Entangled ethnography: Imagining a future for young adults with learning disabilities

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ABSTRACT

Our article draws on one aspect of our multi-sited long-term ethnographic research in New York City on cultural innovation and Learning Disabilities (LD). We focus on our efforts to help create two innovative transition programs that also became sites for our study when we discovered that young adults with disabilities were too often “transitioning to nowhere” as they left high school. Because of our stakes in this process as parents of children with learning disabilities as well as anthropologists, we have come to think of our method as entangled ethnography, bringing the insights of both insider and outsider perspectives into productive dialog, tailoring a longstanding approach in critical anthropology to research demedicalizing the experience of disability.

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Introduction

Our article is a reflection on our experience as anthropologists studying the world of learning disabilities (LD), a social category that first grabbed our attention when each of our children received this diagnosis (Rapp & Ginsburg, 2001). Our initiation as parents entering the disability world, territory previously unknown to us, provided strong motivation to undertake research into the “LD universe”, a place that is marked by both medicalized stigma, as well as cultural innovation. As a result, since 2007, we have been researching Cultural Innovation and Learning Disabilities1 using longstanding ethnographic methods: participant observation fieldwork, long-form qualitative interviews, life histories, and analysis of media and secondary documents. A reflexive approach enabled us to study and theorize our own experiences as parents along with those of our research subjects; we all were navigating the complex medical and educational bureaucracies that shape the world of “special education”. We quickly recognized how we, along with the families we were studying, were all subject to “the paradox of recognition” (Rapp & Ginsburg, 2011a); while we all were dependent on the recognition of medical diagnoses to access entitlements for our children, many paradoxically struggled to demedicalize their children’s identity, in order to situate them in a more holistic and communitarian context. Additionally, we often found ourselves productively caught up in the projects we were studying, at times taking an active role in enabling the very activities we were examining. We think of this process as ethnographic entanglement, part of a long tradition of engaged research in anthropology.

Some have argued that since its Boasian foundations, Americanist anthropology has played a doubled role, producing both ethnographic knowledge as well as cultural critique of embedded prejudices in the United States (Baker, 2010; Marcus & Fischer, 1999). By the early 1970s, an era of decolonization and increasing consciousness of the politics of research and its representation provoked a call for “reinventing anthropology” and a recognition for the potential of our work to either damage or support those with whom we worked (Hymes, 1972). In the same decade, feminist anthropologists pushed this approach further by insisting on a reflexive recognition of the positionality of the researcher and her stakes in the issues under investigation (Reiter, 1975; Rosaldo & Lamphere, 1974). These shifts, both epistemological and methodological, continue to generate lively debates about the insider/outside identity of the anthropologist, and the balancing act of participant/observation as a method, underscoring the significance of reflexivity in the field. Moreover, as an inductive approach, the qualitative and dialogical nature of fieldwork allows for a continuous re-evaluation of the implications of the insights that we encounter as participants, observers and educators.

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1 As one of the reviewers for this essay remarked: “One could argue that ethnographers at all stages have been “entangled” in consequential ways that could not help but shape the research in ways both enabling and constraining...ethnographers often, if not always, do have some kind of “stakes” (if less directly personal) in the processes they study. Indeed, unveiling such hidden “stakes” is the main point of decades of critiques of anthropology.” We concur, and thank this anonymous reviewer for pushing us to clarify what characterizes this particular kind of “entangled ethnography.”

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American anthropologists recently have coined the term “engaged anthropology” (both emerging and differentiating itself from legacies of applied, action, and advocacy projects) to capture a sense of the recent expansion of research that encompasses everything from collaboration to activism (e.g. Low and Mertey 2016; cf. Rapp & Ginsburg, 2001). We see our work as on a continuum with this intellectual history, in which the researcher has stakes in the process being documented, and may even play a role in determining the outcome of circumstances that emerge serendipitously. We add to the emerging vocabulary of engagement another term: “entangled ethnography”. In this language, we hope to capture the particularly complex and distinctive ways in which we are caught up as both researchers and parents. While we identify as kin responsible for the existential inclusion of our own and other children in a world that too frequently draws categorical boundaries that segregate those with disabilities, we ourselves are not (yet) disabled. We seek to express the vertiginous sense we had of being ethnographically entangled, simultaneously inside and outside the world we are studying through ties of kinship and caretaking. Often our research subjects have recognized us as allies because of our shared situation as parents of children with LD. Additionally, they and we recognized that we had resources to offer in support of their culture-changing work. Consequently, we found ourselves not only researching innovative projects but also, in some cases, helping to mobilize them in order to enlarge the practical and existential universe available to young adults with cognitive disabilities in New York City. Thus, we have been implicated deeply from the outset in both observing and helping mobilize a range of activist ventures on behalf of young people with LD. In short, while many anthropologists are “entangled” with their subjects, we offer this term to highlight the distinctive features of studying disability when it is “in the family”. The cases we present below fortunately have positive outcomes; we recognize, of course, that entanglements can also go awry or be misappropriated to the detriment of the goals of both researchers and their subjects.

In this article, we focus on the ways in which we became entangled in both creating and analyzing certain projects that emerged as we came to understand the dilemmas of living with disabilities over the life course more clearly. The predicaments faced by our interlocutors were ours as well; all our children were approaching the end of their school years with no clear horizon in sight. As a consequence, the question of their transition became of pressing concern; fortunately, our research presented us with opportunities for creative intervention. We seized the opportunity to join those we were studying as activist cultural innovators, collaborating in building models for — as well as studying — the process of creating a possible future for young adults with LD. This is what we have come to understand and name “entangled ethnography.”

In this article, we focus on two cases of “future-building” that propelled our research in new and entangled directions. Methodologically, both involved close participant observation and reflection on what are called “transition projects” for young adults with learning disabilities who had finished high school and were struggling — along with their families — to find a path to adulthood that could incorporate their differences. We had not anticipated the significance of this life stage and thus had not included the study of transition as part of our initial research plan. However like many of the families we were studying, we were dismayed by the lack of “road maps” out of high school for young adults with disabilities who didn’t fit the predictable American life course model. We realized that we were not alone in wondering how new pathways might evolve to address this problem. We soon became allies — and ethnographically entangled — with the very people we were studying in building culturally innovative transition programs in New York City.

Methods and research strategies

Initially, we began our research studying how families with younger children who have cognitive differences (known as LD) juggled diagnoses, services, placements, and stigma, gradually developing both advocacy skills and new understandings of familial life, sometimes turning to media as a form of self-representation and possible activism. We interviewed over fifty parents of children with learning disabilities across all five of NYC’s boroughs, incorporating a broad range of research subjects, crossing socioeconomic and cultural/ethnic and religious backgrounds. Whatever their differences, all families had a child with an Individualized Education Plan (IEP), the school-district issued legal document negotiated with teachers, parents, and relevant others that serves as a “passport” to the specific services to which a student with a diagnosed disability is entitled, “the cornerstone of a quality education for a child with disabilities” (Rapp & Ginsburg, 2011) (Khan, 2012). Our sample was recruited via internet support groups for parents of children in special education in the NYC public schools, as well as through snowball sampling that crossed into the private school sector. We stayed in touch with families as they passed through both the life course and the educational system while balancing the demands of complex diagnoses over the course of their children’s school careers.

In addition to families, our fieldwork was conducted with teachers and advocates who were introducing a variety of cultural innovations into special education. For example, in the summer of 2007, we carried out participant observation in a new program that trained special education teachers in an innovative curriculum introduced to the NYC public schools to support the integration of cognitive diversity in their classrooms. We also interviewed thirty advocates for special education, ranging from school principals and teachers, to lawyers to public health professionals. Additionally, we have spent over four years attending laboratory meetings of pediatric neuroscientists studying the brains of atypical children, as well as a multi-disciplinary epigenetic psychiatric team examining inter-generational transmission of cognitive problems. We also have worked with cultural activists in the arts, participating in and observing the development of an annual disabilities film festival in New York City from its inception in 2007, following the efforts and impact of several specific activist disability film projects, and a family run music foundation for people with disabilities of all ages. And, we became actively involved in establishing the aforementioned transition programs discussed more fully in the two case studies below.

The legacy of disability rights

Overall, our fieldwork investigated the quotidian effects of the legal legacies of disability activism in the U.S. Two key pieces of legislation laid the groundwork for the contemporary social landscape shaping the lives of young people with LD. In 1970, Congress passed the Children with Specific Learning Disabilities Act, a part of the Education of the Handicapped Act of 1970 (PL 91-230). In 1975, a broader frame was established with The Education for All Handicapped Children Act (PL 94-142) mandating a free, appropriate public education for all students. In 1990, this law was expanded and renamed the Individuals with Disabilities Act (IDEA), and has since been multiply reauthorized. That same year, the trailblazing civil rights legislation, the Americans with Disabilities Act (ADA) also passed Congress, prohibiting discrimination against people with disabilities in all public activities including employment, housing, transportation and telecommunications, thus extending legal protections beyond the school years. These innovations were the foundation for a critical paradigm shift in
American life, mandating inclusion of all citizens with disabilities, however imperfectly that ideal was carried out. Written into this legislation and the practices that soon became central to educational bureaucracies is the necessity that all children receiving services have a qualifying diagnosis based on medical understandings of children’s typical development and deviations from that standard.

As special education rapidly expanded in the American school system, its application was highly differentiated across lines of inequality shaped by racial, ethnic, class, linguistic and gender divides (Wrightslaw.com). From the vantage point of the early 21st century, the category of LD has become far more widespread and is now part of common social discourse. Now, over 15% of school age children in the US are marked for Special Education, and LD has become the fastest growing classification within IDEA’s fourteen diagnostic categories, doubling in each decade and accounting for almost half of all special education diagnoses. These diagnostic bureaucratic categories require unpacking for their slippery-slope Foucauldian effects; children are often moved from being labeled as having mental retardation (MR) to having LD to having Autism Spectrum Disorder (ASD) over the course of their lifetimes, an issue we have discussed elsewhere (Rapp & Ginsburg, 2011).

**Transitioning to nowhere?**

Despite the sometimes glacial pace of progress toward fulfilling the promise of a society more inclusive of disability, we discovered and documented substantial cultural innovation. The “newness” of the many projects we were encountering was dramatically apparent as we often entered office where the pain was still wet and boxes not yet unpacked. Other social facts constantly reminded us that change comes slowly and unevenly. For example, we interviewed and learned of the concerns of visionary educators who were carrying out their work in NYC where dismal high school graduation rates for students with disabilities remain stubbornly low, hovering at around 25%. Statistics are revelatory but they need the contextual amplification that ethnography can contribute as we seek to understand what might transform special education in particular and the inclusion of those with disabilities more generally.

The question of inclusion does not stop when students age out of high school, exiting the schoolhouse door, a process commonly called “transition.” Under the IDEA reauthorized in 2004, the plan for schooling for any child with an Individualized Education Plan (IEP) must include “person-centered” transition services for the child by age 16, reflecting the student’s interests, preferences, accomplishments and skills, as well as what they need to learn, and what they want to do in order to help them forge a new pathway to life afterwards. Whatever the legal requirements for transition, the reality in NYC where we are conducting our research is grim: a 2011 study by the ARISE Coalition, entitled Out of School and Unprepared: The Need to Improve Support for Students with Disabilities Transitioning to Adulthood confirms earlier findings documenting “pervasive failures of the NYC DOE to plan for and provide transition services to students with disabilities” (Arise Coalition, 2011; Silverman, 2007). Only 25% of students with IEPs complete high school in four years, and of those who graduate, less than 17% are prepared to pursue higher education or careers (2011, NY TIMES).

Without the virtues of an inductive ethnographic approach, the impact of this crucial dimension of living with disability over the life course in the 21st century would have been lost to us. For example, reflecting on the lack of post high school support for her young adult son on the autism spectrum, one mother told us, “It’s an unlatched window out there.” Diagnosed children eventually grow up to be young adults struggling with their particular form of cognitive difference. As we began to see the fragile and fraught nature of the transition to life after secondary school for so many young adults with cognitive disabilities and their families, despite legal mandates, we expanded our focus to incorporate this new direction.

**Case study 1: transitioning to somewhere**

For contemporary Americans, attending college after high school is the aspirational norm; almost any alternative pathway is conceived of as a failure, even when post-secondary academic education might not be the best route to adult success. The hegemonic grip of this narrative became apparent to us as we became entangled with its consequences in our own children’s lives while carrying out this research. For example, Faye’s daughter attended a high school for students with learning disabilities that in its publicity suggested a high college admission rate for all its graduates, a statistic that had influenced her choice of that school. When, by her daughter’s junior year, it became apparent that she and many of her classmates were not on this normative and highly desired path, a little research revealed that there was no game plan for the 20% or more of the students who were virtually invisible in a school culture that valorized only certain kinds of success. Many of the parents we were interviewing encountered similar barriers as their kids aged out of high school; the lack of models to replace the college narrative obliterated the reality of differentiated life trajectories of students with disabilities beyond secondary school. Seeking an alternative to the dominant cultural script that addressed the problem of atypical transition, we quickly found an eye-opening report. “Transitioning to Nowhere” was authored by the highly respected Advocates for Children of New York, a group that, since the 1970s, has been devoted to “protecting every child’s right to learn” (Silverman, 2007). As the report concludes:

As a matter of sound public policy, as well as federal and state law, it is vital that school districts prepare students with disabilities for independent living, vocational training, employment, higher education, and the other post-secondary opportunities awaiting them. Only the meaningful planning and provision of transition services will ensure that this population of students is able to lead fulfilling and productive lives. The most vulnerable students, those who need the greatest assistance in preparing for life after high school, are instead being shuttled through inadequate programs where no real efforts are made to prepare them for their futures. We urge the NYC DOE to address this area of overwhelming failure aggressively and immediately. (Silverman, 2007: 4)

Clearly, the answer to the problem of transition was not “out there” nor was it an individual dilemma. We discovered that New York City along with much of the country was wildly out of compliance with Federal legislation mandating transition planning for young adults with disabilities as they prepared to leave high school. Consequently, those who were not college bound were overwhelmingly left with few publicly articulated options to this crucial rite of passage to young adulthood. As anthropologists and parents, this realization catalyzed us into activist research mode. Through the NYU Council for the Study of Disability that we had helped to establish, we organized a conference. Using the connections we had developed in our research, we mobilized an extensive local network of over thirty visionary educators, dynamic parents, as well as colleagues in special education at our own university for a day-long think tank in June 2008 entitled Rethinking Transition in the 21st Century: The After-Life of Special Education. The invitation
we composed laid out our concerns as ethnographers, activists, and parents:

Educators have been remarkably successful in providing innovative curriculum and social opportunities to students through the age of 18 (or sometimes 21); the difficulty of the transition from the educational system into the broader world is clearly the next challenge... but there is not really a clear, collective map of options in the New York area.

We hoped that this meeting might jump start some cultural innovation around the problem of transition. We were delighted when a hallway conversation at the end of the think tank between the directors of two local high schools serving students with learning disabilities inaugurated an innovative educational experiment: an agreement to pursue a model transition program. This moment of engagement was an instance of the kind of social change that our research showed was crucial. The idea for this project became concrete during 2008–2009: we hosted and participated in weekly planning meetings with the key participants from each school for a September 2009 opening of a pilot program that included academic study, internships, classes on current events as well as daily life activities, and participation in arts and culture around New York City. The new program was named SKILLS, an acronym for Skills and Knowledge for Independent Living and Learning.

We continued to take part in ongoing planning and assessment meetings during the crucial first two years, 2009–2011. Central to the curriculum was the innovative philosophy of “person-centered-planning”, a process-oriented approach to empowering people with disabilities by focusing on their passions, interests, and capacities as they develop a life plan. This includes work, recreation, housing, and other goals appropriate to transitioning to adult life, in tandem with a “circle of support” made up of teachers, family members, social workers, friends and others who can help put the plan into action.

As is often the case in New York City, the question of space for incubating this nascent transition program soon became an issue. The high schools with whom we were collaborating were not only short on space; more importantly, they stressed the significance for students of being in a new and more adult location so that they would concretize their progress beyond high school. Without question, the schools found the possible opportunity to locate such a program on a college campus was enormously attractive. We felt deeply invested in this effort and became ever more entangled in solving this real estate problem. After searching every possible space at an already overcrowded NYU, from the Department of Teaching and Learning to the NYU Medical Center, we came up with nothing. We finally found four classrooms in our own Department of Anthropology that were temporarily available for two years during a renovation project, just the right amount of time to incubate and launch a small experimental transition program — originally just eight students — designed for young adults with significant learning disabilities move beyond high school. We were fortunate to have an amazingly hospitable department comfortable with the full range of human diversity in our building. Faye's daughter Samantha, who has a rare genetic disorder, Familial Dysautonomia, was a frequent and welcomed visitor to our department; her participation in the pilot program's first two years no doubt helped raise the comfort level of our colleagues, while she also helped pioneer an alternative model of how to live a fulfilling life as a young adult with a disability.

Despite the fact that this project was very much an outcome of our engaged anthropological research, along with the support of our department as well as the backing of NYU's Council for the Study of Disability that we had generated, the university administration reversed its initial position of support. Initially, we received an enthusiastic endorsement from our Provost who had provided the funding for the Council and was pleased that our research and activism were strengthening ties between the university and the local community. However, in the second year of the transition pilot, newly-appointed university lawyers began to frame the program as a liability. They suggested to the administration that hosting a “vulnerable population” of young adults with learning disabilities made NYU responsible should anything happen to them on campus, although we had carefully worked out insurance riders with the participating schools. The lawyers then attempted to use the language of the ADA against the project, pointing out that the Anthropology Department was in a building that had no ramp at its front door that has two steps leading into the lobby. When we quickly pointed out that people with learning disabilities do not generally need ramps — although NYU students in wheelchairs might have grounds for lawsuits since they too use the space — they backed off this strategy. Moreover, the administration reversed their original agreement to claim the program as an NYU project, which had first been named SKILLS@NYU. Rather than taking credit for a short-term progressive experiment in educational inclusion — the original spirit in which the program was welcomed — the university legal staff made it clear that including outreach to these young adults with disabilities was seen as nothing but a liability to which NYU should not attach its name.

Luckily, many faculty members from across the campus disagreed with this position and stepped up with enthusiasm to support this innovative effort. They volunteered to help in multiple ways, from classes in DNA sequencing labs, to curatorial tours of the changing exhibitions of the campus art gallery, to an ongoing class in digital media that resulted in video blogging projects, and workshops in acting for the camera in order to create PSA's in the campaign against the “R” (“retard”) word. Thus, unexpectedly, one of the outcomes of our research was a model transition program that we had helped to create and incubate, despite opposition on the part of NYU's administrative bureaucracy.

We are gratified that in addition to grants and articles, our research helped to launch SKILLS. The program has grown from the original eight students to 37 and has moved into a beautiful and much expanded site twenty blocks north of campus. The new space is replete with — among other things — a computer lab, a “Daily Life Lab” with a kitchen for cooking classes and a washer and dryer, as well as a full-size shower-curtain map of the NY City subway system, signaling the effort that goes into the achievement of independent traveling as a first step toward a more autonomous life. According to the Administrative Coordinator of SKILLS, “Thirty-four students have graduated from the SKILLS program. All but one student is engaged in post-secondary programs that meet their needs and fit with their goals.” These range from continuing in educational programs from college to trade school, to part-time employment, supported and unsupported; others are in programs sponsored by social services that combine vocational, recreational, volunteer and social activities. In addition to keeping track of how graduates are faring in life beyond the classroom, SKILLS has also developed a robust alumni program that has monthly activities for all graduates including parties, drama classes, and field trips. SKILLS participants represent a very small number relative to the ever-increasing needs of NYC LD students as they leave high school, seeking a path to an inclusive adult life.

2 For more information, see http://www.familialdysautonomia.org/whatisfd.htm.

2 http://www.projecteyetoeye.org/home.html.
Nonetheless, the program offers an exemplary model of the kind of cultural innovation that we are both studying and on occasion activating.

**Case study 2: the permanent transition?**

The second transition project with which we became involved also had an unexpected origin with another moment of entanglement between personal and research interests. It began when Rayna was browsing books in a then new section in Barnes & Noble on disability and encountered a book that helped her imagine what realistic aspirations might be for her dyslexic son’s educational future. Learning Outside The Lines; Two Ivy League Students with Learning Disabilities and ADHD Give You the Tools for Academic Success and Educational Revolution, written in 2000 by Jonathan Mooney and David Cole, as a college survival guide for those with LD (Mooney & Cole, 2000). Written in an accessible, informal and even goofy style, it is aimed at those who had gone through school with an Individualized Education Plan (IEP). At the end of the book, the authors describe their fledgling efforts to found an organization — originally called Project Eye-to-Eye (PE2E) — to support college students with learning disabilities. Their idea was to replicate and expand the work they did as undergraduates at Brown University. There, they had mobilized a cadre of college students who had grown up with ADHD and LD labels, diagnoses that most had attempted to hide in order to succeed academically. Owning this identity was a critical step toward their activism.

This was exactly the kind of cultural innovation in which we were interested. We tracked down the then-fledgling organization’s founders. As one of them explained in an interview with us,

Lots of people said, “wow! You have an LD, you seem too smart”. In my book, that translates to: “I didn’t know you were stupid? Really! You’re so successful (for a dunce).” I (promised myself) I will hide this, I will fake this, the misconception is their own. I mastered hiding my LD, it wouldn’t come up in life, I’d memorize the paragraph I had to read in public, but I’d have no idea what’s in the first 4 pages. My messy handwriting got worse as I got older, and I can’t spell. I went to one of best education schools in New England for college, where I kept it quiet, but it blew up in my face in sophomore year: I had to discuss my topic for a 20 page paper with the professor. (And it was on LD and she said,) “You have an LD! That’s so cool! you’re gonna write the best paper ever!” She helped me to do research and taught me that my experience could become a positive example for someone else. I got an A, holy shit! (And I knew) I can do this! Maybe these accommodations can help me to do well in school. And my grades started to rise… Every time you come out of the closet you’re changing LDs for someone else.

We have come to understand that the students who founded PE2E (now Eye to Eye) were part of a post-ADA generation of young adults who had intimate experience with diagnoses of disability and came to expect inclusive educational environments. Many of the approximately thirty student activists we interviewed felt empowered to create their own representations that challenge purely medical understandings of their circumstances. We learned that “coming out” as having a “special education” in their past was a critical part of forging their identity as young adults. It also enabled them, we found, to speak and act with conviction as they reached out to students like themselves at local middle schools around their college. As these students contacted their friends from high school, now on other campuses across the country, Eye to Eye took root and flowered.

At NYU, we helped a chapter come into existence in 2008. We found meeting and training space for them on campus, and facilitated their entry to three different local middle schools with strong programs for children “at risk.” It was no accident that we knew which local networks of school-based innovation might welcome Eye to Eye: we had already interviewed many of their principals and assistant principals about the challenges diagnosed students faced. Facilitating school entry in New York City was important to successful program building, as public schools are notorious in their bureaucratic red-tape before any project can take root which is organized by outsiders to the school. Once Eye to Eye was securely established, we observed their method in each school as they worked to enhance children’s self-esteem by demonstrating the skills, creativity, and humor that the young adult mentors have learned to deploy along their own slower route to success. Thus our ability to collect observational data was a direct result of the research we had already undertaken; we then extended contacts made in one aspect of our investigation to another, enabling Eye-to-Eye to spread their novel model in each school in which the project worked.

The innovations Eye-to-Eye is developing are built on a sense of connection to youngsters struggling with the same diagnoses the college students have carried throughout their own life course; this is foundational to the project. It grows out of a recognition that middle school is a critical time in the development of a self-conscious identity in which being labeled as different can be damaging. Instead, the college activists highlight the neglected positive features of being “wired differently”, which are often identified with creativity and imagination. To underscore this focus, a centerpiece of Eye to Eye’s strategy involves running an after-school program in local middle schools that they call the “Beyond Normal Art Club”. Every middle-schooler involved gets a college student mentor; together they work on art projects such as building “dream machines”, fantasy creations that children imagine would make school-based learning easier.

We observed one BNAC class, for example, in a Harlem school where a lot of parents hadn’t communicated the specific diagnosis to their child who was participating in the program. The chapter organizer, sensitive to the problem of disclosure, called out to the class, “Anyone know what ADHD is?” When no one answered directly, he said, “Well I’ve got it, I was way noisier in school than even Scotty or Jamal, and just look at how much I talk now!” Immediately, a participating 10-year old volunteered, “Oh yeah, ADHD, that’s when you can’t sit still and you talk too much and you’re always buzzing around and I’ve got it”. The others chuckled in appreciation, and started to talk amongst themselves about “having ants in my pants” and “always running around”, normalizing what had mainly been until then an unspoken and private issue. At the end of the school year, BNAC hosts an art exhibition to which the entire middle school is invited. They show all the student projects they have created over the year; participating middle-schoolers proudly mingle with their peers and family members as they display their accomplishments. As Eye to Eye explains on their website, “Through art, Project Eye-To-Eye children have the opportunity to access their unique gifts for project-based, spatial, tactile/kinetic, and interpersonal learning within an academic environment.”

When Rayna described this Eye-to-Eye model to her then-high school son Teo, he was intrigued. He attempted to organize a chapter at his school, only to find that there was significant resistance to self-disclosure, even in a school where one-third of the student body had IEPs and participated in a school-wide intensive remedial program. He found that his peers were highly sensitive to labeling themselves, despite the acknowledged benefits they had already drawn from the reception of special education services. Entangled with Teo’s frustration with the situation, Rayna gave a talk to the special education teachers at the school but to no avail. Failure, like success, is instructive: in this case, it illuminates the on—
the-ground difficulties of building a youth movement which asks its members to commit to what they perceive to be a stigmatized identity.

Older students seem more comfortable with this process, especially once they succeed in becoming members of a college community. We interviewed approximately thirty of the college students who chose to work at Eye to Eye mentors in local BNAC after-school activities. Each life story was, of course, particular, but by the time they joined Eye to Eye, every participant testified that it would have made a difference in their school lives to have had a “cool” college mentor to admire, one who would have served as a role model. Demedicalizing their diagnoses and embracing a social model of disability based on the philosophy of “each one reach one,” they valorized self-help across school generations as the central reason for their participation. (Author 2) has also been the informal campus faculty mentor to the group since 2008, helping locate space, connections to middle school partners, and informally advising these students as to how to best navigate their classes given their status as LD students. While Eye to Eye members appreciated resources he could bring as a faculty member to their search for rooms and the occasional film-screening, they were particularly trusting because he always initially identified himself as the mother of a son with dyslexia, talking about him with pride and humor. In their individual interviews, virtually all gave credit to their parents — overwhelmingly, their mothers — for the combination of advocacy, discipline and love that they understood as the basis of their current college-centered success.

Later in 2008, we interviewed the national leadership, and were invited to carry out participant/observation at their Organizing Institute, an annual four-day workshop where new leaders are trained, and new college chapters are incubated. There, we experienced what material accommodations designed by the people who use them might look like: baskets of rubber squeeze equipment were widely available, as were frequent “stairs running breaks” intended to keep people with ADHD on task and energetically comfortable during intense, lengthy meetings. Once, we were asked to move to the back of the gym where training was occurring: some participants were friendly toward the project, but found the click of note taking on computer keyboards highly distracting. These instances of LD-in-action open up a space for imagining the material possibilities of a more democratic framework for accommodations designed by real-time experts. The insights that emerged from their interviews, our interactions with them in their training events, and our growing recognition of the need to transform the space to accommodate alternative learning styles helped us gain greater appreciation of what it means to actually include “all kinds of minds” (Levine.)

By the summer of 2008, Eye to Eye had grown to 27 chapters by 2013 it had 51 chapters and a business plan with support to expand significantly by 2015. Organizational funding comes through family foundations, most often those where a member of the board has intimate experience with learning disabilities and understands the importance of this work. Sometimes, funders are recruited as board members for Eye to Eye as networks of mentoring and support expand and deepen. No longer confined to the Ivy League colleges where it began, the organization has 51 chapters in nineteen states in both public and private institutions, and is found on elite research as well as community college campuses. In each chapter, often working with campus offices for the support of students with disabilities, Eye to Eye leadership identifies and recruits a team of students with learning disabilities to work with local middle schools.

While Eye to Eye works closely with medical researchers, this is the first national organization created for, about and most importantly by young adults with LDs. As they explain in their mission statement:

It starts with a label: Learning Disabled. Attention Deficit Hyperactivity Disorder. Too often, it also ends there. That’s where Project Eye-to-Eye comes in. As the only national mentoring program pairing kids with LD/ADHD with similarly labeled college students, Project Eye-to-Eye encourages labeled children to become their own best advocates.

These kids need a safe place. They need, like all children, to be heard. And most of all, they need self-confidence. With Project Eye-to-Eye, they find not just a safe place, but also a great place. And it’s fun! “Regular” school reminds children with LD/ADHD of what they can’t do. With Project Eye-to-Eye, it’s all about can do. 4

In our fieldwork, we saw that mission pragmatically and literally distributed at the Organizing Institute. Each summer, the group awards tee shirts to the participants who complete their rigorous training program; the vivid colors and slogans on the tee shirts change annually. In summer 2008, the aqua tee shirt we earned had the slogan across the back: “A Special Ed Revolution Coming to A School Near You!”. Most recently, Eye to Eye staff have carried out systematic outreach with a number of corporations to create awareness and potential job opportunities for young adults transitioning from college to the workplace: corporate outreach often begins with the same foundations that generously opened their “deep pockets” to initially fund Eye to Eye chapter development. Now, the board members often take graduates into their business networks, mentoring them through the next stage of transition for “lives with a difference”. As Eye to Eye envisions it, they are building a community that extends from middle-schoolers through college students into working adults, many of whom already have life-partners and children, as well as professional jobs.

Conclusion

We have entitled this article “entangled ethnography” in order to highlight how the roots of our present research grew from questions originating in our familial lives, blossoming into fieldwork, helping us have greater awareness of the processes we were studying. Eventually, these insights gave us the confidence to become entangled in advocacy projects that we both supported and studied. As we have tried to show throughout this article, we have been responsive to a rapidly evolving social landscape in which we are increasingly implicated.

From its inception, anthropology has been particularly open to — and distinguished by — the dynamic unpredictability that comes with empirical qualitative immersion. Despite our best efforts to contain it, we have found the categories that we are studying to be promiscuous violators of the walls erected by medical manuals and school bureaucracies. This finding is crucial to understanding how disability takes shape in concrete, cultural locations. In short, without ethnography, the unruly, unanticipated innovations that are leading to significant social change around cognitive difference would not be documented and analyzed. Our work with the SKILLS Program and Eye to Eye are vivid illustrations of this process. While their inaugural numbers are small, their potential for imagining radical innovation as increasing numbers of young adults with disabilities enter a world where inclusion is more than a

4 For more information, see http://www.projecteyetoeye.org/home.html. Personal communication, Vicki Fowler, Administrative Coordinator, Cooke Skills Program. 24 October 2012.
promissory note. Indeed, with the remarkable escalation of the percentage of the population classified as living with disabilities, the exemplary projects we describe take on significance beyond their small size as models for future action.

Had we not been able to reflect on our own experiences, that research pathway might have never become apparent to us nor would have been in a position to contribute new knowledge on this crucial but emergent area of concern. Our own entanglements helped us to understand the significance of this life transition as an encompassing challenge to the ongoing project of disability rights, and not just for the particular circumstances of our own children. Working together to build new transition models with our research subjects aided us in our efforts to recognize how parents and children struggling with a range of issues became engaged in processes of cultural innovation. This in turn contributed to the articulation of new anthropological knowledge and the field of disability studies. Things could have turned out otherwise with potential negative consequences; entanglements are shadowed by risk.

When the editors of this special issue sent out their mission statement, they suggested that ethnography has a vibrant role to play in understanding when people we study and work with attempt to advocate for themselves against the larger structural forces that entrench health and social inequalities.

They go on to point out that The ethnographic stance of representing alternative worldviews lends itself to envisioning alternative politics and institutions. It also lends itself to participatory research in which research subjects are invited to shape the questions and representations...

As we have shown here, many people who grew up and were educated in the post ADA era of inclusion now take for granted an alternative worldview, one that challenges the limits of medical models. Reasonably enough, they——and we——expect that students with cognitive difference are simply part of the spectrum of diversity, a civic space that mandates their recognition in educational settings and as citizens deserving a place at the table, a concern which is silenced in medical models of disability. Our ethnographic focus in this article on groups that are “envisioning alternative politics and institutions” for life beyond high school is strategic. Although social transformation often starts modestly, we have chosen to both support and amplify the efforts we have witnessed. We see ourselves as allies in making public the realities of this form of human difference. In our collaborative and productively entangled ethnographic research, we have been privileged to work with, and help support, these visionary yet extremely practical transition projects. Their commitments—and we hope ours—will enhance the possibility that young adults with learning disabilities in the U.S. will indeed “transition to somewhere”: a place where their capabilities as human beings—beyond diagnoses—will be recognized.

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