

## **“Although Not Intentional, Some Children May Fall Through the Cracks”**

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### Revisiting the Role of Capital in Disability Advocacy Motherhood and Inclusive Education

*In the current moment, mothers of disabled children are often expected to be their children's full-time advocate. This is particularly true with respect to the educational system: Even where policy acknowledges students' right to accessible and inclusive instruction, in practical terms, funding shortages and resistance from educational professionals often necessitates parental involvement in order to ensure that disabled children's needs are accommodated and their rights respected. In the overwhelming majority of these situations, this advocacy work becomes the mother's responsibility. This paper is a revisitation of Samantha Walsh and Elisabeth Harrison's chapter "If I Had A Normal Job I Couldn't Do This": Exploring The Economics of Disability Advocacy Motherhood and Inclusive Education" that was published in the anthology Maternal Pedagogies: In and Outside the Classroom. The authors draw from Pierre Bourdieu's theories of capital in order to explore the roles of economic, social and cultural capital in mothers' advocacy on behalf of their children with disabilities in the educational system. The paper is grounded in Harrison and Walsh's lived experiences of disability as a social and cultural experience as they reflect on the advocacy work that their own mothers did in negotiating access to education for themselves and their siblings. The authors highlight the inaccessibility of the mother/advocate role to those who lack cultural, social and economic capital, and discuss ways that alternative structures of advocacy can be created, along with opportunities for coalition building in advocacy for inclusive education.*

We are both disabled women whose siblings also have disabilities: Elisabeth Harrison has a psychiatric diagnosis, and one of her sisters has a learning disability. Samantha Walsh has cerebral palsy, as does her twin sister. We are both disability scholars, and are also good friends. We met in a graduate

disability studies course, and from the beginning of our friendship, when we shared stories with each other about our families, we would often remark upon our mothers' very similar personalities and interests. During our conversations about our experiences at school and how we had eventually become graduate students, we noted that we and our siblings were academically successful in spite of the significant barriers to access to education that our disabilities had posed for us. We found that both of our mothers had extensively advocated on behalf of their children within the educational system, and had used very similar strategies in doing so. Our remarkable academic success, along with our mothers' notable similarity and their coincidental employment of virtually identical techniques aimed at facilitating our inclusion made us wonder what factors had made our mothers' advocacy strategies so effective, and what might happen to disabled students without advocates like ours. To explore this issue, we decided to write a paper about our mothers' advocacy work.

This paper is a further meditation on a chapter entitled "If I Had a Normal Job, I Couldn't Do This': Exploring the Economics of Disability Advocacy Motherhood and Inclusive Education" that was published in the anthology *Maternal Pedagogies: In and Outside the Classroom* (Demeter Press, 2011). In this revisitation, we seek to interrogate the roles of gender, class and race privilege in advocate mothers' navigation of the educational system on behalf of their disabled children. We draw from Pierre Bourdieu's theories of economic, social and cultural capital in order to reflect upon the ways in which mothers' ability to perform advocacy on behalf of their children is dependent upon their access to capital, in concert with the relative status of their children (as some children are more amenable than others to acquiring capital themselves via processes of normalisation). Our work is grounded in our experiences as disabled children of advocate mothers, and in our more recent roles as disability scholars theorising about the structural factors that have allowed us to come to occupy these roles. The paper is also animated by the continuing dialogue between ourselves and our mothers and combines our reflections on our experiences with our mothers' advocacy work with a discussion of academic research on this topic. We endeavour to explore both a broader spectrum of research, and to locate our mothers' experiences in the wider context of diversely-situated mothers' advocacy on behalf of their children.

### **What Enables Advocacy?**

When Elisabeth asked her mother, Valerie, what had enabled her to successfully advocate on behalf of Elisabeth and her sister in seeking accommodations for them in the educational system, Valerie said, "If I had a normal job, I couldn't do this."

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In the self-published book she wrote about raising children with disabilities, Samantha’s mother, Karen, warns parents that because the educational system is not equipped to accommodate disabled students, “although not intentional, some children may fall through the cracks if they don’t have an outside adult advocating for them” (Stephenson 54). She tells parents of disabled children to use “every ounce of [their] energy” and “do everything in [their] power” to help their children grow up to become successful, independent adults (Stephenson 8).

Although we are deeply grateful for the work our mothers have done on our behalf, we recognise that most mothers do have “normal jobs,” and no mother has boundless energy. Reflecting upon our mothers’ advocacy stories, we came to realise that the things our mothers did for us are not “in the power” of every mother. As the contrast between our mothers’ stories and those of other disabled children’s advocate mothers shows, successful advocacy appears not to be a matter of commitment, but is instead determined by mothers’ and children’s relationship to capital.

### **Economic Capital and Advocacy Motherhood**

Access to capital in its various forms<sup>1</sup> affords opportunities to be heard and recognised. Economic capital gave Karen and Valerie the chance to change their working lives so as to better enable them to function as advocates for their children. When Samantha and her sister (Karen’s daughters) began kindergarten in Toronto in 1987, they were initially permitted to attend their local elementary school, but Karen was told that after that year, her children would be sent to a segregated school for disabled students. In response, Karen and her husband moved their family to Waterloo, Ontario, where Samantha and her sister would be able to attend a mainstream school. Karen gave up her work as a law clerk and bookkeeper in order to become a full-time advocate for her daughters. Karen’s husband was able to get a new job, and his income supported the family.

Valerie’s eldest daughter (Elisabeth’s older sister) also entered kindergarten in 1987, in Brockville, Ontario, and immediately began to experience severe difficulty with her schoolwork. Valerie thought that her daughter might have a learning disability, and because she and her husband ran their own advertising business, Valerie was able to take extensive time away from her work to provide her daughter with extra help, and to schedule meetings with school officials to demand that her daughter be given an assessment by an educational psychologist from the school board. After her daughter was diagnosed with a learning disability, Valerie was in constant contact with the school, helping to plan and participate in her daughter’s Individual Education Plan.

Valerie also took time away from her role in the business to support Elisabeth

when she was in high school and was diagnosed with depression, and later with schizophrenia.<sup>2</sup> As a result of her periods of hospitalisation and the medication side effects she experienced, Elisabeth was unable to attend class regularly, carry a full course load or meet deadlines. Again, Valerie spent hours that she would otherwise have devoted to her business to attend meetings with teachers and administrative staff, and Elisabeth was eventually granted accommodations.

Because Elisabeth and her sister are “able-bodied,” most extracurricular and community activities were open to them, and they participated in many, all with little involvement from their Valerie. In contrast, because Samantha and her sister are physically disabled, Karen’s work for inclusion extended into the community. She led Girl Guides groups and chaired church functions not only to establish and maintain support networks, but also to ensure that her daughters would be “allowed” to participate in school and community activities that typically exclude physically disabled students. Like Karen, many mothers of disabled children have to work to negotiate access across virtually all domains with which their children have contact: As Patricia McKeever and Karen-Lee Miller write, “Most mothers sought access, sometimes unsuccessfully, to health and social services, medical travel allowances, entry to ‘regular’ schools, and social opportunities with nondisabled children” (1188).

Samantha and her sister often participated in sports, as Karen was able to use her financial resources to involve her daughters in accessible sports programs. On one occasion, Samantha was able to go on skiing with her seventh grade class, not because as a student in the class she would obviously attend but, because she was already taking adapted skiing lessons. Karen arranged for the instructor to come with the class and bring Samantha’s skis. Had Samantha’s family been unable to afford private adapted skiing lessons, or if Karen did not have the negotiation skills to facilitate instructors and equipment for the trip, the trip would not have been accessible. Indeed, other disabled students in the class were not included in the excursion.

The work that Karen and Valerie did to support our inclusion was difficult, and, particularly in Karen’s case, represented an enormous sacrifice. Karen gave up her challenging and rewarding career, left her community and friends, and became heavily involved in organisations and activities in which she would not have otherwise been interested in order to facilitate her daughters’ participation and inclusion. Changes like the ones Karen made are common among mothers of disabled children, many of whom “made their children the center of their lives, redefined their priorities, made personal sacrifices and altered their lifestyle to accommodate this new role” (Nelson 525). This sacrifice is often emotionally and psychologically difficult, as mothers who give up their employment typically have poorer mental health than those who remain employed (Home, “Work” 37).

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Karen’s decision to leave the workforce is also not unusual. Mothers of disabled children often leave paid employment so they can provide their children with care and support (Brandon 668; Francis 172; Home, “All Bad” 10; Leiter et al. 383; Nelson 525). That noted, the career sacrifices made by Karen were enabled by her husband’s employment, and would be absolutely impossible for many women. “Good women” are expected to exhibit qualities of nurturance and dependence, “so long as that dependency is evidenced through a relationship with a male,” rather than on the state, as women who are dependent on social assistance are regarded as failures, rather than as fulfilling a socially valuable role (Malacrida 470).<sup>3</sup>

Many lower-income women with disabled children have no choice but to remain in the paid workforce (Leiter et al. 398). Mothers of disabled children who do not leave the workforce experience severe reductions in the amount of time available to them for leisure and personal care (Green 155), as mothers of disabled children typically perform childcare tasks for an additional five and a half hours each workday compared with mothers of non-disabled children (Brandon 673). Mothers are usually the primary caregivers of disabled children, and they generally receive very little assistance from others, even their male partners (Brandon 672-676; Francis 53; You and McGraw 592-593). For women who are not able to leave the workforce or reduce their working hours, the strain can be extreme (Home, “Work” 43): One mother of a child identified as having ADHD who worked a shift between 4:00 am and 2:30 pm in order to have time to help her child after school reports, “It would be nice to shave my legs and stuff once in a while.... Like I say, I truly felt, not a joke, that my life was being sucked away” (88). The same mother explains that she felt guilty and as though she had “neglected” her other child, and eventually developed insomnia due to stress (Cronin 88).

Another mother of a child identified as having ADHD points out that the expectation that all mothers have an enormous amount of time to spend providing extra help to their children is not realistic:

[The teacher’s] attitude is that you’re just a lousy mom if you can’t spend 2 or 3 hours a night with your child working on this specific thing. That’s not real, and it’s a real barrier block. They’re not up to date on what the life is like for parents out there.... (Cronin 87)

## **The Roles of Social and Cultural Capital in Educational Advocacy**

Social<sup>4</sup> and cultural capital enabled Karen and Valerie to get help from others and to be recognised and understood in their efforts to obtain access for their daughters. Both women employed the social and professional skills they learned

in business to set up and participate in meetings, and to run committees. Karen was also able to get assistance from a network of powerful and privileged people. Thanks to her former work as a law clerk, many of Karen's friends and professional contacts were lawyers, and were often willing to place calls to the school on behalf of Karen's daughters when services were denied to them. As Bourdieu writes,

The volume of the social capital possessed by a given agent depends on the size of the network of connections he can effectively mobilize and on the volume of the capital (economic, cultural and symbolic) possessed in his own right by each of those to whom he is connected ("Forms" 51).

Bourdieu's theory explains that the educational system requires those who participate in it to already have cultural capital in order to access its benefits, which include the acquisition of cultural capital in its institutionalised form via the conferral of credentials ("Forms" 51). People who have cultural capital have been brought up since birth to have "linguistic and cultural competence" (Bourdieu, "Cultural" 58; Sullivan 894), with their way of communicating, language use, taste, and appearance all shaped in accordance with the norms of the dominant social class' culture (Dumais 44, 46). Coming from a middle class background, being white in white-majority contexts, having been born in Canada and speaking English as their first language are all factors that gave Karen and Valerie cultural capital, allowing them to feel comfortable challenging inequities in the educational system, and enabling them to speak with school representatives in ways that would make them understood.

Being understood necessitates the use of sophisticated strategies of self-presentation. In her book, Karen exhorts parents to be assertive, but not aggressive in their dealings with authority figures (Stephenson 54), while the literature on mothers' disability advocacy shows that many mothers have adopted strategies of acquiescing to normative gender roles, appearing "compliant" and "passive" while dealing with medical and social services so as to avoid antagonising the professionals charged with their children's care (McKeever and Miller 1189). Valerie explains that she used her social identity as a businesswoman and a university graduate whose husband had been a university professor<sup>5</sup> prior to going into business to "develop a certain camaraderie—the idea that 'I'm one of you'" with highly-educated teachers and school officials. Valerie also used her own physical appearance to underscore the legitimacy of her claims, saying,

The medium is the message. Part of it is the way you look, the way you act, it's the whole package. I was dressed a certain way. It's totally

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ridiculous on one hand, but the message is “I’m a professional, I’m well turned-out,” these are visual cues that I cannot be fooled around with. I’m not going to lie down, and they’re not even going to attempt to talk down to me or feel like they can get away with dismissing my concerns—because that’s not going to happen.

Parents who lack cultural capital often have very limited access to opportunities to advocate for their children in school: In schools with predominantly white administrations, institutionalised racism limits the ability of racialised parents to intervene with teachers and administrators on behalf of their children (Battle; Lareau and Horvat 44-45), and parents from working-class or poor backgrounds face similar exclusion (Lareau and Horvat 46). Mothers of disabled children who are themselves disabled may also encounter difficulty in facilitating access for their children: Disabled mothers live in poverty at high rates, encounter enormous stigma and generally receive very little support from the community (Malacrida). Claudia Malacrida recounts the story of a mother named Shirley who lives on disability social assistance payments because she has learning disabilities and is hard of hearing. When Shirley’s daughter was identified by her school as also having learning disabilities, rather than working with Shirley to support her daughter, authorities from the school initiated contact with Child Welfare and provided the agency with school records in which staff claimed that Shirley was an unfit mother. As a result of this action, Shirley lost custody of her daughter (481-482).

### **Normalisation and the Transmission of Capital**

Karen and Valerie did not only seek to advance our inclusion by utilising their own economic, social and cultural capital, but also to invest us with our own cultural capital. As Bourdieu writes,

The initial accumulation of cultural capital, the precondition for the fast, easy accumulation of every kind of useful cultural capital, starts at the outset, without delay, without wasted time, only for the offspring of families endowed with strong cultural capital; in this case, the accumulation period covers the whole period of socialization. (“Forms” 49)

We were brought up with the tastes, interests, appearance, and ways of interacting and communicating typical of the middle class, but in order for this cultural capital to be useful to us and enable us to retain our class position, we needed to be recognised as normal, middle class girls. Thus, many of our mothers’ efforts were directed toward achieving our normalisation. Many mothers of



disabled children strive to achieve their normalisation, valuing their children most when they are able to “look like the other kids” (Nelson 527). A mother in McKeever and Miller’s study remarked that her “profoundly disabled” son was more respected and accepted by other children when he used a walker that made him stand upright (1185). Karen makes a similar point in her book when she writes about Samantha and her sister’s decision to use wheelchairs rather than crutches or walkers:

They walk but it is an awkward walk, certainly not “normal.” It is my opinion that my girls are better able to cope because of their wheelchairs. They appear more “normal.” The ability to keep up with the rest of society is vital to survival. (Stephenson 30)

### **Normalisation and the Denigration and Denial of Disability**

For Karen, her daughters’ use of wheelchairs is beneficial to them not only because it enables them to go from place to place, but also because it helps them to look more “normal,” and therefore “less disabled” than they would if they were to use their “awkward walk.” Using wheelchairs, Samantha and her sister look the same as able-bodied people do when they sit. As she advocated for Samantha and her sister in the educational system, Karen employed arguments which sought to erase or marginalise disability. For example, Samantha remembers that Karen often said that her daughters were “smart, it’s just their legs that don’t work,” and that otherwise, Samantha and her sister were “just like everyone else.”

Such assertions accommodate and perpetuate, rather than seek to eliminate, mainstream society’s discomfort with disability and disabled people (Michalko 148-50). Karen regularly claimed that her daughters were “not really *that* disabled.” This implies that her children’s value is dependent upon *not* belonging to a particular oppressed group (Michalko 20-21). By asserting repeatedly that Samantha and her sister were “smart” and/or “not really *that* disabled,” Karen implied that disability is something manageable only inasmuch as it can be cast as an incidental aspect of identity. This constructs the worth of children understood as “not smart” or “really disabled” as relatively limited. Karen’s advocacy, while effective, relied on her performance and endorsement of valued social norms as well as her daughters’ normalisation. The premise became not that disability and disabled people deserve to be acknowledged, valued and respected, but rather that Samantha and her sister deserved to be valued and respected because disability was only a minimal part of their identity. In their case, their mother’s demonstrations of privilege as exercised through social and cultural capital excused the appearance of disability.



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Because Elisabeth’s disability was “invisible,” Valerie had to seek recognition that her daughter required and deserved accommodation. To do this, she explained Elisabeth’s diagnosis of schizophrenia to school staff as being a “medical condition” being treated with pharmacological interventions in order to make them understand that it was legitimate. Constructing psychiatric diagnoses as “real” things, often taking the form of an analogy between them and diseases such as cancer or diabetes seems to be motivated by the notion that people who have those physical diseases are often regarded with compassion,<sup>6</sup> whereas many people considered mentally ill are regarded negatively. Constructing Elisabeth’s disability as analogous to non-stigmatised medical conditions allowed her to access the accommodations she needed while eluding the stigma associated with mental illness.

At the same time as she claimed Elisabeth’s disability was real, Valerie also worked to minimise its importance, telling school staff that Elisabeth was “sick, but still the same person underneath.” Valerie mentioned that she appealed to teachers’ memories of Elisabeth having been a good student prior to her diagnosis in order to convince them that she deserved the accommodations she needed. When Elisabeth asked Valerie about this, Valerie said, “I told them, you were still really smart, but you had a medical problem, and the medication you were taking had a lot of side effects, so you just needed some extra help until you got better.” While this strategy was effective, it also negated any possibility of recognising “mental illness” as socially constructed (Porter 9; Kutchins and Kirk 23), or as a space of neutral or even positive difference (White and Denborough), as many mad or antipsychiatry activists and theorists argue it is. Valerie claimed that Elisabeth’s diagnosis was real, but it was not an important aspect of her identity or experience. Instead, it was simply a medical problem that was being treated and would hopefully “disappear” in that it could be improved enough to restore her to her previous level of functioning.

### **Appearance and Normalisation**

Our mothers’ efforts at enabling us to develop social capital often focussed on managing our physical appearance. Many mothers strive to “normalise” their disabled children by ensuring that they dress in colourful, fashionable clothing: The mother of one poor family explained that she would only buy new clothing for one family member, her disabled daughter (McKeever and Miller 1187).

Although Elisabeth was impaired by the side-effects of the medication she was taking, Valerie encouraged her to act, as much as possible, as though she were still her “normal” self and nothing was really wrong. While Elisabeth often felt too tired to shower, style her hair or put on makeup, Valerie worked to ensure that she maintained as close to a normal appearance as possible. She

carefully monitored Elisabeth's hygiene and dress in order to maintain her image as an ordinary teenage girl. Valerie also kept a close watch over Elisabeth's diet and activity levels so that she would not gain the weight that is often a result of treatment with "antipsychotic" medication (Martin et al.).

Valerie believed that it was important for Elisabeth to "keep up appearances" so that she would be seen as a normal individual, and not be associated with the negative image of people considered mentally ill. The knowledge that the majority of people have about mental illness comes from mass media representations (Wahl 3), most of which depict people regarded as mentally ill as "recognizably different from others in both manner and appearance, [standing] out as deviant and bizarre" (Wahl 36). Further, many studies have shown that in mass media, people identified as mentally ill are characterised as frightening and dangerously violent (Anderson; Blood and Holland; Cassey; Cross; Cutcliffe and Hannigan; Dietrich et al.; Nairn; Olstead; Wahl), and even sometimes as sub-human (Glasgow Media Group; *Selling Murder*, Wahl 36-55). As Valerie was aware of these stereotypes, this informed her efforts at enhancing the normalcy of Elisabeth's appearance and behaviour, but it did not lead her to challenge their basis.

Internalising the emphasis placed on maintaining the appearance of "normalcy," Samantha strove to be normative in her performance of social roles: she managed her weight and appearance, was careful in her choice of friends, worked hard to be academically successful, and took on a number of valued roles both in school and within extracurricular activities. She even sought to avoid others with disabilities unless they were also performing some kind of normalisation of their disability.

### **Cultural Capital and Disability Outside of "Normalcy"**

The objective of the intensive and involved approach to parenting undertaken by middle class parents is to transmit the skills, knowledge and values that will enable their children to remain members of the middle class during adulthood. In large part, such efforts are effective, as social mobility is fairly rare (Francis 3-4); however, class privilege is not always transmitted to children with disabilities (Francis 3). While outcomes are generally better for children with advocates, and whose families have capital, cultural capital does not accrue to all children. Children who are regarded as "really disabled" remain devalued, regarded as unworthy of receiving assistance or resources (McKeever and Miller 1186-1187): When disability is more "severe," other attributes that are valued cannot compensate for it.

Mothers' own status and their work on behalf of their "really disabled" children are often devalued, due to "[b]eliefs that children with severe disabilities

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will remain socially ‘unproductive and burdensome’” (McKeever and Miller 1182). One mother of a boy with severe cerebral palsy explains, “You know, it was even said to me by my mother-in-law at one point ... that I should just let [child] go because he wasn’t worth the investment in my time. He was never, he was never gonna pay off” (McKeever and Miller 1182). Research with South Korean mothers of children diagnosed with autism suggests that in some contexts, mothers’ own value is judged in accordance with the success of their child, and as autistic children are less likely than non-autistic children to attain “success” as measured by normative standards, their mothers’ status is also diminished (You and McGraw 591).

Additionally, regardless of the efforts they make on their children’s behalf, mothers are sometimes blamed for “causing” their children’s disabilities (McKeever and Miller 1182; Nelson 525; You and McGraw 587), and mothers of children whose disabilities lead them to behave in “socially inappropriate” ways are often blamed for their children’s “misbehaviour” (Cronin 87; You and McGraw 587).

### **Normalisation and the Medical and Social Models of Disability**

Mothers are blamed for causing their children’s disabilities because having disabled children is typically regarded as negative, and therefore as blameworthy: The medical model of disability is currently dominant, and it conceptualises disability in negative terms, as caused by individual deficit, lack, or dysfunction. The social model of disability was developed in opposition to the medical model, by British disability activists and scholars (including Paul Hunt of UPIAS, and Michael Oliver). It posits that disability is more than an individual embodied experience by drawing a distinction between impairment and disability. An impairment is a physical “defect” (such as a missing limb, or an organ that does not function correctly), and disability is caused by social organisation that excludes people with impairments (for example, the normative expectation that everyone can walk leads to the creation of built environments that do not accommodate those whose impairments necessitate the use of a wheelchair) (UPIAS 14). Thus, the social model of disability understands disability as produced by the interaction between individuals with impairments and the social and physical environments with which they interact.

The social model of disability has emphasised the experiences of people with physical disabilities, and has been criticised as paying inadequate attention to the situation of people identified as having problems with mental health (Nabbali), but the model’s location of problems in social relations rather than within the individual is clearly useful for people identified as having mental health problems. First, it attends to the fact that disabling environments and

conditions—and not individual characteristics—produce disability. This renders the different ways of thinking, feeling and behaving that are sometimes associated with “mental illness” as not inherently problematic, revealing their construction as negative as produced by a fundamentally intolerant society oriented toward the creation of “productive” subjects who function well in accordance with the dictates of the neoliberal economic system that is currently dominant (Kramer). Disability studies and critical psychology scholars have shown that the medical model of disability is harmful in that it depoliticises situations rooted in power relations by locating them not in culture, society or economics, but in physiological processes taking place inside individual bodies (Cosgrove and Riddle 128-9; LaFrance and Stoppard 308).

Because our mothers’ understanding of disability was shaped by the cultural dominance of the medical model, their interventions with us sought to produce individual change within our bodies. Valerie accepted the idea that Elisabeth’s emotional and social difficulties were caused by a brain disorder, and was supportive of the psychiatric treatment that Elisabeth received. Her compliance with the dominant understanding of mental health as an individual medical problem positioned her as a rational and responsible advocate. Similarly, Karen exhausted the available medical interventions and surgeries aimed at normalising Samantha’s body before ultimately using her financial resources to purchase adaptive equipment (such as wheelchairs and adapted sports equipment) and seek out opportunities to participate in normative activities of childhood in order to produce a “functionally normal” experience for Samantha.

### **Access to Education and Equity**

Economic, social and cultural capital enabled Samantha and her sister to participate in many of the aspects of school life that ordinarily excluded disabled students. Rather than highlighting the inequities in the school system or the taken for granted positioning of disability as a deficit, Karen worked to ensure that her daughters would be understood as separate from disability (or, at worst, as overcoming disability). Erasing disability allowed Karen and Valerie’s daughters to move through the school system without making any changes to the system itself, and it perpetuated the individualistic narrative that the onus is on disabled people and their family members to fill the gaps that society does not (Griffith and Smith 129).

Neither Karen nor Valerie sought alliances with the parents of other disabled children, much less with disability rights groups. The idea that their children were generally “normal,” having only an incidental relationship to the devalued status of disability made this pointless. Access, for Karen and Valerie, was simply a matter of ensuring that their children were recognised as able, intelligent

girls. It did not occur to them that other parents may not be able to marshal capital effectively in making a claim to legitimacy on behalf of their children, and that capital may not accrue to certain children. Valerie regards access as an individual matter, telling Elisabeth that when it comes to disabled children’s education, “If parents don’t get involved, the kid will pay the price.”

We argue that disabled children’s access to education is not determined by mothers’ efforts at involvement, but by relations of capital. Those who lack capital will have limited access to the educational system. We know that in its current form, the educational system is a primary means of legitimising the oppressive norms of society (Nicholson 73-9). We can understand how this process occurs when we think about the contrast between our and our mothers’ stories, and those of the mothers and children who did not have access to capital. Our mothers’ efforts to gain inclusion for us were extremely successful—we graduated high school, then completed undergraduate and masters’ degrees, and are now Ph.D. students; however, it is imperative that we recognise that their individual efforts on our behalf took place within a context of structural inequality, where access to economic, cultural and social capital is shaped by classism, racism, sexism and ableism.

Access to education should not be determined by access to capital. Mothers should not have to reshape their identities, experience immense time pressure, and sacrifice their personal and professional interests in order to attempt to secure access to education for their disabled children. Children whose disabilities are regarded as more “severe” should be recognised and valued. To this end, policy changes must be undertaken to support and value the work of mothering, to encourage participation by fathers and other family members, and to “deprivatise” care work by providing adequate external support to disabled children, both in and outside the educational system.

We propose that an alternative to individual activism can be found in coalition-building. This would create a means to bridge activist movements, as well as an opportunity to incorporate and link individuals with communities seeking social change. Further, it would reveal systemic histories of oppression, establish a critical mass of support, and create links between marginalised groups. It is far easier to exhaust and silence a single individual than a group. Moreover, when disability issues are linked with other social justice issues through the creation of coalitions between equity-seeking groups, people in power might be better able to understand that a large faction of the community is invested in equity. This may help create a climate in which the rights of disabled students—along with students who are disadvantaged as a result of other forms of oppression—cannot be ignored. This type of collaborative work may also afford opportunities to foster connections between parent advocates of disabled children and the broader disability activism community, which could assist

in improving some of the problematic aspects of parent advocacy work, such as the tendency toward individualism and the over-valorisation of normalcy.

It is imperative, in all of these areas of action and inquiry, that we imagine beyond the level of the individual and address systemic inequities. It is only when marginalisation is understood as a manifestation of social organisation and not as a hallmark of individual deficit that lasting and effective social change can be created. This will support both disabled children and their mothers in achieving equity and moving away from the margins.

<sup>1</sup>The relationship of the forms of capital to the concept of class is as follows: Bourdieu understands class as resulting from the “hereditary transmission” (Bourdieu, “Cultural” 57) of status via the conferral from one generation to the next of capital in all of its forms (Weininger 122, 124). He regards the family and the educational system as the two social institutions that are primarily responsible for the inculcation of cultural capital (Weininger 126), and therefore of the knowledge and norms that function as a means of maintaining the social hierarchy (Bourdieu, “Forms” 47). Mothers’ performance of “supplementary educational and related work” (Griffith and Smith 24) in the home creates disparities not only between individual students’ performance outcomes, but also broader disparities between schools and communities (Griffith and Smith 24, 117-122). Mothers who are middle-class tend to carry out the “shadow work” of developing their children’s “school-readiness” by performing educational tasks prior to their children’s school entry, and by supplementing their school-aged children’s education (Griffith and Smith 117-118, Lareau 74). In contrast, poor and working class mothers are less likely to undertake these tasks, and their children’s education is regarded as suffering as a result (Griffith and Smith 68-69, 104-106). In the increasingly neoliberal political and social context, schooling has increasingly become understood as an individual family responsibility (Griffith and Smith 129), so this tendency has allowed for the retrenchment of public educational services and has therefore exacerbated the class-stratifying tendencies of education.

<sup>2</sup>When she was in Grade 10, Elisabeth was being bullied by her peers, and was experiencing feelings of anxiety and sadness. She was prescribed antidepressant medication, but rather than feeling an improvement in her mood, she began to exhibit “psychosis-like” symptoms and was diagnosed with schizophrenia. The symptoms Elisabeth experienced would later be recognised as a fairly common side-effect of antidepressant use in children, but that information was not available at the time of her diagnosis.

<sup>3</sup>The recent American election campaign provided a good example of this phenomenon: As some commentators pointed out, the Republican party’s

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campaign glorified Presidential candidate Mitt Romney’s wife Ann’s status as a nurturing, traditional “stay-at-home mom.” At the same time, the campaign vilified “welfare mothers,” women who do not happen to have wealthy husbands and are dependent on the state as a result of being excluded from the workforce due to barriers to employment including the extremely high cost of childcare. By way of demonstrating their “respect” for mothers, the Republican campaign promised to reduce or even eliminate the government benefit programs that enable many women to prevent themselves and their families from starving.

<sup>4</sup>The terminology of “social capital” has been employed to describe a variety of sociological phenomena. For instance, Robert D. Putnam defines social capital as “features of social organization such as networks, norms, and social trust that facilitate coordination and cooperation for mutual benefit” (67). In his work, Putnam emphasises the importance of civic engagement and social bonds as means of developing social capital and thereby creating a foundation for the good function of society as a whole. In our discussion, we draw specifically from Bourdieu’s usage of “social capital,” which he defines as the resources that can be marshalled by an *individual* by virtue of their being connected to others, or through “membership in a group” (“Forms” 51). This can take place through direct interpersonal connection or through association with an institution conferring social capital via the granting of credentials (“Forms” 51).

<sup>5</sup>Valerie’s reference to her husband’s professional status is significant here, as Bourdieu explains that women’s use of cultural capital is sometimes directed toward acquiring husbands, whose own use of cultural capital tends toward to focus on fostering a career (*Distinction* 105). Thus, the fact that Valerie was married to the father of her children gave her social capital in the context of dealing with Catholic school administrators, and his claims to cultural capital further enhanced her status.

<sup>6</sup>The effectiveness of this as a rhetorical strategy may be decreasing in the contemporary context, where moral panic over the “obesity epidemic” is leading to the stigmatisation of people diagnosed with type 2 diabetes, and there is a growing focus on the “lifestyle factors” associated with cancer risk. These trends reveal the increasing dominance of the understanding of health as an individual concern, rather than as produced by social relations.

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