Child and Youth Care and Disability Rights: Listening to Young People, Challenging our Practice

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Abstract

Expansions to Child and Youth Care (CYC) service, particularly in Canada, have included supports to young people labeled with diagnoses such as autism spectrum disorder (ASD), global developmental delays, intellectual developmental disorders, and other such disabilities. For a population of young people who are inundated with deficit-based and overly medicalized means of support, strength-based CYC practice allows for an opportunity to provide them with something better. However, this can only be done when practitioners begin to challenge their practice methods, listen to young people, and commit to rights-based approaches to care. Through an analysis of best practice methods, disability rights, and the opinions of young people, this paper aims to examine how strength-based CYC practice can best serve young people with disabilities.

Keywords
Child and Youth Care practice, disabilities, disability rights, young people’s voice

In recent years, Child and Youth Care practitioners (CYCPs) have expanded their scope of support to include young people living with a diverse array of disabilities. Some of the most prominent expansions to CYC service, particularly in Canada, have included supports to young people labeled with diagnoses such as autism spectrum disorder (ASD), global developmental delays, intellectual developmental disorders, and other such disabilities. These disabilities are defined by the medical field via categories of severity ranging from mild to profound (American Psychiatric Association, 2013). According to the United Nations (2007), over one billion people, or roughly 15 percent of the world's population, live with a disability. Young people with disabilities face innumerable barriers and limitations, which result in low self-esteem, poor educational outcomes and poor employment outcomes in adulthood. In Ontario, between 2013 and 2014, 3.8% (83,600) of the total population of young people aged 0-14 years lived with disabilities that contributed to barriers to daily life activities, low self-esteem, depression and thoughts of suicide (Provincial Advocate for Children and Youth, 2016). In 2009, Human Resources and Skills Development Canada found that 19.7% of youth labeled with disabilities experienced lengthy school interruptions and 16.1% discontinued their education. Furthermore, young people with developmental disabilities are four times less likely to achieve a high school diploma than their non-disabled peers (Bizier, Fawcett, Gilbert & Marshall, 2015). Finally, in the most recent school graduation study of 5,800 students with autism who entered mainstream high schools in Ontario in 2011, only 1,400 were projected to graduate with a diploma (MacKay, 2010).

Irrefutably these few statistics, amongst the many more that could be cited here, are unacceptable. As CYCPs committed to the optimal development of all young people, I know we can do better to help mitigate these negative outcomes. CYCPs have embraced this work within schools, residential programs, mental health centers, homes and hospitals across the country. Until recently, these young people and their families have had to rely almost solely on the expertise of medical and behavioural specialists claiming to provide the most current evidence-based treatments to 'cure' their 'dysfunctions'. In the academic journals that publish the latest best practice methods for supporting young people living with disabilities, it is rare to find research on the therapeutic effects of strength-based and relational approaches to care. More likely to be found are advances in pharmaceutical treatments and behavioural interventions to improve maladaptive behaviours. Where then, do CYCPs fit in? It seems critical that in this medically dominated, deficit-focused field of assessing and diagnosing disabilities, CYCPs advocate for a distinct strength-based and relational approach to working with these young people and their families. Aside from the rich practice knowledge that we are able to draw on from our own discipline, various movements are emerging that recognize the diversity and strengths of young people living with disabilities. Unfortunately, these approaches are still underrepresented in the CYC literature, making it difficult to incorporate into training and practice.

It is time to address this gap in the literature and examine our practices to better support young persons with disabilities. This paper will discuss the existing best practice approaches utilized by CYCPs, noting experiences both from my own practice and the opinions of young people and families from the *We Have Something to Say Report* organized by the Provincial Advocate for Children and Youth (2016) in Ontario. Next, the paper will introduce disability rights discourse to help practitioners address the systemic barriers and pervasive attitudes that affect professional practice. Finally, this discussion will explore how practitioners can incorporate disability rights into CYC practice to best meet the unique needs of young people and their families living with disabilities. It is important to note that throughout this paper, the use of the terms ‘diagnose’ and ‘disorder’ will be used sparingly. From a disability rights perspective, it is important to mitigate the stigma that can be caused by labels that perpetuate an overly medicalized model of disability. Thus, this paper will utilize the terms ‘labeled with’ and ‘with’ disabilities.

Best Practice Approaches to Support Young People with Disabilities

In 2014, the Provincial Advocate for Children and Youth collected the voices of over 170 young people labeled with disabilities to share their experiences of the services and supports made available to them in Ontario (Provincial Advocate for Children and Youth, 2016). The consensus of the opinions in this report was that although young people and their families were grateful for the supports they were receiving, they felt the government, teachers and service providers need to do more to address service gaps. Young people felt that when they did receive support, particularly in schools, teachers and support staff were often not equipped to address their needs. They further felt left out of the decisions behind the interventions they received. They expressed a desire to have their disability explained to them in direct, concrete terms and to be included in the decisions that affect their development. There are numerous recommended best practice models delivered to this population daily in schools, community programs and family homes. They are delivered with the best of intentions by caring practitioners and teachers. Unfortunately, these interventions are often delivered without the input or permission of young people. They are often blanket, one-size-fits-all approaches that do not take into account individual and developmental needs. What follows is a discussion of the most common approaches used by CYCPs and the pitfalls involved in delivering these programs without the valuable input from young people.

Social Skills

The number of textbooks, handbooks, manuals and online resources available to support young people with disabilities in developing their social skills is astounding. These are available to teachers, parents, and practitioners for use in a variety of settings. These programs tout successful outcomes based on evidence from the field. A common strategy for delivering these programs is to decide what skill young people need help with in order to adapt to the socially accepted norms of the classroom, home or community. For example, the practitioner may decide young people need help regulating their emotions, making polite conversation, staying organized, staying on-task, etc. There are dozens of behaviours on which practitioners feel young people with disabilities need to work. Without a doubt, mastering some of these skills is often a very valuable experience as young people aim to improve their self-esteem and social acceptance. However, critical considerations, such as participant voice, are often missing from the creation and delivery of these programs.

When I started out in practice, I had the fortunate experience of delivering social skills programs to a variety of young people who, for the most part, seemed engaged and willing to participate. Things began to change in 2011 when I landed a job working with a group of spirited and strong-willed young people (traits I believe to be great strengths) on the autism spectrum. I came into this job with a big heart and the best of intentions. The vice principal informed me that it was a challenging role that would require supporting these students with some very difficult behaviours. I began by developing the same engaging lesson plans I had relied on in the past. However, what I experienced on my first day of attempting to deliver a lesson plan on ‘anger management’ changed my perspective forever. A young man, aged 16, spoke up (in much more colorful language than I will put in writing here): “But I’ve already got good social skills! Why not try teaching this lesson to those students out in the hallways who bully us every day? Why are you targeting us?” This, I realized, was a very good point. How could I expect them to manage their anger when it was such a valid expression of frustration and even resilience? Sadly, young people with disabilities are often the target of bullying and are rarely protected (Provincial Advocate of Children and Youth, 2016). I soon learned that if I was going to get anywhere with these young people, I would have to start listening to their experiences *before* I attempted to teach them anything. I began to wonder how many young people with disabilities think about why they are being targeted for an intervention when, perhaps, it was those around them that needed the interventions most? Also, how many of the reactionary behaviours that I had experienced in the past were a result of this unfairness? Most importantly, how many young people with disabilities felt stifled when trying to advocate for themselves? These thoughts forever changed my approach to providing social skills training for young people with disabilities.

Applied Behavioural Analysis (ABA)

In 2016, the Ontario government invested $333 million in the new autism program strategies that include interventions such as Applied Behavioural Analysis (ABA) (Ministry of Children and Youth Services, 2016a). Since that time, the government has invested another $200 million to be spread out over the next four years (Ministry of Children and Youth Services, 2016b). The families of young people with autism put much hope in these types of programs and often encounter long waiting lists (Provincial Advocate for Children and Youth, 2016). Once they enter the public school system, students can begin to receive some limited ABA services provided by teachers and support staff (Ontario Ministry of Education, 2007). In their policy memorandum, PPM 140, the Ontario Ministry of Education notes that while these services were developed to support students with autism, ABA approaches can be used to support other students with special needs as well. Thus, these approaches are used widely in special education programs to support students with all disabilities. The ABA guidelines outlined in PPM 140 are meant to "strengthen collaborative working relationships between parents, schools, and the community….an example of such collaboration is the development of an Individual Education Plan (IEP) for a student" (Ontario Ministry of Education, 2007, Purpose section, para. 3). As positive as this collaborative effort sounds, young people expressed frustration about being excluded from the development of these plans (Provincial Advocate for Children and Youth, 2016). The families of these young people expressed similar frustrations and reported waiting months or years for the IEP development process, which is needed to start receiving ABA services. They further reported frustration about spending thousands of dollars of their own money to seek private psychological assessments in order to qualify for ABA in schools.

What is ABA and why is it the most popular intervention for young people with disabilities in Canada? According to the Geneva Centre for Autism (2015), the formal definition of ABA is as follows:

> *Applied behaviour analysis is the science in which procedures derived from the principles of behaviour are systematically applied to improve socially significant behaviour to a meaningful degree and to demonstrate experimentally that the procedures employed were responsible for the improvement in behaviour.* (p. 12).

In less formal language, the Geneva Center describes it as devising a relationship between behaviour and environment, making plans to change behaviour, and applying those plans to improve behaviour. This simpler definition aligns much closer to a support plan a CYC practitioner might devise. Terms such as ‘analysis’, ‘apply’, ‘experiment’ and ‘procedure’ convey scientific implications of treatment modalities performed *on* individuals rather than *with* them, which is quite antithetical to relational CYC practice. Such terminology further risks a medicalization of young people’s needs to the extent they are seen as “perpetual children” with less capability than their non-disabled peers to develop into adulthood without our support (Provincial Advocate of Children and Youth, 2016). Thus, it is important that CYCPs adopt a more relationally nuanced approach to ABA principles with young people. A holistic assessment of the environment and behaviours is a critical component of effective support plans. As a practitioner with over 8 years of training and practice in ABA, I can personally attest to its value in this regard. In order to benefit from this value, ABA supported plans must be co-created alongside young people and their families. Without full transparency about the support plan and an investment from young people, the goals of the service meet the needs of the adults, not the young people.

Positive Behavioural Support (PBS)

For those practitioners who have never received training in ABA, it is likely difficult to imagine how to implement support plans devised from this behavioural science. At my particular workplace, we use Positive Behavioural Support (PBS) which is directly derived from ABA principles and utilized by practitioners in many school-based and community settings to support young people with disabilities (Dunlap, Kincaid, Horner, Knoster, Bradshaw, 2014). A PBS plan is individualized and relies on a Functional Behavioral Assessment (FBA) to decipher the reasons behind why behaviours occur (Ontario Ministry of Education, 2007). The Ontario Ministry's mandate in the PPM 140 instructs practitioners to prepare a checklist of antecedents, behaviours and consequences to assess the needs and environmental factors contributing to the students' challenges in the classroom. Although PPM 140 states the importance of assessing students for their strengths, the reality is that often only negative or maladaptive behaviours get recorded in practice. Following this assessment, CYCPs come up with a plan to improve these behaviours through targeted goal setting and social skills lessons.

I remember starting my new job in 2011 and pulling out student files for the first time. I was overwhelmed with thick piles of documents that recorded what adults believed to be disruptive behaviours. Determined to support these students in overcoming their individual challenges, I devised their PBS plans with great detail. I developed individualized binders with their names on them and filled them with checklists so that I could begin recording their behaviours and elements of the environment that I observed to be contributing to their behaviours. What I failed to do was let the students know what I was recording on these checklists and why. In the beginning, when students approached me to see what I was writing, I would close the binder and try to divert their attention. After all, I didn't want them to see all the negative things I was writing about them. I wanted them to know I was focused on their strengths, which I made a conscious effort of verbalizing for them often. Looking back, I am shocked at how naive I was in thinking that they were fooled by my diversions. They knew I was recording things about them and I am ashamed now to have hidden that from them. Van der Westhuizen (2011) points out that the most important aspect missing from well-intentioned assessments of children is the assessors themselves. He argues that practitioners, as the outside 'experts' who observe and formulate solutions for the problems young people face, need to be included as a factor in the environment that may contribute to those problems. I could not agree more.

I wonder how many times my highly organized binders and checkboxes contributed to my students' feelings of being targeted objects who needed external observation in order to receive help and support? No matter how many times I praised them or tried to focus on their strengths, my continued checkboxes and targeted intervention plans must have perpetuated their feelings of being less adequate than their non-disabled peers. After each assessment of an angry outburst or avoidance of schoolwork, I would debrief with my students about what they felt was the problem and how we could work on improving the situation next time. Confined by the policies and procedures of my workplace, I could never fully address the structural disadvantages they faced on a daily basis. After all, a part of high school is to sit in a desk, do school work, and pay attention to the teacher.

In our case, the students and I were lucky to work in an environment where the teachers and administrators were open to feedback and a continued commitment to accommodating student needs. As a staff team we understood that expecting young people with disabilities to conform to normative standards of education was unfair. Thus, after my assessments, student PBS plans would allow for frequent breaks, the use of fidget toys, mobile devices and any other accommodation that might make the school day more manageable. Unfortunately, this is not the case in every school. Caregivers who contributed to the *We Have Something to Say Report* stated that “acting out behaviour is not the failure of the child; instead, it is the failure of the adult, who did not respond to the child’s needs with patience, understanding, calm and skill” (Provincial Advocate for Children and Youth, 2016, p. 59). They reported teachers and support staff who used harsh words to address their children’s behaviours in front of the class. Further, the young people in this report overwhelmingly asked for better accommodations and better understanding of their needs. It seems to me that if we are going to utilize PBS plans in schools, as staff teams we might consider making these plans for ourselves as well.

Disability Rights Movements

Singer (2016) explains that if you were to ask most non-disabled people to define disability, they would define it in terms of a tragic personal deficit with a person’s mind or body. Singer describes this response as the medical view of disability, known particularly in this way by the disability rights community. Singer goes on to identify the social model of disability which stands in stark contrast to this medical view. The social model of disability was introduced to the western world in the 1970s as a political movement that viewed societal barriers as a person’s main challenge to participation in society rather than their individual impairments (Oliver, 2013; Singer, 2016). Today, this view is upheld by human rights organizations around the world including the Council of Canadians with

Disabilities (CCD) who aided in Canada’s ratification of the United Nations Convention of the Rights of Persons with Disabilities (CRPD) in 2010 (CCD, 2010).

In the 1990s, Judy Singer (2016) coined the term *neurodiversity* to further enhance the work of the social model of disability. Singer argues that when disability is described in this way, as a neurological difference rather than a disease, stigma is reduced so that people need not feel ashamed or blamed for their challenges. Singer further argues that viewing disabilities as neurologically diverse aligns with other emancipatory approaches used to support those oppressed by race, ethnicity, sexual orientation and socio-economic status. Such concepts embedded in disability rights-based frameworks can greatly enhance practitioners’ support of young people with disabilities.

Disability Rights and a Child and Youth Care Approach

Fortunately, practitioners are beginning to recognize the value of the social model of disability, neurodiversity, and disability rights as concepts that can not only support, but also empower young people living with disabilities (Armstrong, 2012; Bristow, 2015; Gural & MacKay-Chiddenton, 2016). Using the concept of neurodiversity, classroom resources and education plans are being adapted to reflect the strengths of students with disabilities (Armstrong, 2012); CYC practitioners are using creative relational practices to meet the needs of young people with disabilities (Bristow, 2015); and postsecondary educational resources are writing chapters on CYC approaches to incorporate disability rights into practice (Gural & MacKay-Chiddenton, 2016). This is a fantastic start, although it is just the beginning.

As I have noted through accounts of my own experiences supporting this population, it is easy to get caught up in the desire to support these young people without realizing we may be further perpetuating their oppression. With all the best of intentions, we target, exclude, assess and accommodate, often without taking a moment to hear what young people and families have to say about our efforts. With our ever expanding presence in settings that support young people with disabilities (Gharabaghi, 2010), it is important we take a step back to assess our own behaviours and imbed a disability rights lens into our practice. To begin this process, I ask readers to learn from some mistakes I have made and take time to listen to the voices of young people with disabilities. The following is a list of suggestions I have created that readers may or may not find useful depending on their program setting. The most important message I am trying to convey is that practitioners take the lead of young people. Once that is established, my suggestions can be adapted any way readers see fit.

First, instead of diving into your next planned and targeted social skills lesson, spend a day or two asking young people about their experiences. Devise a suggestion box where students can provide ideas about what kind of lessons they feel will be most useful for them. In the case of young people labeled as non-verbal, spend time getting to know their peers and teachers to find out what kinds of strengths and interests they have. Be creative in your communication style to incorporate sign-language and other non-verbal strategies. Plan open sessions where young people play or engage in any activities they wish. These open sessions can still be structured with timers, breaks, and discussion circles. The aim is to get them comfortable in disclosing the real issues behind their behaviours, which in most cases stem from oppressive experiences that they have become accustomed to. When I took the time to do this with my students, I found out that their desks were uncomfortable, their schoolwork was too challenging, their peers were teasing them, and the list goes on. Much of this was surprising to me because they had rarely made specific complaints about these things. Instead, they had exhibited general behaviours deemed ‘inappropriate’ by staff. After developing my trust, students disclosed that they felt they were not allowed to express their concerns because they were expected to simply ‘behave’. However, the pressure of ‘behaving’ and conforming to the norms of their environment proved too stressful for them. Thus, they often ‘acted out’. Taking time to listen to young people taught me the importance of targeting environmental factors, peers, teachers, and even myself instead of targeting the students with disabilities. Interestingly, this environmental approach is the crux of good CYC practice and an approach I had used naturally with non-disabled young people. It seemed I inherently believed that young people with disabilities exhibited challenging behaviours due to their disabilities, not their environment. Surprisingly, I am not alone in this. Practitioners often possess biases and beliefs about disabilities that they may not be aware of unless they spend time reflecting on those beliefs before practice (Gural & MacKay-Chiddenton, 2016).

Second, it is critical that practitioners are transparent about the assessments and plans that are developed through ABA approaches. In my class, I was surprised that all ten students had never seen their Individual Education Plans. What is more, when I showed these plans to each of them, they did not understand the language and disagreed with both their strengths and needs listed on the paper. These documents are often passed along from grade to grade, signed, and filed without updates from teachers, caregivers or students. I was surprised that by grade 9, being placed in a program explicitly labeled as an Autism Program, half my students did not know they possessed this label or what it meant. They had heard the term, often used to describe them, but were unaware of why. It is important to have an open discussion with caregivers concerning their views about disclosing or not disclosing diagnostic labels to their children. Article 7 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (2006) states that "... the best interests of the child shall be a primary consideration... children with disabilities have the right to express their views freely on all matters affecting them". Thus, it is imperative that we be open about our language, labels and support plans. This is in their best interest. They have a right to know and express themselves accordingly. How can we expect them to trust us when we do not trust them to understand their own circumstances?

Once young people with disabilities understand their labels and reasons for their specialized supports, practitioners can begin to co-create support plans alongside them. This investment from young people from beginning to end will greatly improve any behaviour outcomes or social skills deemed worthwhile to develop. In my own case, goal plans for students included a commitment from me to teach their teachers and peers about neurodiversity and strength-based language when referring to their exceptionalities. To take things even further, practitioners can include timelines and indicators to show students regularly what they have done to achieve their end of the bargain. Such accountability from the practitioner will lessen young people's feelings of being individually targeted for circumstances that are beyond their control. Honesty and openness in this process are key factors. Without complete transparency about their disability, this holistic approach is much harder to achieve as young people will not understand why their peers and teachers need to be empathic to their particular needs.

Third, adopt a rights-based approach in every area of your practice. As I have discussed, a rights-based approach means listening to their voices, being transparent, and targeting environmental barriers. A great way to do this is to promote the concept of neurodiversity throughout the school. World Autism Awareness days and Mental Health Awareness weeks provide perfect opportunities to promote inclusiveness. Again, it is important to take the students' lead on these activities and let them create the kind of awareness that works for them. Youtube is a great resource for young people speaking out about neurodiversity and disabilities. Show these videos to both young people with disabilities and their non-disabled peers. Teach all young people, caregivers, and staff about the diversity of the brain. Discussing the brain as a diverse organ that works differently in all individuals eliminates the stigma attached to normative ideas of typical brain development. There is no such thing as a ‘normal’ brain. Each brain is individual and unique to each person. Understanding this concept can be a very liberating experience. In the same way, teaching the concept of ableism in regards to physical impairments can be just as liberating. Ableism refers to the idea that persons without physical or neurological disabilities are ‘normal’, whereas those with disabilities are ‘abnormal’ (Gural & MacKay-Chiddenton, 2016). Everyone’s body is unique to each individual. There is no need for thinking there are ‘normal’ ways of doing or being in the world. As long as we are respectful of one another, it does not matter how we look or accomplish things.

Finally, be vulnerable. Admit to your mistakes and learn from them. In 2011, I became an ally to persons with disabilities. No amount of training in social skills, ABA, or PBS would teach me as much as what I learned from listening to young people. I was fortunate to be learning about disability rights and advocacy movements during my part-time university studies while working with these young people. As I included this learning into my practice, these students trusted me with their personal experiences and gave me permission to guide them on their own advocacy journeys. It was often a bumpy road, but we travelled it together and did not give up on one another. In 2015, I assisted six of my students to submit entries to the *We Have Something to Say Report* (Provincial Advocate for Children and Youth, 2016). Their voices are now among the 170 entries of young people who were brave enough to speak up and tell us how to support them better. I could not be more proud. I had to be vulnerable and allow them to criticize the supports they were receiving, even the ones I provided for them. Allowing for this vulnerability helped me become a better practitioner and I continue to learn.

Last year, this continued commitment to learning from my mistakes hit home while attempting to advocate for these young people. I began a statement, “Students who are struggling with disabilities need…” Before I could finish, a passionate young lady interrupted, “Miss, you mean *striving* with disabilities!” With the best of intentions, CYC practitioners, like me, perpetuate oppression on a daily basis without even knowing. CYC educational materials perpetuate this language in their chapters with headings such as “How Many Young People Struggle with Neurodevelopmental Disorders?” (Gural & MacKay-Chiddenton, 2016, p. 121). Gural and MacKay-Chiddenton have developed a wonderful resource that speaks to the harmful effects of ableism and the positive effects of advocating for disability rights. Yet, within the same chapter they perpetuate a language that assumes these young people are ‘struggling’ with ‘disorders’ and are in need of our rescuing. I challenge practitioners to consider that it is not the disability itself which causes young people to ‘struggle’. It is society’s perpetual labels and assumptions that hinder our ability to emancipate them from oppression.

Conclusion

In conclusion, the goal of this paper is not to instruct, critique, or direct practitioners how to practice their support. Rather, the goal is to begin a conversation on how we can improve our practice when supporting young people with disabilities. I have encountered many practitioners who believe that to be effective with this population we need to learn entirely new skills and do things differently than we are used to. Indeed, authors have even suggested that supporting young people with diverse disabilities is beyond the CYC scope of practice (Gharabaghi, 2010). I disagree. Baizerman (2001) notes that, “Fixing, therapy, intervention are not the basic youth work task. Indeed, they may have no role in clinical youth work. The youth work goal is never to change the youth, it is to join with her in a joint exploration of the possibilities of a relationship” (Para. 14). The same premise can be applied to young people with disabilities. I propose that we forget any notion of specialized ‘fixing’ or ‘intervening’ with these young people. We already possess the skills necessary to advocate for and support them in the same way we would any other young person striving through their challenges. The needs of young people with disabilities are no more ‘special’ than the needs of other young people we support. Of course it is important to gain new practice knowledge in teaching particular social skills, using ABA approaches, and developing individualized support plans. I argue that the upgrading of such skills is embedded in the nature of ethical CYC practice anyway. CYC practitioners are in a perfect position to support young people with disabilities, despite arguments otherwise. Gharabaghi (2010) questions whether we are qualified or ready to take on this responsibility. With the ever-increasing demands to support this population, I argue that we need to stop questioning. The reference list of this article provides several resources to aid practitioners who wish to embark on this wonderful journey alongside young people with disabilities. My hope is that these readings, along with my own personal accounts of lessons learned, will improve the supports and advocacy efforts we provide for them.

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