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## The social life of health records: Understanding families' experiences of autism

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### Introduction

In the U.S., an on-going transition from paper to electronic health records (Plovnick, 2010) has resulted in a mandate for 'meaningful use,' i.e. the use of health information technology for improving the quality, safety and efficiency of health care, while engaging patients and families and facilitating healthcare coordination (ONCHIT, 2010). In the approaching era of electronic health records, patients' access to their health information is intended to facilitate their participation in health care, a development that exemplifies "both the dilemmas and productivity of actually existing health services in rich countries" (Valentine, 2010: 951). What meanings and experiences will be engendered when patients and their families access their health records, and what impact will this have on patient-practitioner interactions, and ultimately, on the healthcare services that patients receive? How is the introduction of electronic health records expected to address health and healthcare disparities that persist in the U.S. (Feagin & Bennefield, 2014)? Paradoxically, the term 'meaningful use' does not address these questions, and we argue that neither the term nor the questions are uniquely relevant to electronic health records. It would be critical to put 'meaning' back into the 'meaningful use' mandate and to consider these questions for any kind of health records, electronic or otherwise, if we are to understand how health records figure in healthcare and what 'social life' they have.

This article addresses these questions in relation to one diagnostic category, autism, and for families who often face health and healthcare disparities across illness categories, African Americans (CDC, 2011). Focusing on the health records of African American children diagnosed with autism, we describe parents' experiences of reading and using their children's records. We consider health records' impact on interactions among parents and practitioners during diagnostic evaluations and intervention planning, showing how parents draw upon the material-discursive properties of records to display epistemic authority and expertise. We also consider the children's health records in relation to disparities in autism diagnosis, interventions and services experienced by underserved children and families

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(Magana et al., 2012; Mandell et al., 2009). Yet we do not intend to offer a “definitive race story” that “speaks only or uniquely about the experiences of African Americans” (Mattingly, 2010:7). Rather, we provide an analytic perspective and a methodology to inquire into the complex place of health records in the reproduction of healthcare disparities for children with autism.

To this end, we aim to disrupt the assumed neutrality of the term ‘meaningful use’ and the illusory objectivity of health records themselves. The development of electronic health records, Berg (2004) reminds us, is “no neutral affair” because they “reconfigure health care practices and are deeply involved in intra- and inter-organizational and professional politics”; thus framing them only in technological terms makes “important political and organizational aspects disappear from sight” (2004:12). Similar claims, however, could be made about paper medical records as digital scanning and storing technologies have made the boundaries between the two especially blurry. Whether the records are paper or electronic does not make much difference because it is the inter-connectedness of the technological, socio-interactional, discursive and politico-economic processes that is implicated in the fact that health records are not, in any form, neutral.

The neutrality is conjured by the image of a hospital or a clinic where medical records are usually found. Our data show, however, that children’s health records inhabit not only the clinical settings in which they were produced but also families’ homes. These health records are organized into binders and carried from one clinical encounter to another - or scanned and emailed - by the parents. In the processes of their replication, movement and use they gain their meanings and significances as both material and discursive artifacts. Whether paper or electronic, the physical space inhabited by health records, be it inside a 3-ring binder or on a hand-held device, becomes pivotal in the records’ co-construction and interpretation during the clinical encounter and beyond. While most studies focus on the role of professionals in the production of medical records, we examine the participation of parents in these processes, including how they experience the representations of their children in the health records; what meanings they attribute to these representations; and how they shape and negotiate what is entered into their children’s health records. We view the interactional work of parents and professionals from a discourse analytic perspective, arguing that a dialogue may take place not only between people, but also between texts. Such a perspective is helpful in rendering the children’s health records as simultaneously *co-constructed* during social interaction and *heteroglossic* (Bakhtin, 1986) because multiple voices (e.g. parents’, practitioners’, teachers’) may contribute to a health record.

We show that while health records are perceived as objective, seemingly authorless, and always used as intended, they are highly contingent on the contexts in which they are engendered and the power relations among those by whom they are used. Our study examines health records as experienced by African American families of children with autism, who often face disparities in age at diagnosis and access to interventions and services (Magana et al., 2012; Mandell et al. 2009). We elucidate ways in which family members and practitioners engage in the production, interpretation and use of the children’s health records as certain kinds of texts and artifacts that give rise to certain kinds of experiences and actions.

Autism offers a unique view of what we call the ‘social life’ of health records because it may be diagnosed in multiple clinical settings. We use the term ‘health,’ rather than ‘medical,’ records because our data consist of medical, developmental, and educational records that were collected, curated and given to us by the parents of the children in our study. Autism also provides a unique view into the ‘social life’ of records because of widespread diagnostic disagreement, due in part to the subjective nature of the diagnostic processes (Solomon, 2010). It has been established that both at major U.S. autism research centers and at community sites there is great variability in how autism spectrum diagnoses (i.e., autistic disorder, PDD-NOS, and Asperger syndrome; APA, 2000) are assigned to individual children (Lord et al., 2012; Williams et.al., 2009). Because of this variability, for several children in our study the diagnostic status and consequent eligibility for services changed over time. Moreover, some children in our study qualified for an autism diagnosis and services at one community site but not at another.

In light of widespread diagnostic disagreement, disparities related to autism diagnosis and services are especially troubling. Prevalence of autism among African American children (12.3 per 1,000) is significantly lower than in non-Hispanic White children (15.8 per 1,000) (CDC, 2014), a difference believed to be influenced by structural and interactional processes (Smedley et al., 2003). African American children are diagnosed later than White children, are less likely to receive an autism diagnosis on the first specialty visit, and are more likely to be misdiagnosed with adjustment disorder, conduct disorder or ADHD (Mandell et al., 2002, 2009; Valicenti-McDermott et al., 2012). These population-level findings reveal systematic delays in diagnosis, frequent misdiagnoses, and challenges to receiving appropriate services once the diagnosis is established. The promise of early diagnosis and early intervention for favorable developmental outcomes (Matson, 2007; Howlin et al., 2004) makes these statistics even more troubling. The analysis presented here is intended to contribute to health disparities scholarship by providing an ethnographic, discourse analytic perspective on the complex role of health records in how children’s development and behavior are framed, and ways in which their healthcare needs remain unmet.

## Methodology and analytic approach

This ethnographic, discourse-analytic study draws from a larger data corpus collected between October 1, 2009 and August 31, 2012 for a mixed methods, urban ethnographic study (*Autism in Urban Context: Linking Heterogeneity with Health and Service Disparities*, National Institute for Mental Health, R01 MH089474, 2009–2012, O. Solomon, P.I.) on disparities in autism diagnosis, interventions and services experienced by African American families of children diagnosed with autism. While a health records review was originally included in the study design, health records emerged during data collection as more significant than we expected in families’ experiences of autism diagnosis, interventions and services. To capture this significance, we combined an ethnographic perspective with a discourse analytic approach (Wodak, 2004), which allowed us to iteratively analyze our data, moving between family members’ narratives related to their children’s health records and the records themselves. This process was also used to analyze other health records-related data in our corpus to identify the themes and patterns emerging across families, practitioners, and clinical settings (Solomon & Lawlor, 2013).

The families were recruited through four California Department of Developmental Services' regional centers, a university hospital, and a center for developmental disabilities located in Los Angeles County. Ethical approval for the study was obtained from the University of Southern California Health Science Campus Institutional Review Board (protocol # HS-09-00386) and the study sites. All parents reviewed and signed informed consent and Health Insurance Portability and Accountability Act (HIPAA) forms. Besides standard Institutional Review Board training, all study personnel completed HIPAA training and certification. Ethical conduct of research specific to the use of health records was discussed during research meetings and carefully monitored in supervisory relationships.

Families were recruited via anonymous mailings sent to a randomly computer-generated list of eligible families at a study site; placement of recruitment brochures in waiting rooms; website postings; and clinician referrals. To qualify for the study, parents had to self-identify as African American, and their children had to be eight years old or younger at the time of enrollment, have a documented autism diagnosis by a licensed professional, and have a projected need for interventions or services at one of the study sites. During the data collection period, participating children's ages ranged between four and ten years.

Twenty-five children diagnosed with autism from 23 families who lived in Los Angeles County participated in the study. There was a wide range in socio-economic status and educational attainment among the parents. The sample consisted of 22 mothers; 15 fathers and stepfathers; 17 extended family members; and 65 professionals (e.g., physicians, behavioral therapists, occupational therapists, speech pathologists, teachers, and service coordinators). The data analyzed in this article were collected through narrative interviews; participant observation in home, clinical and community settings; fieldnotes; and health record reviews.

Families of 14 children of the total cohort of 25 shared their children's health records with the research team. The largest number of records for one child is 25, and the smallest number is two. The unevenness of our health records corpus is a limitation of this research in that we do not have health records for every child in the study. The total number of health records analyzed for this article is 95, including 24 Individualized Educational Program (IEP) documents, 18 developmental and 16 psychological assessments, eight speech and language assessments, eight Individualized Program Plans, five behavioral and other specialized assessments, six Individualized Family Service Plans, five medical pediatric records, three occupational therapy assessments, one regional center case documentation and one fair hearing file. Additionally, the following data related to families' and practitioners' experiences of health records were analyzed: Eight audio-recorded interviews with parents, three video-recorded clinical visits, two audio-recorded interviews with practitioners, one observed IEP meeting, and one e-mail that described a mother's experience of her child's healthcare visit. Due to space limitations, we provide selected examples from the data to illustrate the identified themes and patterns.

Critical discourse analysis illuminates how subjectivities are shaped, maintained or resisted through discourses in people's everyday life (Rudman, 2006; Wodak, 2004). The ethnographic and discourse analytic perspectives together generated a rich and complex

understanding of the problem that could not have been attained by one perspective alone. This combined approach allowed us to examine parents' experiences involving health records, how parents contested or ratified the discursive authority of health records, and how they marshaled the health records to negotiate services for their children. This approach provided a lens onto the central role of health records in parents' work to maintain the continuity of their children's autism diagnosis, and consequently his or her interventions and services, in the context of diagnostic disagreement (Lord et al., 2012; Williams et al., 2009). The examples below are intended to illustrate and describe larger processes involving health records while reflecting particularities of each family's experiences. This analytic approach provides a level of richness and detail so that data from a comparatively small number of subjects inform a more general understanding of the issue.

### When parents read health records

As discussed above, we analyzed the health records that the families had in their possession and shared with the research team. For some families, reading these records was a very difficult experience. For example, Katrina<sup>i</sup>, a mother of three daughters of whom the two youngest were diagnosed with autism, remembered her first experience reading her middle daughter's diagnostic report:

She was too young to even understand but I was on the offence, but more hurt, you know, by the scrutiny and having her described in the reports...Going through the diagnosis and reading the reports of her described in black and white, I could not even stand to read those reports until many years later, and reading the prognosis and what the future might be for my child, I couldn't even stand it.

Analyzing descriptions of the children in the health records, we found them to be greatly varied by the professional affiliation of the practitioner and the setting. The same child, for example, was described in one evaluation as *“an adorable 37 months old boy of African descent whose interests are toy cars and trucks”* and in another as *“a 37 months old African American male”*

The parents, mostly mothers, were also variably portrayed in the health records. Katrina remembers in a subsequent interview:

The reports and descriptions that I could not even stand reading for years because of the description of how the doctor saw me. Nothing really bad but I'm just sensitive. “Unemployed mother.” No. “Unemployed welfare mom.” You know. That's how it felt.

Six months later, in yet another interview she returned to the theme of how difficult it was to read her daughters' records: *“Even to this day I don't read the reports in the IEPs. I have my oldest go through it with a fine comb. It's hard to read them”*

How parents were described varied greatly from one record to the next. Almost all of the health records noted parental employment status, but how this was accomplished was

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<sup>i</sup>All names are pseudonyms.

consequential. In some cases, an additional remark was made if a parent's employment was high positioned. The unemployment characteristic was also variably portrayed. One child's parents, for example, were both described as "*unemployed*" in one record; in another, it was stated that the mother was a "*full-time homemaker*" and the father was a "*college student*." Both descriptions were technically accurate, but only the latter portrayed the parents in more family-centered terms and was more reflective of how they would describe themselves.

These descriptions are consequential for how a parent is perceived by professionals. During health care encounters, parents are at work to present themselves as 'good parents,' a task that may become more or less difficult if the parent is described in their child's health record in more positive or more negative terms. These descriptions may also impact whether one is seen as an 'autism parent' (deWolfe, 2013; Silverman, 2011). Being an 'autism parent' involves the precarious task of engaging practitioners in narrative and moral reasoning related to framing children's challenges and planning a program of interventions and services (Solomon & Lawlor, 2013). This requires what Mattingly (2008) calls "narrative mind reading," the "practical capability of inferring (rightly or wrongly) the motives that precipitate and underlie the actions of another" (2008:137). Challenges to parents' "narrative mind reading" reside in the contrast between the informal, personal, and intimate nature of caregiving and the formal, professional, and argumentative nature of being an 'autism parent' who has to 'fight' to 'win' needed services for their children (Lilley, 2011; Zarembo, 2011).

This is reflected in a narrative told by Olivia, a mother in the study, to the first author (A.M.A.) about learning that handwritten notes to the school to request an IEP meeting were not useful. Parents of children with disabilities have a legal right to call an IEP meeting at any time; however, the request must be in writing. Olivia recalled how, knowing this, she sat outside her son Simon's school office, jotting down a request with a red pen on a scrap of paper. She was later told by an advocate to type all requests using a formal template, and to keep them for her records. In another context, her handwritten note might have signified the personal nature of the parent-teacher relationship, such as a note explaining why her son was late to school. In this case, however, the handwritten note failed to represent her as a knowledgeable 'autism parent' (de Wolfe, 2013; Silverman, 2011). The vulnerability and intimacy of a mother's handwritten note, Olivia learned, must be hidden least it is interpreted as weakness and lack of expertise.

As the example above illustrates, for parents of children with autism, "narrative mind reading" (Mattingly, 2008) in the context of acquiring therapeutic interventions for one's child involves the often unsustainable task of interpreting and making sense of service providers' beliefs and actions. This requires institutional and legal understandings, an awareness that professionals may be under pressure to ration services, and the ability to preempt threats to one's epistemic authority (Heritage, 2012) and to anticipate problems related to the production of evidence.

Such problems were abundant in our data corpus. Besides the descriptions of themselves and their children that were difficult for some parents to read, we found that *what* parents said during evaluations was also variably described. Specifically, the developmental history and



the perceptions of the children's abilities that the parents contributed to the record were framed differently, i.e. were either ratified or subtly negated by the evaluating practitioner. From the discourse analytic perspective, records contain 'voices' of not only the practitioners but also the parents, teachers and others who contribute information to the text (Bakhtin, 1986; Solomon, 2010). How these voices and perspectives are portrayed in the health records, however, is far from neutral. In some records, the 'parental report' information was recorded as epistemically authoritative (Heritage, 2012) and framed as congruent with the evaluator's view: "*Mother reported today's behavior during testing is somewhat typical.*" In other records, the evaluator subtly contrasted the parent's views of the child with the presumably realistic picture described in the report: "*Michael reportedly likes to play with cars, balls and trucks, all 'boy stuff.'* Little meaningful play was observed"; and shortly after, "*Mother said Michael is 'very social' and gets along well at day care, and 'has lots of friends.'* His eye contact was observed to be inconsistent."

Such subtle and not-so-subtle practices of description powerfully communicate who holds and who lacks discursive authority. Although 'autism parents' (deWolfe, 2013; Silverman, 2011) often acquire specialized expertise about autism, professionals may hold 'discursive authority' over parents' knowledge (de Wolfe, 2013; Eyal & Hart, 2010; Lilley, 2011; Solomon & Lawlor, 2013). Similarly to Rosenberg's (1987) observation that a hospital "replicated in microcosm the social realities that shaped the larger society outside of its... walls" (1987:309), it appears that health records replicate and encode inequities that exist outside of its paper covers or digital borders, and by doing so, become implicated in reproducing disparities in healthcare, and ultimately in health.

Access to health records by patients and their families, whether in paper or electronic form, presents a fascinating challenge to the family-centered care movement. Even though the "*adorable boy*" and the "*full-time homemaker*" descriptions may serve as evidence that the practitioners anticipated that the parents would read their children's health records, it does not fundamentally change how the records are created and for whom they are intended. The "recipient design" (Grice, 1989) of these texts evinces that they are primarily written for practitioner and administrator audiences. Thus parents' experience of reading them can be devastating, because of the portrayals of the children and the parents themselves, and of the subtle negation of the parents' epistemic authority and views of their children.

In spite of these troubling experiences, parents in the study recognized the critical importance of health records in negotiating their child's diagnosis, services and interventions. On multiple occasions, they told stories about their strategies to use their children's health and educational records, both in terms of their content and their materiality as an artifact. For example, Olivia recounted being told by a special education advocate to organize her son Simon's records in a 3-ring binder in order to be differently perceived by school personnel during IEP meetings. Another mother, Zoe, shared how she would come to an evaluation "*armed and dangerous*" with her daughter's records in a neatly organized folder, knowing how to wield these records to channel the authoritative voices of other professionals who attested to her daughter's challenges and need for services.

## When health records disagree

Besides recording contrasting views of parents and practitioners, health records may also disagree with each other. Diagnostic disagreement (Lord et al., 2012; Williams et al., 2009) makes the dialogic nature of autism-related health records especially visible. For several children in the study, the initial evaluation stated that the child did not meet autism criteria and thus did not qualify for services under an autism diagnosis, while a second evaluation documented that the child *did* meet diagnostic criteria and thus was eligible for services. In such situations, the second evaluator had to address, within the boundaries and constraints of professional discourse, the implicit question of why her assessment yielded an autism diagnosis. In all cases, the second evaluation was far more detailed than the first, perhaps because it had to substantiate why one professional, using standardized assessments, would arrive at a diagnosis that was previously ruled out.

For example, Simon, whose mother, Olivia, was quoted in the previous section, had two diagnostic evaluations that were two months apart. He was first evaluated for autism at age 2 years, 9 months “*to assist in the process of determining continued eligibility*” by the regional center beyond early intervention. During the first interview for our study, Simon’s father, Carl, described an upsetting experience that he would return to several times over the course of data collection: When the first evaluator briefly tested Simon, he reported that Simon was able to carry out tasks that his parents knew he was unable to perform.

And look, excuse me now, professionally, if somebody diagnoses somebody as autistic, how long you think they should know him before they even qualified to tell me they autistic or not? They can’t just meet ‘em fifteen-, twenty-, half an hour and say that. No. Okay? ‘Cause one of ‘em did. I said, “For one thing, how could you say he’s not autistic, and you was not around him long enough to even say that? You’ve been ‘round him like, fifteen minutes.” If you really wanna know about somebody, you gotta spend some time.

Olivia, Simon’s mother, was also present and observed that Simon was unable to carry out the tasks that the report claimed he completed. At their request, a re-evaluation took place two months later. The first evaluation found that Simon had Pervasive Developmental Disorder-Not Otherwise Specified (APA, 2000), a diagnosis not considered severe enough to warrant services at the regional center. The second evaluation diagnosed Simon with Autistic Disorder (APA, 2000), a diagnosis that qualified Simon for services. The discrepancy was significant. The first evaluation used two standardized assessments for autism, and both indicated that he did *not* have autism. The second evaluation utilized a different autism assessment, which indicated that Simon *did* have autism. The second health record ‘speaks’ to the first as follows:

The most recent psychological evaluation conducted under Regional Center auspices was completed by Dr. Jones within the last few months. Dr. Jones diagnosed Pervasive Developmental Disorder-Not Otherwise Specified. Parents report that they disagreed strongly with those findings - stating that other therapists and doctors who have worked with Simon have indicated that autism is present. As a result, they requested a re-evaluation.



The second evaluator builds her epistemic authority (Heritage, 2012) by providing a detailed description of Simon's behavior and echoing the voices and opinions of the professionals who, as the parents reported, worked with Simon and thought that he had an autistic disorder. The multi-voiced quality of this evaluation is striking, as perspectives on Simon's diagnostic status are embedded within other supporting perspectives, creating a heteroglossically amplified argument.

Following extensive clinical descriptions, the second evaluator addressed the necessity to discontinue certain test items due to Simon's inability to complete them:

It should be noted that Simon's lack of interest and aloofness resulted in the need to discontinue efforts to administer assessment instructions...Simon was not able to solve any of the items associated with the measure of receptive language skills, the Peabody [developmental test] and could not imitate any of the line drawings associated with the Beery [developmental test].

The first evaluator interpreted the same behavior as disinterest: Simon "*was not interested in completing these instruments*" and "*ignored the examiner's attempts to demonstrate drawing horizontal and vertical lines.*" The second evaluator framed Simon's behavior differently, suggesting disability over disinterest. Aloofness and inability to imitate are associated with autism, and there is a significant difference between "*could not imitate*" and "*ignores.*" The second evaluator notes: "*Parents report that Simon had exhibited similar behaviors at the previous evaluation - being surprised that the report indicated that he was able to complete a number of the items.*" Finally, Simon's second evaluator addresses the discrepancy in results more directly:

The discrepancy between the previous evaluation results and the present evaluation result cannot be easily explained. Parents believe that it must have been a mix up of test results of the previous evaluation as they did not see Simon was able to complete any item.

Given this discrepancy, the second evaluator recommends that Simon is re-evaluated after one year of school attendance, noting that "*It would be very important to have available for the evaluating psychologist any descriptive data from teachers or therapists who will have worked with Simon.*" Thus the evaluation ends with an admonishment to include a contextualized description of Simon, from multiple perspectives of those who work with him on a daily basis, emphasizing the importance of the opinions and voices of the people who have known Simon over time.

A similar example can be found in the health records of twins Kellan and Kofi, who were evaluated by a regional center psychologist just before they turned 3 years old. Although the purpose of the evaluation was "*the assessment of developmental disabilities, including Mental Retardation and/or Autism,*" no autism-specific instruments were used. Intelligence and visual-motor test scores differed for the boys, but their diagnoses were identical: "*(Name of child) is functioning within the low-average range of intellectual ability. He continues to present with expressive and receptive language delays.*" With this evaluation, neither of the boys qualified for services through the regional center.

When the boys were almost 4 ½ years old, they were reevaluated by a different regional center because the family had moved to another part of Los Angeles County. The next evaluator used several screenings and assessments for autism and diagnosed Kellan with Autistic Disorder and Kofi with Pervasive Development Disorder-Not Otherwise Specified (PDD-NOS), with a secondary diagnosis of Mild Mental Retardation<sup>ii</sup>, which qualified them both for services (Kofi qualified under the secondary diagnosis). As in Simon's case, the twins' second evaluations were more detailed. Unlike Simon's situation, these evaluations happened almost a year and a half apart, a time during which the twins did not receive services from the regional center.

The twins' mother, Kendra, compared the two evaluations:

At that time I kinda felt that he [the first evaluator] was being a little bit dismissive. That's how I felt. Like, "Oh, they'll be all right." Y'know? "Uh, it's nothing." You know? But the second assessment, it felt like they really took the time to listen to what I was saying. Oh! And that was another difference. They asked a lot more of the questions about the things that I was seeing that was related to the autism, or related to their developmental delay.

The second evaluator's disagreement with the first is expressed subtly: "*Upon exiting the Regional Center a psychological evaluation was completed by Dr. Smith, Ph.D., which indicated a Mixed Receptive-Expressive Language Disorder. Re-evaluation was recommended if improvement did not continue.*" This detail validated the re-evaluation, indicating that it was recommended by the first examiner. While neutralizing these evaluations' conflicting results, these discursive practices also appear to build consensus with the previous examiner, a tacit strategy that creates an impression of practitioners' agreement in the face of a diagnostic disagreement.

## When health records go missing

The meaning of a health record in the lives of children and families becomes especially visible when it is suddenly missing. It can be missing, however, in two ways: The material body of the record may become unavailable, or the text of the record may remain unread.

For Simon, a missing health record became a barrier to receiving services under his existing autism diagnosis. Until the age of 7, Simon had received healthcare services at a large medical group called an Independent Practice Association (IPA). His physician was Dr. Norton, who had also been his mother's physician when she was a child, and thus the family's relationship with this doctor was especially close. In the 1990s, a managed care model appeared in California that transferred operational control from insurers to physicians in return for transferred financial risk (Kerr et al., 1995; Robinson, 2001; Robinson & Casalino, 1995). The main characteristic of this model was capitation, i.e. a fixed rate per member per month for any patient enrolled in a health plan regardless of services received, which meant that physicians had to carry the financial burden if the costs of providing healthcare exceeded capitation rates.

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<sup>ii</sup>A term still used in the records even though it has been officially changed to Intellectual Disability.

In hindsight, it is not surprising that such a system was doomed to fail. Robinson (2001), a health economist, refers to the downfall of this system as the “crash.” Like many IPAs, Dr. Norton’s medical group declared bankruptcy and closed its doors in 2010 in the wake of this “crash.” By the time of its demise, the network served patients who were enrolled in nine major HMO healthcare plans and Medi-Cal, a public health insurance program for low-income families in California. It contracted with approximately 400 primary care physicians, one of whom was Dr. Norton; and served 120,000 patients, one of whom was Simon. A Los Angeles newspaper reported that when “the last big wave of new doctors’ groups snapped under the pressure of too much financial risk... More than 700,000 patients were abandoned – some in the middle of care – and some of those patients’ medical records were locked away forever” (Gallegos, 2010).

Simon’s parents were notified in advance of the medical network’s closure, but instead of a copy of his medical records, they were given a flyer with an address where the records were stored. Simon’s parents interpreted this as a promise that the records were going to be available for pick up. When the family drove to the address, they found a dark, locked and boarded-up building. Stunned, they sat for two hours in the car waiting for someone to pass through the locked doors. Nobody came. They were unable to reach anyone on the phone listed on the flyer. Two years later, they were still unable to gain access to Simon’s health records. This created an unexpected complication when the family went to see Simon’s new physician who also did not have Simon’s health records.

When Simon, in first grade, began having behavioral problems, his parents requested behavior modification services through the regional center. Due to California’s state budget cuts, regional centers began to require proof of denial from insurance companies before services could be provided. In order to receive this denial, a child’s physician had to write a referral to the insurance company. In an interview with the first author (A.M.A.), Simon’s mother Olivia shared that Dr. Norton, Simon’s previous physician, was working on the referral when the medical group went bankrupt. Olivia remembers: *“All of a sudden they went bankrupt, and all of their doctors got snatched up in, I don’t know, some kind of mysterious whirlpool, you can’t find them on the Internet, nowhere.”*

Olivia turned to Simon’s new physician, Dr. Grace, with a request for a behavior modification referral. Simon, now verbal and at times social, was on his best behavior during his first visit with Dr. Grace. As a result, Dr. Grace did not believe Olivia’s assertion that Simon had autism. Olivia left that visit upset, and without the referral for behavior therapy. Months later, during a second visit with Dr. Grace, Simon behaved more characteristically of a child with autism. His autism diagnosis was re-confirmed in writing by this new physician, and a new health record continued the diagnostic thread that was temporarily lost when the previous physician’s practice closed down. This example illustrates that neither the continuity of autism diagnosis nor the continuity of services are automatic but rather have to be vigilantly maintained and negotiated by parents.

The next example illustrates how a record can be ‘missing’ if it remains unread. While records are assumed to be a reliable means for communication among providers (Charon, 2006), their messages may become what we call ‘one-way’ messages. Sebastian, born

prematurely and frequently hospitalized throughout his toddlerhood, was not diagnosed with autism until he was 3 years, 6 months, despite being followed by multiple physicians. A narrative told by Sebastian's cardiologist, Dr. Villalobos, along with Sebastian's medical records shared by his parents, revealed the cardiologist's repeated attempts to alert Sebastian's pediatrician to delays in his development. Dr. Villalobos began seeing Sebastian every six months when he was 18 months old due to a heart anomaly. Because he was born prematurely, she was concerned about his development and indicated it in his record. In California at the time, prematurely born children automatically qualified for early intervention. At Sebastian's next visit, Dr. Villalobos again indicated in the chart that Sebastian had "*speech/motor/developmental delay*" and had "*yet to be seen by the Regional Center.*" She told the first author (A.M.A.) that, although she is a cardiologist, developmental issues were often addressed in her practice because she spent more time with the families than primary care pediatricians, which increased her opportunities to observe developmental delays.

Dr. Villalobos's clinical notes for each visit with Sebastian were accompanied by a letter to his pediatrician, listing Dr. Villalobos' concerns. At the 32 months' visit Dr. Villalobos's entry in the health record indicates that Sebastian's speech was delayed and that, per his mother, he would soon receive speech and occupational therapy evaluations. These evaluations, however, were significantly postponed. When Sebastian was finally evaluated by the regional center, he received an autism diagnosis. However, he never received early intervention services, which would have been beneficial both because of prematurity and autism. When asked what she thought happened in Sebastian's case, Dr. Villalobos expressed her frustration that the pediatrician to whom she was addressing her letters was unresponsive:

Sometimes the pediatrician does not initiate that. But it's kind of obvious. I mean, the kid is entitled to have early intervention. Because we sent the letters to the pediatrician, so if they read the letter, it says right there and then. You know? I don't know.

What can be seen from this example is that information in the health record that remains unseen loses its ability to mediate a practitioner's next-relevant action. For Sebastian, this had significant consequences, as he did not receive early intervention services, which have been shown to be important for developmental outcomes (Howlin et al., 2004). Information entered *into* the medical records must consequently be extracted *from* the record by relevant recipients in order for the health record to do its work of mediating communication and actions among practitioners as well as parents. This dialectic process requires both properties of a health record, its materiality and its discursivity, to be engaged. Another possible interpretation of Sebastian's data is that his pediatrician had read but never acted upon Dr. Villalobos' letters, a problem that we are currently unable to address.

## Discussion

We aimed to provide a nuanced, ethnographic and discourse analytic perspective on the meaning and significance of health records in the lives of children with autism and their families. To illuminate ramifications and consequences of the 'social life' of records, we

chronicled the ways in which health records are negotiated, co-constructed and positioned in clinical encounters that take place both between people and between texts. We began our argument by suggesting that the mandate for ‘meaningful use’ of electronic records (ONCHIT, 2010) is paradoxically lacking a focus on meaning; and that ‘meaningful use’ should be considered not as a technological, theoretical or regulatory notion, but as a complex multi-dimensional process that impacts the lives and experiences of patients, their families, and the practitioners who serve them.

‘Meaningful use’ of health records as relevant to autism is not *a fait-accompli* but rather requires deliberate, strategic and collaborative efforts on the parts of parents of children with autism and the practitioners who serve them. To inquire into what constitutes ‘meaningful use’ of health records in families’ lives, we examined the meanings and experiences engendered when parents read their children’s records, the impact the health records had on interactions during clinical encounters, and the roles that they played in disparities in autism diagnosis, interventions and services.

Our data show that health records produce not only a certain kind of a patient, (Berg & Harterink, 2004), the child with autism, but also a certain kind of a parent. The latter process enfolds at both the material and the textual - discursive levels. Practices of being and becoming an ‘autism parent’ (de Wolfe, 2013; Silverman, 2011) are inextricably tied with the use of children’s health records, which parents marshal to negotiate interventions and services for their children, and to display their epistemic authority and expertise about autism in general and their child’s autism in particular (Eyal & Hart, 2010; Gray, 2008; Lilley, 2011). We showed that practices of being an ‘autism parent’ are far from straightforward, and that parents’ use of their children’s health records during clinical encounters requires considerable psychological resilience and “narrative mind-reading” (Mattingly, 2008).

At the textual-discursive level, the health record produces a certain kind of parent through practices of characterization and description. Medical sociology and health informatics literature have examined the social organization which underlies the creation of the record, showing how the acts of reading and writing the record are contingent upon the socially organized practices of the clinic (Clarke et al., 2003; Gorman et al., 2003; Greatbatch, et al., 2001; Heath & Luff, 1996). Our data show that these practices are far from neutral and that they involve not only the practices of documenting the diagnosis and intervention planning but also the practices of describing the parents. Seemingly neutral demographic facts of parental employment, education level, marital or mental health status appear in the health records as signposts of ‘psychosocial risk’ or well-being and gain power as they are echoed from one record to the next as sub-texts for whose child is deemed more, and whose less, “service-worthy” (Marvasti, 2002, Solomon & Lawlor, 2013).

We considered how records are engendered as certain kinds of texts and material artifacts and how they give rise to certain kinds of experiences and actions. This approach afforded a unique view of families’ experiences of their children’s autism and of the processes of acquiring interventions and services for their children. This attention to particularities of patients’ and families’ experiences has been part of family-centered care movement that was

meant to change the nature of healthcare and the expectations of families and practitioners, emphasizing collaborative relationships among them and recognizing families' unique cultural worlds (Lawlor & Mattingly, 2014). The principles of family-centered care support the participation of families in the construction of health records, their contribution of unique knowledge about a family member, and their goals for treatment outcomes. Many of the assessments and reports in our data corpus display a marked difference from traditional medical records in their style and format. From the parents' perspectives, however, it seems that these family-centered attempts have not sufficiently transformed health record-writing practices related to children's autism. Our data reveal the significant impact this can have on parents' experiences of reading descriptions of their children and of themselves in their children's records.

Autism is positioned at the intersection of multiple institutional worlds and provides a unique vantage point from which the 'social life' of records becomes especially visible. Our analysis provides unique insights into the role of records in the naming and framing of children and their families in ways that contributes to healthcare disparities related to autism. With the looming inevitability of transition to electronic health records and persisting healthcare disparities in the U.S., consideration of the 'social life' of health records is critical for improving professional awareness and enhancing family-practitioner collaborations to provide timely and accurate diagnosis, interventions and services for children with autism. This article lays out an empirically grounded foundation for future studies that will contribute to putting the 'social life' of health records in the service of equitable healthcare.

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## References

- American Psychiatric Association. Diagnostic and statistical manual of mental disorders: DSM-IV-TR. Arlington: American Psychiatric Publishing; 2000.
- Bakhtin, MM. Speech genres and other late essays. Austin: University of Texas Press; 1986.
- Berg, M. Health information management: Integrating information technology in health care work. New York: Routledge; 2004.
- Berg M, Harterink P. Embodying the patient: Records and bodies in early 20<sup>th</sup>-century US medical practice. *Body & Society*. 2004; 10(2–3):13–41.
- Centers for Disease Control and Prevention. CDC health disparities and inequalities report - United States, 2011. *Morbidity and Mortality Weekly Report*. 2011; 60(Supplement) <http://www.cdc.gov/mmwr/pdf/other/su6001.pdf>.
- Centers for Disease Control and Prevention. Prevalence of autism spectrum disorder among children aged 8 years — Autism and Developmental Disabilities Monitoring Network. 2014 11 Sites, United States, 2010.



- Charon, R. *Narrative medicine: Honoring the stories of illness*. Oxford University Press: New York; 2006.
- Clarke KM, Hartswood M, Procter RN, Rouncefield M, Slack R. Trusting the record. *Methods of Information in Medicine*. 2003; 42(4):345–352. [PubMed: 14534632]
- de Wolfe, J. *Parents speak: An ethnographic study of autism parents*. Columbia University; 2013. Unpublished Doctoral Dissertation
- Eyal G, Hart B. How parents of autistic children became experts on their own children: Notes towards a sociology of expertise. *Berkeley Journal of Sociology*. 2010; 54:3–17.
- Feagin J, Bennefield Z. Systemic racism and US health care. *Social Science & Medicine*. 2014; 103:7–14. [PubMed: 24507906]
- Gallegos E. Doctors sue to collect unpaid bills from failed health care provider. *Los Angeles Daily Journal*. 2010 Nov 24. Retrieved from [http://www.mrlp.com/images/presscoverages/DJarticle\\_Selesnick\\_LaVida\\_November2010.pdf](http://www.mrlp.com/images/presscoverages/DJarticle_Selesnick_LaVida_November2010.pdf).
- Gorman P, Lavelle M, Ash J. Order creation and communication in healthcare. *Methods of Information in Medicine*. 2003; 42(4):376–383. [PubMed: 14534637]
- Gray DE. Coping with autism: Stresses and strategies. *Sociology of Health & Illness*. 2008; 16(3): 275–300.
- Greatbatch D, Murphy E, Dingwall R. Evaluating medical information systems: Ethnomethodological and interactionist approaches. *Health Services Management Research*. 2001; 14(3):181–191. [PubMed: 11507812]
- Grice, H. *Studies in the way of words*. Cambridge, MA: Harvard University Press; 1989.
- Heath C, Luff P. Documents and professional practice: “Bad” organisational reasons for “good” clinical records. 1996 Retrieved from <http://cleo.ics.uci.edu/teaching/Spring08/163/readings/p354-heath.pdf>.
- Heritage J. Epistemics in action: Action formation and territories of knowledge. *Research on Language & Social Interaction*. 2012; 45(1):1–29.
- Howlin P, Goode S, Hutton J, Rutter M. Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry*. 2004; 45(2):212–229. [PubMed: 14982237]
- Kerr EA, Mittman BS, Hays RD, Siu AL, Leake B, Brook RH. Managed care and capitation in California: How do physicians at financial risk control their own utilization? *Annals of Internal Medicine*. 1995; 123(7):500–504. [PubMed: 7661493]
- Lawlor, MC.; Mattingly, C. Family perspectives on occupation, health and disability. In: Boyt Schell, BA.; Gillen, G.; Scaffa, ME., editors. *Willard and Spackman’s Occupational Therapy*. 12th edition. Philadelphia: Kluwer Lippincott; 2014. p. 150-162.
- Lilley R. Maternal intimacies: Talking about autism diagnosis. *Australian Feminist Studies*. 2011; 26(68):207–224.
- Lord C, Petkova E, Hus V, Gan W, Lu F, Martin DM, Risi S. A multisite study of the clinical diagnosis of different autism spectrum disorders. *Archives of General Psychiatry*. 2012; 69(3): 306–313. [PubMed: 22065253]
- Magaña S, Parish SL, Rose RA, Timberlake M, Swaine JG. Racial and ethnic disparities in quality of health care among children with autism and other developmental disabilities. *Intellectual and developmental disabilities*. 2012; 50(4):287–299. [PubMed: 22861130]
- Mandell DS, Listerud J, Levy SE, Pinto-Martin JA. Race differences in the age at diagnosis among medicaid-eligible children with autism. *Journal of the American Academy of Child and Adolescent Psychiatry*. 2002; 41(12):1447–1453. [PubMed: 12447031]
- Mandell DS, Wiggins LD, Carpenter LA, Daniels J, DiGiuseppi C, Durkin MS, Kirby RS. Racial/ethnic disparities in the identification of children with autism spectrum disorders. *Am J Public Health*. 2009; 99(3):493–498. [PubMed: 19106426]
- Marvasti AB. Constructing the service-worthy homeless through narrative editing. *Journal of Contemporary Ethnography*. 2002; 31:615e651.
- Matson JL. Determining treatment outcome in early intervention programs for autism spectrum disorders: A critical analysis of measurement issues in learning based interventions. *Research in Developmental Disabilities*. 2007; 28(2):207–218. [PubMed: 16682171]

- Mattingly C. Reading minds and telling tales in a cultural borderland. *Ethos*. 2008; 36(1):136–154. [PubMed: 20706549]
- Mattingly, C. *The paradox of hope: Journeys through a clinical borderland*. Berkeley: University of California Press; 2010.
- ONCHIT. Office of the National Coordinator for Health Information Technology: Supporting meaningful use. 2010. Retrieved December 27, 2013, from <http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/downloads/TempCert-SCC-Slides-072210.pdf>
- Plovnick RM. The progression of electronic health records and implications for psychiatry. *American Journal of Psychiatry*. 2010; 167(5):498–500. [PubMed: 20439396]
- Robinson JC. Physician organization in California: Crisis and opportunity. *Health Affairs*. 2001; 20(4): 81–96. [PubMed: 11463094]
- Robinson JC, Casalino LP. The growth of medical groups paid through capitation in California. *New England Journal of Medicine*. 1995; 333(25):1684–1687. [PubMed: 7477222]
- Rosenberg, CE. *The care of strangers: The rise of America's hospital system*. Baltimore: Johns Hopkins Press; 1987.
- Rudman DL. Shaping the active, autonomous and responsible modern retiree: An analysis of discursive technologies and their links with neo-liberal political rationality. *Ageing & Society*. 2006; 26:181–201.
- Silverman, C. *Understanding autism: Parents, doctors, and the history of a disorder*. Princeton: Princeton University Press; 2011.
- Smedley, BD.; Stith, AY.; Nelson, AR., editors. *Unequal treatment: Confronting racial and ethnic disparities in health care*. Washington, DC: National Academies Press; 2003.
- Solomon O. Sense and the senses: Anthropology and the study of autism. *Annual Review of Anthropology*. 2010; 39:241–259.
- Solomon O, Lawlor MC. “And I look down and he is gone”: Narrating autism, elopement and wandering in Los Angeles. *Social Science & Medicine*. 2013; 94:106–114. [PubMed: 23890970]
- Valentine K. A consideration of medicalisation: Choice, engagement and other responsibilities of parents of children with autism spectrum disorder. *Social Science & Medicine*. 2010; 71(5):950–957. [PubMed: 20619521]
- Valicenti-McDermott M, Hottinger K, Seijo R, Shulman L. Age at diagnosis of autism spectrum disorders. *The Journal of Pediatrics*. 2012; 161(3):554–556. [PubMed: 22683037]
- Williams M, Atkins M, Soles T. Assessment of autism in community settings: Discrepancies in classification. *Journal of Autism and Developmental Disorders*. 2009; 39(4):660–669. [PubMed: 19051002]
- Wodak, R. Critical discourse analysis. In: Seale, C.; Gobo, G.; Gubrium, JF.; Silverman, D., editors. *Qualitative Research Practice*. London: Sage; 2004. p. 197-213.
- Zaremba, A. Warrior parents fare best in securing autism services. *LA Times*. 2011 Dec 13. Retrieved from <http://www.latimes.com/news/local/autism/la-me-autism-day-two-html,0,3900437.htmlstory>

### Research Highlights

- Chronicles families' experiences of autism through analysis of health records.
- Argues that health records have a 'social life,' are dialogic, and multi-voiced.
- Describes how health records disagree, become lost, and are not acted upon.
- Explores the intersections of health records and health disparities.
- Discusses health records in relation to family-centered care movement.