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COMMENTARY

Separate and Unequal: Students with HIV/AIDS and Mathematics Education

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with
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> We must take sides. Neutrality helps the oppressor, never the victim. Silence encourages the tormentor, never the tormented. Sometimes we must interfere. When human lives are endangered, when human dignity is in jeopardy, national borders and sensitivities become irrelevant. Wherever men and women are persecuted because of their race, religion, or political views, that place must—at that moment—become the center of the universe.
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> – Elie Wiesel[1]

Human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) constitute a true pandemic affecting 36.7 million people worldwide (UNAIDS, 2016). This pandemic creates a complex set of problems regarding health and development, power and identity, gender and racial bias and inequalities, and justice and social ethics that aggregate as a singular phenomenon (Coombe,

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[1] See the Nobel Peace Prize Acceptance Speech delivered by Elie Wiesel in Oslo, Norway on December 10, 1986: https://www.nobelprize.org/nobel_prizes/peace/laureates/1986/wiesel-acceptance_en.html.

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2004). Adolescents and youth represent a substantial number of individuals living with HIV/AIDS (hereinafter HIV[2]) in the United States. Infected youth and young adults aged 13–29 (*n* = 100,724) made up 10% of all U.S. individuals living with HIV at the end of 2014 (Center for Disease Control [CDC], 2016). This same age group comprises 42% of all new HIV diagnoses, with young Black and Hispanic/Latin@/x people suffering at disproportionate rates (CDC, 2016). For young males aged 13–19 and 20–24, Blacks and Hispanic/Latinos accounted for 84% and 76% of all new HIV infections in 2015, respectively, while cumulatively representing 35% of people these ages (CDC, 2016). Similarly, young Black and Hispanic/Latina females represented 83% of young teenagers aged 13–19 and 79% of young women aged 20–24 in the U.S. living with HIV in 2015, but they are 30% of the population of U.S. women in these age brackets (CDC, 2016). Young Black and Hispanic/Latino men who have sex with men are most at risk, with HIV diagnoses among both young Black and Hispanic/Latino gay and bisexual boys and men aged 13–24 increasing 87% from 2005 to 2014 (CDC, 2015).

Despite the rising number of students with HIV attending U.S. schools, equitable educational policies and practices for these individuals are nearly nonexistent. Students with HIV remain consigned to the ideologies and practices of segregation, *if they are thought of at all*. What is also significant, however, are the conversations "stirring" in the *Journal of Urban Mathematics Education* (*JUME*; see Stinson, 2016) and the tenor of equity these conversations are bringing to the collective Black (cf. Martin, 2015) and the possibility it presents for advancing the position of students with HIV. Recently, the discussion of Grand Challenges (Stephan et al., 2015) within the field have stressed the critical importance of achieving equity in mathematics education and of including all children—a call newly echoed by the National Council of Teachers of Mathematics' (NCTM) endorsement of the joint equity statement put forth by the National Council of Supervisors of Mathematics (NCSM) and TODOS: Mathematics for ALL (2016), and tethered to prior position statements (e.g., NCTM's 2000 Equity Principle in *Principles and Standards for School Mathematics*; NCTM's 2012 position statement on Closing the Opportunity Gap in Mathematics Education; NCTM's 2014 Access and Equity Principle in *Principles to Actions: Ensuring Mathematical Success for All*).

In this commentary, I take sides, furthering the issues of equity for marginalized populations articulated in Martin's (2015) and Meyer's (2016) prior *JUME* commentaries. Furthermore, I raise two issues. First, I call to question the authenticity of position statements and documents regarding equity that generalize their expectations to "all students." Such statements are ambivalent to each and every student and do not explicitly reference students with HIV and critical illness more broadly. To leave "all" undefined in this way creates a blindspot (e.g., Winkle-

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[2] HIV diagnosis refers to all individuals with an HIV diagnosis regardless of the stage of disease (stage 0, 1, 2, 3 [AIDS], or unknown; CDC, 2015).

Wagner, Hinderliter Ortloff, & Hunter, 2009), a view obstructed from the center. I also build on Martin's and Meyer's commentaries to address how NCTM's (2014b) *Principles to Actions* (and other policy statements/documents aimed toward equity[3]) might be reimagined to bring the marginalized to the center and to ensure equitable practices for students with HIV (and other critical illnesses[4]), taking specific aim at the essential elements of access and equity, curriculum, and professionalism.

Separate and Unequal

"Children with critical illness live under an educational apartheid" (Nickels & Cullen, 2017b, p. 23). Despite the passage of 70 years since the landmark *Brown v. Board of Education* (1954) decree that "separate educational facilities are inherently unequal," students with HIV may be "physically, socially, and academically removed from their healthy peers" (Nickels & Cullen, 2017b, p. 23), even though significant strides in advancing technologies, clinical practices, and pharmacology for the diagnosis and treatment of HIV have made isolation unnecessary. Quite simply, the practices of apartheidism affecting the education of students with HIV have far less to do with medical necessity than asserting prejudice and bigotry and perpetuating powered relationships (Herek, 2014). Students with HIV are distinguished in important ways from children with other disabilities and indeed from other populations of critically ill students. Although all students with critical illness (e.g., cancer, sickle cell disease) suffer from inequitable mathematics education

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[3] While addressing NCTM's (2014b) *Principles to Actions* specifically, the challenges I raise regarding equity for students with HIV/AIDS and other critical illnesses are intended to problematize all recent policy documents and statements from equity organizations within mathematics education (e.g., Association of Mathematics Teacher Educators [AMTE], 2015; NCTM, 2014a).

[4] Children, adolescents, and young adults (AYAs) with critical illness (e.g., cancer, HIV/AIDS, sickle cell disease, traumatic brain injury) are an emerging, broad and complicated topic within mathematics education research. There are a variety of ways in which the literature of pediatric medicine describes critical illness including critical, chronic, and long-term health conditions; all can apply to children who have been diagnosed with life-threatening or life-limiting conditions that require lengthy treatments (Hinton & Kirk, 2015). As there is ambiguity within these terms, the number of children reported who are afflicted with critical illness can vary from source to source. The literature reports between 10% (7.4 million) and 43% (32 million) of children and AYAs living in the United States suffer from some critical, chronic, and/or long-term malady (Bethell et al., 2011; Hinton & Kirk, 2015; Nabors, Little, Akin-Little, & Iobst, 2008). For my purposes, I define critical illness to be any disease or traumatic injury that is life threatening and requires treatment at a minimum of 3 months' time. The choice to use the descriptor critical versus chronic is made to convey the insidiousness of such diseases and the virulent treatments that accompany them; alternatively, chronic is focused only on the length of time the child experiences the illness. While I choose to focus on students with HIV/AIDS in this research commentary, the vast majority of students with critical illness are affected by chronic and structural marginality in mathematics education (Nickels & Cullen, 2017a).

practices (Nickels & Cullen, 2017b), the insidiousness of HIV stigma—both felt and enacted (Herek, 2014)—renders students with HIV among the most disenfranchised. In contrast to the sacralized image of the innocent, White, bald child with cancer, the child with HIV is envisioned as depraved and blameworthy. Moreover, the population of students with HIV reflects diverse racial and cultural backgrounds, cognitive profiles, physical and socioemotional needs, interests, and aims. HIV is comorbid with physical and cognitive disabilities (e.g., static or progressive encephalopathy), compounded by stigma (e.g., the cultural and gendered identities of lesbian, gay, bisexual, and transgender or minority youth), or geographically weighted to urban centers and low to middle income households. Additionally, most children (aged 0–12) with HIV also have a parent with HIV (Steele & Grauer, 2003). These comorbidities further the enduring notion that individuals with HIV are inferior in status (Herek, 2014) and may contribute to perceptions of a student's mathematical capability or ableism mentality. These misconceptions or negative perceptions are communicated both through overt and subtle messages (Nickels & Cullen, 2017a), the effects of which may result in an insufficient or complete absence of meaningful and complex mathematical work and the debasement of the student's mathematical power and identity. The trend in diagnosis rates predicts thousands of U.S. citizens who, without an equitable mathematics education, will be ill-equipped to enrich their lives and to live a life of their own choosing; likely they will be condemned to becoming the working poor and/or isolated from democratic and socially just opportunities for participation in society because their understanding of fundamental and complex mathematics will yield little else.

Although "calls for mathematics for all and the discourse of equity have become normative in the field of mathematics education" (Lawler, 2005, p. 29), concerns of equality within mathematics education, however, are often only concerned with broadening students' access to high-quality mathematics activities and opportunities (Larson, 2016). Although this aim is well intentioned, it stops short of extending equitable notions to the nature and use of mathematics and the student's mathematical agency (Lawler, 2005). Strict equality for students with HIV would mean simply to provide them with a mathematics education identical to that of their peers. However, the mathematics education of students with HIV must necessarily be, in part, contextually bound to their disease, cognitive profile, and any number of comorbid issues.

Mathematics education is indeed an intricate process of a student's developmental maturation and a social/cultural and institutional enterprise of transmitting our knowledge and, subsequently, our values (e.g., what counts as mathematics, who does mathematics, what mathematics matters). Access alone does not guarantee equality. Paradoxically, if we too severely delineate this population of students (i.e., grouping them only by disease and functional levels for educational purposes), we run the risk of furthering the segregation paradigm and marking them for stigmatization. Consequently, I argue HIV, and critical illness more generally, must be regarded as a contextual variable that not only influences processes and student outcomes at all levels within mathematics education but also as a variable that must necessitate a shift in the goals, content, and role of mathematics.

Attention to what we deem as equitable mathematics for students with HIV further problematizes NCTM's (2014b) *Principles to Actions*—a document purposed with describing the five essential elements of effective mathematics programs to address "a range of troubling and unproductive realities that exist in too many classrooms, schools, and districts" (p. 3). Here, I employ three of the essential elements—access and equity, curriculum, professionalism—to describe "what is" coming to know the current policies and practices for teaching mathematics to children with HIV, and thus revealing the limiting nature of *Principles to Actions* and other such policy documents and statements in addressing and attending to these concerns.

Access and Equity

Viral load (i.e., the amount of HIV in a person's blood) suppression—and consequently disease progression and mortality—for students with HIV can be well controlled by strict adherence to antiretroviral therapy (ART; Merzel, VanDevanter, & Irvine, 2008). ART may include a dosing regimen of 15–20 different medications throughout a single day administered in relation to complicated dietary guidelines. The intensity and frequency of ART constitute an appreciable challenge to students with HIV in schools. Deviation from adherence to ART is correlated with statistically significant progression of disease and central nervous system dysfunction; yet, here too, HIV stigma may limit students' access to support (e.g., choosing not to disclose serostatus to teachers or school nurse; Steele & Grauer, 2003). HIV positive students with a suppressed viral load may experience little to no decline in cognitive function and present as presumably normal within the classroom. As viral load increases, young people with HIV develop cognitive and neuropsychological impairments that may include "insufficiencies in attention, concentration, expressive language, fine, and gross motor skills including oral-motor functioning and neuromuscular functioning" (Collins, 2005, p. 49).

Public schools, however, are theoretically and functionally designed to educate healthy children (Tseng & Pluta, 2016). Although federal law mandates a free and appropriate public education (FAPE) for all children (Individuals with Disabilities Education Improvement Act [IDEA], 2004; U.S. Department of Education, 2007), children with HIV often occupy a gray space between federally established and recognized programs (Gordon, 2015). For example, HIV does not often qualify as a disability until AIDS status is reached. Although few youth and adolescents progress from HIV to AIDS within 12 months, many receiving early and continuous stringent care will not advance to AIDS status until their early thirties (Collins, 2005).

Historically, students with HIV whose viral loads are not suppressed or who have reached AIDS status have received mathematics education via hospital/homebound instruction (Murphy, 1990). There are no federal guidelines for hospital/homebound instruction, and, as such, guidelines vary between states and often from district to district (Tseng & Pluta, 2016). The common model in the United States is to provide hospital/homebound students 1 hour of tutoring per week per core subject they are enrolled in, resulting in a modal value of 4 hours of tutoring per week as compared to the 25 hours of instruction per week healthy children receive (Hull & Newport, 2011). Although the disparity in hours is certainly egregious, the quality of educational service is also called into question because tutoring bears little resemblance to school-based mathematics instruction. Tutors hired to provide hospital/homebound services are often not required to be certified teachers, and instruction may be provided in a variety of formats including via telephone. Thus, hospital/homebound practices regularly infringe upon a student's rights to FAPE and entitlement to a highly qualified teacher (Irwin & Elam, 2011).

Furthermore, no general state aid or hospital/homebound reimbursement is made available to a school district for services provided to a student who is not enrolled in the district. Thus, students with HIV can be made to un-enroll from the school district in which they live and enroll in the school district in which the hospital is located to receive services. In the case of intermittent absenteeism, the burden of un-enrollment and re-enrollment dissuades many parents from seeking services for their child. Compulsory attendance and fiscal priority can also lead schools to delay educational services or enrollment or even withdraw children with HIV (often without parental consent) to remove them as impediments to annual yearly progress (Irwin & Elam, 2011). Students with HIV who meet the requirements for special education services are not necessarily better served than those who do not meet the threshold requirements. Despite having written accommodation plans, these students are presented with the same service model of hospital/homebound instruction.

A final concern for access and equity involves the right for students with HIV to have their perspectives heard. Silencing is one of the most potent and easily committed acts of inequity. There are many who will claim explicit recommendations for equitable practices for students with HIV are unwarranted because these individuals would be served by the extensive literature on special education, mathematics education reform, or students who identify as Black, Hispanic/Latin@/x, or queer (Nickels & Cullen, 2017b). The faulty logic behind this suggestion is that adolescence is largely undifferentiated, at least concerning those dimensions that may affect mathematical thinking and learning; this reasoning furthers that disability and disease also present with analogous issues (e.g., research on educational attainment for children with autism would apply also to children with HIV). Even if students with HIV were perfectly matched to another population represented in special education literature, this body of literature assumes that most individuals with disabilities will be served in a least restrictive environment integrated into the regular classroom. Educational issues and outcomes for students with HIV including physiological, psychosocial, and neurocognitive effects are well documented within medical literature and delineate a clear path for educational research and practice specific to this population, whereby it becomes indefensible to produce equity documents that do little more than provide tokenistic platitudes for benefitting "all" students, when the reality is that the needs of diverse student groups cannot be addressed by blanket approaches.

Although very few studies and far fewer policy or practice documents have explicitly sought students' perspectives, the voices of children with HIV are even less audible, and yet who better to provide the most valid interpretation of the beliefs and practices affecting their mathematics education than the individuals who have experienced the lived reality of marginalization and oppression. An argument, albeit deficient, for excluding the voice of students in these documents posits that researchers and practitioners as adults are knowledgeable of students' perspectives, not only having a wealth of educational, sociological, and psychological literature at their disposal, but because they too were students (i.e., recalling their lived experiences). Many counter arguments can attack this premise—chief among them, the vast majority of researchers and practitioners were not once students with HIV. That we as researchers, teachers, and policy makers have no basis for understanding what it is to live with HIV and to receive mathematics instruction concurrently, is sufficient reason alone for seeking the voices of students with HIV. An equity document that contains the perspectives of students with HIV with respect to mathematics education would serve to help develop a set of practices and polices that are appropriate to the students' experiences and circumstances and, importantly, to create a record of the multiplicity and diversity of students with HIV.

Curriculum

The aforementioned beliefs and practices related to access and equity are not discrete from concerns regarding high-quality mathematics curriculum. Standards documents are often interpreted as a curricular checklist as opposed to a set of expectations guiding the teaching and learning of mathematics. This checklist mentality manifests as mere surface adherence to impersonal and decontextualized mathematical objectives rather than serving to promote deep conceptual understanding of key mathematics concepts. This manifestation is arguably a problem affecting most students, but students with HIV experience an even greater hardship when this teaching mentality is transferred into the hospital/homebound setting or reflects upon their experiences in regular mathematics classrooms.

Mathematics curriculum is highly fragmented for students with HIV in a hospital/homebound or bi-enrollment setting (i.e., receiving instruction in both the hospital/home setting and in the regular classroom) because often no specific guidelines for providing homebound instruction exist and tradition dictates the hospital/homebound instructor is given the curriculum from the student's local school (Daly-Rooney & Denny, 1991). Hospital/homebound teachers may or may not have any familiarity with the curriculum, content, or the required materials needed to enact the curriculum; and vice versa, the regular classroom teacher may lack the required knowledge of the student's disease, symptoms, and treatment to modify the curriculum to his or her academic, physiological, neurocognitive, and sociological needs (Irwin & Elam, 2011). Often, all parties involved "remedy" this situation by swapping out the usual curriculum for worksheet packets that isolate problem types and provide repeated skill practice outside of meaningful contexts (Nickels & Cullen, 2017a). Even if the student with HIV mostly remains in his or her classroom utilizing the regular curriculum, frequent absences or lack of facilities and resources make it difficult to keep up with the learning expectations of the teacher and school and district imposed pacing guides (Fowler, Johnson, & Atkinson, 1985; Thies, 1999).

Equally troubling is the value placed on the transience of childhood and adolescence—in which young people are nurtured and educated towards adulthood with little appreciation for the individual's immediate being (Nickels & Cullen, 2017b). Many students with HIV are thus left in a state of educational uncertainty, receiving little to no access to mathematics curriculum while their chances of entering adulthood wait to be seen (Nickels & Cullen, 2017a). This emphasis on adulthood supports the narrative of mathematics education as a market-driven practice; however, mathematics education has significance above and beyond socio-economic advancement. Mathematics, many have argued (e.g., Ernest, 2010; Gutiérrez, 2012; Gutstein, 2005; Skovsmose, 1994), allows us to understand our natural and social worlds, our relationship to both worlds and to others within them. It advances both our human and social capacities. In relation to their disease, mathematics can allow children with HIV to regain control over their quality of life and the circumstances surrounding their treatment including leveraging powered positions that contribute to differential access to valued resources. This view of mathematics stands in direct opposition to the meritocratic culture of formal mathematics instruction. Here the value lies in a student's ability to learn and make sense of the real world and the opportunity he or she is then given to live authentically, creatively, and happily.

Professionalism

In large part, policy and government regulations concerning the education of students with HIV have constrained professionalism in the practice of teaching these individuals (Bogden, Fraser, Vega-Matos, & Ascroft, 1996; Newhart, Olson, Warschauer, & Eccles, 2017). Little attention is paid to persons who volunteer or are hired to provide mathematics instruction to children with critical illness (Nickels & Bello, 2017; Tseng & Pluta, 2016). Many individuals who are drawn to hospital/homebound programs out of compassion or religious affiliation believe that "feel good" activities should take precedence over core academic content or best pedagogical practices (Richards, 1957/2013). This altruistic spirit is thus favored in teacher selection over actual merit (e.g., certification, experience; Nickels & Bello, 2017; Tseng & Pluta, 2016). However, HIV stigma often guarantees that this altruism is not extended to students with HIV (i.e., children with non-transmissible disease are favored or served first or only; Synder, Omoto, & Crain, 1999). Much too frequently schools are also complicit in providing a second-class education for students with HIV. Hiring highly qualified teachers is expensive and thus deemed unaffordable for many school districts and hospitals that receive little to no state aid for hospital/homebound programs (Tseng & Pluta, 2016). The lack of qualified teachers also means that, either consciously or not, schools and hospital/homebound programs offer curricula based on the competency level of the teacher, not necessarily the curricula best fitting the needs of the student (Ware, 1990). Thus, the variability in teachers' professional backgrounds and personal beliefs are not conducive to creating a community of mathematics educators for students with HIV that, "hold themselves and their colleagues accountable for the mathematical success of every student and for their personal and collective professional growth toward effective teaching and learning of mathematics" (NCTM, 2014b, p. 5).

Teachers who are characterized as highly qualified within the regular classroom report feeling unprepared, unsupported, and fearful to teach children with HIV (Collins, 2005; Fishbein, 2003). These concerns are coupled with the conspicuous heterosexism of public schools. Heterosexism and heterocentrism are communicated through teachers' actions and their acceptance or lack thereof for different populations of students, most notably for students with HIV, a disease publicly focused on sex (Collins, 2005). Thus, even in the best-case scenario in which a student with HIV is positioned to receive mathematics instruction from a certified and competent teacher, he or she may presumably remain at a disadvantage and subject to further marginalization.

Periodic migration between hospital and home and frequent absenteeism also leave students with HIV poorly served by educational interventionists, programs, and facilities, placing an undue burden on the parents to step in as their child's primary educator (Newhart et al., 2017; Nickels & Bello, 2017). Current policy and practices of mathematics education for students with HIV ignore the structural barriers that nuclear families face in the wake of a critically ill student's diagnosis and treatment such as poverty, privilege, and lack of access to resources students need to achieve academically (Bessell, 2001). The prospect of teaching mathematics to their child leaves many parents needing to find their bearings and reconstruct their own mathematical understanding in the context of a new, unanticipated scenario

(Nickels & Bello, 2017; Nickels & Cullen, 2017a). Parents who lack sufficient mathematical content knowledge or disposition for teaching may neglect engaging their child in mathematical work or employ dysfunctional pedagogy to teach standard algorithms and procedural fluency (Nickels & Bello, 2017).

Moving Forward

Currently, little is being done to preserve the civil rights of students with HIV, including that of a meaningful and appropriate mathematics education (Nickels & Cullen, 2017a). Similar to Martin (2015) and Meyer (2016), my purpose in writing this commentary is to further problematize NCTM's (2014b) *Principles to Actions* and other equity oriented policy documents and statements in service of students who arguably face some of the greatest educational disparities. If equity focused organizations mean to keep true to their assertion that every student has the right to equitable opportunities to learn mathematics, then expanding what is meant by "every" must be addressed. Although many readers of *JUME* may agree to this avowal, we must take seriously that the onus does not lie alone with organizations such as AMTE, NCTM, NCSM, and TODOS. This reimagining must be a collective project. The question we face is—*How and when?*

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