

Panning for Gold – an institutional ethnography of health relations in the process of diagnosing autism in British Columbia*†

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Abstract:

Health reform practices in Canada and elsewhere have restructured the purpose and use of diagnostic labels and the processes of naming such labels. Diagnoses no longer tell doctors and patients what may be wrong and inform of potential courses of treatment; some diagnoses activate specialized services and supports for persons with a disability and those who provide care for them. This is seen in the diagnostic process of autism in British Columbia, where a provision of health care and educational services and supports are made available based on the outcome of a standardized process of diagnosing autism spectrum disorders. Such processes enter individuals into a complex of text mediated and regulated relations, based on the principles of evidence-based medicine. However, the diagnosis of autism in children and the process itself is notoriously uncertain. Because of this ambiguity, standardizing the diagnostic process of autism constitutes a *Social Problem*, as it is often an essential hurdle for parents who have children with problems that may lead to a diagnosis on the autism spectrum in gaining help and support. Such processes and their organizing relations are problematized, explored and explicated below. Grounded in the epistemological and ontological shift offered by Dorothy E. Smith (1987; 1990; 1999; 2005), this paper reports on the findings of an institutional ethnographic study that explored the diagnostic process of autism in British Columbia. More specifically, this paper focuses on the processes involved in going from the actual experiences of mother's talking about their child's problems to the formalized and standardized, and thus "virtually" produced, diagnosis that may or may not give access to services and supports in different systems of care. Two psychologists, a developmental pediatrician, a social worker (all of whom are individuals that make up a specialized multidisciplinary assessment team in British Columbia), and mothers of children with a diagnosis on the autism spectrum were interviewed. The implications of standardizing the process of diagnosis where the disability is not clear-cut and where funding is attached are discussed. This ethnography also provides a glance into health reform practices and their impact on people's everyday doings.

Key terms: autism spectrum disorders, institutional ethnography, textually mediated relations, standardization, evidence-based medicine, and health reform practices.

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It was nearly 65 years ago, in 1943, that Leo Kanner reported findings from eleven case studies of persons who had “autistic disturbances of affective contact” (1943). He described individuals who “had failed to develop normal relationships, were upset by changes in their environment and showed abnormalities in speech and language” (cited in Freeman, 1997: 641). Thus, autism entered into a process of becoming an institutionally diagnosable and actionable disorder. This process culminated when the disorder was officially included in a master text of mental disorders under the category of “schizophrenic reaction, childhood type” (American Psychiatric Association, 1952: 25), and has been continually re-defined as new information became available. For instance, it is now recognized that there is no “all-or nothing form [of autism] but rather” a continuum of severity, known as Autism Spectrum Disorders (ASD)² (Smith et. al., 1994).

My interests in ASD developed out of my experience as a behaviour therapist working with children with a diagnosis on the autism spectrum at a residential treatment-care facility. Following my experience at this facility, I re-entered the academic setting with an interest and focus on autism. While the study of ASD is relatively rare in sociology, I felt that autism, and more specifically the social impacts of autism, allowed for an entry point into many “sociological” areas that were of interest to me. For instance, for my graduate research, I chose to study mothers’ experiences of caregiving for children with ASD, with a specific focus on how they experienced stressors, joys, and how they coped before and after out-of-home placement. In this area of research, I came across many journal articles suggesting the need for early intervention therapy in order to

² I use the terms ASD and autism interchangeably.

help both children with ASD and their families. The study initially arose out of what I saw as a need to explore the diagnostic process of autism to gain a better understanding of the disjuncture between the need for early intervention and treatment for children with autism, and the difficulties associated with gaining a diagnosis of autism to obtain this help. However, as I began interviewing parents of children with autism (both for my masters thesis and for this study), a pediatrician, two psychologists (an Autism Specialist and a psychologist), and an intake social worker, my initial problematic expanded to explore the institutionally coordinated everyday doings of mothers and others³ involved in the process of diagnosis.

The focus of this paper is on the institutional processes that translate the experiences of mothers of children who exhibit the kinds of behaviours that may lead to a diagnosis of autism into a standardized textual representation of autism. This inquiry does not concentrate on the individuals involved in the process per se, but on how these individuals are coordinated and organized by texts that mediate their experiences and doings. I do so by utilizing the sociological and methodological approach of institutional ethnography (IE). IE problematizes the everyday world by focusing on the translocal, and often invisible, relations that organize and coordinate people's everyday doings. The research described in this paper focuses on the complementary work⁴ of professional practitioners and parents in arriving at a diagnosis of autism, and on the textually mediated sequences that produce a particular situation and experience as a standardized

³ The phrase *mothers and others* refers to a number of individuals who participate in the process of diagnosing autism, including mothers, fathers, siblings, the child with autism, doctors, teachers, therapists, social workers, other family members, friends, etc. I focus on mothers as they are often the primary caregivers of children with autism (Gray, 2003) and practitioners who are a part of the assessment process.

⁴ Institutional ethnographers apply a “generous” concept of work, not understood in the traditional sense of paid work but anything that people do that takes time, effort, and intent (see Diamond, 1992; Smith, 2005).

representation of “autism” or “not autism”. What I discovered throughout this investigation, and try to explicate below, is how relations of ruling, that is how “the lives of people are regulated and governed by institutions and individuals vested with authority” (G. Smith, cited in Frampton et al., 2006: 55), coordinate the work of mothers and others throughout the process of diagnosing autism in which a diagnosis of autism may or may not be the end product.

This paper is organized into four sections. The **first** section provides a brief overview of autism spectrum disorders and the process of diagnosing autism in the context of current conceptualizations⁵. This section ends with an attempt to provide the reader with a brief overview of the context of, what I call, “autism relations” in British Columbia. Section **two** provides a brief overview of IE as a sociology and method of inquiry. I discuss key aspects of IE and bring into view how IE can provide a lens to explore the process of diagnosing autism and, more generally, health relations. In the **third** section, IE is put into practice. This section includes a depiction of map work, exemplifying how texts coordinate and organize people’s doings at a specific point in time during the diagnostic process of autism (the assessment stage). The purpose of this section is to make visible what is invisibly present in people’s everyday doings by explicating how an individual’s actuality is made institutionally actionable, and thus a “virtual reality” (Rankin, 2003, cited in Smith, 1990: 103). I show how the work of both parent and practitioner is textually mediated with the intent of filling “autistic shells” through a “sifting” process. This work activates further social relational sequences down

⁵ It is important to note that I was not guided by the literature discussed. As George Smith writes, “instead of starting with a review of the literature, this was left to the end of the research so that the analysis of the data could provide a structure of relevance for the reading rather than the other way around” (cited in Frampton et al., 2006: 67).

the line. The **fourth** section discusses the implications of this analysis in the context of the process of diagnosing autism and the broader implications to health relations and practices. I discuss the limitations of the process of diagnosing autism based on the standardization of a disability that is not so standard.

Section 1 – Autism Spectrum Disorders and the diagnostic process:

Overview:

Autism Spectrum Disorders (ASD), or pervasive developmental disorders, is a spectrum of disorders that can be characterized by a triad of qualitative impairments, as outlined in the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 1994) and by the International Classification of Diseases, version 10 (World Health Organization, 1992). While ASD broadly consists of five related disorders⁶, the core deficits are manifested in the areas of 1) communication, 2) reciprocal interactions, and 3) restricted, repetitive behaviours and interests (Seltzer et al., 2004). Impairments in communication are manifested in both expressive and receptive language development, where some children may “never develop meaningful communication skills” (Seltzer et al., 2004: 236). For those who do develop verbal communication, often those with Asperger’s Syndrome, “abnormalities in prosody and volume” (ibid) in addition to limited topics of speech may be present. In the area of non-verbal communication, impairments include lack of eye contact⁷ and inappropriate body gesturing (Gray, 1998). The second major qualitative impairment includes deficits in reciprocal and social interactions, including inappropriate use of “nonverbal behaviors to

⁶ Autistic Disorder, Rett’s Disorder, Childhood Disintegrative Disorder, Asperger’s Disorder, and Pervasive Developmental Disorder-not otherwise specific (PDD-NOS).

⁷ From my experience of working with children with ASD and from what I have heard from parents and practitioners, children with ASD might not look at you but look through you.

regulate social interaction, difficulty making friends, limitations in shared enjoyment of interests with others, and a general lack of social or emotional reciprocity” (American Psychiatric Association, 2000, cited in Seltzer et al., 2004: 237). The last core area of deficits includes restricted, repetitive behaviours and interests, primarily in three overlapping domains: behavioural (such as perseverations, aggressions, tantrums, head banging, and self-injurious behaviors), communicative (repetitive speech), and cognitive (obsessive tendencies and limited interests).

While these are all core deficits that constitute ASD, it is important to reemphasize that ASD is a spectrum disorder – individuals who are diagnosed on the autism spectrum are heterogeneous; the severities of impairments for individuals who have ASD vary from person to person (for further discussion, see Duchan, 1998; Gray, 2003; Seltzer et al., 2004). ASD is also often accompanied by mental retardation (Gray, 1994) and other co-occurring disorders (see Fombonne, 2003). Diagnosing a person with autism differs from diagnosing other disabilities and medical diagnoses. While many medical problems can be diagnosed by some definitive technical procedure, such as taking a blood or bone marrow sample, there is no definitive test for diagnosing children with autism (Nissenbaum et al., 2002). Autism is therefore diagnosed primarily through observing the child over a period of time, often in different settings (Ibid.) and by speaking to those who know the child best; in the cases discussed below, with the help of standardized assessment tools.

Autism Relations in British Columbia – the Process of Diagnosis:

The process of diagnosing autism can be a significant source of stress for families, whether the outcome is a diagnosis of autism or not (Corman, 2005; Corman, 2007; Howlin and Moore, 1997 cited in Whitaker, 2002). In addition, the diagnosis process is

often long and a significant challenge for all individuals involved in caring for the child suspected of having autism (Mansell and Morris, 2004). The length of the process is especially problematic when the consequences of a late or long diagnosis process are taken into consideration; this delay often results in parents and children with autism not receiving the kind of care (like early intervention) they need (Brogan and Knussen, 2003).

In an earlier institutional ethnography, Corman (2005) explored the lived-experience of a mother as she moved between parenting, caring and worrying about her child, and the world embedded within the biomedical model of health during the process of diagnosing autism in British Columbia (BC). It was a stressful and difficult process in which she gradually learned how to work with and within the health care system to secure the help and support she and her child needed. In speaking to this and other mothers about the diagnostic process of autism and other caregiving experiences (Corman, 2007), I was drawn to explore the process of diagnosis from other standpoints, specifically the standpoint of practitioners, in the hope of gaining a better understanding of mothers' experiences. In order to do this, I must first contextualize the process of diagnosing autism in BC from the institutional optic.

Restructuring practices in the health care setting refer to systemic transformations, where actions are based on "explicit and specialized information", with the intent to make "visible and knowable whatever is to be managed...the new public management brings a specific set of knowledge practices to bear on health care, making its content visible in new and standardized ways" (cited in Rankin and Campbell, 2006: 8). In 2004, British Columbia (BC) experienced a "restructuring practice" whereby diagnostic services for

autism spectrum disorders for children six years of age and under were transformed to a standardized process based on principles of evidence-based medicine⁸. This reform process deployed one master text that governed the entire process of diagnosing autism in the Province. The *Standards and Guidelines for the Assessment and Diagnosis of Young Children with Autism Spectrum Disorder in British Columbia (2003)* (the *Standards and Guidelines* hereafter) is a policy document implemented by the Ministry of Health in BC that provides “minimum standards required in British Columbia to make a diagnosis of ASD in children under the age of six, to assist in establishing eligibility for ASD intervention services, and to establish consistency in the ASD diagnostic process across the province” (1). In other words, it provides a clinical pathway that outlines what should be done, when, and by whom. It ends with the assessment stage of the process, which is the focus of this analysis. Based on the *Standards and Guidelines*, individuals under the age of six who might have an ASD need to be assessed by a “multi-disciplinary” team consisting of an intake social worker, psychologists (an autism specialist⁹ and a psychologist), speech-language pathologist, and a pediatrician. The team is to meet at the end of the process and, based on their findings, agree on a proper diagnosis.

During the assessment stage of the process, “a standardized diagnostic interview [about the individual suspected of having ASD] with the primary caregiver/parent(s) and a standardized observation of social and communicative behaviour and play [of the individual suspected of having ASD] are necessary components of a diagnostic

⁸ Timmermans and Berg (2003: 3) describe evidence-based medicine as the “conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients”.

⁹ I refer to this individual as the “Autism Specialist” as this was how he was described to me by other members of the assessment team. According to what I heard, he was referred to as the Autism Specialist because of his specialized training and the number of individuals with autism he has assessed over the years. I was told this “informs his expert clinical judgment”.

assessment for ASD” (Standards and Guidelines, 2003: 16). Respectively, the Autism Diagnostic Interview – Revised (ADI-R) and the Autism Diagnostic Observation Scale (ADOS) are instruments that achieve this goal. These tools were introduced in 2004 because, as described by the pediatrician interviewed, they are “the gold standard in autism diagnoses”¹⁰. The purpose of these, and other tools, is to assist practitioners in the diagnosis process; they are used to help those who are trying to “measure” the qualitative impairments of autism and quantify them. (For an overview of the goals, description, and scoring of the ADI-R, refer to Appendix A. While I focus specifically on the ADI-R due to the confines of this paper, it is important to note that the analysis applies to the ADOS as well. I briefly discuss this in Section 3.

The *Diagnostic and Statistical Manual of Mental Disorders*, Fourth Edition (DSM-IV) (American Psychiatric Association, 1994) is embedded within the *Standards and Guidelines*, the ADI-R, and ADOS. This document outlines the criteria for autism spectrum disorders used by a variety of organizations (including the government) and practitioners in North America. Smith’s (2005) concept of intertextuality, where “...higher level texts establish the frames and concepts that control and shape lower level texts” (226), is relevant here. The *Standards and Guidelines* and the instruments are framed by the DSM-IV, which outlines specific criteria for autism to be diagnosed. In other words, the *Standards and Guidelines* outlines what should be done (i.e. the ADI-R and ADOS) to assist practitioners in assessing children who might have an ASD, based on the criteria outlined in the DSM-IV. (See Appendix B for the criteria of Pervasive

¹⁰ Timmermans and Berg describe the gold standard as standards that are considered to be definitive and decisive (2003: 26-27).

Developmental Disorders as outlined in the Diagnostic and Statistical Manual of Mental Disorders IV (1994)).

When a diagnosis of ASD is given, mothers and practitioners alike gain a better understanding of what may be wrong with the child. In addition, services and supports become available for children and their caregivers as the child ages into adulthood (see Table 1). In fact, a diagnosis on the spectrum enters the child and their caregivers into ongoing institutional processes throughout their life course¹¹. The point is, diagnoses no longer simply tell patients and practitioners what may be wrong and potential courses of treatment, an autism diagnosis actually makes available specialized services and supports for the person with a the diagnosis and those who provide care.

Table 1: Funding and other services are attached to a diagnosis of Autism Spectrum Disorder:

<p>0-6 years of age:</p> <ul style="list-style-type: none">• \$20,000 annually to purchase autism intervention• Early Intensive Behavioural Intervention Program• Family focused support• Other services	<p>6-18 years of age:</p> <ul style="list-style-type: none">• \$6,000 annually to purchase autism intervention services• Educational program – special education services	<p>19+ years of age:</p> <ul style="list-style-type: none">• Community Living BC services if IQ is 70 or less• Mental health services if individual qualifies
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This reform practice standardized the diagnostic process of autism from the inception of a problem to the final assessment stage. The focus of this paper is the final assessment stage, which results in the child who is suspected of having ASD and their

¹¹ It is important to note that the changes in funding from 0-6 to 6-18, and 19+ result because the individual with ASD, and proxy, their families, are moved between different institutional systems of coordination. For instance, from 0-6, the child with ASD “resides” in the Ministry of Health and Ministry of Children and Family Development, whereas from the ages of 6-18, the child is moved to the Ministry of Education and as well as the Ministry of Children and Family Development. This paper focuses on the individuals between the ages of 0-6. Further investigation is needed to explore how these other systems organize and coordinate caregivers and care receivers as both age over the life-course.

caregiver(s) being entered into a multifaceted text-mediated and regulated process of social relations with a multi-disciplinary team. This team is given the task of identifying or ruling out a diagnosis on the autism spectrum. I problematize and interrogate the assessment stage of the diagnostic process, which involves the team administering tools to create a “textual representation” of the child suspected of having ASD, via textually mediated relations (relations between people that are mediated by texts). In doing so, I explore and explicate an aspect of the “textual representation of health care” (Rankin and Campbell, 2006: 15), whereby, in this case, services are allocated based on the textual coordination and representation of people’s experiences and doings. My hope as an institutional ethnographer is to explicate the process of diagnosis in order to explain how this process works and is accomplished. The following section briefly describes the sociology and method I used to explore this restructuring practice.

Section 2 – Method:

Institutional ethnography (IE) is a sociology that focuses on the everyday world as its problematic. As a method of inquiry, it focuses on social relations as they are coordinated and organized via texts. Differing from other approaches to social inquiry, IE begins with people’s everyday lived-experiences, or actualities (where people are actually located), and problematizes their everyday/night doings. In doing so, it recognizes that knowledge is situated in the actual social context of lived-realities (Campbell and Gregor, 2002). If IE did not begin in the actualities of people’s everyday doings, it would not offer a unique lens for social inquiry; the alternative is to begin in a world already penetrated by discursive ways of knowing and doing.

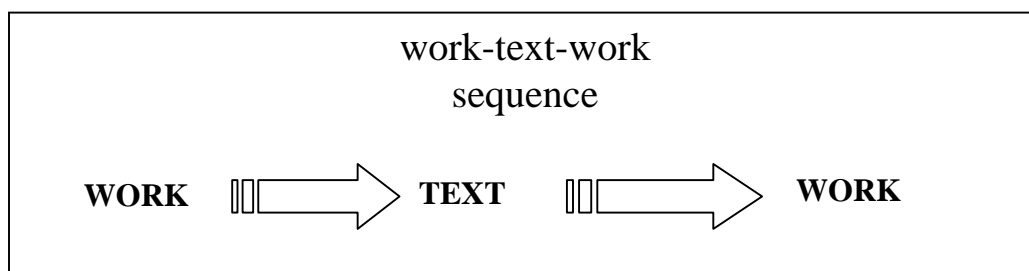
IE relies on using “interviewing, observation and documents as data...treating those data not as the topic or object of interest, but as ‘entry’ into the social relations of the setting” (Campbell, cited in Smith, 2006: 92). As such, for the first level of data collection, I decided to use semi-structured, open-ended interviews to “talk with people” (DeVault and McCoy, cited in Campbell and Gregor, 2002: 77). The people I spoke with included individuals that make up a multidisciplinary assessment team, including a developmental pediatrician, an Autism Specialist (psychologist), a general psychologist, and a social worker. In addition, I spoke with mothers of children with ASD, one specifically for this study and others for my thesis research. Interviews took place between 2005 and 2006 in British Columbia and Alberta, Canada. Interviews with the practitioners took place at an autism assessment centre in BC. I did not observe practitioners diagnosing children with autism; rather, I asked practitioners to teach me how they do their work as if I were to do it. The mothers I interviewed spoke retrospectively about their experiences of caregiving for a child with autism, which often included discussing the diagnostic process. Because they were retrospective accounts, often reflecting on experiences that occurred prior to 2004, the inserts I use below are simply meant to illustrate what they were experiencing and the work they were doing during the time leading up to a diagnosis. Inserts are further used to exemplify how practitioners might orient to a specific aspect of parents’ actualities, based on the *Standards and Guidelines* to make or rule out a diagnosis. By exploring different perspectives and experiences of individuals who are or were a part of this institutional process, it becomes possible to “map” the different work knowledges and “begin to assemble the sequences of action built from complementary work” (Smith, 2005: 159).

Smith (1987) points out that the object of inquiry for IE is not on people themselves but on explicating social relations as they extend beyond people's everyday/night doings. As such, the goal of research is to penetrate "sequentially deeper in the institutional relations in which people's everyday lives are embedded" (Smith, 2005: 38,158). The purpose is to shed light on how the social world is put together; in other words, to bring "into view the interface between [people's] individual lives and some set of institutional relations" (McCoy, cited in Smith 2006: 109). Knowing how things work provides the potential for individuals to use the knowledge produced from an institutional ethnography as an extension of their ordinary, everyday knowledge (Smith, 2005). In order to explore how things work and are discursively organized, exploring texts (anything that is replicable across time and space) and how they mediate social relations is key to IE. The hope is to move beyond the objectified subject of knowledge to explore and examine how people's experiences are connected to extended social relations that are textually mediated (Smith, 1990; 2005).

In IE, texts are viewed as major organizers and coordinators of people's everyday lives and are thus "constituents of social relations" (Campbell, 2001: 323) (for further discussion, see Smith, 2005: 7-26; 1990: 1-11; 1999). As constituents of people's everyday/night experiences, texts represent the juncture between people's daily lives and the method by which individuals are coordinated extralocally. The capacity for texts to coordinate people's doings extra-locally is accomplished by the nature of a text being a material thing that is able to surface in identical forms across time and space. In order to see how texts are constituents of social relations, IE views texts as active. Through the work-text-work sequence depicted in Figure 1, texts are conceptualized as being made

active by the work of people, which further coordinates and organizes people's doings. Texts are also seen as intertextual – texts do not stand alone from other texts, higher-level texts interact with and frame, shape, and control lower level texts (for further discussion, see Smith, 2005). Because of how texts are viewed and utilized in IE, the second level of data collection for this study moves beyond how people talk about their experiences to explore how their experiences are organized and coordinated via texts. In other words, I explore how people's experiences are hooked up into social relational sequences with others, and by others, via the medium of texts because texts are part and parceled with most things that happen (Campbell and Gregor, 2002). As such, in order to gain a better understanding of people's everyday doings and more generally, how things work, texts were ongoingly identified and explored as constituents of social relations and people's everyday doings. Multiple texts were identified in this study. For the purposes of this paper, I use three of them in my analysis; the *Standards and Guidelines*, the DSM-IV, and the ADI-R.

Figure 1 – The Active Text:



Using IE, I explore and explicate the standardized process of diagnosing ASD in BC. In doing so, I shed light on restructuring practices in BC and ethnographically describe how this ruling standpoint enters into and mediates people's everyday doings

(Rankin and Campbell, 2006). By making use of texts that process and reformulate people's experiences at the local setting and translate experiences into virtual realities at the institutional setting, IE provides a way of addressing hidden dangers in restructuring practices. Similar to Rankin and Campbell (2006), my analysis "enters water that looks calm and troubles it" (18). In saying that, I show the dangers in taking virtual realities as "truth".

Section 3 – Making the actual actionable and the diagnostic process of autism:

I begin this section with a brief overview of how mothers and others get to the assessment stage of the diagnosis process in BC. My overview begins with the point in time described by mothers and others when concerns arose about their child in the areas of social interactions, communication, and stereotypical patterns of behaviours – all of which are characteristics (diagnosable features) of autism. I have termed this time period *the perception of a problem*. Through a variety of textually mediated processes (one of which is briefly discussed below), the child is eventually suspected of having autism by certain individuals vested with authority. With the recognition that autism may be a possible diagnosis, further social relational sequences are activated. These activated sequences lead to the assessment stage of the diagnosis process – a mother and child come to an autism assessment centre where they are seen/assessed by a multidisciplinary team.

The Perception of a Problem and the activation of social relational sequences:

The process of diagnosing autism starts with the perception of a problem, often by parents. Teachers, teacher's assistants, friends, other parents, or anyone else who expresses concerns to parents might also initiate the perception of a problem. One mother

I interviewed, Jess¹², started having concerns about her child Kate during the early years of her development. What she explains below is similar to some of the mothers' experiences I heard.

So she was eleven years old [when diagnosed], but when she was a baby, it was constant crying all the time...And then we noticed that she wasn't sitting up, she wasn't doing proper eye movement... Things just weren't right and she was doing these jerking movements like when a baby's lying on the floor, she'd be like this all the time and they said that it was involuntary reflex movements or whatever. Then as the years went by, they finally figured out, ok there's something wrong but during that time it was, you couldn't do anything and this kid was screaming...Like, for example, going into a crowded store, she'd scream her head off, the windshield wipers going on the car, she'd absolutely go nuts; you'd pray it's not going to rain. Backing up, going reverse in a car um, anything like that, the broom, get out the broom she'd go nuts, the vacuum she'd go crazy, loud noises, constant, constant crying all the time.

During these early years of her child's development, a perception of a problem emerged for Jess, where she just knew something was wrong, perhaps comparing the development of her child to her older children's development. Knowing something was wrong, Jess continuously sought support by going to her family doctor expressing the concerns she had. While the diagnosis process began for Jess during the early years of Kate's life, the "clinical pathway" did not start until Kate fit within the discourse of medicine – this process of fitting in consisted of struggles between Jess's beliefs and knowledge as a

¹² A mother of a child who at the age of 11 received a diagnosis on the autism spectrum. All names have been changed to protect anonymity and assure confidentiality.

mother and the beliefs and knowledge of those who had the authority to make Jess's knowledge and beliefs "officially" recognizable.

When concerns of autism arise for mothers, often their first step is to go and see their general practitioner to voice their concerns. General practitioners, or other "qualified" personnel, act as a metaphorical gatekeeper vested with institutional power as outlined by the *Standards and Guidelines*; they are responsible for activating the "professional" referral process. This referral process is based on certain textually mediated relations. It is from this referral process that the parent(s) and child are referred to a general pediatrician, speech pathologist, psychiatrist, registered psychologist, or neurologist. Depending on what these individuals observe, the *Standards and Guidelines* gives them the institutional power to finally refer the parent(s) and child to the autism assessment network where the child will be assessed by a multidisciplinary team that specializes in autism diagnoses.

While Jess experienced one of many different pathways that may lead to the assessment centre, it is important to note that texts are active at different points throughout the entire process, even before the perception of a problem. These texts coordinate and organize the work of mothers and others. Furthermore, these texts (re)produce out of the parent(s) and child's actuality an organized and institutionally recognized "virtual reality" made actionable by and through the character of the text. In other words, institutional processes transpose "...aspects of their [both parent(s) and child in this case] everyday worlds into shapes that fit the topic-assigned spaces provided" (Smith, 2005: 226). This process is indicative of the assessment process described and

explicated below, where social relational sequences are activated depending on the virtual reality created.

What follows is an explication of one particular social relational sequence, when the child is being assessed by a multidisciplinary team of practitioners vested with authority to make a diagnosis on the autism spectrum. Here the work of mothers complements the work of practitioners. This sequence leads the actuality of mothering a child suspected of having autism to being made actionable via quantifying and standardizing, thus displacing her lived-experiences. This sequence occurs after the intake social worker has activated the assessment stage of the process of diagnosing autism and has set up an assessment appointment with the multidisciplinary team at the autism assessment centre.

Assessing and Textualizing the *Perception of a Problem*: the filling of “autistic shells”

At the assessment stage of the diagnostic process, the family would be called and scheduled for an assessment by the intake social worker. Once a date is agreed upon, parents would be given an “Assessment Schedule” outlining what is to be done, when, and by whom over the assessment period. The schedule not only orients the mother and child to the work to be done by practitioners, but also orients the mother and child to institutional processes, entering them into text-mediated and regulated relations aligned with the ruling apparatus. A generic schedule is listed in Table 2.

Due to the confines of this paper, I focus specifically on the social relational sequence between a mother and psychologist, which is organized and coordinated by the ADI-R. It is important to note that other members of the multidisciplinary team are at work before and after the point in time described below, which contributes to the

outcome of a diagnosis. For instance, at a point during the assessment process, the pediatrician would meet with the child to “do a medical consultation...do a physical exam” (Pediatrician) to determine if there is a medical cause of the child’s problems. Furthermore, the coordinator (intake social worker) of the process, while not listed in the assessment schedule (see Table 2), is “behind the scenes” coordinating the “different pieces” of the process, even before the official schedule begins. For instance, his work consists of gathering all of the referrals that indicate a need for an assessment that are sent to the Centre, ensuring the referrals are filled out correctly by the correct practitioners that “we can accept” (based on the *Standards and Guidelines*), and sending the referrals to the appropriate team throughout the jurisdiction.

Table 2 – Assessment Schedule:

<p>One-day Assessment:</p> <p>Gather all referral and supporting documentation prior to the assessment (Intake Coordinator)</p> <p>9:30 to 11:00am: medical consultation with (Developmental Pediatrician).</p> <p>11:00-1:00pm: ADI-R with (Psychologist: Autism Specialist)</p> <p>11:00-1:00pm: ADOS with (Psychologist)</p> <p>1:00-2:00pm: team meeting</p> <p>2:00-3:00pm: family conference</p>	<p>Two-Day Assessment:</p> <p>Gather all referral and supporting documentation prior to the assessment (Intake Coordinator)</p> <p>Monday:</p> <p>9:30-12 noon: ADI-R with (Psychologist: Autism Specialist)</p> <p>2:00-3:00pm: Psychology assessment (Psychologist: Autism Specialist)</p> <p>3:00-4:00 pm: Pediatric Consultation (Developmental Pediatrician)</p> <p>Tuesday:</p> <p>9:30-12 noon: ADOS & SLP assessment with (Psychologist)</p> <p>12noon to 1:00pm: team meeting</p> <p>1:00-2:00pm: family conference</p>
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At a point during this time of the process, in an attempt to “promote the application of evidence-based practices in the identification, assessment and diagnosis of children with ASD” (*Standards and Guidelines*, 2003: 2), the clinical Autism Specialist (psychologist) whom I interviewed is required to conduct two standardized tools. One

tool is the Autism Diagnostic Interview-Revised (ADI-R). This tool is a “standardized, structured caregiver ASD interview” that draws the parent(s) of a child suspected of having autism and the Autism Specialist into a very specific dialogue. The other tool is the Autism Diagnostic Observation Scale (ADOS) (discussed later), in which members of the assessment team observe the child suspected of having autism. These tools are used to assist practitioners in making the mother and child’s actuality actionable. In this paper, I focus on the social relational sequence mediated through the use of ADI-R. I exemplify the work involved in making the mother’s actuality as a caregiver for a child with autism (textually) actionable to practitioners.¹³

I begin by illustrating the complementary and complex work-text-work sequence between a practitioner and a parent (Diagram 1), where the ADI-R is used to assist the practitioner in diagnosing a child with autism based on a mother’s actuality. Diagram 1 shows the practitioner being guided extralocally by the ADI-R, which further guides the social relational talk between himself and the parent(s). At this point during the diagnostic process, the parent(s) would be sitting in an office, as I did during my interview with the Autism Specialist. The practitioner would take out (or already have set up) the ADI-R. In the activation of this instrument, the dialogue between the mother and practitioner would be mediated by this text (as depicted in the work-text-work sequence illustrated in Figure 1), organizing and coordinating their complementary work¹⁴. This diagnostic interview focuses on “getting maximal information from the parent about the

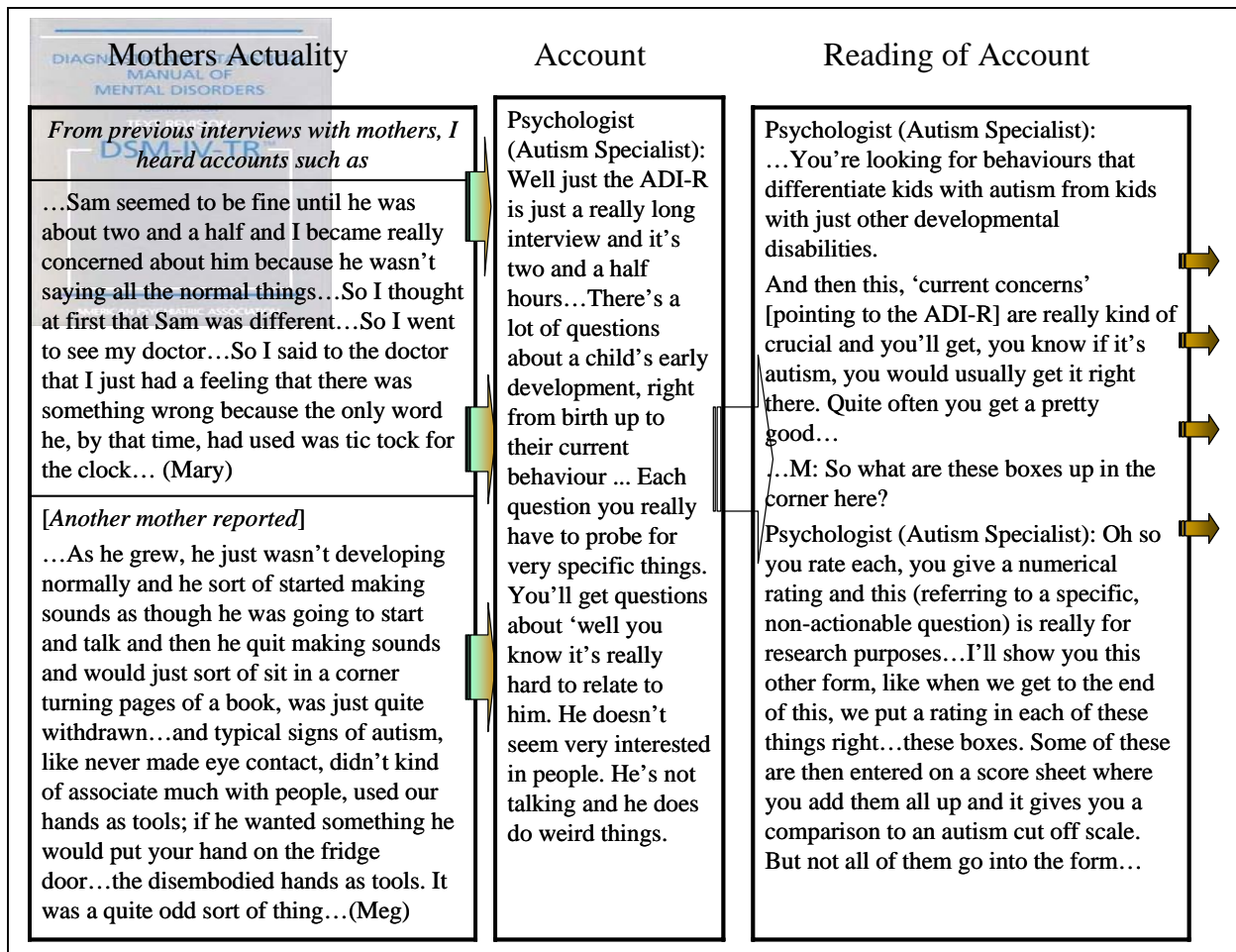
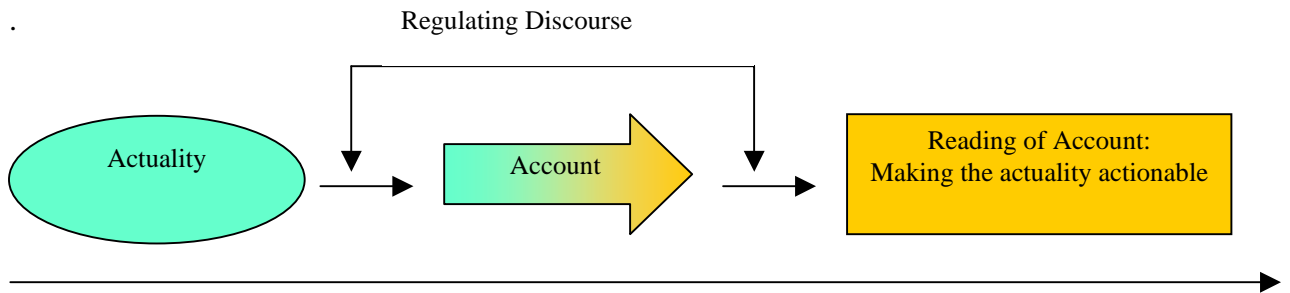
¹³ I focus on this sequence because of the nature of the work involved in this parent-practitioner interaction. Also, as mentioned above, this sequence is a microcosm of other social relational sequences throughout the process of diagnosing autism, and exemplify the work involved in making the parent and child’s actuality actionable.

¹⁴ Similar to a mother’s work being mediated by this text, my work in interviewing the practitioner was also mediated by the ADI-R.

three key areas that make up autism: (1) reciprocal social interaction; (2) communication and language; and (3) repetitive, stereotyped behaviors”¹⁵ and is an essential component of the assessment process.

¹⁵ http://www.health.state.ny.us/community/infants_children/early_intervention/autism/screenin.htm
(accessed December, 2006)

Diagram 1 – The work of interpreting via the ADI-R - the actual made actionable:



The left side of the diagram (actuality) represents inserts that I previously heard from mothers about their experiences leading up to a diagnosis on the autism spectrum. These inserts are meant to represent what might be spoken in this interview. The middle column (account) is the Psychologist: Autism Specialist discussing what the ADI-R is and what he looks for in a mother's actuality to diagnose ASD. The column on the right represents how the practitioner reads the account given in the first column, based on the account given through the ADI-R (Column 2). The DSM-IV is located behind the scenes in the upper left corner of the diagram to represent how it governs the entire sequence.

Diagram 1 shows how this social relational sequence is textually mediated with the intent of quantifying¹⁶ a mother's actuality to assist the practitioner in the assessment process. This process is governed by the *Standards and Guidelines* through the implementation of the ADI-R. The ADI-R and its attempts to quantify are further organized by the DSM-IV¹⁷. This process ultimately displaces experiential knowledge of both parent and practitioner into a textually mediated form that makes the actual actionable through the psychologist and parent's complementary work.

As Diagram 1 shows, the ADI-R asks very specific questions and requires very specific answers from parents in order to fulfill criteria specified in the "scoring" section of the assessment. In order for the practitioner to get very specific answers, the practitioner "probes" the mother's actuality. The Autism Specialist describes this probing process:

...And then you get to how much this child understands, again...So you start with a really open-ended question, 'tell me what his understanding is like now. How much do you think he understands?' So you get sort of a general description from the parent but then you start probing very specific things like 'if you send him into a room to get something, would he understand the instructions? Would he understand those two steps?' Or can he deliver a message like call dad to come to lunch? Etc...Yeah...Then, this is an interesting one um, where you ask about um 'before the kid had words, how did he communicate when he wanted something?' And so you get the parent to describe that and they might say 'well he just, he

¹⁶ "For most pediatric behavioral disorders...it's a matter of quantifying, measuring behaviour" (Pediatrician).

¹⁷ McCarthy uses the metaphor of a charter document to explain the impact of the DSM; "it thus stabilizes a particular reality and sets the terms for future discussions" (McCarthy cited in Bazerman and Paradis, 1991: 359).

would stand in front of the fridge and fuss’ or ‘he would drag me by the hand’ or ‘he would get it himself’ (see Diagram 1, left column, Meg). And then you ask **probing questions** (my emphasis) and, what you’re looking for here is whether the child ever takes your hand and places it on an object as if it was a tool. You’ve seen that right?... (You) start with a general question but you have to ask only specific questions to make sure if you really got what you’re looking for.

What happens in this interaction between the mother and practitioner is a dialogue that is put through a regulating discourse (the ADI-R). In the process of probing, the practitioner finds the information he needs from the mother’s actuality, knowing what the ADI-R requires in order to give a diagnosis. The end product is a reading of the mother’s account as framed by the regulating discourse. In doing so, the practitioner’s work of probing displaces the experiential knowledge of the parent(s) until he gets what he wants or needs to fill in a box (a metaphorical “autistic shell”¹⁸) with a number from 1-3 outlining the severity of the autism criteria displayed by the child as outlined in the specific section of the assessment tool. In the end, a few questions out of this 1-2 hour interview are calculated to make a final score, which determines whether the child meets ASD cut-off criteria for this tool, and thus the filling of autistic shells is complete. In other words, some questions from the ADI-R are scored while others are not. The questions that are scored are the ones that activate and refer back to the DSM-IV criteria, for the purposes of making the mother’s actuality actionable. Other questions might activate and inform

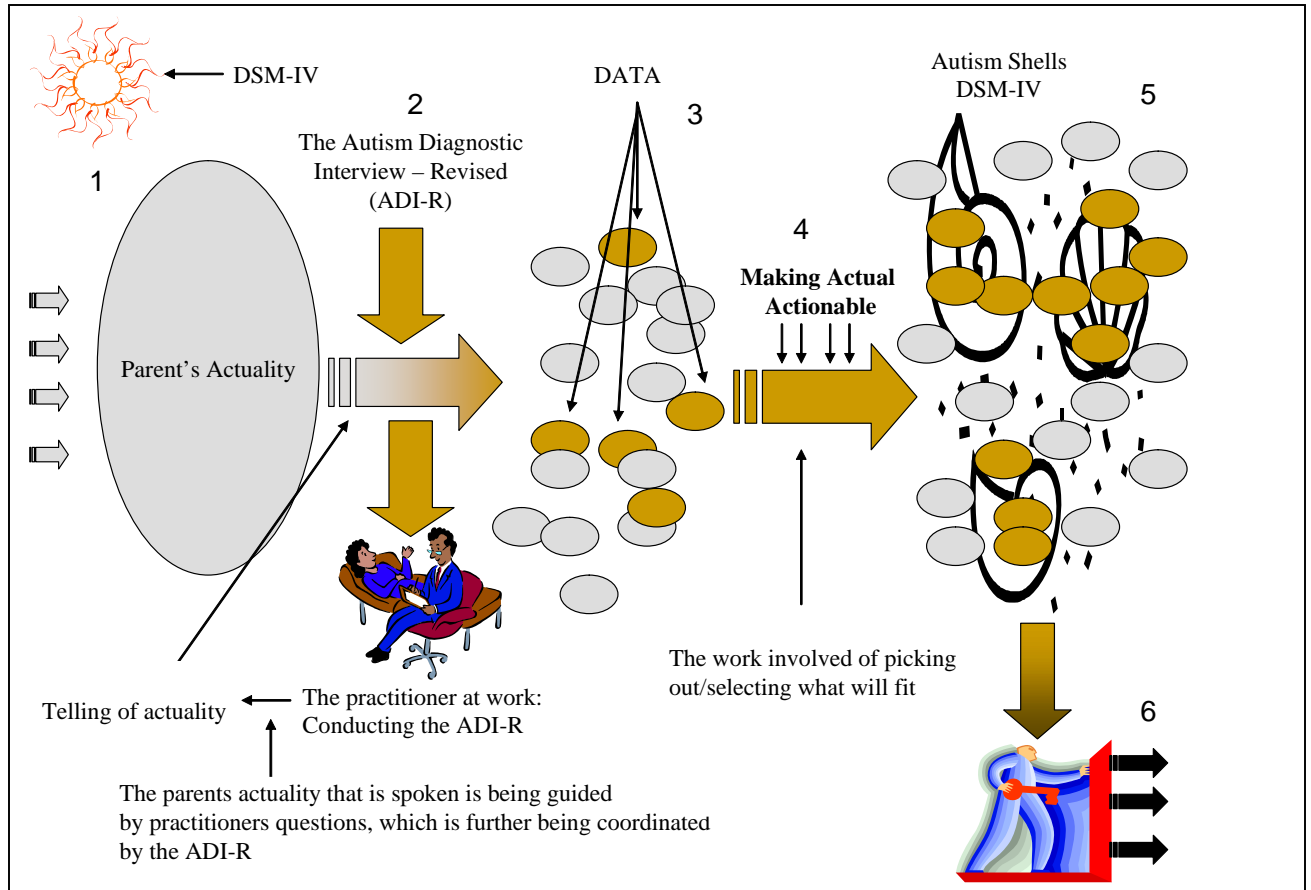
¹⁸ In describing the work involved in picking apart actualities to fit certain criteria, Smith uses the metaphor of filling a shell. I use this metaphor in the same sense of representing how aspects of actualities have to fit within categories (shells) in order to be made institutionally actionable. It is important to note that fitting into categories always displaces actualities because no category or description can ever be exhaustive of actualities, so there is always work involved in picking out or selecting what will fit.

social relational sequences down the line, such as an individualized care plan. Diagram 2 further explicates this process through map-work.

Map-work is a technique used by institutional ethnographers to show how knowledge is socially organized through institutional and social processes that textually mediate the work of individuals' doings. The purpose of mapping is twofold. First, like reading a road map, mapping allows individuals to locate themselves within the terrain of the ruling apparatus. Second, mapping assists individuals in gaining more knowledge about the processes in which they are embedded, helping them to ultimately become subjects instead of objects of social relations.

This map begins with the actual lived experience of the mother (1). This experience is represented in column 1 of Diagram 1 (parent's actuality). At this point in the assessment process, the mother is participating in an interchange with the practitioner that is being guided by the ADI-R (2) (shown in Diagram 1, column 2). In other words, the telling of the mother's actuality is being guided by the practitioner's questions, which is further being coordinated by the ADI-R. This sequence in which the practitioner's work orients to the actuality that is to be made actionable according to the ADI-R results in the picking apart/sifting of actualities into data (depicted as gold nuggets) through the work of probing (3). Point (4) in the map is the product of the complementary work of the mother and practitioner, and the work of the practitioner in picking out/selecting what will fit into the "autistic shells". This process concludes with filling, or not filling, of "autistic shells" according to this text (5) and the social relational sequences that may or may not follow (6), making the mother's actuality actionable in some way. This specific point is also represented in Diagram 1, column 3.

Diagram 2 – The Actuality Made Actionable (by the ADI-R):



This active map represents one aspect of the process of diagnosing autism (the assessment stage) after being referred to the autism assessment network by a practitioner vested with authority. This sequence of relations between practitioner and parent occurs during the implementation of the ADI-R, as required by the *Standards and Guidelines*. This map shows how the complementary work of a parent and a practitioner is textually mediated in order to meet specific criteria to assist the practitioner in the process of diagnosing autism. It is important to note that the practitioner is coordinating and organizing the mother's actuality but is also being coordinated and organized extralocally by the ADI-R, *Standards and Guidelines*, and DSM-IV. This coordination represents textually mediated relations in which the work of the parent and practitioner is being organized extralocally through a sifting process that attempts to fill "autistic shells" based on "evidence" (gold nuggets) to support a designation of autism. Notice the sun at the top left corner of the Diagram and how it shines down on the whole process.

Diagram 2 makes visible how the complementary work of practitioner and parent makes the parent's actual lived experience actionable by drawing on it to fill "autistic shells" according to the criteria outlined in the ADI-R. This sequence of actions is further being framed by the *Standards and Guidelines* in an attempt to fulfill requirements

outlined in the DSM-IV. The mother's experience is "textually" made "experienced" and what she has observed throughout her work of parenting is "textually" made "observable".

The Standardization of a Process:

As mentioned, the ADI-R is one of many tools used to assist practitioners in making the actuality of mothers and others actionable during the assessment stage of the process of diagnosing autism. Diagram 3 represents a broader picture of the process of diagnosis in which the actuality of mothers and others (Diagram 3, 1) is made actionable through the work of practitioners (Diagram 3, 2) and a series of standardized tools (Diagram 3, 3), including the ADI-R and ADOS. The ADOS, when implemented, is a tool used to observe the child who is suspected of having autism in different types of simulated activities, with the focus on observing social and communicative behaviours. In the course of the practitioner's work of observing the child's behaviours, the ADOS produces standardized descriptions of behaviour that can then be used to fill the diagnostic shells. This tool orients a practitioner's work¹⁹ to look for very specific behaviours associated with autism. This is accomplished through the work of the practitioner in observing and "pressing" the child's behaviours, similar to the work of probing activated by the ADI-R. This assists the practitioner in scoring/quantifying the actuality of the child into some actionable observation that he then textualizes via the ADOS scoring sheet. After the practitioner's work of implementing these tools, and the work of others (including the mother and child, members of the multidisciplinary team, and so on), the "data" is gathered and the team meets (Diagram 3, 4), because "the

¹⁹ With the intent of organizing and coordinating the practitioners experiential knowledge with a standardizing effect.

Guidelines now call for a team-based diagnosis” (Pediatrician), to determine whether the child fulfills the required criteria for a diagnosis of autism based on the *Standards and Guidelines* (Diagram 3, 5).

Diagram 3 – A broader view of the process of diagnosing autism and textually mediated relations:

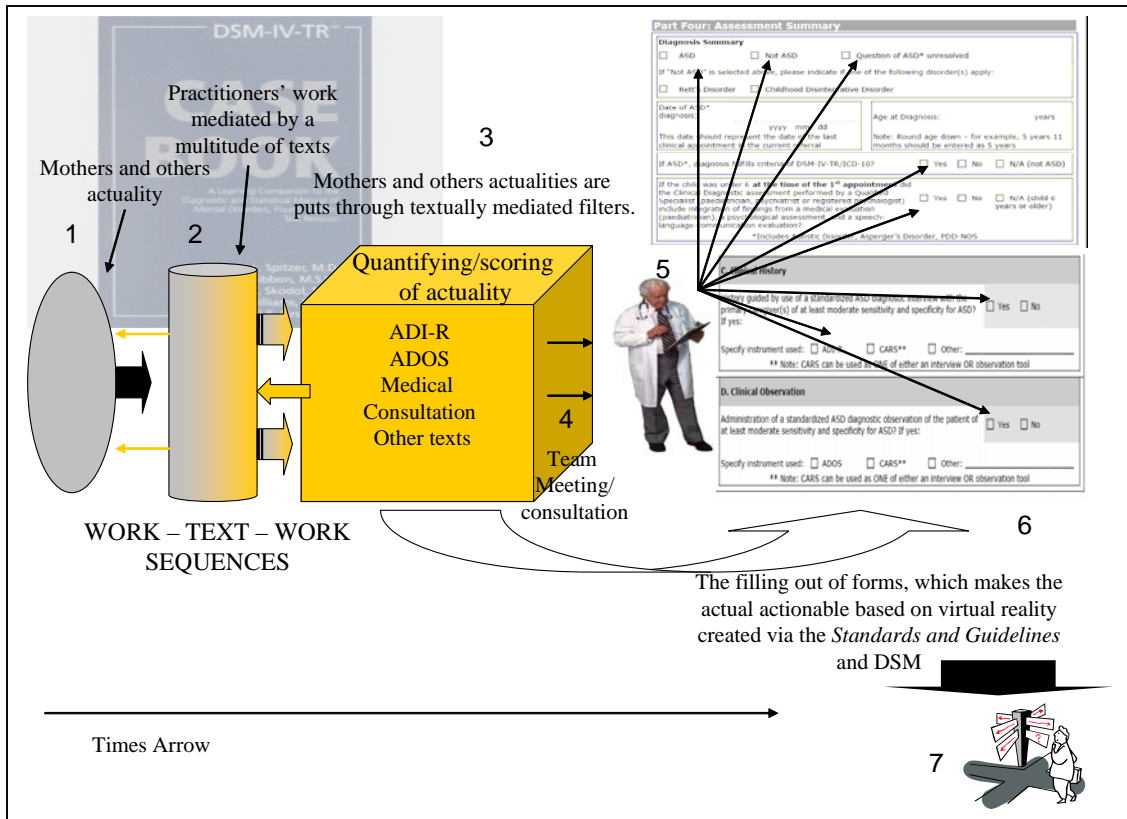


Diagram 3 represents a broader view of the assessment process in which the parent and child’s actuality is put into a dialogue with different practitioners (as discussed above) through textually mediated social relational sequences. These sequences are mediated by the practitioner’s work, which orients to assessment tools and requirements set out in the *Standards and Guidelines* (Diagram 3, 1-3). Through the complementary work of mothers and others, a consensus must be made between practitioners in the form of an outcome during the team/consensus meeting at the end of the assessment process. Based on the team meeting/consultation (Diagram 3, 4), forms are filled out that specify the outcome of the process, assuring the *Standards and Guidelines* were followed (Diagram 3, 5). These forms then activate other social relational sequences down the line (depending on the designation given) in the form of services and support in different systems (education, early intervention, community living, etc) (Diagram 3, 6,7). Notice how the DSM-IV is in the background of Diagram 3, representing how this master text governs the entire assessment stage of the diagnostic process of autism in BC.

The interview insert below represents how the actualities of mothers and others and their complementary work are made official and thus actionable at the end of the assessment. This is depicted in Diagram 3 (6, 7).

Autism Specialist: Yeah...our assessments are done as part of a big network of facilities around BC that do autism assessments. And there's something called the BC Autism Assessment Network [BCAAN]...around the province where there's a team that does diagnostic assessments. And so when kids are referred to me the referral is entered into a database run by BCAAN. They track how long it takes kids to be seen, and that sort of stuff...So they have a database and they just keep track of how many kids are referred for autism assessments/ How long does it take to get them to Centres? How many end up being diagnosed as autism or not? And so after I see a child (and after the team meeting), I go online and there's this form (PANTER²⁰) with the child's name entered into it 'cause he's already been referred, and then I just fill out this form, I say that 'I've completed an assessment. I used these instrument', and I give the scores on the instruments, and I say 'I've followed the *Guidelines*' basically, and then I put the outcome, 'the child is diagnosed with autism' or not. And then I **print** (my emphasis, textually making actualities actionable) a form right there, and I hand it to the parent and it's like four pages long. And it says that an assessment has been completed, the child has autism...and they go to the Ministry (of Children and Family Development).

²⁰ Provincial Autism Network Testing Evaluation Report (PANTER).

At the end of the assessment process, the practitioner, based on the work knowledges of the multidisciplinary team, fills out forms that are handed to parents and put into a database outlining the team's work and the outcome of the assessment, making the actualities of mothers and others institutionally actionable. If the metaphorical autistic shells are filled, the PANTER form activates other social relational sequences for the family and child, such as services, access to funding, education support and/or interventions. In addition, a "longer version" of the PANTER form is sent to BCAAN for administrative purposes. Depending on the outcome, mothers and others are further entered into other institutional processes, organizing and coordinating their ongoing work (Diagram 3, 7).

Section 4 – Discussion:

This ethnography has shown how the work of mothers and others is textually mediated to fill "autistic shells" as outlined by the *Standards and Guidelines* and other texts. The following discussion problematizes the use and intent of these texts and the process itself in diagnosing children with autism. I discuss the implications of a process that attempts to render uniform and actionable a disability that is not standard.

I refer to this process, now, using the metaphor of panning for gold to illustrate the implications of the diagnostic process. Panning for gold metaphorically refers to the work of panners, in this case health professionals, who sift through the "dirt" of mother's actualities in search of gold – institutionally actionable experiences/representations. My hope in using this metaphor is to put an image into readers' minds of a person or people working very hard to find very specific things (in the case of a panner, gold). I suggest that this panning process, in some cases, creates a pile-up of unaccounted actualities that

fall through the cracks, resulting in individuals being left outside the scope of services and supports.

Autism Spectrum Disorders and panning for gold:

As previously mentioned, autism is a disability characterized by qualitative impairments in social interaction, communication, and behaviours that occur on a spectrum. There is no single type of autism; rather, the nature of the disability results in many varieties of autism(s). The work that goes into diagnosing autism differs from other types of quantifiable medical problems, such as high blood pressure, Downs Syndrome, diabetes, etc. that can be diagnosed by specific tests. Furthermore, some practitioners describe autism as in flux; descriptions of “autistic” behaviours fluctuate “varying with one’s goals, audience, frame of reference, and point of view” (Duchan, 1998: 108). As Duchan (1998) states:

The way their [people with autism] behaviors are described and explained can differ considerably across different reports and even within a single report...Descriptions also serve different discourse functions. Some illustrate a large point being made that the child exhibits certain traits, that a child is difficult to deal with, that a child is autistic...Behaviors are selected and interpreted in light of a prevailing theoretical paradigm or discourse agenda (94-95).

As such, the characteristics of autism are unique to each person who has the disability. Furthermore, there are differences among the individual(s) doing the work of describing or measuring the disability. Autism is a disability with many gray (immeasurable and ambiguous) areas.

In an attempt to standardize the diagnosis process and make qualitative impairments decisive and definitive (Timmermans and Berg, 2003: 24), the *Standards*

and Guidelines outlines a process of procedural standards²¹ that are to be followed. These standards tell practitioners what to sift through and look for in their search for actionable items. This panning process is achieved through the work of mothers and others as they are extralocally coordinated and organized by texts. Through regulating discourses, such as the *Standards and Guidelines* and the ADI-R and ADOS, actualities are socially organized and made actionable based on a standardized definition of autism. The product of this process is the creation of a dichotomy of autism/non-autism out of a spectrum of autisms. This dichotomy allows the ruling apparatus to definitely and decisively diagnose or rule out autism (based on the work of sifting and filling autistic shells) under the ideological guise of evidence-based medicine and the implementation of the gold standards of autism diagnoses.²²

What I problematize through this investigation is how restructuring practices are employed to not only coordinate and organize people's doings, but also to provide services and supports based on a textual representation of the work of mothers and others. In order to do so, "new" methods of accounting logic are put in place to formulate, reformulate, calculate, and enumerate people's experiences, which are then made into a textual representation where they are "worked up and worked on as virtual realities" (Rankin and Campbell, 2006: 15). There is a problem inherent in this process. Ian Hacking explains:

²¹ Procedural standards are one of four types of standards discussed by Timmermans and Berg (2003) that specifically relate to the process of diagnosing autism. Procedural standards outline which "steps to be taken when specified conditions are met" (ibid, 25). Furthermore, this type of standard forms the heart of evidence-based medicine (Timmermans and Berg, 2003).

²² "...[T]hese texts prompt standardized and universal courses of action to address ideologically construed local 'situations'...to regulate a multitude of experientially different moments" (A.K. Thompson, cited in Frampton et al., 2006: 106).

‘Enumerating requires categorization’ and ‘defining new classes of people for purposes of statistics has consequences for the ways in which we conceive of others and think of our own possibilities and potentials’ (1990: 7, cited in Rankin and Campbell, 2006: 15).

Integral to the process of panning for gold, and what is made visible in Section 3, is that in order to make disabilities uniform and institutionally actionable based on the *Standards and Guidelines*, categories/units (gold nuggets) must be created out of people’s actualities. These categories “valorize some point of view and silences another (Bowker and Star 1999: 5, cited in Rankin and Campbell, 2006: 15); some responses (gold) are accounted for and some are not.

The implications are drastic; displacing people’s everyday doings into standardized processes by forcing their actualities to fit within specific frames that are interconnected with the text doing the framing and organizing leaves realities unaccounted for. This exclusion occurs because no category or description can ever be exhaustive of a person’s actuality. The process of panning for gold might therefore perpetuate un-accounted for areas of autism where individuals are left outside the purview of services and supports in a funding-driven system like BC. This was exemplified in the cases of some of the mothers I spoke with. For instance, Anne’s child was nine and Jess’ child was 11 when they received an actionable diagnosis. This provided the key to services and supports, which they had previously missed out on. The implications are significant when you consider that what a child with autism experiences “in their early years will shape the rest of their lives” (Auton et al.,: 1).

Supporting this previous point, in some cases, assessment tools/instruments used in the diagnostic process of autism in BC do not necessarily assist practitioners in diagnosing a child with autism. In fact, they may make it harder. The Autism Specialist explained, “sometimes you get below the [cutoff] line, a little above in another”, where the outcome is not necessarily as clear as, for example, a blood test. The other psychologist interviewed expressed similar sentiments, where “there are certainly lots of times with a child that’s really (emphasis) borderline. I mean even being able to observe the child overtime; it’s really hard ...” This dilemma is exemplified in Diagram 2 (5) where “data” (sifted actualities) often teeter on the edges of the “autistic shells”. Through the implementation of these standardized processes discussed above, I suggest that practitioners might experience a bifurcation of consciousnesses, whereby on the one hand they want (and have a duty) to help their patient(s) while on the other hand, they must follow procedural standards that prescribe what they can and cannot do.

Research further suggests that the instruments required by the *Standards and Guidelines* are restrictive in their requirements needed to diagnose children with autism. These restrictions further perpetuate the pile-up of un-accountable actualities; it is specifically apparent in the use of the ADI-R compared to other assessment tools of its kind used in the past. For instance, in a study that looked at two different diagnostic instruments, the ADI-R and the Childhood Autism Rating Scale (CARS), Saemundsen et al (2003) found that the ADI-R classified less ASD diagnoses than the CARS. Researchers concluded that the ADI-R “seems to be more restrictive than the category of autism as defined by the CARS” (Ibid, 325). In other words, their findings suggest that the CARS “represents a broader diagnostic concept of autism than the ADI-R” for the

specific age group studied (Ibid, 326), possibly making it harder to diagnose a child with autism using the ADI-R. Furthermore, in a more recent study, Lecavalier and colleagues (2006) found,

The ADI-R might overemphasize qualitative impairments in the social domain over impairments in communication and repetitive and restricted patterns of behaviors and interests. One can argue that items representing deficits in communication and repetitive behaviors seem to be underrepresented (213).

These findings are extremely problematic because the standardized process might limit those who become eligible for services and supports, therefore limiting those who receive help but are still in need of help. The pediatrician explained, “[services and supports are] not based on need, it’s based on diagnosis, the money that you get. That is a problem”.

He went on to explain:

So you give the diagnosis and the child receives funding. The family receives funding...If the diagnosis is not given, then basically there is no funding. So that’s one of the problems with funding-driven diagnoses; if you get the diagnosis fine, if you don’t get the diagnosis, you then go back to go...you don’t collect the two hundred dollars.

Such processes described above, whereby peoples’ actualities are produced, filtered, and reproduced to be made virtually, and thus institutionally, actionable constitutes *social problems*. Instead of being based on need, “designations” are allocated based on standardized procedures that limit the practitioner’s expert clinical judgment, further limiting the activation of social relational sequences down the line that potentially have the ability to help those who are in need of services and supports but do not “qualify” for

them. In other words, some individuals and loved ones might be left outside the purview of services and supports based on criteria outlined by ruling apparatuses.

Conclusion:

Using institutional ethnography, I explored new technologies of management and governance in the healthcare setting of diagnosing children with autism. I showed how work processes of both patients and practitioners are being transformed from actions based on experiential knowledge into objectified, textually organized representations. These processes whereby the “coordination of knowledge, judgment, purposes, and action are organized” (Rankin and Campbell, 2006: 16) were the focus of this inquiry. More specifically, this paper focused on the assessment stage of the process of diagnosing individuals suspected of having autism, when standardized assessment tools were activated and administered by practitioners (to both the mother and the child suspected of having autism), resulting in a textual representation of health. These tools, and others, were used to assist practitioners in their work of diagnosing or ruling out a diagnosis of autism, further activating social relational sequences down the line.

I problematized the attempt made by the ruling apparatus to make autism decisive and definitive. Key to this process are textually mediated relations that organize and coordinate the work of mothers and others, making their actuality actionable in some way. In doing so, I interrogated this process, showing how a pile-up of unaccounted for actualities is produced when a process of diagnosing a disability like autism is standardized, leaving some people outside the purview of services and supports. Similar to Rankin and Campbell’s (2006: 20) critique of healthcare reform practices, I argue that the “objectifying technologies” employed in the diagnostic process dominate the

experiential knowledge and actions of health practitioners, in a sense restructuring the conscience of these individuals as they become agents of texts and the ruling apparatus. In order to illustrate this point, I showed how texts are active constituents of people's everyday doings and key to the work of practitioners in the process of diagnosing autism. The end product of the process is a "textual representation" of autism. I suggest that the process limits the possibilities of what is made available to mothers and children suspected of having autism.

Families of children with autism have a multitude of needs that require different types of services and supports for both child and caregiver (Kohler, 1999). Having the necessary services and supports available impacts the development and possible life gains of the child and the ability of family members to cope with the demands of caregiving. In BC, services and supports become available based on actionable "designations" and are not based on need. However, families of children who have (via texts) some but not all characteristics of autism are also in need of services. The Pediatrician interviewed explained:

...So when we're looking at autism, there are a list of symptoms and if you have a certain number of those symptoms, you have the diagnosis of autism. But say you've only got two out of three out of the symptoms, you don't have a diagnosis but you still got the symptoms. Right?

Services should not be solely based on a diagnosis but should also be based on the needs of the family and child; services provided to children with a diagnosis of autism can be just as helpful (and necessary) for children without a diagnosis of autism.

Moving beyond the immediate implications of utilizing IE to investigate the diagnosis process of autism, the findings and implications of this study explore and explicate what Ranking and Campbell (2006) call “technologies of management and governance”. By “mapping” different work knowledges of the diagnosis process and “begin[ing] to assemble the sequences of action built from complementary work” (Smith, 2005: 159), this study shows how IE can be used to explore and explicate health relations and objectified forms of knowing. As such, this paper provides an ethnographic look “inside Canada’s health care reform” (Campbell and Rankin, 2006) and contributes to the critical and ongoing look at restructuring practices and its effects on health relations and sequences, and peoples’ everyday doings.

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Appendix A: Autism Diagnostic Interview-Revised (ADI-R)²³

GOALS

The Autism Diagnostic Interview-Revised (ADI-R) is a clinical diagnostic instrument for assessing autism in children and adults. The ADI-R provides a diagnostic algorithm for autism as described in both the ICD-10 and DSM-V. The instrument focuses on behavior in three main areas: qualities of reciprocal social interaction; communication and language; and restricted and repetitive, stereotyped interests and behaviors. The ADI-R is appropriate for children and adults with mental ages from about 18 months and above.

DESCRIPTION

The ADI-R is a standardized, semi-structured clinical review for caregivers of children and adults. The interview contains 93 items and focuses on behaviors in three content areas or domains: quality of social interaction (e.g., emotional sharing, offering and seeking comfort, social smiling and responding to other children); communication and language (e.g., stereotyped utterances, pronoun reversal, social usage of language); and repetitive, restricted and stereotyped interests and behavior (e.g., unusual preoccupations, hand and finger mannerisms, unusual sensory interests). The measure also includes other items relevant for treatment planning, such as self-injury and over-activity. Responses are scored by the clinician based on the caregiver's description of the child's behavior. Questions are organized around content area, and definitions of all behavioral items are provided. Within the area of Communication, for example, "Delay or total lack of language not compensated by gesture" is further broken down into specific behavioral items: pointing to express interest, conventional gestures, head nodding, and head shaking. Similarly, within the area of Reciprocal Social Interaction, lack of socio-emotional reciprocity and modulation to context include the following behaviors: use of other's body, offering comfort, inappropriate facial expressions, quality of social overtures, and appropriateness of social response.

All questions ask about current behavior, with the exception of a few behaviors that only occur during specific age periods. In these cases, specific age restrictions are given. For example, items inquiring about group play are coded only for behavior displayed between the ages of 4 and 10 years; questions about reciprocal friendships are scored only for children ages 5 and above; and questions about circumscribed interests are scored only for children ages 3 and above. In addition to asking about current behavior, each question focuses on the time period when the behaviors were likely to be most pronounced – generally, between the ages of 4 and 5 years.

The interview starts with an introductory question followed by questions about the subject's early development. The next 41 questions cover verbal and nonverbal communication. Questions 50 through 66 ask about social development and play. The next 13 questions deal with interests and behaviors. The final 14 questions ask about "general behavior," including questions about memory skills, motor skills, over-activity and fainting.

SCORING

The ADI-R interview generates scores in each of the three content areas (i.e., communication and language, social interaction, and restricted, repetitive behaviors). Elevated scores indicate problematic behavior in a particular area. Scores are based on the clinician's judgment following the caregiver's report of the child's behavior and development. For each item, the clinician gives a score ranging from 0 to 3. A score of 0 is given when "behavior of the type specified in the coding is not present"; a score of 1 is given when "behavior of the type specified is present in an abnormal form, but not sufficiently severe or frequent to meet the criteria for a 2"; a score of 2 indicates "definite abnormal behavior" meeting the criteria specified; and a score of 3 is reserved for "extreme severity" of the specified behavior. (The authors of the measure recode 3 as a 2 in computing the algorithm.) There are also scores of 7 ("definite abnormality in the general area of the coding, but not of the type specified"), 8 ("not applicable"), and 9 ("not known or not asked") given under certain circumstances, which all are converted to 0 in computing the algorithm.

²³ What follows is directly taken from the Autism Genetic Resource Exchange website: <http://www.agre.org/program/aboutadi.cfm?do=program> (accessed, April, 2007).

(Scoring Continued)

A classification of autism is given when scores in all three content areas of communication, social interaction, and patterns of behavior meet or exceed the specified cutoffs, and onset of the disorder is evident by 36 months of age. The same algorithm is used for children from mental ages 18 months through adulthood, with three versions containing minor modifications: 1) a life-time version; 2) a version based on current behavior; and 3) a version for use with children under the age of 4 years. The algorithm specifies a minimum score in each area to yield a diagnosis of autism as described in ICD-10 and DSM-IV. The total cutoff score for the communication and language domain is 8 for verbal subjects and 7 for nonverbal subjects. For all subjects, the cutoff for the social interaction domain is 10, and the cutoff for restricted and repetitive behaviors is 3.

PRACTICAL ISSUES

This interviewer-based instrument requires substantial training in administration and scoring. A highly trained clinician can administer the ADI-R to the parent of a 3- or 4-year old suspected of autism in approximately 90 minutes. The interview may take somewhat longer when administered to parents of older children or adults. Training workshops are available in the United States as well as internationally.

Appendix B: Criteria for Pervasive Developmental Disorders – The Diagnostic and Statistical Manual of Mental Disorders IV²⁴:

299.00 Autistic Disorder:

(I) A total of six (or more) items from (A), (B), and (C), with at least two from (A), and one each from (B) and (C)

(A) qualitative impairment in social interaction, as manifested by at least two of the following:

1. marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction
2. failure to develop peer relationships appropriate to developmental level
3. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people, (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
4. lack of social or emotional reciprocity (note: in the description, it gives the following as examples: not actively participating in simple social play or games, preferring solitary activities, or involving others in activities only as tools or "mechanical" aids)

(B) qualitative impairments in communication as manifested by at least one of the following:

1. delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
2. in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
3. stereotyped and repetitive use of language or idiosyncratic language
4. lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(C) restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least two of the following:

1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
2. apparently inflexible adherence to specific, nonfunctional routines or rituals
3. stereotyped and repetitive motor mannerisms (e.g hand or finger flapping or twisting, or complex whole-body movements)
4. persistent preoccupation with parts of objects

(II) Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:

- (A) social interaction
- (B) language as used in social communication
- (C) symbolic or imaginative play

(III) The disturbance is not better accounted for by Rett's Disorder or Childhood

²⁴ This is just one of the disorders on the autism spectrum. For a complete review of all disorders, visit the Autism Society of Canada website at <http://www.autismsocietycanada.ca> (accessed September 2007).