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# The School of No Fun and No Play: Learning How to Create Supportive Environments from Children with Osteogenesis Imperfecta

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## Abstract

Children with medically complex dis/abilities hold sophisticated views on effective school leadership, adapted built environments, inspiring peer solidarity, catalyzing transformational solutions and a possible school-hospital liaison model to support student well-being. Using child-centric collaborative techniques, this ethnodramatic study engaged children with osteogenesis imperfecta (OI), a rare genetic disease, to create a children's book describing their moral experiences to be disseminated to other children and families. Children living with OI experience ongoing medical interventions and dis/ability that broadly jeopardized the quality of their academic experience relative to their peers. As such, children living with OI offered trenchant insight into what supports and thwarts operationalization of their values and highlights the programs, leadership, services and paradigm shifts they feel that they need to flourish in the academic context.

## Keywords

Dis/abled Children – Osteogenesis Imperfecta – Return to School – Medicine in Literature – Education

## 1 Introduction

The worlds of children are largely dominated by the work of schooling. Lessons, homework, socialization, principals, reading, intramurals, friends and teachers, all contribute to the rhythm of a child's schooling life. This article explores the lived experiences of childhood osteogenesis imperfecta (OI), children's vision for inclusive education and recommendations to empower

their peers and adult allies to transform ableism in the education system. “Ableism” refers to practices that treat children with dis/abilities as subhuman, invisible, disposable, and excludes them based on the assumption that able-bodiedness is the state of successful human citizenship (Dolmage, 2014). Dis/ability, spelled with a slash through this study, challenges this biological binary of an abled or disabled state and points readers to view dis/ability as a complex psycho-socio-cultural-linguistic construction entangled in material reality (Goodley, 2014; Naraian, 2021; Srikala, 2021). While school and health care systems remain largely separate, both systems have enduring impact on the children’s well-being, as either a source of support in the child’s resistance of ableism, or a locus for the recapitulation of ableist oppression.

Children living with OI have lived expertise in dealing with the confluence of medical complexity, dis/ability and the work of seeking sustained support and understanding from members of their school communities. Euro/western conceptualizations of childhood surfacing in both health and educational systems can stress the child as the object of adult moral action, in need of assistance as opposed to the subject of their own rich moral lives (James & Prout, 2003). This view converges with a long Euro/western historical precedent of framing dis/ability as a ‘personal tragedy, biological deficiency and psychological trauma’ to justify their marginalisation in society at large (Goodley, 2013, p. 634).

Such narratives deny the moral agency of dis/abled children, both individually and collectively, and their power to affect their own well-being, political solidarity and offer insights on how to promote positive systemic change (Davis, 2017). A sense of peer acceptance remains a primary determinant of successful hospital to school transitions drawing questions as to how to harness the power of childhood cultures to create inclusive school environments for dis/abled children (Chatzitheochari et al., 2016; James & Prout, 2003; Vanclooster et al., 2018). There is much to be learned from the stories children imagine about how they would transform a school environment that signals marginalization into a just and inclusive one. Indeed, children’s stories reveal their marginality, when paired with a sense of community, is a rich ground for the development of counter-hegemonic discourse, mutual aid and healing from internalised oppression (Agmon, 2016; hooks, 2015; Jóhannsdóttir, 2022; Piepzna-Samarasinha; 2018).

This ethnodramatic study used collaborative child-centred methods to elicit children’s own perspectives on what constitutes the transformational change from oppressive towards inclusive academic environments. From this research, we derive a child-centered design of effective school leadership, adapted built environments, peer solidarity, means to catalyze transformational solutions, and offer a school-hospital liaison model to support well-being.

### 1.1 *Theoretical Frameworks*

This ethnodramatic study drew from three interrelated frameworks: moral experience, child-centred design research and critical disability theory. Moral experience, firstly, is defined as the way in which an individual experiences their values either supported or thwarted and illuminates what moral harms may need to be addressed in a given environment (Hunt & Carnevale, 2011). Inspired by research demonstrating that children are significantly more ethically sophisticated than stage-based developmental models predict, the core concept of moral experience strived to examine how children's moral convictions and values are enacted and responded to in the community setting.

According to critical disability theory, dis/ability is not a biological identity but a social category resulting from a dynamic relationship between disability and ability as designated in the use of the spelling dis/ability throughout this text (Goodley, 2014). These categories interact in a materialist-discursive assemblage circumscribing the lived experience of people living within so-called dis/abled bodies and communities (Bacon, 2022; MacLure, 2013; Srikala, 2021). Children living with dis/abilities are embedded agents within these assemblages and must navigate ableist social institutions who threaten their quality of life, ability to adequately meet basic needs, and constrain opportunities (Ho, 2007). Children act agentially within these spaces to resist, care and promote representative youth cultures supporting the premise that dis/ability can be both a subject of social control and a fulcrum of social change away from ableism and towards the betterment of all human lives (Flynn, 2021; Piepzna-Samarasinha). As a natural progression of the dis/ability rallying cry "nothing about us without us", we seek to radically centre children's creative autonomy in accessible research in the self-expression of their own lived experience (Charlton, 1998; Shaw et al, 2022; Bernardi, 2020). Child-centred design research elevates the voice of the child so that research, and the policies emerging from it, are informed and guided by their perspectives (Shaw et al., 2022).

### 1.2 *Use of Storytelling to Promote Inclusivity*

Despite the steady rise in dis/ability diagnoses, the invisibility of representation, let alone the authentic representation of dis/abled children in children's literature and television endures (DuPaul et al., 2018; Götz et al., 2019). The lack of positive representative role models for dis/abled children reflects their marginalisation on a social scale. Cameron and Rutland (2006) demonstrated that children's interaction with stories, featuring students with dis/abilities, proved effective in creating a more inclusive classroom even when socialization

with dis/abled children was not available. Hence, the early equitable integration of dis/abled persons into childhood academic environments, and the inter-group solidarity amongst dis/abled students, could be meaningfully enhanced by such literature and other media representations.

The United Nations Convention on the Rights of Disabled Persons and the Rights of the Child both reference the importance of equality of experience between all students in integrated academic environments (1989, 2006). To ensure this equitable experience, the United Nations recommends provision of academic services to support dis/abled children's sense of belonging in the community through individualized support measures and sensitive environmental design (United Nations, 2006). Realizing these recommendations, unfortunately, is compromised by neoliberal hegemonies that assign token resources to create inclusive environments (Goodley, 2014; Lum et al., 2017). For instance, the parents of children living with OI may not have the choice of enrolling their child in a school that would best nurture their child's gifts and talents. Rather, parents must prioritize accessibility, choosing a school with an elevator and a teacher willing to set aside ableist norms and adapt to the needs of a dis/abled student (Dogba, 2013). In spite of physical limitations associated with bone fragility, children with OI excel in many academic, extracurricular and vocational activities including flourishing in the arts (Ablon, 2003; Tsimicalis et al., 2016). Globally, the OI community is replete with critically acclaimed artists who celebrate their community, through a myriad of art forms: music, theatre, visual arts, storytelling, and other media. Through these means the OI community, at large, engages with the work of changing the deficit discourse, limiting stereotypes and pejorative attitudes that too often peruse their social experiences (Tsimicalis et al., 2016). The success of artists living with OI refutes the ableist assumptions around dis/abilities and physical differences.

### 1.3 *Ethnodrama: Storytelling as Research*

Children with OI, especially those with severe OI, share many common life experiences of diverse children with medically complex dis/abilities (Arundel, 2015). The severity of OI symptoms extends from a mildly elevated risk of fracture, chronic pain, to severe limb deformations requiring lifelong wheelchair use (Tauer et al., 2019). Regardless of the presentation, children living with OI experience wide ranging bio-psycho-social impacts, and ethical harms, that may touch every aspect of their academic experiences (Wang et al., 2019; Tsimicalis et al., 2016; Cleary et al., 2022). Ethnodramatic storytelling invites participants to theatrically, co-create a representative story

of their hopes and experiences with the help of a facilitator (Saldaña, 2005). The methodology seeks present empirical findings in ways that engage the empathic and ethical capabilities to collaboratively reflect upon and change recurrent social issues (Taylor et al., 2017). The performative medium reflects on the injustice within what “is” and has the flexibility to imagine flourishing within what could be. In this case, the ethical harms experienced by children and their imagined solutions to those harms can be imagined and shared in ways accessible to other children, academic and non-academic audiences.

In the well-known ‘Theatre of the Oppressed’ tradition developed by Augusto Boal ‘spect-actors’ work with theatre facilitators to transform oppressive scenarios into liberating scenarios by making plot suggestions, or performing with/as actors themselves, to transform the outcomes of familiar oppressive life circumstances (2006). In the methodology that follows, this technique was blended with ethnodramatic storytelling to bring ‘spect-actors’, or audiences that become actors, in representations of their own lives, into the hospital research setting (Boal, 2006). Using improvisational spect-actor theatre games, at the hospital bedside, allowed participants to express their insights, if not direct experiences, anonymously, through storytelling leaving these insights to be woven together, drafted and illustrated by the artist-researcher into a final story. By representing research insights as fiction, readers can explore the context of the narrative as they experience it, arriving at their own conclusions of what the story means and what may be possible in the “real” world based on these reflections (Leavy, 2017). The specific choice of generating fiction accessible to children reflects the child-centred research framework in both the study design and knowledge dissemination process.

## 2 Methods

### 2.1 *Study Design, Purpose and Setting*

Following institutional ethical approval, a practice-based research study was conducted to collaboratively create an ethnodramatic story wherein what children called a “bad” school was transformed into what they saw as a “good” one for children with OI. In this way, children identified what they experienced as moral harms (i.e. injustice, power imbalances, emotional abuse, etc.) and moral goods (i.e. belonging, solidarity, adapted environments etc.) in their school environment, as well as how they would apply their agency and capacity for resistance to provoke transformational social change. This study was part of a three-phase ethnography seeking to understand the moral experiences of children with OI during hospitalization and in their community (Wang

et al. 2019, Cleary et al. 2022). The last phase of this ethnography entailed creating resources to promote social change towards more positive childhood moral experiences (such as the ones detailed in the present study and others forthcoming). The study was conducted at a university-affiliated, not-for-profit, bilingual, paediatric orthopedic hospital located in Montreal, Quebec, which specializes in the treatment of children living with OI.

## 2.2 *Sample and Recruitment*

Purposive and maximum variation sampling were used to recruit participants who were either children with an OI diagnosis or their siblings (either living with or without OI symptoms) under the age of 18 (see Table 1 for inclusion and exclusion criteria). Families were approached by a non-authoritative person unrelated to the study to invite them to participate. If they agreed to meet with the researcher, they were explained the study and informed consent and assent was obtained from children and adults both. A sample size range of 8–12 was estimated to generate enough separate storylines from the children to combine into one narrative without sacrificing precise creative contributions from individual participants.

## 2.3 *Interview Guide and Props*

Story development through collaborative, improvisational, ethnodramatic play followed from a semi-structured interview guide and the selection of props, to help maximize children's engagement, discussions and creative choices. The researcher was a nursing graduate student with experience as a

TABLE 1 Inclusion and Exclusion Criteria for Child Participants

Inclusion	Exclusion
– 3–17 years	– Over 18 years
– Is a current child OI patient diagnosed with any of the OI*	– Not diagnosed with OI or sibling of affected patient
OR	– If any team member suggests that participation in the study may be harmful to the child
– A sibling of a child receiving treatment by the multidisciplinary healthcare team at the study site	– Does not speak French, English, or Spanish

children's community artist. The interview guide consisted of the following three questions:

- (1) Imagine a terrible school: What is it like?
- (2) Imagine the best school in the world: What is it like?
- (3) Can you tell me a story of how a terrible school becomes a good school?

Some children chose to consult by commenting on different facets of the ethnodramatic story, as opposed to other children who created one themselves according to their preferences. The interview further incorporated the children's preferences for prop options and using puppets, collaborative graphic storyboarding, and/or directly commenting on what they would add to other anonymized children's stories or how they related to their own lived experiences. The puppetry and graphic storyboarding involved use of "triggers" by suggesting a plotline of a "bad" school, however children imagined it, transforming into a "good" one working with an array of puppets (Carter & Ford, 2013). Fourteen puppets were available and included: finger puppet family members, finger puppet animals, a dragon, ballerina, a patient, a nurse, a physician, and more generic large sized puppets. The variety of puppet characters made available to the children encouraged maximum imaginative, open-ended, exploration of the child's conceptions of "good" and "bad" as well as the transformative process between the two (Carter & Ford, 2013). The simplified interview guide was created to permit children to govern not just the creative process but also the spatial dynamics of staging the puppets and videorecording to experience a greater sense of power and agency within the interview process (Bird & Donelan, 2020; Carter & Ford, 2013; Elwood & Martin 2000). For example, children decided whether or not they wanted to film the puppet play, animate the puppets or perform voiceovers. One participant preferred improvisational graphic storyboarding as opposed to puppetry because it felt more private than playing with puppets in a busy clinic. The participant directed the artist-researcher to draw a cartoon storyboard for an imagined plot as she invented it using the same improvisational skills used with puppets. Three participants opted to comment on anonymized summaries of children's stories.

#### 2.4 *Data Collection*

The researcher explained the interview process to the children and their parent(s) and collected the data in the child's private hospital room or in an outpatient clinic behind a semi drawn curtain (see Table 2). Parents were welcome to stay for the duration of the interview. The interview guide and choice of props served as a starting point to adjust to children's unique preferences, engagement and capacities. Children were invited to invent stories combining



TABLE 2 Child Study Participant (n = 11) Characteristics and Overview of Interview Locations and Modality

<b>Gender</b>	Male	5	47.61
	Female	6	52.38
<b>Age</b>	3–5 years	0	4.76
	6–11 years	4	52.38
	12–17 years	7	42.85
<b>Diagnosis</b>	Mild form of OI	4	33.33
	Severe form of OI	2	67.67
<b>Participant</b>	Child with OI	6	54.55
	Unaffected Sibling of a Child with OI	5	45.45
<b>Study Site</b>	<b># of Participants</b>	<b>Interactions</b>	
<b>Outpatient clinic</b>	6	– 5 plot consultations (patient & sibling; 2 affected siblings; 1 individual) – 1 individual semi-structured cartoon storyboarding interview	
<b>In-patient Room</b>	5	– 5 puppet mediated ethnodramatic interviews	
<b>TOTAL</b>	<b>11</b>		

Note. Diagnosis categories based on Shapiro, Glorieux, & Sponseller, P. D. (2014). *Osteogenesis imperfecta*. Elsevier, Amsterdam.

“good” or “bad” school characteristics. For children uncomfortable with imagining a complete story, the researcher would act out school characteristics mentioned by other children as “good” or “bad” and welcomed the children’s input (e.g. if the characteristics were right/wrong and what characteristics should be changed). For all children, the researcher regularly paused to allow time for children to develop, integrate and build the storyline in a fluid and iterative process. The one-time interviews lasted from 15 to 65 minutes, varying with participants’ age, interest and discussion topics. Interviews were audio-recorded and professionally transcribed within 48 hours, and films, where applicable, were uploaded on the server and reviewed as needed for data analysis. After each interview, observations, field notes, and reflections were

also transcribed. During the course of recruitment and data collection, one youth participant requested to meet the researcher again to help collate the children's anonymized stories during their prolonged hospitalization. This lead participant and the researcher meeting three times and combined all participant stories into one coherent narrative.

### 2.5 *Data Analysis as Ethnodramatic Story Development*

Ethnodramatic storytelling was the collective creative practice, data source, and analytical technique used for the study. This technique was iterative, inductive, and continuous over the course of data collection and analysis. After each interview, the data from observations, field notes, transcripts, artwork from graphic storyboarding, and puppet videos were anonymized and archived. The guided interview was updated to offer new potential storylines and probes of "good" and "bad" school characteristics that were shared with remaining participants. All stories were holistically analyzed to understand characteristics defining a "good" or "bad" school environment. Summaries were created and key ideas were presented to one youth participant who helped create the full fictional story with the researcher. All characteristics children identified as "good" or "bad" in a school environment and how to effect social change were included in the final story. Details such as name, place and personal attributes of characters were changed for plot coherence and to preserve anonymity. The researcher proceeded to draft the story according to the specifications of the participants and continuity of plot structures detailed in the critical reflection below.

## 3. Results

### 3.1 *Sample Characteristics*

Of the 13 children approached for participation in the study, two declined, and 11 children, ages 6 to 17, consented or assented to participate. No children withdrew from study (see table 2 for full sample characteristics). Two of the participants had severe OI symptoms requiring permanent wheelchair use, five had less severe symptoms (primarily an elevated risk of fracture). The remaining four participants were siblings without OI symptoms.

### 3.2 *The School of No Play and No Fun*

The resulting children's book called "The School of No Play and No Fun" was collaboratively produced with the 11 participants. This 1,600 word story is available as supplemental material and is in production as a book. The story

offers trenchant insight into how child and adult cultures can synergistically create the kinds of support medically complex children wish for and require.

The book begins by introducing readers to two siblings: Maria lives with invisible OI symptoms while her brother Mikey lives with visible OI symptoms and uses a wheelchair. The children arrive at their new school only to discover there is no wheelchair ramp, the bathrooms are tiny and there is no room for Mikey to maneuver his wheelchair in class around his classmate's desks (Figure 1). Coach Meanie Weenie, the main teacher, is an overly enthusiastic physical education teacher. The teachers forbid all children to play outside and permit only games that carry an elevated risk of fracture to be played. Children sit in classes and regurgitate boring information. Children who are "disobedient" are turned into turtles by their teachers (Figure 2). Maria and Mikey take refuge in each other and their imaginary friends, actively hiding from the school bullies, and trying to avoid the pushing and shoving that ensues in the classroom (Figure 3). During gym class Maria sits on the sideline forlorn unable to join high fracture risk activities encouraged by the gym teacher (Figure 4). Mikey, however, refuses to sit on the sidelines and speaks out, declaring that he is capable of doing many activities but not the ones allowed in gym class. He is punished for speaking up and turned into a turtle (Figure 5). In his new transformed state, Mikey can communicate with the other turtles. The turtles explain the school was cursed by a girl living with OI, who spent so much time in detention, that her bitterness and sorrow bewitched the school.

Mikey learns of a way to break the curse. He leaves for the forest and avails of the animals to make a magic potion capable of lifting the curse (Figure 6). The potion comprises of calm, a sense of humor, confidence, determination, community acceptance, a sense of play and love. The forest animals and Mikey travel underneath the school and discover a river of tears



FIGURE 1 No room for Mikey to maneuver his wheelchair in class.



FIGURE 2 “Disobedient” children are turned into turtles by their teachers.



FIGURE 3 Maria and Mikey take refuge in each other and their imaginary friends, actively hide from the school bullies, and try to avoid the pushing and shoving that ensues in the classroom environment.

flowing from a weeping door. As they approach this door, the witch begins throwing dodgeballs defensively. Instead of reacting, the animals surround her in a loving, warm and fuzzy circle and throw roses in return. As the witch experiences a sense of love and belonging, she at last transforms into a grown



FIGURE 4 Maria stammered, “But Coach my bones are too fragile to play!” while the other students laughed at her next to the monkey bars.



FIGURE 5 Mikey punished for speaking up and turned into a turtle.



FIGURE 6 Mikey leaves for the forest and avails of the animals to make a magic potion capable of lifting the curse (Figure 7).

woman. She subsequently assumes the leadership of the school. She makes the school socially inclusive and with a wave of her wand invites an occupational therapist from the hospital to transform the school into one that is wheelchair accessible (Figure 7).



FIGURE 7 With a wave of their wands the physiowizard and witch create an accepting and supportive environment, with bright colors, a soft playroom, large bathrooms, an elevator and many adapted play opportunities. The physiowizard teaches a special class to the students on how to welcome the children to their school, so students living with OI can experience a genuine sense of love and belonging.

The wizard occupational therapist (the “physiowizard”) mandates the creation of a wheelchair friendly built environment with bright colors, a soft playroom, large bathrooms, an elevator and many adapted play opportunities. He teaches a special class to the students on how to welcome the children to their school, so students living with OI can experience a genuine sense of love and belonging. The children are concerned about others in the OI worldwide community suffering from discrimination and invite them through a magic portal to come to the inclusive school. The story ends with the children going to play outside in the snow and the children in wheelchairs can participate because special skis have been fitted for them (Figure 8).

### 3.3 *Critical Reflection*

Throughout the ethnodramatic story, the importance of physical play to the child living with OI was highlighted. In the unjust school, the play is conceived in ableist terms and it is assumed that wheelchair users have no



FIGURE 8 The story ends with the children going to play outside in the snow and the children in wheelchairs can participate because special skis have been fitted for them.

capacity for physical activities. Dodgeball, monkey bars, and rope climbing were among the unsafe activities but Mikey, who uses a wheelchair, suggested including adaptive sled hockey and dancing so there could be safe activities. One participant, when consulting on the developing story, mentioned that the simple considered act of allowing a friend of her choice to stay with her during non-adapted activities spared her from the isolation and stigmatization experienced by Mikey and Maria. Readers see evidence of the internalisation of ableism in the contrast between Mikey, an outspoken wheelchair user, and a more passive Maria throughout the story. The latter female identified character “passes” as able-bodied and does not make the same demands for systemic change as her brother. Maria suffers alienation and isolation as she struggles to conform to the school’s tacit compulsory ableness. Her character fades in the background as Mikey creates dis/ability positive community in the process of catalysing transformational change.

This character development is derived in part from a participant, without visible signs of OI, who did not report receiving any gym class accommodations. She appeared visibly upset by the detail of sitting on the sidelines during physical recreation in the story but dreamed of being a dancer. The constraints imposed by OI appeared to heighten the importance of freedom of mind and creativity integrated into their school assignments as well. Children who consulted on the developing plot reported appreciating opportunities for “complete freedom” and “choice” in academic assignments, as many

commented on the incomprehensible or otherwise boring information learned in school. Notably, bullying was increased in the story for older children and “pushing and shoving” was reported as a pervasive form of anti-dis/ability violence due to the heightened fracture risk experienced by all children with OI. This violence contributed to an environment of intimidation and felt powerlessness. Mikey’s outburst against the injustice in the gym was amplified with similar commentary from other participants who emphasized their physical and mental *abilities*, rather than dis/abilities inscribed upon them.

The ethnodramatic story also revealed children’s insight into school culture: negative leadership created ineffective classrooms and negative student experiences. Yet, the participants noted that the source of the adverse leadership was a sense of unhappiness amongst leaders themselves who, much like the children, required a sense of love, support and belonging. Mikey, the main character, expresses an affinity with the natural world, making a potion comprising of participants’ sources of resilience. Inclusive leadership was demonstrated in the story by specifically casting a central character, the school principal, as an individual who intimately understood children with dis/abilities from the vantage point of her own lived experience. The transformed witch’s first acts of leadership include rejecting so-called normalcy, as reflected in an unadapted built environment, and interrogating ableist institutional processes to create a school culture of solidarity and belonging. An environment of acceptance, happiness and understanding, created a social culture that potentiated changes in the built environment to reflect the needs of wheelchair users and adaptations needed for students with a high risk of fracture.

The ethnodramatic story also highlighted the positive experiences enjoyed by one participant whose occupational therapist “sensitized” her classmates before her school arrival. As a result, the participant supported her peers in creating a culture that would be safe and welcoming for all. The participant credited this intervention, and her long-standing team of care providers, with her early successful integration into the academic environment, positive self-concept and prevention of bullying in her social environment. The principal of her school had even taken personal responsibility for fitting her wheelchair with skis so she could go outside and play in the snow with other students. The participant stated that she “wouldn’t stop at the negative opinions of others” and felt confident in her plans to move to a new city and pursue higher education.

#### 4 Discussion

This ethnodramatic study was conducted with 5 children living with OI and their 6 siblings to devise a story about their preference for inclusivity in mainstream



school settings. Children's desired school location revealed they preferred an integrated environment instead of a "special" school. Their preference echoes the greater dis/ability rights movement for greater social integration of dis/abled students at large, to optimize social membership, emotional well-being and educational achievement (Ballard & Dymond, 2018). They did, however, express a desire to have a higher percentage of dis/abled students represented in these integrated environments. This key difference alludes to a resistance to "politics of dispersal" that prevents dis/abled students from congregating, developing a collective consciousness and resisting the internalisation of able-ism (Kumari-Campbell, 2008).

Nevertheless, even an ideal integration process brings challenges of reconfiguring painful environmental barriers, unlearning stigmatization and catalyzing collective consciousness (Campbell, 2008; Cleary et al., 2022; Wang et al., 2020; Dogba, 2013). The story, mediated by puppets and graphic cartoon notetaking, illuminated how dis/abled children hold sophisticated recommendations for effective school leadership, adapted built environments, varied peer microsystems, transformational solutions and a possible school-hospital liaison model to support their well-being. This creative approach permitted a fullness of children's dialogic, visual and creative modes of expression to facilitate trenchant means of understanding, interpreting and re-presenting children's perspectives on how to solve complex issues (Carter & Ford, 2013; Hodgins, 2017).

The power dynamics of society at large, for instance, are reflected in the exclusion encountered by students using wheelchairs and living with a high risk of fracture. Navigating small spaces between desks with a wheelchair, inappropriate recreation equipment, and walking through densely packed narrow hallways were varying examples identified by the children showcasing the dangers of their built environments. In the literature, particularly for female identified wheelchair users, there is a long-standing othering inherent in bathroom design (Slater, 2018). Children's conceptualization of a just environment necessitated an inclusive design for wheelchair accessibility, a safety fracture management plan, and a new playground equipped with soft areas and low monkey bars. Despite the clear importance of inclusive design of built spaces, children's sense of place is also a product of co-constituting peer and adult relationships. Children imagined a school leader who had shared their lived experiences of dis/ability, understood the need to adapt barriers in the built environment and took swift action on their behalf.

Children with complex health care needs are 3.8 times more likely to repeat a grade, and relative to their peers, parents report their dis/abled children as 4.6 times more likely to suffer from low social confidence (Lum et al. 2019). Chronically hospitalized children undergo prolonged school absences that

create a disjointed social and academic experience compared to their siblings (DuPaul et al., 2018; Tsimicalis et al., 2018; Yi et al., 2016). The structural violence faced by dis/abled students in the social environment is reflected in institutional priorities: dis/abled students do not receive significantly more academic or psychological support than their peers (Lum et al., 2019). As seen in the story, villain teachers frustrate individual choices, allow bullying, and do not honour children's needs for dis/ability accommodation. One chronically hospitalized participant specified that bad teachers alternate between "really hard" lessons and speaking in unintelligible gibberish. Teachers have expressed feeling ill prepared to accommodate and anticipate the needs of a chronically ill child, and struggle to differentiate between the health impacts of the disease and the child's academic function (Tresman et al., 2016). These elements of the story highlight the need to create inclusivity beginning with the preparation of disability-inclusive teachers capable of encouraging children with medically complex dis/abilities to enjoy academic flourishing.

The story created by the children further highlighted variable childhood cultures that existed in response to, or distinct from, teachers and other adult characters. In the "bad school" for instance, older students mirrored the attitude of their teachers and appeared physically and relationally aggressive. Maria notably shows signs of internalizing ableism with her visible shame and despondency sitting on the sidelines watching others play games she cannot partake in (Campbell, 2008). Younger students in this environment appeared frightened and submissive in response to an authoritarian teacher in the classroom (Shaw, 2013). These younger students, poor classroom leadership compounded the stigmatization of their complex care needs by peers. Such stigmatization can include fears about contagion and worries about associating oneself with an individual who is "different" resulting in dis/abled students feeling ignored, othered, isolated or rejected at school among (DuPaul et al 2018; MacArthur et al., 2014). Bullying, sadly, is a prominent aspect of dis/abled children's social experience. Dis/abled children are 2 to 3 times more likely to experience both relational and physical bullying compared to their peers (Hernandez et al., 2017; Lum et al., 2019). Sixty percent of dis/abled students report frequent bullying compared with 25% of all other students (Hernandez et al., 2017; Lum et al., 2019). Bullying undermines a sense of self and agency in children and is thus implicated in negative life course outcomes that extend well into adulthood (Chatzitheochari et al 2016; Powell et al., 2019). Perceived peer support, by contrast, is both a coping mechanism and predictor of mental health, academic success, rehabilitation adherence and positive life course outcomes (Canberry, 2019; Chatzitheochari et al 2016). This ethnodramatic study suggests that by collectively engaging young children in

a prejudice-reduction and welcoming process, with the support of leadership, can create a welcoming school culture that learns from the challenge of ableism and embraces the unique needs of all children (Birtel et al., 2019; Cameron & Rutland, 2006; DeMatthews, 2020). Clearly, the transformation of inclusivity must embrace teachers, students and leadership alike. Supportive leadership in the school environment can transform both the dis/ability oppression of the built environment as well as the social exclusions inherent in ableist structural violence. In the world of children, bullying is a primary vector for internalizing ableist oppression (Campbell, 2008; Hernandez-Saca & Cannon, 2016). This ethnodramatic story stresses that school leaders must model a supportive and warm bearing for classroom peers to emulate. Such role modeling supports children to shift their peer microsystems away from bullying and towards inclusivity and emotionally safe space for all children (Davis, 2017). Leadership towards accessible activities and adaptations to the built environment provide tangible evidence of an intangible paradigm shift. In effecting change, leaders become a role model for children demonstrating how to resist and challenge marginalization in their classrooms and society at large (DeMatthews, 2020). The character of 'The Witch' offers unique insight into the way in which children conceptualize where school leadership goes wrong. Specifically, the transformation of the witch from an unhappy girl that replicates cultures of ableism into a capable woman-leader that disrupts ableism within the education system she leads (DeMatthews, 2020). Indeed, the ethnodramatic story uniquely demonstrates that inclusive leadership on the part of adults inspires children's own inclusive leadership development.

#### 4.1 *The Hospital-School Liaison as Catalyst for Inclusivity*

The ethnodramatic story suggests that the skillful interfacing of clinical and school environments can also co-catalyze a school culture capable of understanding and accommodating the needs of the 01 community (Canberry, 2019). Coordination between schools and health care systems is a woefully underutilized and powerful opportunity to effect positive change in the life of children with medically complex dis/abilities (Vanclouster et al., 2018). Common characteristics of hospital-led interventions in the school setting have included supporting parents to become more effective advocates for their children, making presentations to staff, and promoting a supportive peer environment (Carberry, 2019). The ethnodramatic story does not directly reference parental liaising but instead suggests that there is a clear and needed role for hospitals in supporting schools in creating peer presentations and leadership sensitization. With sufficient skillful support, the "happy ending" of a supportive environment may very well be within reach for children with

medically complex dis/abilities. The enduring absence of evidence-based guidelines for hospital to school transitions for children with medically complex dis/abilities is a further glaring knowledge and knowledge translation gap (Carberry, 2019). Extrapolation of some school transition programs or validated assessment tools derived from research with certain chronically ill children, such as the well documented successes in pediatric oncology, may not translate to the specific needs of all populations, highlighting the need for further research (Elam et al. 2019; Bruce et al. 2012). As increasing populations of children with medically complex dis/abilities continue to enter schools, research into cost-effective coordinated hospital to school transitions and specific validated tools for children with OI and other populations are imperative.

#### 4.2 *Strengths and Limitations*

This study contributed to the scant research available, from the child's perspective, as to what they need to flourish in an inclusive school. Above all, this child-centric design generated an ethnodramatic story to disseminate these insights broadly, to adult-knowledge users and children, completing the arc of child centric research design, knowledge translation and representative children's media for the global OI community. The book may be used as a means of fostering peer support and demonstrating approaches to transformative inclusivity leadership endorsed by children. Art-based approaches, including the participatory ethnodrama technique that generated our data, are an appealing and empirically valid method of child-centred design research that elevate a variety of children's voices (Carter & Ford 2013; Shaw et al., 2022).

This study presents a novel ethnodramatic praxis that generated translatable knowledge in how school environments can engender positive moral experiences for children. Nevertheless, common quandaries of arts-based research surfaced: the question of difficulty in accessing children for sufficient time and language barriers, placed the researcher in typing the final draft of the story and filling in gaps left by the informal conversation wherein all participant storylines were concatenated by the researcher and a volunteer. While the use of ethnodramatic storytelling generation facilitated anonymous insight into the children's perspectives, the method offered only sporadic insight as to how the fictional stories were tethered to their individual experiences. The representation of characters in the story proved to be a double-edged sword. On one hand, the study produced a meaningful work of literature by, for, and about dis/abled children that challenged their lack of representation in stories through the central heroic role of a wheelchair user and the presence of a female villain and leader (Götz et. al, 2019). On the other

hand, it perpetuated problematic tropes of male heroes capable of using their intelligence and skill to make change and “beautiful” female heroines relying on the use of magic to accomplish meaningful action (Götz et. al, 2019).

## 5 Conclusion

Traditional social models of disability focus on the material, structural determination of disability and have focused less on the structural violence behind persistent material and social exclusion (Hernandez-Saca & Cannon, 2016; Thorneycroft, 2020). This ethnodrama highlights the interdependent and co-arising nature of physical accessibility, effective leadership and social-emotional well-being for children with OI. The story highlights how the solidarity and agency of children sculpts and informs the institutions with which they interact in contrast to the preponderance of emphasis on the ways in which adult institutions sculpt and inform children (Davis, 2017). The “School of No Fun and No Play” further teaches us that children have not only sophisticated preferences for their academic environments but also cast themselves, and clinicians who support them, as protagonists in the work of social change. They see themselves as strong, resourceful, resilient, visionary and capable because of, and not in spite of, their dis/ability, challenging the incompetence and fragility inscribed on their bodies by various social scripts (Scully, 2012). In all, the tremendous progress marked by the ratification of the United Nation Convention on the Rights of Disabled Persons (2006) is still marked by major lags in the full inclusion of dis/abled children in school settings (Powell, & Pfahl, 2019). While the research methods engaged fiction to imagine ideal solutions to creating empowering academic environments, we must continue to make this imagined transformation a living fact for vulnerable students. Children living with dis/abilities are the experts in their own lived experience of ableism and this expertise must form the foundation of movements towards inclusive education.

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We have no conflict of interests to declare.

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