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Philosophical Inquiry in Education

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Volume 28, Number 2, 2021

URI: https://id.erudit.org/iderudit/1082919ar
DOI: https://doi.org/10.7202/1082919ar

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Publisher(s)

Canadian Philosophy of Education Society

ISSN

2369-8659 (digital)

Explore this journal

Cite this article

Dhingra, N. & Miller, J. D. (2021). Dependent Rational Activists: Disability, Student Activism, and Special Education. *Philosophical Inquiry in Education*, *28*(2), 110–128. https://doi.org/10.7202/1082919ar

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***Philosophical Inquiry in Education*, Volume 28 (2021), No. 2, pp. 110-128**

Dependent Rational Activists: Disability, Student Activism, and Special Education

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Historians of student activism have rarely focused on students with disabilities, while educational historians who study students with disabilities have focused on legal reforms, not activism. We present a philosophical argument for an inclusive definition of student activism that can take place within legal and bureaucratic processes in which students act collaboratively with parents or guardians. Drawing on the new disability history and critical disability studies, we first argue that such activism is necessary because those processes routinely involve the conceptual objectification, silencing, and invisibilization of disabled people. Further, we argue that activism is necessary to shift individualized education plan (IEP) meetings from bargaining to collective deliberations for the common good. Finally, following Alasdair MacIntyre, we argue that activism, legal and otherwise, may involve families acting collaboratively, because parents and others can become attentive to the rational reflections of those with disabilities.

Introduction

Studies of disability have long laboured under a conceptual error about the nature of activism, leading them to neglect an important legacy of students' self-advocacy in special education contexts. Histories of student activism almost always describe students acting autonomously and assertively (Hale, 2018) through kinetic actions such as walkouts (Geis, 2019). If they mention disability at all, historians portray disabled students as the passive subjects of legal protection, often relying on objectifying medical categories of disability (Longmore & Umansky, 2001, pp. 2–3). Meanwhile, special education historians emphasize legal and policy developments but not the agency of individual students (Osgood, 2005; Stroman, 2003; Switzer, 2003). We argue that the definition of activism needs to be expanded to encompass collaborative, developmental forms of self-advocacy, to include students acting jointly with caretakers at individualized education plan (IEP) meetings and court proceedings, sites where the adversarial interplay between families and schools often unfolds.

Reconceiving activism as collaborative and procedural (rather than autonomous and kinetic) allows historians and disability scholars to interpret the full extent of student agency, but it depends on two fundamentally philosophical insights: First, that all students need to have recourse to activism when deliberative democracy within schools fails, especially for disabled students, because forms of democracy rooted in the bargaining process of the modern state are structurally incapable of discerning an inclusive common good for disabled and nondisabled community members (Klingner & Harry, 2006; Taylor, 2016). Second, that if students with disabilities require recourse to activism, their participation must include a form of agency that includes, as Alasdair MacIntyre has argued, an acknowledged dependence on others, even if others speak for a student with disabilities as a "second self." We ground this capacity for others to speak in a specific, if not exclusive, form of unconditional and transformed attentiveness that parents and other caregivers may have formed. To say that disabled students act with and through others, then, is not to diminish their place in the advocacy process. This

project effectively separates activism from ableist presumptions, such as that someone acts assertively when that action is physically provocative or clearly independent and autonomous, free from the putative confines of interdependence. Instead, we argue that activism, whether kinetic or not, or in conjunction with others or not, can be distinguished simply when it asserts the visibility of persons whose existence is otherwise obscured by the imposition of inadequate and often cramped and alienating categories.

Understanding Disability in Social and Institutional Contexts

Since the late 20th century, disability activists have sought to dismantle rhetorical conceptualizations of disability that are premised on individual deficits, yet objectifying presumptions continue to inform popular and political constructs of disability well into the 21st century. Invisibility and subjection to generalization are common circumstances for disabled people participating in social and institutional contexts. Public schools, which are both social and institutional, share this history. Scholars in fields such as disability studies have demonstrated ways that state bureaucratic mechanisms mirror and interact with popular, rhetorical understandings of disability (Scotch, 2001). Disability policies are often mediated at the points of input, process, and outcome by enduring, generalized disability definitions. As a result, disabled people are often marginalized, rather than centred, in policy discourse and implementation, and their experiences, preferences, and relationships are often blurred by uneven definitions and imprecise deployments of disability labels.

This convergence of ideology, rhetorical understanding, and policy is presented and even justified through the language of medical expertise and the law. A product of 20th century social and political developments, interactions between medical and legal language continue to inform disability-related regulations placed on public institutions, including public schools, and through policies like special education (Artiles, Dorn, & Bal, 2016). Disability policies, nominally designed to confer social benefits to classes of people attached to disability labels, often lead to the conceptual objectification, silencing, and the invisibility of disabled people. For instance, disabled students in contemporary legal processes such as IEP meetings are required to be labelled within a medicalized disability category and must often declare inferiority in academic ability relative to peers in order to bargain successfully for special education benefits. As such, special education students are subject to "paradoxes" of identity construction in which they are granted benefits and simultaneously marked as separate or different (Artiles, 2003, p. 165).

Disability categories – as used in administrative proceedings for the purpose of deploying public benefits – are primarily conveyed through medical and legal definitions, but they also have deep roots in popular social beliefs about human difference (Campbell, 2005 Winzer, 1993). For instance, Fiona Kumari Campbell suggests a tight ontological connection between "ableism" and "legislation," such that the law conveys only a fictive depiction of disability through pared down definitions and provides only illusionary possibilities of a future of rights and freedom for people labelled through a disability category. Breaking through this impasse, Campbell argues, requires an "ontological" reckoning with disability legislation (Campbell, 2005, pp. 110, 126). One might consider looking to the past to understand what needs breaking through or reckoning with. Historians like Douglas Baynton illuminate a lengthy history of public policies that define disability at the meeting point of popular understanding and medicalized, scientific language. Specifically, Baynton reminds readers that "disability is everywhere in history, once you begin looking for it" (Baynton, 2001, p. 52). Baynton's remarkable analysis shows how the particularities of medical disability language have been abstracted as an exercise of power and control, and as a means to "justify" discrimination. Specifically, Baynton documents historical examples of ways that disability language was applied along gender, ethnic, and racial lines in order to deny access to the legal enjoyments of citizenship through the early 20th century. Extending his argument, Baynton

shows how members of oppressed groups distanced themselves from disability language, indicating that they should not be denied rights *because* they were not disabled. Identifying the presence of disability in these past struggles for rights and justice requires a close and thoughtful reading of archival evidence (Winzer, 1993). Some scholars, particularly in disability studies, have worked to illuminate and reframe "foundational assumptions" embedded within academic fields, including history and philosophy, as scholars within these fields come to construct the meaning of disability in the past and present (Tremain, 2008, p. 2). Historically speaking, those foundational assumptions are often located within interlocking constructions of morality and aesthetics (Giordano, 2007; Trent, 1994), preserved over time through forms of visual and narrative expression, from art to advertisement (Fraser, 2018; Siebers, 2010). Relationships between disability representations, attitudes, and policy implementation illuminate the "materiality of culture," the "imbrication of thought and action," and their potential to influence public policy (Fraser, 2018, p. *x*).

Policy processes and popular beliefs about disability commingle in historical and contemporary contexts, objectifying disability through ideology and image. Rosemarie Garland-Thomson's analysis of disability as represented in popular photography demonstrates ways that disabled subjects in photographs are positioned "in service to their onlookers" rather than as people representing themselves (Garland-Thompson, 2001, p. 346). Photographic subjects, Garland-Thompson argues, are objects of particular gazes, the real thought occurring from the position of onlookers rather than those depicted on film. Such images may conjure a sense of wonder for nondisabled observers, even evoking a sense of the sublime through "awe and terror" (Garland-Thompson, 2001, p. 341). Paul K. Longmore (2003) explores this phenomenon through the surprising prevalence of disability in television and film, describing common portrayals of disability as monstrosity, whether via internally damaging character traits or in obvious physical disfigurement and tendencies towards acts of violence.

At times, these disability frames work in tandem with popular, rhetorical understanding of the meaning and implications of disability. Consider, for instance, how fear associated with disability might also evoke pity from the viewer. Pity and other forms of sentimentality, Garland-Thompson argues, situate and simplify the disabled subject as a "helpless sufferer needing protection or succor" (Garland-Thompson, 2001, p. 342). In either case, the disabled character loses the dynamism of their humanity. The virtues of disability objectification on display in popular narrative and imagery may operate simultaneously in other social and institutional spaces. For example, many have examined ways that physically disabled people are depicted in popular images as "feel-good tools," reframing nondisabled observers' perceptions of their own capabilities or hardships (Young, 2012, para. 12). On the one hand, this sort of visual messaging is often meant to be inspirational to nondisabled audiences. On the other hand, when disabled people are subjected to the interpretive gaze of nondisabled onlookers, the rhetoric of "inspiration" may simultaneously objectify or devalue them by subsuming their meaning and identity into the "undesirable" physical characteristics displayed in the image (Grue, 2016). While framing disability as inspiration – or "inspiration porn," as many have increasingly been calling it (Grue, 2016, p. 838) – may be construed as "benevolent," the construct of disability conveyed in the image is coded as neither enviable nor desirable (Nario-Redmond, Kemerling, & Silverman, 2019, p. 729).

Attitudes towards disability, James I. Charlton describes, are formulated amid a host of interlocking cultural and belief systems. Among them is an embodied paternalism that inspires feelings of "pity" (Charlton, 1998, pp. 53–55) and a perception to help disabled people do day-to-day tasks, even in public places and among strangers. Consider, for instance, Emily Ladau's narrative of experiences in airports among wheelchair users (Ladau, 2019). Charlton adds that particularities of culture and belief systems also contribute to common dispositions toward disability. In particular, he demonstrates relationships between normative aesthetic assumptions about the human body, religious beliefs, and patterns of socialization (Charlton, 1998, p. 62). These assumptions lean upon moral and aesthetic judgements in answering questions about what people are expected to contribute to society as well as implications for nondisabled people who come into contact with those labelled with a disability.

The rise of bureaucratic institutions in the US and Canada between the mid-19th and mid-20th centuries saw disability definitions change in conjunction with normative moral and political structures (Artiles, Dorn, & Bal, 2016). Take, for instance, James W. Trent, Jr.'s trajectory of "feeble mindedness" and "idiocy" in the US. Each of these labels, Trent argues, were bound by issues of state control, the legitimacy of elite voices in shaping disability definitions, and the economic conditions that supported or denied the will and ability of states to provide support (Trent, 1994, p. 5). Similarly, both Paul Davis Chapman and Jason Ellis explore relationships between policy regimes in public institutions such as schools as they pertain to the centralization of the legitimacy of medical expertise in research institutions. Chapman explores how and why the use of instruments of medical expertise like intelligence tests became "conventional wisdom" in North American public schools, which he positions amid changing bureaucratic needs to maintain order in schools, changing professional networks and their association with schools, and changing beliefs about disability (Chapman, 1988, pp. 27, 175). For Ellis, structural shifts in schooling policy occur along varied trajectories of beliefs about "the cause, nature, and treatment" of disabilities (Ellis, 2019, p. 202). Two bonds connecting these assessments – as well as a host of other analyses – are tight linkages that authors draw between social beliefs about disability and policy processes, each magnified by the absence of disabled peoples' voices in those processes (Osgood, 2008, p. 8). As a result, Benjamin Fraser argues, disability experiences are taken as symbolic, relegated to specific aesthetic assessments, and disabled people categorized as resource recipients (Fraser, 2008). Labels like "laggard," "feeble minded" (Trent, 1994, p. 5), or "special needs" lead to disability being codified *as* difference in institutional spaces like public schools (Gillborn, et al., 2016, p. 38).

As some argue, disability markers position students as institutional "objects" that are to be either "protected" or derided, depending on the needs of, or relationships between, policy regimes and social and cultural attitudes towards disability (Artiles, Dorn, & Bal, 2016, p. 778). While 20th century scholars and activists pushed for more comprehensive, social interpretations of disability that account for relationships between social, political, and institutional constructs, contemporary policies in state institutions remain tethered to medicalized understandings of disability (Connor, 2013; Gabel, 2005). Often construed as the medical model, medicalized interpretations are rooted in individuals' departures from biological norms. Critical scholars warn that the medical model understands disability as an individual problem. This individualized framing absolves institutions of various forms of inequity and exclusion at the nexus of identity, policy, and society (Artiles, Dorn, & Bal, 2016; Dudley-Marling & Burns, 2014). Furthermore, medical definitions often frame disabilities solely as problems and couch explanations of impairment in the language of deficit (Christensen & Dorn, 1997). Taken together, the approach to disability undergirded by the medical model fails to compel reflection of the proximities of power inherent in institutional behaviour and casual acceptance of rhetorical objectification of disability. A challenge to the primacy of the medical model is not a denial of the existence of physical disability or of people's needs, but instead a check on assumptions of the objectivity of medical language applied to disability, particularly when that medical language is central to policy logic and implementation.

Special Education Policy and Activism

Disability definitions and categories have overshadowed and/or substituted for student action and experience in much of the historical record and in special education scholarship. In the historical record, mention of students ranges from the minimal to the nonexistent (Osgood, 2008). This phenomenon also rings true, however, in contemporary street-level engagement between schools and families, as well as in the work of activists seeking systemic change in democratic institutions. Students have undoubtedly played a role in shaping their own schooling experiences through the history of

special education law, but what accounts for their silence in policy and practice? In part, the obfuscation of students stems from the same intersections of culture, ideology, and power that situates disability as an object through the historical record. However, this absence also stems from a narrow read of the meaning of activism in scholarship.

Few books were published on the history of disability and schooling, to say nothing of special education, before the late 20th century. We do not suggest that there was no reflection on the history of the field prior to the latter decades of the 20th century. In fact, there are compelling reflections on the history of the field of special education from a legal perspective found in the annual meeting papers of the Council for Exceptional Children (CEC), as well as in the CEC's academic journal, *Exceptional Children* (Birch, 1961; Geer & Deno, 1965; Zedler, 1953). A charitable interpretation of the absence of a deep, earlier base of scholarship is that the federal special education law was not passed until the mid-1970s, leaving little legislative evidence from which to build a narrative. Indeed, services for disabled students were not readily available in the US prior to the 1970s (Sonneborn, 2012). Even in states and school districts that did offer services for disabled students, few resources existed beyond the schooling years through much of the 20th century (ibid.). However, this state of affairs also reflects the fact that data sources of disabled students in history are difficult to find, rarely preserved, and otherwise devalued by prior generations of educational historians. The extant written record on special education, activism, and advocacy is largely one of court battles and legislative victories. This literature typically describes those battles as being led and waged by adults fighting on behalf of children in need. Adult leadership is not problematic in and of itself, but as Carey, Block, and Scotch (2020) show, disabled activists and their nondisabled parents do not always share the same political priorities. Parents may, wittingly or unwittingly, embrace the same objectifying frames and/or prioritize the same medical model as many institutional actors, policymakers, or members of the lay public. Regardless of these potentially divided dispositions, parent-led organizations were central to the creation of disability legislation in the US and Canada in the mid-20th century (Ellis & Axelrod, 2016).

Organizations that led the judicial attack on unjust education policies in the 1960s and 1970s such as the National Association of Retarded Children (NARC) effectively reshaped special education in the US. Their tactics included legal and popular appeals. In court, NARC aligned with professional organizations such as the CEC to mount attacks on state laws that allowed local education agencies to reject disabled students from enrolling. They successfully argued that such behaviour violated state constitutional mandates to educate children, as well as the 14th Amendment's equal protection clause in the US constitution (Yell, Katsiyannis, & Bradley, 2017). These courtroom efforts were supplemented and followed by a host of popular appeals through visual media such as print and video. "Retarded children can be helped," was the refrain emblazoned on NARC-themed materials, from newspapers to US postage stamps (Smithsonian National Postal Museum, n.d.). This phrase was also used on televised commercials. Barbra Streisand sings sweetly in one TV spot, appealing for pity among the viewing public to support "helpless" children labelled with "mental retardation" (Buchanan, 2011). Similar appeals have been made by other disability-related charitable organizations, particularly through live events like telethons (Altenbaugh, 2006; Longmore, 2015). Organizations like NARC successfully advocated for more public services for disabled people and simultaneously embraced an objectifying framing of disabled children as helpless.

Special education laws in the US are remedies for school systems' historical and rampant exclusion of disabled students by way of federal funding and accompanying statutory requirements (Yell, D. Rogers, & E. L. Rogers, 1998). In the US, special education services are guided by the federal Individuals with Disabilities Education Act (IDEA), which tasks the states with fulfilling special education regulations at local levels. The IDEA's legislative history begins in 1975, when Congress passed P.L. 94-142, then known as the Education for All Handicapped Children Act (EAHCA). The law was grounded by several premises that are sustained through subsequent reauthorizations and renaming. Among them was a "zero reject" premise, meaning that all students must be granted access to education (Yell, D. Rogers, & E. L. Rogers, 1998, p. 227). EAHCA was preceded by a host of "right

to education" cases that struck down state laws that permitted states and districts to reject students on the basis of perceived ability (or inability) to learn (Osgood, 2008, p. 123). More than simply enrolling disabled students in school, the law required that educational programs for disabled students provide a "free appropriate public education" (FAPE), and that they do so in a "least restrictive environment" (LRE) (ibid., p. 101). Finally, the law required these assurances to be documented by a legally binding agreement, introducing IEPs to the schooling landscape (IDEA, 2004). Historians have referred to the IEP as the "centrepiece" of EAHCA, as it is designed to assemble a host of interested parties in the collaborative project of determining an individual child's needs (Gilhool, 1973, p. 598). Furthermore, the IEP represents the procedural requirements that states owe to students in special education. The recourse that was long unavailable to parents was now captured in writing and attached with a host of timelines and "procedural safeguards" through a formal complaint process. Special education promised a deliberative process by which IEPs are constructed collaboratively and through which a student's plan for FAPE is specified.

While the premises and outcomes of special education policy are at times lauded by critical scholars as a sign of progress, there is disagreement regarding the prospects of an equitable future for disabled students and the persistent lack of attention to student participation in those deliberative processes (Connor, 2013; Christensen & Dorn, 1997). The historical narrative of disability and student activism in the US shows that disabled students have gained access to education but without equity or the recognition of personal agency. Student voices are simultaneously amplified and silenced by the legal strictures of IEP meetings and courtrooms. Indeed, attorneys have successfully argued that excluding disabled students violates the Equal Protection Clause and that sorting tools like intelligence tests result in discriminatory class placements (Osgood, 2008, pp. 101–102). However, IEP eligibility remains dependent on parents and teachers convincing a medical expert – such as a school psychologist – that a student *should* be given a disability label. Furthermore, these services are defined not only by the services promised on the page, but by the promise of mandatory future interactions with institutional representatives. This "social geography" at once grants rights and also inculcates difference (Smith, 1999, p. 125; Smith & Routel, 2010). It separates students from peers by a marker of difference via the disability label itself, which naturally limits opportunities for solidarity among students. Furthermore, access to services depends on demonstrating students' lack of capacity to do well in school without support. Parents and guardians must therefore bargain for services in isolation, at a table where medical expertise is prioritized. In essence, the bargaining is successful if parents can demonstrate to experts such as school psychologists that their children are likely to fail. Finally, these negotiations are critical given the likelihood of long-term engagement with the school system (Carlson & Parshall, 1996).

The promises of deliberative democracy in special education are challenged by interactions between social interpretations of disability and the ways these perceptions manifest through institutional and policy settings. For example, minoritized populations are often cast by an advantaged majority as outsiders in deliberative democratic processes (Levinson, 2002). Special education research shows a similar phenomenon for disabled students, their families, and their guardians within the deliberative processes associated with special education in the US, such as in IEP meetings (Klingner & Harry, 2006). In effect, as Curt Dudley-Marling and Mary Bridget Burns argue, children in special education are not disabled by a medical condition, but by a school system that regards them as problematic, deficient, or weak (Dudley-Marling & Burns, 2014, p. 22). What does this mean for understanding advocacy and activism for and among disabled school children? Often, disabled students become objects of the gaze of other actors in ways reminiscent of Garland-Thompson's aesthetic interpretation of disability in photography: subjected to "wonderment," "sentimentality," or fear (Garland-Thompson, 2001, pp. 340–341).

More recent theoretical constructs illuminate ways that teachers, administrators, and school systems characterize and treat disabled students as threatening, problematic, or otherwise disruptive to schools, resulting in education experiences that are more punishment than pedagogy. Critical disability scholars demonstrate the disconcerting effects of coercive, controlling practices used by school

practitioners who privilege ableist assumptions about student ability (Waitoller & King Thorius, 2016). In effect, students labelled with disabilities are often disproportionately disciplined and silenced rather than integrated into the deliberative process of special education. Indeed, a substantial percentage of incarcerated youths in the US were also eligible for an IEP under IDEA while in school (Kim, Losen, & Hewitt, 2010, p. 51). School actions that label students as "disruptive" or otherwise "problematic" may serve as steps to eventual incarceration and other interaction with the criminal justice system (Annamma, Morrison, & Jackson, 2014, p. 58). Scholars including Subini Annamma, David Connor, and Beth Ferry have inspired scholarship to illuminate persistent injustices at the intersection of race, gender, and dis/ability through Dis/ability Critical Race Studies, or DisCrit (Annamma, Connor, & Ferri, 2013). Annamma's work demonstrates the possibilities of this conceptualization of the ways that "racism and ableism inform and rely upon each other" in the very structure of school systems (ibid., 2013, p. 5). For example, Annamma (2018) collaborates with incarcerated "girls of color with disabilities" to present schooling experiences as counter-narratives to reveal "carceral logics" of schooling amid other social systems that result in the criminalization of Black and dis/abled students (pp. 21–22). DisCrit is not designed to "give voice," but instead emphasizes that "people of color and/or those with dis/abilities already have voice" and seeks ways to illuminate "insider voices" as counter-stories that reveal racism and ableism embedded within institutions and systems (Annamma, Connor, & Ferri, 2013, pp. 13–14). In schools, practitioners come face-to-face with students in the socially constructed settings that are governed by the norms and values that may situate disability as something to inspire and/or as something to fear. Each interpretation removes student agency, objectifying them, yet fulfilling federal regulations.

Redefining Activism

Just as a linguistic turn – as Tobin Siebers articulated – was necessary to move away from medical interpretations of ability, we suggest that the philosophy of education requires a conceptual turn to redefine student activism (Siebers, 2008, p. 2). As we argue, philosophers might achieve this redefinition by revisiting students' collegial participation in deliberative democratic processes like IEP meetings. In a sense, we propose a new way of understanding student activism. Special education serves as our context for reevaluating the meaning of activism, but we also explore possible applications for broader schooling contexts. Histories of education in general, and special education in particular, rarely interrogate the roles that students might play in fostering systemic change. Instead, students, and particularly disabled students, are variably objectified within institutional and professional networks that position them as helpless, dangerous, inspirational, or some combination thereof. We therefore hope that our analysis serves as a framework for recalibrating historical and contemporary interpretations of student activism and as a challenge to scholars to view student action in a new light.

MacIntyre, IEP Meetings, and the Modern State

Our analysis interprets IEP meetings according to Alasdair MacIntyre's characterization of the modern state, so we might describe activism within those meetings as more than just action to secure procedural goals. First, we claim that activism can and should occur to shift the character of IEP meetings from bargaining to collective deliberations for common goods. Second, we claim that activism in IEP meetings might occur as students speak through their parents or guardians, whose voices have been transformed through caring for their children, so that their children in fact have become teachers regarding goods. We do not claim that students with disabilities, their guardians, and IEP meetings are, as a group, unique; we hope to use them as examples to make a more general philosophical case that

"activism" need not be limited to kinetic actions by students acting as independent agents. We believe that activism can occur within school-sponsored meetings – rather than by just walking out from them – and with students whose dependence on parents and others is acknowledged and recognized, even to the extent that these others speak for the students as "second selves." In other words, we argue against any sharp distinction between parental activism on behalf of students and student activism per se.

But would activism, however defined, be necessary within IEP meetings that are marked by neither procedural failings nor substantive legal violations? As suggested, we argue that IEP meetings – even if they are meant to be "cooperative" (*Schaffer v. Weast*, p. 53) and "emphasize collaboration among parents and educators" (*Endrew F. v. Douglas County School District*, slip opinion, p. 2), and do not involve votes like political elections – remain characteristic of the modern state. In *Dependent Rational Animals: Why Human Beings Need the Virtues*, MacIntyre (1999) claims that nation-states, however necessary for security and the provision of other public goods, remain governed "through a series of compromises between a range of more or less conflicting economic and social interests" (p. 131) whose bargaining power can be adjusted through the exercise of legal judgement or political and financial influence. Therefore, governance does not depend on the formation of a common mind. The governed instead look to the government of the modern state *transactionally*, as if it were the equivalent of a very large utility company – a phone company that "never quite provides value for money" (Cavanaugh, 2004, p. 266).

Most reforms of the IEP process have sought to equalize the bargaining power of parents and students to that of school officials. Amendments to IDEA made in 1997 required that students with disabilities aged 14 and over be invited to participate in IEP meetings. Presently, school officials have to take steps to include parental participation on IEP teams, including providing both meeting times to accommodate work schedules and translators and interpreters for non-English speaking and deaf parents, respectively. The history of IEP litigation has also seen the increase of the relative legal power of parents – at least those financially capable of mounting litigation – by their emphasizing that a FAPE has both procedural and substantive aspects (*Board of Education of the Hudson Central School District v. Rowley* [1982]) and cannot be narrowly defined as providing educational benefits that are more than merely *de minimis* (*Endrew F. v. Douglas County School District* [2017]).

While there are other salutary reforms that can further equalize the bargaining power of parents and students to that of school officials, including the use of facilitators (Test, et al., 2004), training sessions before IEP meetings (Van Reusen & Bos, 1994), and even simply waiting to complete IEP forms until parents first enter the room (Fish, 2008), it is unclear if the achievement of full equality is a realistic goal. Presently, school officials retain distinct advantages, even with the active participation of parents and students of age. The relevant factors are as different as parents' desires not to appear antagonistic towards institutions with which they will have long-term relationships and insurance coverage for special education litigation that creates a moral hazard, as it insulates schools from the costs of litigation (Chopp, 2012).

Further, even if the bargaining power of school officials were to be levelled, the formation of a common mind through deliberation would nevertheless be preempted by four factors. First, the politics of the modern state facilitate and legitimate bargaining, here through the use of medical language to classify students in an "efficient, streamlined process" (Hess, Molina, & Kozleski, 2006, p. 152), in which personalization is perceived as inefficiency – as an obstacle to standardization: the typical finding of formulas for common disorders (Nussbaum, 2006, p. 2,008). Even if school officials and their experts are cautioned to avoid unnecessary medical jargon, the state and its courts privilege the technical language of the schools over the messier anecdotal reports of parents and children. This is not a translation problem with a procedural solution. Nor is it merely a hypothetical epistemological problem of arrogant experts making damaging if infrequent misdiagnoses through oversight. In a study, parents of students with disabilities said that they want educators to see their children as *children*: "much more than a disability label or a set of IEP goals about mathematics and reading and speech therapy" (MacLeod, et al., 2017, p. 392). Disability scholars like Susan Wendell (1996) have suggested that the

privileging of even sophisticated and rigorous medical and scientific third-person descriptions of those with disabilities can create an alienation from one's own body, which is no longer seen through phenomenological or metaphorical language. Eva Feder Kittay (2020) has written, after receiving a genetic diagnosis of her "beautiful, joyful, and intense" daughter, "Sesha is poorly represented by this description" (s44–45). Medical categorization may also require abstracting a student from his or her cultural or religious background, so that a recent circuit court ruled that the "relevant circumstance" regarding a child with Down syndrome is that he is "disabled, not that he is of the Orthodox Jewish faith" (*ML v. Smith*, 2017, p. 21; Dhingra & Miller, 2020). The predominance of medical language for informed bargaining may seem necessary in IEP meetings, yet it can be reductionistic and alienating as well.

Second, the same medical language that facilitates and legitimates bargaining requires professional evaluation. Professionals, as Kittay has written, have a different set of virtues than parental figures. While both are outside a competition for goods, the professional is meant to be functionally specific, while the parental figure – or social worker or early-grade teacher – is functionally diffuse, with tasks that are less demarcated. The professional applies systematic knowledge and expertise to specific interventions that benefit the community and its normative expectations (and is remunerated accordingly). The professional's response, then, is characterized by "affective neutrality," while the parental figure must remain indiscriminately affective and particularistic (Kittay, 1999, p. 171). Kathryn Scorgie's 1996 dissertation on life management in families claims that, in times of difficulty, parents turned to other parents and not professionals, because parental optimism depended upon first accepting the child *as he or she really was* and only then discerning hope. Perhaps inevitably, one respondent said: "Almost without exception, I have found 'professionals' to be overbearing, overly assertive, almost arrogant, lacking in sensitivity and warmth" (Scorgie, 1996, p. 163. See also Reinders, 2000, p. 189). (That preference and mistrust remained when the subjects were revisited a decade later [Scorgie & Wilgosh, 2008].) Professional virtues, too, may be necessary in IEP meetings, but they clash with the virtues of caregivers. Ironically, the reform of IEP meetings to individualize students, as suggested in the *Endrew F.* decision to ease the reductionism of medical categories, may serve to re-centre experts, whose language becomes ever more necessary to set individualized standards and measures of progress (Raj & Suski, 2017).

Third, even in IEP meetings characterized by equality, school officials and parents will have different incentives. As Debra Chopp (2012) writes, an inevitable tension exists "between the IDEA's guarantee of a free appropriate public education and the resource constraints faced by school districts [that] constantly lurks in the background," so that, at its very root, the problem with IDEA implementation is "inadequate funding" (pp. 425, 460). This is not to say that school officials do not care about students or that courts cannot rule in their favour. Rather, drawing from MacIntyre's thought, it is to say that the tension between internal goods and external goods is especially severe in these proceedings. For MacIntyre (2007), internal goods represent those intangible goods or ends internal to a practice and are "good[s] for the whole community who participate in this practice," while external goods are "somebody's property and possession" and the "objects of competition in which there must be losers as well as winners" – fame, prestige, money (pp. 190–191). External goods are the concerns of institutions, and because practices must be housed in those institutions, practices are left vulnerable to their "corrupting power" – here, school officials' understandable need to efficiently conserve resources in an environment of inelasticity, if not outright scarcity. Thus, an IEP meeting will likely retain an implicitly adversarial nature. And it will have the character of a negotiation involving not only normative-centred arguments but also strategic behaviour such as horse-trading accompanied by the threat of litigation (Caruso, 2004).

Fourth, and finally, as Anita Silvers has written, IEP meetings may manifest the shortcomings of a compensatory policy that focuses on special services rather than removing artificial and arbitrary obstacles that prevent the flourishing of disabled people. Silvers (1998) distinguishes between the Americans with Disabilities Act, which prescribes reasonable accommodations to grant those with

disabilities equal access, and IDEA, which requires the demonstration of specific "need." She fears that the IDEA construction could preempt self-reliance. By incentivizing demonstrable "need," IDEA defines people with disabilities as regretful, sad, or implicitly inferior, obviously "deserving" of compensatory relief, and students with disabilities are tacitly discouraged from forming the identities that would foster mutual or reciprocal relationships (pp. 133–134. See also Nussbaum, 2006, p. 209). Essentially, IEP meetings may prevent students from developing the capacities for full participatory citizenship to instead increase their bargaining power by demonstrating need (Michael J. Eig, attorney for M. L., personal communication, 22 August 2020).

If procedural reforms, however necessary, cannot fix IEP meetings because they privilege the objectification of medical language and professional norms for the purpose of efficient bargaining, maintain an adversarial or near-adversarial relationship between families and school officials (and, perhaps, given inelasticity and the lack of positive externalities, between different groups of students and parents), and incentivize the showing of "need" by already marginalized students for leverage, what is the role of activism? We argue, based on existing studies, that activism can shift IEP meetings from the problematic bargaining process characteristic of the modern state to a different model of democracy: that form of collective deliberation more common in local communities in which participants learn from one another in shared forms of education. We believe that students and parents can collaboratively provoke this shift by introducing a transformed perspective that is rooted in the acceptance of students for who they are, in the particular lives that they are presently and inescapably living, rather than a set of diagnoses and possibilities, needs, and accommodations. A recent study on facilitated IEP meetings focuses on rules and seating arrangements to facilitate a power balance, but judiciously suggests that the facilitator "place [a] picture of [a] child at the center of the meeting" (Mueller, 2009, p. 66). Our contention is that the full meaning of a picture of a child at the centre of the meeting not only creates a power balance but also may change the character of the meeting itself.

For MacIntyre, the modern state can be distinguished from communities bound up by common goods that can only be enjoyed by participants as members of those communities. For example, he describes crews of workers whose shared deliberation is not only equitable but also communally directed towards mutually recognized forms of excellence that are not externally imposed by managerial expertise but are internal to their practices, whether the making of "excellent" cars or the successful stewardship of a good and lasting farm. As such, MacIntyre contrasts education in which students are initiated into these practices with internal goods and gradually discern an overall directedness in their lives in schools that are shaped by those common goods, and recognized as students *qua* students working alongside teachers, to education in schools in which individuals merely pursue private goods. In MacIntyre's preferred communities, deliberations are meant to constitute and sustain a way of life that is inseparable from the goods obtained through that way of life; in the others, deliberations are only meant to allow individuals to obtain their preferences as much as possible, with schools ideally, if not inevitably, serving as means and not obstacles. Likewise, MacIntyre (2016) contrasts the parents, teachers, children, clergy, and representatives of African American neighbourhoods who argued that some Chicago public schools "served the common goods of the local communities" and sustained the "already fragile bonds of local community" (p. 203), to the administrators of the Chicago Public Schools systems who could not recognize arguments that were not expressed in terms of weighted preferences – here, as forms of financial or political influence. We can distinguish between IEP meetings characteristic of the modern state (and, presumably, the Chicago Public Schools system), and those of a MacIntyrean radical democracy, in which political participation is not managed but occurs as the way to discern common concerns in "messy, robustly cross-traditioned dialogs that nation-states cannot enable" (Newson, 2016, p. 259).

The questions to answer, then: How can parents speak for a student in order to make the disruptive particularity of the student visible? If the student becomes visible through or with parental actions, how might that change the character of the IEP meeting in a way analogous to activism for radical democracy?

Activism and Parents Speaking for Students

As law professor Randy Lee has written about Drew, the child at issue in the recent Supreme Court *Endrew F.* case, it is likely "that Drew's circumstances became so visible while he attended school in the District that those circumstances overshadowed everything else that was Drew" (Lee, 2019, p. 395), so that school officials saw entitlement to merely more than a *de minimis* standard of educational progress and only that. These legally and medically defined "circumstances" overshadowed the person. However, Drew's parents, out of love, removed Drew from public education, paying initially (and indeterminately) out of pocket for a private education, and filed an expensive lawsuit on his behalf – actions that may not fit any utilitarian calculus. While impressive, we do not make an argument that love's intensity or sentimentality itself allows parents to speak for a child in IEP meetings as a form of activism.

The question of when a parent or guardian can speak for a person with disabilities is admittedly a complicated and thorny one. We reject, at least partially, three possible answers. The first suggests that an "expert" voice, however defined, supersedes the reasoning of a person with disabilities; this falls under the critique of medical language and professionalism described above. The second claims that a parent or guardian channels a specific lesson to be taught about disability, which seems, as Silvers (1998) argues, to implicitly place a burden on persons with disabilities to earn their participation through the putative importance of this lesson (p. 38). The third, as Stacey Clifford (2012) insightfully writes, suggests that someone speak alongside the physical presence of a person with disabilities. While this embodied presence remains important to counter the beliefs that spoken language should always be clear, that the person with a disability might be "enfolded into his or her caregiver" (p. 219), and that human beings are normatively independent and self-sufficient, Clifford's view does not suggest how collaborative speech enables the *rational* participation of persons with disabilities in deliberations except by preempting otherwise common misperceptions through the visibility of those with disabilities. We see ourselves as supplementing Clifford's account.

MacIntyre (1999) argues that a proxy can speak for one who is "radically disabled" as a "second self," "in just the way that that particular disabled individual would have done so for her or himself, had she or he still been able to speak" (p. 139). This proxy must "know" the person with disabilities, and their relationship has to be one akin to "friendship" (ibid.). The proxy must know the person with disabilities in more than just one or several social roles, and, through conversation marked by truthfulness, be able to "speak with the other's voice" through knowledge of the "other's conception of our common good" (ibid, p. 150). If, for instance, the proxy is a family doctor, this friendship would be rooted in "a long-term relationship to the patient and the patient's family, a presence at births and deaths," and through sharing in the same "moral point of view." Importantly, the "conception of our common good" held by a person with disabilities or anyone else is not valued in a compensatory way but because it contributes to our shared education. The person with disabilities is not in a fixed or unique (or fetishized) position because we will all likely have to entrust ourselves to care, and we came to be ourselves in the first place under the gaze of a parental figure. In other words, we have been and are all enmeshed in networks of giving and receiving in which the receiving has been – and will in all likelihood again be – primary and asymmetric; the judgements of the "disabled" are neither additive nor optional to "normal" life, but revelatory of what that life really is.

The question is whether parents or guardians are most likely, if not exclusively, able to serve as proxies. And, if so, we can then ask whether their actions recognizably constitute activism. We argue that parents of students with disabilities, like Drew in *Endrew F.*, are most likely to have developed a particular form of attentiveness to the particularity of their children, which lets them speak for them and voice their conceptions of the common good. Our proposal is similar to and different from that of Sue Donaldson and Will Kymlicka, who distinguish between three forms of knowledge that collectively can be used to interpret the behaviour and preferences of those with cognitive disability: expert

knowledge, folk knowledge, and personal knowledge – the latter deriving from a caregiver's "shared history of interaction, social codes and systems for mutual understanding" (Donaldson & Kymlicka, 2016, p. 194), and additionally rightly stress the need for humility. While we share many of their concerns with coercive and restrictive forms of wardship, the difference is that Donaldson and Kymlicka recommend a form of public role for those with cognitive disabilities that is based on their being "responsive" to norms (2017, p. 860) – and, thus, their focus on a caregiver's careful interpretation of behaviour and preferences, instead of rational reflection, whereas we specifically claim that the rational reflections of those with cognitive disabilities can be included *via* "second selves." In other words, Donaldson and Kymlicka may adequately describe how those with disabilities, as well as children and domesticated animals, can be included in deliberations controlled by preferences, such as bargaining, while they do not describe how those with cognitive disabilities may be included in the formation of a common mind with others with whom they share common goods. We suggest that those with disabilities can participate in this second form of shared deliberation through parental attentiveness that has two sources, neither of them exclusive to but more pronounced in the lives of those who care for those with disabilities. However, both are obscured to medical language and professional expertise.

How can parents and guardians serve as proxies for the rational reflection of those with disabilities?

First, MacIntyre draws on the British psychoanalyst D. W. Winnicott to argue that the emergence of a sense of self requires the unconditional love of any "good enough" parent whose protective trustworthiness frees the child to engage in play and develop a sense of "I am" – their own agency and creativity that will eventually allow for participation in society (MacIntyre, 1999, p. 90). The alternative is a damaging inability to distinguish between fantasy and reality, realizing in either wishful thinking or the inability to consider any alternatives at all. While the emergence of a self usually takes place in childhood, this emergence is not necessarily an isolated developmental episode. MacIntyre draws on the history of Winnicott's analysis with an adult woman who says, "It's as though there isn't really a ME," and speaks of "not mattering," but who in therapy is able to finally pose the existence of "ME" from the act of searching for herself, in an act of creativity akin to "rudimentary playing." She is able to do this in "relaxation" during therapy because, as she realizes, "People use God like an analyst – someone to be there while you're playing," to whom one matters (Winnicott, 1971, p. 62ff).

In other words, the parent provides care for *this* child as *the* particular child for whom they are responsible in a way that is unconditional and places the needs of the child as paramount. This distinguishes parents from professionals, even very good teachers, who in certain contexts must practice "ruthless exclusion" (MacIntyre, 1999, p. 89) through grading or promotion. Just as the parent's place may be later (temporarily) taken by a therapist, the parent's own role, and the need for unconditional giving for the child in their particular circumstances, may be extended in time for those with children with disabilities. Nevertheless, the *unconditionality* of the giving means that the life of a parent of a child with disabilities is not abnormal but exemplary and even paradigmatic. MacIntyre's thought shows, subversively, that families without disabilities may even be at a disadvantage in terms of developing the virtues and practical rationality that come with the recognition of interdependence (Fitch, 2009).

Second, while this form of parental self-giving may be broadly similar for those with children with disabilities and those with nondisabled children, the parents of children with disabilities often themselves report that their experience has been *transformational*. As Scorgie writes, parents who receive a child's diagnosis embark on a journey that begins with challenges posed to previous beliefs, such as in the benevolence of the world itself, and continues to adaptations that include the acceptance of the child as they are, with realistic expectations. The reframing further involves the determination to be successful in this life, the discovery of purposes within the events of life, strengthened feelings of competence, and the ability to live with indeterminacy in the here and now. But the root of the transformation is in the acceptance, and the abandonment of the search for either an escape-hatch cure

or desperate bargaining with God: "This is who your child is." As a result, the parents became more "child-focused," and, as Scorgie writes, could see life "not just from their own point of view, but from that of their child" (Scorgie, 1996, pp. 104, 106). One parent would later claim that the reframing allowed her to focus on her daughter "as a person who has her own life and her own needs, you know, very much apart from me" (Scorgie & Wilgosh, 2008, p. 107). The loss of previous images and the creation of new ones allows for focus to be redirected to the significance of the newly visible child in this life and on this day, so that meaning is found here or deferred in hope. In a recent study, the parent of a daughter with Down syndrome describes the transformation of an initial feeling of "loss" into the realization that her child was a "blessing that enabled me to understand the reality of life" (Kausar, Jevne, & Sobsey, 2003, p. 41). The language strikes us as illuminating.

Philosophically, Hans Reinders (2000), whose work is the first disability scholarship that MacIntyre cites, explains the possibility of this transformational outcome. He notes that Thomas Nagel (1986) has described how we can see ourselves from a third-person standpoint that in its detachment causes the questioning of our commitments and may lead to alienation. If this "objective" view is privileged over the "subjective" perspective, it can lead to contemplative impersonality. In any case, the existence of two incommensurable perspectives leads to a division of the self that can only be mended by a "nonegocentric respect for the particular" – "an immediacy of feeling and attention to what is present that doesn't blend well with the complex, forward-looking pursuits of a civilized creature," as Nagel opines (1986, p. 223. See also Reinders, 2000, p. 182). For Nagel (1986), this unlikely and passing "immediacy" requires that particular things "have a noncompetitive completeness," such as when beauty "makes distinctions among points of view irrelevant" (p. 223). Reinders suggests that Nagel fails to see that "immediacy" may proceed from love.

Philosophically, we can add that Nagel (1986) does not grasp that the third-person viewpoint, which he describes as "external" and capable of mounting a "takeover" (p. 188), may itself be noncompetitive. That is, instead of being "abstract" and "over against" the world, it may be an excessive transcendence present within immanence as the movement or orientation towards a yet unrealized *telos* (te Velde, 2009). It may be in taking care of disabled children that parents lose the abstract transcendence of possibility – the "cured" or measurably improved children finally seen as, themselves, "objectively" meaningful by professional expertise – and grasp the excessive transcendence in the language of journeying, attributional rather than goal-oriented success (Scorgie, 1996, p. 152), and hope in place of optimism. Thus, the parents of children with disabilities may rightly see the disabled child as a teacher of a new perspective towards the "objective," third-person perspective and a very new concept of transcendence. "[My child] is my teacher, my mentor, my inspiration," one parent says (Reinders, 2000, p. 186). The reason is not one particular lesson that people with disabilities can teach their parents (or anyone else) – a burden unique to them – but their parents' newfound capacity to render judgements with "unconditional love," no matter the challenges or societal validation, because of a recognition of a transcendent call within the particular (Burrell, 2011. For love as disclosive or revelatory, see Gaeta, 2002, pp. 21–22).

More concretely, we argue that Kittay's *Learning from My Daughter: The Value and Care of Disabled Minds* (2019) shows how a parent with this transformed perspective might communicate the rational reflections of a person with cognitive disabilities, even if Kittay occasionally speaks of love as displacing "rationality and other elements of cognition" (p. *xx*). Kittay recognizes that her daughter, Sesha, has an "ability just to be" (p. 53), a "capacity to be" (p. 122), and an "intensity in enjoyment" of art and in the love of others so pronounced that it "enhances the well-being of others" much more than even intellectual achievements, and in fact the world would be "poorer without her joy" (p. 91). And when Kittay ends with a string of adjectives describing her daughter as a "soul," the penultimate word, before "unique," is "comprehending" (p. 251). In order to grasp this, Kittay, or any other caregiver, needs to have "engrossment" (p. 172) in the person with disabilities, and ascetically to have developed over time a suitably "transparent self" (p. 201), capable of responding to a concrete – and not generalized – other who has been fundamentally and unconditionally her daughter. Sesha's "capacity" and "ability is

described in relation to music – once Raffi and now Bach, Louis Armstrong, and Bob Dylan – and Sesha's enjoyment carries the same teachings as what MacIntyre (2016) had learned in Oscar Wilde, that there are artistic goods that are constitutive for the good life of any human being prior to any conceivable choices and preferences, and that there may be further goods in going from children's music (Raffi, Barney) to a Bach partita. Finally, insofar as the significance is in the capacity "to derive joy from life," which in turn communicates the capacity to "learn the wonder of being," this is a *rational* reflection (Kittay, 2019, p. 251). Presumably, Sesha teaches us that alongside *ratio* – discursive thought – there is *intellectus*, what Josef Pieper calls the capacity of *simplex intuitus*, which is that reality is perceptible through an affirmative yet effortless contemplation of what seems beautiful (Pieper, 2009, p. 28ff. See also Gary, 2006; Warne, 2018; and Jo, 2019. For Pieper and disability, see Watson & O'Keefe, 2014), and shows us [how] to have "soul" beyond whatever instrumental use to which we may be put. Without Kittay's attentiveness to her daughter and ability to speak for her in *Learning from My Daughter*, public deliberations would likely be less attentive to what can be learned about musical goods and *intellectus* from Sesha's joy.

If parents of children with disabilities are able to speak for their children because they, not unlike other parents but only more so, have provided unconditional care for their children and theoretically undergone a transformation in which they have accepted their children and the way that they discern meaning within their particular disabled lives, how does this result in activism? We hold that their articulation of their children's perceptions of the common good, perhaps commingled with their own transformed views, is not merely an enhanced bargaining position that neatly fits within the confines of the IEP and the modern state. Instead, it is likely to be a perspective that emphasizes the dignity and joy within disabled lives as itself a source of meaning that spurs behaviour marked by generosity. One clear sign of this might be the actions of the parents in the *Endrew F.* case, whose motivation, as Lee writes, took a decade, cost over a million dollars in litigation costs, and provided results that, given the slow speed of court cases, Drew could not himself enjoy, and, given the uncertain implementation of even a Supreme Court decision, disabled children may only enjoy incompletely in the foreseeable future. While the actions of those parents attracted the attention of the Supreme Court, other less visible actions by marginalized parents without financial or other resources, which did not attract this level of attention, likely displayed the same generosity.

Conclusion

In this paper, we have argued for a redefinition of activism that would include students with disabilities. We argue that such activism can be found in meetings, such as IEP meetings, that take place within schools, and in interdependence with parents who may even speak as proxies. That activism takes place because such meetings often presuppose the structure of the modern state, which is an arbiter for bargaining among special interests. While the bargaining power of parents may be more or less equalized, the nature of these meetings will privilege medicalized language and professional expertise to facilitate and legitimate bargaining, place parents and school officials in an adversarial relationship, and incentivize the showing of "need" (and, implicitly, inferiority) by disabled students and their families. The place of activism is not merely to change the nature of the bargaining but to challenge the very character of these meetings. We argue that parents' relationship to their children with disabilities may be characterized by unconditionality and a transformed subjectivity that is inclined to emphasize the dignity and meaning in the lives of disabled people *as they are*. This relationship provokes actions that may not be comprehensible to professionals or even the facilitators of a bargaining practice. This relationship also challenges the categories into which we place students with disabilities, whether they are medical categories or visions of wonder and sentimentality. As such, parents, with their children with disabilities, may effectively challenge our understanding of the common good.

With MacIntyre (1991), we reject communitarianism and "see no value in community as such," because a narrow community may lack an adequately shared conception of human good (MacIntyre, 2007, p. xiv). We also do not mean to suggest that there is a tension, productive or otherwise, between bureaucratic procedures and the family as a proverbial haven in an otherwise heartless world (Lasch, 1995). As MacIntyre (1999) illustrates, the family needs to exist in a larger ecosystem that makes sense of its unconditionality and transformed outlook. He notes the Lakota expression "wancantognaka," which expresses a sense of familial and tribal responsibility that is characterized by, *inter alia*, "ceremonial acts of uncalculated giving, ceremonies of thanksgiving, or remembrance, and of the conferring of honor" (p. 120). (However, we acknowledge that MacIntyre could describe relationships outside the family in more detail [Dunne, 2020].) Writing theologically, Reinders (2008) discussed a similar source for "uncalculated giving," in the sense of envisioning one's relationships to others as responses to an indebtedness to a primordial and asymmetric graciousness, calling one to see those relationships as gifts to be given again with something of the same generosity. This is likely the rational and public significance of Sesha's joy in simply being. In admiration of Baynton's work, we argue that student activism is everywhere in history, once we begin looking for it. It is in those societal resources for beneficence that are often lost, but, we argue, remain visible in the lives of those with disabilities and their caretakers, in litigation and other forms of resistance which will tend to be interruptive of our otherwise impoverished conceptions of the common good, trapped as they are by the interpretive gaze of nondisabled onlookers.

Acknowledgments

We extend tremendous gratitude to Ashley Taylor and Kevin McDonough for their thoughtful guidance and insight. We would also like to thank Campbell Scribner, Virginia Byrne, and Erin Hogan for their time, generosity, and support.

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