



## 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 Disabilities<sup>1</sup> 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/outsider 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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<sup>1</sup> 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.”

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 Merry 2010](#); 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 socio-economic 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

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