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Janet Story Sauer  
*Lesley University*

Priya Lalvani  
*Montclair State University, lalvanip@montclair.edu*

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# From Advocacy to Activism: Families, Communities, and Collective Change

Janet Story Sauer\* and Priya Lalvani†

\*Lesley University, Cambridge, MA, US; and †Montclair State University, Montclair, New Jersey, US

## Abstract

Although countries across the globe support the United Nations Convention on the Rights of Persons with Disabilities (2006), when faced with competing economic priorities, their policies and practices too often negatively impact children with disabilities and their families (Ferguson, 2008). Current social and educational structures are implicated in inequitable services, particularly for those families from nondominant languages and minority racial and ethnic groups (McCall & Skrtic, 2009; Ong-Dean, 2009). Recognizing the importance of contexts and power imbalances, we posit that the broader communities in which families live and that determine the opportunities they are afforded, should be explicitly addressed when evaluating a family's quality of life. This article provides an analysis of family quality of life in the context of parents' struggle to access equitable education for their children with disabilities, and suggests that the Quality of Life (QoL) conceptual framework (Brown, Schalock, & Brown, 2009), having already expanded to include the *individual* to the *family* unit, be further extended to engage the *community*. To illustrate, we describe two community-based projects aimed at moving family involvement in special education away from a model of individual advocacy, situated within western ethnocentric organizational structures that rely on sociocultural capital, to grassroots collective activism.

**Keywords:** disability studies, family quality of life, intellectual disability, parents of children with disabilities, special education

## Introduction

Individuals with disabilities continue to face discrimination, violence, and seclusion (Human Rights Watch, 2010). Current literature from across the globe acknowledges the negative social influence on and long-term outcomes for people with physical and/or cognitive impairments and suggests policies need to be more effective in supporting people with disabilities as valued members of society (Ajuwon, 2012; Bjarnason, 2008; Ferguson, 2008; Sharma & Deppeler, 2005; Smith, 2009; World Health Organization, 2014). Concerns over troubling unemployment and health statistics and inequitable education for children with disabilities have led to policies guided by the Salamanca Statement (1994) and the United Nations Convention on the Rights of People with Disabilities (2006). Researchers have developed theoretical frameworks to guide such policy development and evaluation of practices that aim to improve the outcomes of people with disabilities. The Quality of Life (QoL) conceptual framework (Brown et al., 2009) serves as a useful guide for evaluating features of a person's quality of life across a variety of domains. Notably, the concept of Quality of Life has shown to have a positive relationship with the Articles of the UN Convention (Verdugo, Navas, Gomez, & Schalock, 2012). As professors of

preservice educators whose work is invested in educational equity and who are committed to making change in our respective local communities, we especially value and recognize the importance of cultural context that led to the more recent expansion of the QoL concept to include the family unit resulting in the Family Quality of Life (FQOL) framework (Brown et al., 2009).

Our understanding of cultural context has also been informed by our personal experiences as parents of children with intellectual disabilities. Shortly after my first child was born in a small town in Middle America, when I (Janet) and my husband found ourselves seated across from a physician who asked us if we knew what Down syndrome meant, we wondered what *he* thought it meant. Was he familiar with (and possibly an unwitting participant in) the oppressive practices and attitudes that our child would likely face? He was certainly quick to suggest we meet with a genetics counselor to discourage us from having a second child. Shortly thereafter a team of professionals talked with us about early intervention and specialized services to “fix” our infant son offered at a segregated program thirty miles away. Like many families of children with disabilities, we began years of conversations with people who had negative assumptions about our son's future and we became increasingly concerned about what seemed too often like a disconnect between our family's vision of what was meant by a quality of life and what we continue to see as a limited and often misguided view of our son (Sauer, 2007, 2013). Similarly, I (Priya), a South Asian professor in New Jersey, and also a mother of a child with Down syndrome, am alarmed at the extent to which my husband and I have, over the

Received October 30, 2015; accepted November 8, 2016  
Correspondence: Janet Story Sauer, Lesley University, College of Liberal Arts and Sciences, Cambridge, Massachusetts, United States. Tel: 617-349-8702; E-mail: jsauer2@lesley.edu

past fourteen years, needed to rely upon the cultural capital available to us when attempting to access our daughter's right to an equitable education, and the extent to which the cultural and institutional discourses which we encountered are steeped in negative assumptions about disability.

While our experiences are in many ways unique, we share not only a resistance to dominant discourses on disability that center on tragedy and deficit, but also a commitment to questioning such negative assumptions and the underlying societal structures that contribute to them. Our personal and professional lives have taught us about the complicated interaction between individuals with disabilities, families, and the larger community. Our separate community projects involving culturally and linguistically diverse families with children with disabilities provide examples of the power imbalances that develop within institutional structures. These community-based projects have led us to posit that in order to improve individuals' quality of life, we need to mobilize families to collective activism. In this article, we propose the fQoL conceptual framework (Brown et al., 2009) that moved from focusing on the *individual* to the *family* be further extended to explicitly include the *community*. This conceptual paper provides a critical analysis of families' quality of life in the context of many parents' struggle to access equitable education for their children with disabilities (Wang et al., 2004). We hope our analysis contributes to this discussion about FQOL with the shared goal of improving the quality of life for children with disabilities and their families around the world. We utilize related research from the interdisciplinary field of Disability Studies about families, education, and civil rights in our analysis to explain our position.

### Responding to the Call: Exploring New Grounds

The Convention on the Rights of People with Disabilities was passed by the United Nations General Assembly in December 2006, and as of January, 2017 included 160 state signatories. It claimed to take

to a new height the movement from viewing persons with disabilities as 'objects' of charity, medical treatment and social protection towards viewing persons with disabilities as 'subjects' with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society (United Nations, 2017).

We aim to contribute to this movement as professionals and parents who acknowledge our positions of relative power. While we are admittedly not QoL researchers per se, we are committed to improving the quality of life for people with disabilities all over the world and we are hopeful that the QoL indicators will indeed lead us toward a more humanistic, "action-oriented change agent in the field" (Claes, Hove, Loon, Vandeveldel, & Schallock, 2010, p. 61).

In their chapter, *Enhancing quality of life of families of children and youth with disabilities in the United States* (Turnbull et al.,

2004) FQOL researchers at the Beach Center on disability at the University of Kansas explain the interaction between sociopolitical and disability-specific trends and their influences on families. They note the co-occurrence of poverty, single-parent families, cultural/linguistic/ethnic diversity, and disability at a time when expectations for the role of the government in family lives changed emphasis from federal to state responsibility. They also describe an increased focus on civil rights citing the Americans with Disabilities Act of 1990 and individual rights to a free and appropriate public education guaranteed under the Individuals with Disabilities Education Act (IDEA). Finally, they illustrate an emerging change of paradigm at that time "from 'fixing' the individual and the family to 'fixing' the social, and physical environments" (IDEA, 2004, p. 59). This shift in emphasis is of particular interest to us.

The Beach Center developed an extensive long-term research program based on a "family centered model and on an equalization of the power relationship between families and professionals" (Turnbull et al., 2004, p. 65) that intended to advance families' quality of life. Their "theory of change" involved families as participatory action researchers in their effort to develop tools to measure fQOL outcomes. As part of this process they identified nearly 20 core concepts of disability policy and several interpersonal partnership domains and indicators which informed their FQOL Scale for Families.

Over a decade has passed since this shift from the individual to the sociopolitical context was described and "horizontal organization" with integrated services for education, human and social services, and health care has since evolved in certain geopolitical places. However, we continue to live under service-delivery models based on "discrete laws and funding streams [that] have sought to address narrowly targeted problems" (Turnbull et al., 2004, p. 61), and we are concerned about the slow pace in which changes in practices occur. So we appreciate this opportunity to respond to the call to explore new grounds for the FQOL concept. Central tenets in the IDEA (i.e., family involvement and transition planning being based on students' dreams, interests, and strengths) do not appear to be occurring for one-third to one-half of American students with disabilities and their families (Shogren & Plotner, 2012, p. 27). Outside of the United States, in spite of focused efforts to promote the UN Convention on the Rights of Persons with Disabilities by involving young people from developing countries, young people continue to make troubling assertions about the lack of opportunities they and other youth with disabilities face (Quigley, Kamara, Gangadhar, Paybeyee, & Chandralal, 2009). Large scale studies of FQOL echo this issue. For example, Meral, Cavkaytar, Turnbull, and Wang (2013) found Turkish families of children with ID and autism have similarly moderate perceptions of satisfaction as Chinese and Spanish/Catalan families, all of which are lower than samples from the United States. Therefore, it is of utmost urgency that we work collectively toward transformational change both at the international policy level as well as in our local community contexts.

Our contribution to the discussion about exploring new grounds is to suggest local community-based activism is necessary to improve the quality of life for people with disabilities and their families. To make our point we first describe institutional ableism from a Disability Studies theoretical framework and how

this relates to a family's quality of life in general terms. Then we describe new models for family engagement based on our two different community projects. Finally, we discuss how the FQOL conceptual framework could be extended to explicitly include *community* in a way that involves collective activism so that it might inform related evaluation tools and policies that lead to more immediate and formidable transformational improvement for people with disabilities of all ages across the globe.

### Institutionalized Ableism and Family Quality of Life

A special double issue featuring global family narratives using a Disability Studies perspective illustrated the intersectionality of disability (Sauer & Ferguson, 2013). Disability Studies scholar Mark Sherry explains "disability is always a sexed, gendered, racialized, ethnicized, and classed experience [that] operates within a framework of multilayered and complex patterns of inequity and identities" (as cited in Sauer & Ferguson, 2013, p. 6). Within the issue there was a study about immigrant mothers seeking to understand the "algorithms of access" to special education and support services in the United States, in which Wilgus, Valle, and Ware (2013) explain:

Whereas *racism* was acknowledged as a significant issue to address in the implementation of equal rights for African Americans, it is worth noting that no comparable acknowledgement was made in regard to *ableism* as a significant issue to address "free and appropriate public education" for children with disabilities. (p. 80)

Disability Studies theorists explain that institutional ableism involves the systematic discriminatory practices against people with disabilities. The special education system in the United States has been argued to exemplify institutional ableism (see Beratan, 2006; Connor & Ferri, 2007).

Students with disabilities continue to be marginalized in American schools in spite of our being one of the more progressive and affluent nations. Educational discourses and practices reveal troubling situations in which special education remains entrenched in an ideology of *separate but equal* and in notions of the otherness of students with disabilities. Deficit-based perspectives on disability coupled with dominant narratives about families of children with disabilities as dysfunctional and needing "expert" guidance, frame institutional discourses, and perhaps nowhere is this more apparent than in the context of special education. Additionally, despite monumental changes in disability rights, and the treatment of individuals with disabilities during the past few decades, perceptions of a poor quality of life among families of children with disabilities have persisted (Lalvani, 2015a). In special education discourses, not only do children need "fixing," but also their parents (Valle, 2009). There exist many (negative) assumptions about parents who reject recommendations for the evaluation of their children for special education services, those who resist certain labels to their children, or those who "fight" the system to gain access to an inclusive education for their children with intellectual and developmental disabilities. These parents' decisions, and their parenting in general,

are often viewed as suspect or dismissed as the result of parents being in denial about their children's disabilities. Indeed, in educational discourses, a wide range of responses among parents are unquestioningly attributed by professionals to their being "in denial," particularly when they involve parents' refusal to acquiesce to professionals' judgements or recommendations (for a full discussion, see Lalvani, 2015a). Additionally, many teachers believe that parents of children with disabilities lead more burdened lives than parents in general, have a lower quality of life, and that they are likely to make irrational and poor choices about their children's education (Lalvani, 2015b).

Valle (2009) points out that negotiations between parents and professionals take place against the context of broader discourses and discursive practices of schools and societies. Although, in many cases, parents' efforts to seek an equitable education for their own children undoubtedly yields positive results for some, it is this very engagement of individuals in advocacy for their own children with which we are concerned, and which needs to be problematized. For one, it might be unreasonable to expect that all parents would be willing and equipped to be effective advocates in the context of their children's schooling; contesting professionals' judgments requires a certain amount of cultural and economic capital which may not be available to all parents, particularly culturally and linguistically diverse (CLD) parents or those from lower income backgrounds (Ong-Dean, 2009). As Mueller, Draper, and Singer (2008) point out, although procedural safeguards in special education are in place, for many families this places an immense financial and emotional strain, and further stresses the professional-family relationship. Parents who are engaged advocates and who file for due process or mediation are more likely to have greater household incomes (Burke & Goldman, 2015). Overall, although expectations of parent advocacy place an unfair burden of vigilance on *all* families, individual advocacy reifies social hierarchies and further serves to sort children based on socioeconomic factors, while leaving institutional barriers to equitable education largely unexamined.

Thus, in the context of special educational discourses rooted in ableist notions of disability as deficit, as well as a system in which benefits are accrued by parents who routinely draw upon their cultural capital in order to access their children's educational rights, some relevant questions and concerns arise: How can we engage in meaningful discussions about quality of life among families of children with disabilities and the professionals who seek to work with them/us? And, can we engage in these conversations while acknowledging whose perspectives have hitherto been privileged, and whose voices have been relatively silent? We suggest the context and underlying sociocultural organizational structures need to be overtly addressed through local community activism if an individual and/or family quality of life is to be discussed or evaluated.

Overall, the conceptual frameworks which guide QoL research acknowledge that quality of life is a social construct subjective in nature (Schalock, 2004; Schippers, 2010). This is consistent with a Disability Studies framework which emphasizes disability in context; in contrast to medical model paradigms about health and disability as embodied in individuals' bodies and minds, disability studies scholarship posits that the

experience of disability is linked with access, inclusion, and acceptance in society (Connor & Gabel, 2013; Linton, 1998).

In this article, we argue that, if QoL is an interaction between personal and environmental factors (Schippers, 2010), then any discussion about QoL of families of children with disabilities should include an examination of sociopolitical and institutional climates. Specifically, consistent with the assertion of Claes et al. (2010) that QoL measures should take into account interpersonal relationships, rights and social inclusion, we contend that QoL for families of children with disabilities needs to be examined in the context of institutional discourses and practices which continue to marginalize students with disabilities in schools, and which lend sanction to a segregated system of education for many students with disabilities based on implicit ideologies of *separate but equal* and notions about children with disabilities as “other.”

### Which Way Forward? New Models for Family Engagement

Mueller et al. (2008) highlight the value of making systemic changes rather than dealing with problems one at a time. It is imperative that we move toward new models of kinship involvement that account for the inequities resulting from individual advocacy, and alternatively are situated at a grassroots level and aimed at systemic change. In the United States and elsewhere, there is a long tradition of family and grassroots activism in the history of the education of students with disabilities (Winzer, 2009); indeed, the sweeping changes in educational laws pertaining to children with disabilities in the latter half of the 20th century were, in part, a result of the relentless efforts of family members who were among those who lobbied and organized for radical change at local, state and national levels.

As with researchers who examine organizational structures in international contexts (Bjarnason, 2008; Ferguson, 2008; see also Sauer & Ferguson, 2013) we have experienced both personal and localized power imbalances (Sauer & Albanesi, 2013; Lalvani & Hale, 2015). Troubling discourses that refer to families as “complicated cases” as mine (Janet’s) was recently referred to by the school district, and barriers to collaboration where requests to bring peers into the transition planning meeting or requests for language interpreters were denied (Rossetti, Sauer, & Bui, in press), are illustrative of the issue. Beth Harry, who also shares our experiences as mothers of a child with disabilities as well as researchers focusing on CLD families, finds deficit views of CLD families and cross-cultural misunderstandings persist (Harry, 2002, 2008). She recommends a fundamental shift to address these barriers and suggests professional “preparation and practice in the actual communication process” with CLD families is needed along with developing critical perspectives. Harry’s work and the research of others (Kalyanpur, Harry, & Skrtic, 2000; Olivos, Gallagher, & Aguilar, 2010) who analyze discriminatory and ableist organizational structures informed each of our present family engagement projects. In this section, we describe two locally based projects as examples for how families might become engaged in community activism for systemic change. While one of these projects is underway (Janet’s), the other project (Priya’s) has only recently been designed and is in its planning stage, that is, it has yet to be implemented. We describe these two projects

as examples of community-based responses to the problematic current state of affairs for children with disabilities and their families; as such, these two projects are resonant of the spirit of grassroots activism in which this group of families has historically engaged, and focuses on collective change, which can benefit all children (Lalvani & Sauer 2015). Grassroots activism refers to a method of campaigning for change, engaged in by members of a community. Grassroots activists do not hold institutional or political power; rather they represent a group of allies, often at the bottom of the political pyramid, who are committed to making social changes with regard to a particular issue (Crystal, 2016). These models are based in an understanding that in order for families to engage in collective advocacy toward radical change, they first need to (1) gain a conceptual understanding of the socioculturally constructed nature of disability labels and educational practices; (2) position inclusive education as a practice related to democracy, equitable societies, and social justice; (3) recognize and name ableist ideology at work in institutional policies and everyday practices that make connections between social justice and the need to confront all forms of segregation; and (4) have opportunities for engagement in transformative dialogues which empower families to act. While each of us have “skin in the game” so to speak, in which our daily lives are directly influenced by the current organizational structures within our own sociocultural and geographical spaces, we have independently and separately from one another begun family empowerment and action groups. We discuss these separately, below.

### Priya’s Project

The Parent Empowerment and Action project, which I describe here, emerged conceptually as a response to some of the aforementioned issues, and is a locally based, grassroots effort in its initial stages of planning in the North New Jersey area; its current status is that families who will engage in the project have been identified and a structural framework has been developed, however, it has not yet been implemented. During a meeting with a local advocacy group of parents of children with disabilities the objectives and structure of the proposed project was presented, and family members who were interested in becoming involved signed up. Again, the project discussed here is not a research study and data is *not* currently being collected. Rather, I discuss the goals, structure, and design of this project as an illustration of the kinds of grassroots work for which we make an argument in this article.

The proposed project aims to create forums that bring together diverse families invested in moving toward a collective model for effecting systemic institutional changes. Through guided discussions, members will be invited to problematize individual advocacy and to examine the educational inequalities which it ultimately perpetuates. The eventual goal is that, through participation in the project, small groups working together will identify specific issues or practices that present barriers to equitable education for students with disabilities and will receive support and training to work toward effecting changes within their local school districts.

Theoretically, such a project is grounded in a Disability Studies framework, which seeks to retract its gaze from the deficits of

individuals with disabilities and focus instead on institutional structures and practices which marginalize many students with disabilities (Linton, 1998). As such, it orients parents and kin to evaluate information about special education through a conceptual understanding of the constructed nature of disability labels and indeed, of “knowledge” itself. Furthermore it is based in conceptualizations of inclusive education as a fundamental right and as a practice inextricably linked with social justice and democratic societies (Slee, 2011).

The project is expected to be carried out in three phases, which I describe below.

### Phase I

In this initial phase, the aim is to create a space for diverse families to engage in sustained dialogue on issues related to disability, educational equity, and the role of kin in the education of students with disabilities. Additionally, members will be introduced to a conceptual understanding of disability through a disability studies lens; they will engage in guided discussions related to the constructed nature of disability labels and the ways in which educational discourses and practices are sociopolitically situated. Specific issues will be examined, such as the practice of ability-based grouping in schools and its consequent segregation of many students with disabilities, as well as the intersections of this practice with issues of race and socioeconomic privilege. Through these discussions, members will gain a conceptual understanding of relevant issues in the education of students with disabilities, particularly as they relate to educational equity and diversity in a democratic society.

### Phase II

In this phase, members will receive information pertaining to navigating the special education system, and to understanding IDEA laws and their children’s educational rights. The information gained in this phase will be connected to the conceptual framework developed in Phase I; members will evaluate information about special education laws by connecting it to a conceptual framework of inclusive school practices from a social justice perspective as well as an understanding of school inclusion as a vehicle for broad social change. Members will be provided with language/tools to understand, evaluate, or question special education practices through the lens of ableism in society, with the intention that they should be equipped to recognize/disrupt institutional discourses and practices which marginalize students with disabilities; as such, they are invited to consider whether spaces can be considered “inclusive” if some are denied access to it.

Additionally, during this phase, critical questions will be raised about parent advocacy, and members will be encouraged to reflect on personal complicity in reifying inequitable outcomes for students in schools through their engagement in advocacy for the needs of their own children, using the capital they have available to them. Through guided discussion, members will be encouraged to consider that individual advocacy, on the part of those who have the greatest cultural capital is yet another mechanism through which segregation of schools through a special education system in which there is a disproportionate

representation of children of Color or from lower socioeconomic status groups in segregated classrooms operates (Ong-Dean, 2009). They will then engage in guided dialogue about alternative ways of engagement with schools, toward a redefined goal of making broad changes, the benefits of which are accrued by all children.

### Phase III

This final phase of the project is aimed at empowering parents to view themselves as agents of change and to support them in developing initiatives for structural change in their community schools. Toward this end, members will gain an understanding of the value of collective activism; they will consider, for example, that if we are to advocate for access to inclusive education for our own children, perhaps it is worth addressing the obstacles to inclusivity at their own schools/district, and in this, we need to invite and engage all families. As such, they will be invited to consider that organizing to effect broader change will benefit not only their own children but the community as well.

Finally, working in smaller groups (generally based on local residency or the school that their children attend), members will identify specific goals with regard to effecting changes at their own local school district as well as any barriers in working toward those goals. They will be supported to develop a strategic plan for an action project within their local communities, with the ultimate aim of removing barriers to the full participation and achievement of children with disabilities in inclusive classrooms. Families will have opportunities to meet periodically to discuss progress on their action project and are supported to strategize further or to respond to obstacles they might encounter. Thus, the Family Empowerment and Action initiative is based on a conceptual understanding of collective change as shared responsibility. It is hoped that, through their participation, members learn to recognize ableist ideologies in institutional policies and everyday school practices and to be agentic in seeking positive change for *all* students with disabilities. By explicitly drawing attention to the problematic aspects of advocating for children on an individual basis, and by providing information and support for groups of parents to identify broader objectives for change at the institutional level, this project represents a way in which families can use collective voices and collective activism to benefit a wider range of students. For example, we might work with a school to create a support network for parents of newly classified children to join with parents of “typically developing” children to discuss educational rights within inclusive systems that have shared or collective benefit.

It should be stressed here, that our discussions of new models of parent engagement are *not* intended to be a critique of parents who advocate; indeed we concur with Ong-Dean’s (2009) assertions that within a system where parents of children with disabilities are able to influence the services their children receive, one cannot reasonably expect that parents who are able to advocate for their children will not. Thus, rather than critiquing individual choices made by parents, the alternative approach we propose is intended to bring community members together to work at a local level for systemic change.

## Janet's Project

Janet's project is also multifaceted, involving collaborative work with Cultural Outreach Brokers from the local Parent Training Institute (Federation of Children with Special Needs) and another Institute of Higher Education (Boston University). While working with preservice professionals who are studying to become general and special education teachers, counselors, and therapists, I found my students needed greater opportunities to learn from families, particularly those from CLD backgrounds who have children with disabilities. I recognized my students' lack of understanding of the complexities of family dynamics and the impact of institutional ableism was largely a result of a lack of opportunity, so I set out to cocreate a collection of miniportrait narratives based on local individual family experiences for use in preservice and in-service professional development.

Using portraiture research methodology (Gaztambide-Fernandez, Cairns, Kawashima, Menna, & VanderDussen, 2011; Lawrence-Lightfoot, 2005) in preservice training programs, I hope to disrupt the traditional imbalance of power between the privileges often afforded an academic research/professor and his/her students, and the families of Color in my community. In addition to reading related scholarship about issues such as the over-representation of minorities in segregated special education placements (e.g., see Hehir, Grindal, & Eidelman, 2012), each semester the university students I teach are provided with opportunities to engage with CLD families at community events in their neighborhoods. Additionally, the CLD families come to the university campus to share their local knowledge and experiences and the university students use their notes to write up short portrait narratives in which they try to demonstrate cultural humility (Tervalon & Murray-Garcia, 1998). These miniportraits are then shared with the families for feedback and critique to inform the University faculty about (in)accuracies, as well as the degree to which or the nature of what they think the students heard.

Thus far we have drafted a few of the cocreated portraits (Bui, Rossetti, Sauer, & Van Loan, 2014). They include a two-year-old son of Chinese immigrants who has gone in and out of early intervention services for communication and developmental delays, a 14-year-old African American daughter of a single mother who was labeled with Down syndrome and autism, a 12-year-old Vietnamese girl whose mother immigrated with her as a toddler in order to acquire support services for her after she was diagnosed with Kabuki syndrome and autism, and a 17-year-old son of East Asian Indian Americans who was diagnosed with autism. The following themes emerged: portraiture as pedagogy can be effective in changing attitudes of preservice professionals toward CLD families; preservice teachers learned to see the whole child and to see disability as difference, not deficit; and the mothers modeled high expectations and dedicated advocacy. Creating a counternarrative that raises awareness among the involved participants, therefore, represents an important tool of discourse that can be used to reframe the interactions between families and professionals (e.g., IFSP/IEP meetings, staffings). These cocreated portrait narratives provide families with a voice (Ferguson, Hanreddy, & Ferguson, 2013) that challenge the prevailing norms, and can therefore play an invaluable part in redefining what and who is valued and why with local, immediate, actionable responses.

I am currently working with the families to revise the portrait narratives for use in developing new curriculum for use with subsequent classes as well as with in-service trainings of local professionals. A related study surveying CLD families and holding focus groups of Chinese and Vietnamese families served in Massachusetts has taken place (Rossetti, Sauer, & Bui, 2015), and at the time of this writing our community is organizing focus groups with Arabic speaking Muslims and Haitians.

During one of the meetings to discuss the project involving Cultural Outreach Brokers and university students, one of our most outspoken advocates from the local Southeast Asian community repeatedly asked how we might get their stories out to the Department of Education and to legislators in order to effect policy change. Like us, this cultural outreach broker has personal "skin in the game" as a parent, and as a professional engaged with helping increasing numbers of families who advocate individually in a case by case manner. Thus, as a result of our collaborative work we are rethinking our approach. We have begun to seek tools to activate political and social change on a systematic level while acknowledging the complexity of the child, the family unit, the local geopolitical, and sociocultural contexts.

## Discussion

Our respective projects working in local communities with CLD families have implications for understanding and enhancing the quality of life for children and youth with disabilities and their families. This critical analysis is useful in informing the discussion of FQOL. Our projects are conceptually informed by a body of literature in Disability Studies highlighting how families of children with disabilities resist dominant narratives about the quality of their lives and are framed within an understanding that any attempt to understand the experiences of any group of individuals should originate from the subjective perspectives of those individuals. As such, our work responds to the challenge made by Turnbull and colleagues (2004) in their international book on FQOL "to critically assess innovations, lest they—and our research and knowledge—become fossilized" (p. 92). The families with whom we work have challenged our thinking about how we might be inadvertently contributing to an inequitable system in which cultural capital and its privileges have developed an inequitable system in which culturally and linguistically diverse families are further marginalized by their status as having children with disabilities. We are engaging in self-critical analysis, like all reflective practitioners need to do (K. H. Smith, 2010). As privileged parents ourselves who are professors in education and who conduct research about CLD families for our own livelihood, we are questioning current practices in which we work to inform families about ways to advocate for their individual children, and instead work together as allies toward creating systemic change. We think the FQOL principles (Claes et al., 2010) and evaluation scales (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006) will be useful in advancing our work and the work of other scholars interested in moving the quality of life framework (Brown et al., 2009) from individual family advocacy to collective community activism.

We hope our projects and this article will be useful in informing future QoL developments. We also think that incorporating

discussions about FQOL principles within our communities could “shed more light on the dynamics of families and how resources contribute to family interactions” (Hoffman et al., 2006, p. 1080). Our projects will provide real life local examples of immigrant families with children with disabilities that have the potential to inform state, federal, and international policy that determines services based on increased accountability. When hearing daily stories of the challenges the CLD families face in trying to carve out time and money to advocate for their children under current policy-informed practices we have come to realize that the way to create transformative change is through collective activism at the community level.

Our critical analysis of family service systems reveals ableist notions that discriminate against those with disabilities and perpetuate inequitable practices. Therefore, we have proposed in this article that family involvement, particularly as practiced in special education, needs to move from a model of individual advocacy to grassroots collective activism. These two projects are examples of community-based responses to the problematic current state of affairs for children with disabilities and their families; as such, these two projects are resonant of the spirit of grassroots activism in which this group of families has historically engaged, and focuses on collective change, which can benefit all children (Lalvani & Sauer, 2015). Our work with different CLD families along with our personal experiences suggest that the QoL concept that Brown et al. (2009) described as needing to change from a focus on *individuals* with disabilities to their *families*, needs to further expand to include a focus on the *community* context in which families live.

The statistics reported from various health and welfare organizations, while better than they were two decades ago, are still troubling enough to warrant a much stronger worldwide movement than we have yet to see. The disability rights movement has been able to change some aspects of the material world with greater access for some to gainful employment and certain health care, but it needs a more rapid response and agenda than what we have witnessed so far. We hope our local community-based projects provide useful models for those invested in improving the quality of life for people with disabilities across the globe through collective activism.

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