavior “secret,” or who married while pregnant with a wink and nod to social convention. But there was certainly no socially sanctioned role for women outside their relationship to men. Women were the weaker sex. They were considered biologically, emotionally and psychologically disabled in a world dominated by masculinist ideals.

For people of color (including women of color), the discourse of psychological, biological, and emotional disability had even stricter



November 2018

ISSN 1605-7406

boundaries and far more severe sanctions. The bodies of people of color were designated as animalistic and sub human. These bodies were seen as inherently and properly subordinate to white bodies. The body of a person of color was to serve and pay deference to white society. While there was a developing tension over the reading of bodies of color as intellectually and emotionally disabled, any attempt to challenge this view was often violently and savagely put down. I need only remember the lynchings, shootings and school bombings that made up the evening news broadcasts of my childhood and early adolescence.

I often reflect on this when I hear people suggest that we live in a post racial society or that all of that is behind us. It all happened within my lifetime. Which means that people who attended lynchings, or whose parents or grandparents attended lynchings, are still alive and live free of any kind of social or legal accountability for what they sanctioned or did. Even more painfully, there are people of color alive today whose relatives were killed and/or brutally savaged, whose loss has never been properly acknowledged and to whom the denial of any sort of accountability on the part of the dominant society must be an ongoing insult of massive proportion. Of course, in the past few years the thin veneer that had veiled this brutal history has been torn open by the resurgence of overt white supremacy and new discourses of racial disability.



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November 2018

ISSN 1605-7406

112

The hierarchies and taxonomies of disability premised in race and gender were the most visible and obvious effects of the masculinist insistence on an impermeable body ideal. In a sense the bodies of women and people of color operated in an apartheid world in which they were allowed limited access to the world of white male privilege in exchange for subordination and service. As long as they were useful, they could be visible, but there were limits. Curfews and segregated spaces created an apartheid of ghettos, barrios and suburban homes to which women and people of color must return at the end of the day or be subject to surveillance and discipline. And of course, children's bodies were to be seen and not heard. Those differences that exceeded the alterity of being female or a person of color, such as being non-heterosexual, required levels of deep masking and risk of arrest, physical assault or death.

However, there was an even deeper level of difference that ran so counter to the masculinized ideal and impermeable body as to require institutionalization and "medical" intervention. These were the supposedly "broken" bodies of the emotionally, physically and psychologically disabled. Such bodies had proven themselves vulnerable and imperfect, unable to meet the requirements of the dominant model of masculine stoicism. Disabled bodies, or in another term, those lacking the valorized abilities of "whole" bodied men, were to be hidden away in varying forms of institutions, schools and asylums. These were those designated as crazy, mad, idiots, crippled, and/or retarded that were to be erased from our awareness except as diseased bodies that needed to be healed through subjection to the kind mercies of science and medicine. The project to homogenize and perfect bodies and minds included an insistence on an ideal body to which we must all aspire, even if we can't attain it. We must all strive to "heal" away our differences.



November 2018

ISSN 1605-7406

During the years of my childhood and early adolescence, medicine was treating neurological difference with lobotomies, shock treatments, ice baths, insulin shock, and other best practices of the time. Physical differences such as blindness or deafness could lead to a lifetime sequestered away from normal children. Massive asylums, schools and hospitals were constructed to house those whose bodies and minds were constituted outside of “normal” parameters. Ashamed and embarrassed by the imperfection of our children and family members we hid them away and tried not to think of them.

Of course, I am pleased to say, that as time went on, we opened those asylums. Former patients initiated rebellions such as the neurodiversity movement. Deaf culture began to be valorized in places like Galudet University. Physically disabled peoples demanded rights and accessibility accommodations. Women broke down some of the barriers that defined them as subordinate to men, the civil rights movement challenged racism and white supremacy, and the gay rights movement made significant progress in challenging medical heteronormativity. These enormously courageous advocates have challenged the masculinist ideal and opened the warehouses of misery and invisibility to the fresh breezes of difference as a normal part of who we are.

And yet, to some degree, the notions of a perfect body still haunts us. We have a hard time thinking of bodies that fall outside an unspoken norm of perfectibility. We want the blind to see, the deaf to hear, the mad to be sane and non-heteronormative people to act like the heterosexual couple next door. We don't mind difference as long as it is not too extreme and we want our “disabled” friends, family members, and colleagues to be at least mildly heroic in overcoming their disability and fitting in with the rest of us. It seldom occurs to us, that perhaps that difference is something we could learn from. Maybe being a neurotypical is not an advantage, but a disability



November 2018

ISSN 1605-7406

114

in its own way. I am not suggesting romanticizing the lived experience of physical, emotional or psychological difference. But, I am also not comfortable with romanticizing the lived experience of “normal.” After all, to some degree it is really a question of accommodation. Do we, as a society make it easier or more difficult to be different. Do we offer acceptance or assimilation? Do we see capacity in difference, or only deficits that require remediation? Is disability a negative thing that needs fixing and heroic efforts to overcome it? Or is it just another way of life?

Which brings me to the term disability itself. In the *Ouch Blog* on BBC News, Rebecca Atkinson (2015) wonders if the term disability needs to be retired. She reflects that a number of her readers who have responded to her blog (many of whom are parents of “disabled children”) have started using different terms such as, differently-abled, special needs and simply different. She notes that the prefix “dis” might be somehow problematic. Tracing the term, she remarks how it is defined in profoundly negative ways as in to “have a primitive, negative or reversing force.” She cites common usages such as, “To discredit. To disengage. And in recent parlance ‘diss’, with an extra s, has been popularized as an abbreviation of disrespect – ‘Don’t diss me.’”

Atkinson struggles in the blog with the question of how to wrestle with the issues of language and definition for those of us who stand outside the normative body/mind conventions of our time. She asks about the range of human variability and when exactly it exceeds ability and becomes disability. We are, after all, each of us quite different, so when does difference cross the threshold? She admonishes us to remember that “Disability is a delicate flower around which the public tread with care.” After all terms such as “special” and “unable” or “inspirational” can be seen as quite dismissive of the actual lived experience of a person so described. Aren’t those outside the social spectrum of “normalcy” just as likely to



November 2018

ISSN 1605-7406

115

range from talented to mediocre like the rest of us? Which makes me wonder, isn't this necessity to overachieve a remnant of the masculinist superman impermeable body?

So, for those of us in CYC, who are dedicated to relational and respectful care, how are to move forward? Atkinson cites, the bio-ethicist Rosemary Garland Thomas who suggests we replace disability with the notion that we have instead human variation that is a "reality to be accommodated, not a problem to be eliminated." I would suggest that we can go a step further.

One of things that is a hallmark of a healthy ecology is genetic diversity. The richer the diversity of plants, animals and micro-organisms, the more likely it is that a given ecology can survive a crisis that threatens it. I would argue that human variability is more than a reality to be accommodated, it is absolutely necessary to a thriving human ecology. To care for difference and nurture multiplicities of capacity, is to work towards ensuring our own survival. It is the logic of colonial empire that makes a claim for the superiority of a certain set of cultural, social and genetic characteristics. The idea that societies should seek the homogeneity of perfect human form is a suicidal tendency that has led to the deaths of millions. There is nothing perfect, except the immense variability of life itself.

As CYC workers, we have the opportunity to engage the world in its infinite complexity of broken edges, hopeless entanglements and limitless imperfections. In the opening quote to this column Leonard Cohen admonishes us to remember that is not perfection that brings light and hope to the world, but the crack in the smooth surface of living relations. Instead, of seeking to find a perfect bell to ring, he tells us to "ring the bells that still can ring," even the cracked and broken ones. In reflecting on Cohen's words, I was reminded of an odd kind of pottery that, to me, evokes the beauty of our work and its relation to human variation. It is



November 2018

ISSN 1605-7406

116

called Kintsugi or golden joinery. It begins with broken pottery that is joined together with powdered precious metals to create a pot of singular beauty. The philosophy behind it is, that we should treat breakage as a part of the history of an object, rather than something to disguise or discard.

I thought long and hard about including this example, because I don't want to imply human variation as a kind of brokenness. But then it occurred to me, it isn't the individual who is broken. It is the web of social relations that is fractured when we attempt to disguise or discard human variability. In our work, we have the chance to take all the irregular edges of the bodies and minds we engage in our work and bind them together with the most precious and beautiful adhesive I know of—the use of ourselves through love. That is the craft and the art of what we do, and it deserves the highest artistry and craft we can bring to it.

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November 2018

ISSN 1605-7406

117

Child and Youth Care, Disability and Some Cautions

Kiaras Gharabaghi

Some years ago, I wrote a column for CYC-Net titled *Expansion to What End?* In it, I told the story of my first encounter as a child and youth care practitioner with a young person impacted by disability, and I recounted the strange and often harmful advice I received from child and youth care practitioners on how to deal with a very particular behaviour of this young person. This led me to question whether child and youth care is the appropriate practice field to get involved in disability contexts; perhaps other fields, such as developmental services, are already well placed to do this work.

Much has happened since I wrote that column. The field of child and youth care has paid much more attention to the disability sector(s). Many practitioners are working in the context of autism service systems, doing everything from implementing Applied Behaviour Analysis (ABA) and Intensive Behavioural Intervention (IBI) strategies to playing with young autistic people to supporting their learning and education in schools. Indeed, as this special issue on disability clearly demonstrates, we have become much more open to engaging disability issues, usually from a critical lens. The other thing that has happened and continues to unfold is that the settings where child and youth care practitioners often work, such



November 2018

ISSN 1605-7406

118

as residential programs, foster care, hospital units, youth custody facilities and so on, increasingly are serving young people who are described as having 'special complex needs'. It is, these days, very difficult to find a child and youth care job that doesn't involve in some form engagement with young people impacted by disability, and very often such disability turns out to be Autism Spectrum Disorder (ASD) or Fetal Alcohol Spectrum Disorder. Occasionally, disability may also pertain to a range of other developmental, regulatory or physical disabilities, such as hearing impairments, visual impairments, or mobility impairments.

While it is undoubtedly true that child and youth care practice and disability are intertwined, encounter each other often, and need each other to interface in some form or shape, it is also true that in many settings and contexts, such encounters and interfacing is not going particularly well. In Ontario, Canada for example, recent reports detailing serious occurrences in residential settings (where many child and youth care practitioners but also people with a range of or absence of qualifications work) demonstrate quite clearly that young people with disabilities are consistently on the receiving end of the worst of practice, including questionable and sometimes clearly dangerous physical interventions and other punitive measures. It is also true that a large number of child and youth care practitioners are working in service settings that require them to implement evidence-based practices, which in the context of ASD almost always means at least ABA and often IBI. Neither of these have much in common with child and youth care principles, and neither of these in any form or shape correspond to the recently updated 25 Characteristics of Child and Youth Care Practice.

So, here we are, as a professional field of practice that continues to seek an identity and a definitive location on the landscape of professional human service fields, doing things that we may not associate with



November 2018

ISSN 1605-7406

119

excellence given our own values, standards and indeed, training and education. Something has to give; it seems irresponsible to continue an organic slide into an arena of practice that is not accompanied by some authentic reflective thought and meaningful theoretical and practice oriented intellectual infrastructure. I don't question the passionate endorsement of orthodox child and youth care concepts, ideas, and ways of being as having acute relevance to working with young people with disabilities. I agree that there is room for relational practice, for young people's participation, undoubtedly for children's rights, and also for many of the other key words embedded in the Characteristics of a Relational Child and Youth Care Approach. But I also believe that we owe ourselves, and perhaps more importantly our 'stakeholders' (such as young people with disability, their families, and their communities) more than relatively thin and primarily rhetorical pronouncements of strength-based practice, empowerment, participation and so on. And surely we are not going to allow ourselves to fall into the trap of offering child and youth care approaches only to those young people who are on the higher ends of various spectrum disorders, leaving those on the lower end to find support elsewhere.

To this end, I want to offer some cautions as we embark on this journey of expanding our horizons to include disability as a practice context. I emphasize that I am not for or against anything in this context; I am merely conscious about how I experience our field and the discussions within it, and these experiences lead me to at least be cautious. These are the things I think we need to still work on and think about in order to move forward:

1. Given that there is a strong, sophisticated and highly critical field of disability studies, we should probably engage that field with more intention in order to make sure we are up to date on the evolution



November 2018

ISSN 1605-7406

120

of thinking and the learning that has unfolded in this context already. It seems to me somewhat arrogant to wade into a field of practice equipped not with an intensive engagement of already existing narratives, dialogues and debates, and instead based on what sometimes seems like a slightly superficial adapting of child and youth care ideas and concepts.

2. Similarly, developmental service practitioners have for many years been present with young people impacted by disability; perhaps we can learn something from them.
3. One thing that we are currently learning and trying to improve on is rendering central in our own field explorations of intersectional contexts and the social relations that comes with these, including racism, ableism, hetero-normative ideas and approaches, and so on. Let's make sure that we apply the lenses of critical race theory, desire-based research, and Indigenous ways of being to the context of disability as well.
4. Much of the story telling at least in the orthodox child and youth care literature either explicitly or implicitly presumes able-bodied young people as characters in those stories. It is difficult to imagine that our current literature can adequately or even meaningfully support an intensive engagement with disability.
5. We have not, as of yet, integrated a substantive component of study pursuant to disability into post-secondary curriculum in child and youth care.
6. Many settings where child and youth care practitioners work are not well equipped to serving the needs, much less the desires, of young people impacted by disability. Indeed, at least in Canada, most child and youth serving settings do not even have explicit accessibility policies, either for service consumers or for staff.



November 2018

ISSN 1605-7406

7. In some aspects of disability-related work, medical models of practice are the only kinds of practices that are funded. IBI, for example, which relies entirely on medical model values and practices, is in many provinces in Canada the only fully funded service in the context of autism.
8. Universal design is largely a foreign concept in child and youth care, and appears almost never in either our literature or in curricula of post-secondary education programs.
9. Finally, to repeat a point made earlier, we have no mechanisms, including widely understood ethical frameworks, by which we can avoid the very likely appearance of embracing young people deemed to live at the high end of functional and communication spectra and ignoring young people deemed to live life at the lower end of these spectra. That would be a sad development for our already at times contested ethic.

I emphasize that these points are not inherent and insurmountable barriers to the engagement of disability in child and youth care practice. But they raise questions that require answers. Some of the least acceptable experiences of young people with disabilities unfold at the hands of trained and otherwise very competent child and youth care practitioners. We cannot, and should not, complacently accept that.

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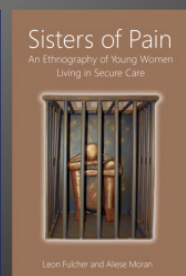
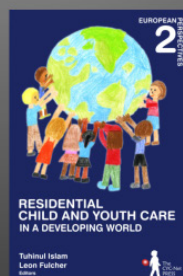
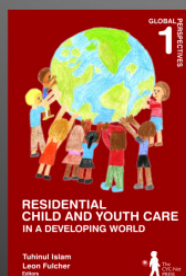
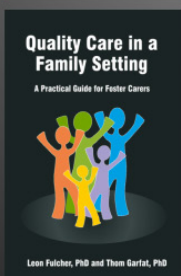
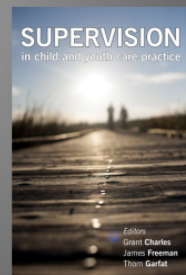
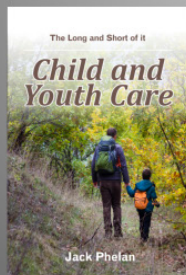
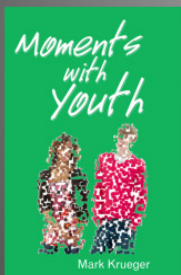
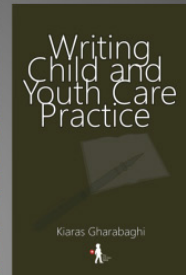
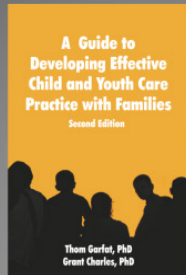
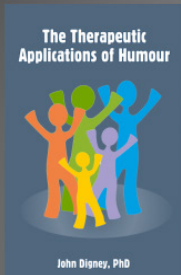
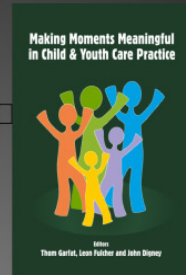
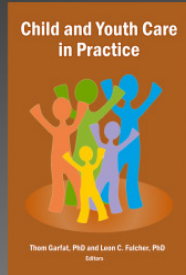


November 2018

ISSN 1605-7406

122

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Postcard from Leon Fulcher

New Zealand

Kia Ora
MaComrades! I
hope this finds
those of you in the
Northern Hemisphere
now well into your
woolens, Puffer jackets
or body warmers along
with turning heat on
for the winter.

To support this
CYC-Online Journal
Special Issue on
Disabilities, I found

myself reflecting on children, young adults and older people in our community who live with 'so-called' disabilities even though they live lives that offer rich demonstrations of capabilities. Some health and welfare professionals get so oriented towards disabilities that they never really get around to seeing the 'whole person' in front of them, a relational connection that mostly falls to Mothers.

A list of values caught my attention that were reinforced daily in Mrs Themm's early primary school classroom my grandson attended. Children



At Halloween, it's hard to tell the difference between able or disabled children



November 2018

ISSN 1605-7406

124

with mixed capabilities supported children with mixed disabilities in a daily life space that nurtured having fun as active learners.

Young artist, Alan, has lived in his ancestral community as a child diagnosed by early health professionals as being Autistic. While he might have been sent away to a residential special school, Alan was maintained in his family home and attended the local school with other children his age. All accepted that Alan was different and his speech was guttural but his artwork was amazing, as in using a Maori Independence flag flying over his ancestral house!

Mothers of children with a disability are fundamentally important in determining what happens to their children – through childhood and adolescence, becoming young adults living semi-independently. Unfortunately, health and welfare professionals are not always that supportive of parents with children who are disabled in some form or another.



Poster on the Primary School Classroom Wall identifying learning capabilities



Ancestral House with Tino Rangatiratanga Maori Sovereignty Flag – by Alan

Mothers are not unfrequently referred to as 'pushy' or 'difficult' but she may be the only person in the world who is one-eyed about what may be possible for their child or children.

Pause for a moment and look closely at Alan's portrait of ancestors, where whakapapa or genealogy is fundamentally important. Gaze at Alan's ancestral creation by someone now in receipt of a disability allowance as someone on the Autism Spectrum with language challenges. Now



Autism Spectrum Young Maori Artist Alan with his Mother Jenny and Uncle Piri



Whakapapa or Geneology is embedded in Alan's portrait of ancestors



November 2018

ISSN 1605-7406

126

stop to think about Alan's three youngest nieces, including twins, also diagnosed on the autism spectrum as preschoolers without language.

Parallel challenges were experienced by young Ngarangi's family as he grew up as a survivor of cerebral palsy. Mobility was his major challenge, relying heavily on a wheelchair, even though capable of moving with the support of walking sticks, although it tired him easily.

Another 'disabled' young artist provided his personal

interpretation of Maori ancestors setting forth in a war canoe to challenge Captain Cook when the Endeavour appeared off the east coast of Gisborne in 1769. History reads that Captain Cook sailed away from Poverty Bay.



Young Ngarangi is mostly wheelchair bound though he can get around on sticks



Gisborne art gallery gave prominence to this waka advancing on Captain Cook



Capability is too often blinded by disability in the eyes of helpers!

Health and welfare professionals – including child and youth care workers – bring valuable knowledge and skills that can be of real assistance to families with children or young people living with disabilities. It is also easy to become blinded by disabilities and fail to support family members – especially Mothers – who commonly nurture their children’s capabilities.



How the World works and how children work as learners in their World

Silva

Information

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November 2018

ISSN 1605-7406

129