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

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Abstract:

In the context of contemporary health care institutions, diagnoses are no longer simply a way of telling doctor and patient what may be wrong and what course of treatment might be applicable; diagnoses have the potential to activate specialized services and supports for persons with a disability and those who provide care. British Columbia's health care and educational services, for example, provide special sources of support for individuals with a diagnosis on the autism spectrum and their caregivers. Restructuring practices in British Columbia that attempt to standardize the process of diagnosing autism enter patients and practitioners into a complex of text-mediated and text-regulated relations, specifically based on principles of evidence-based medicine, that control the kind of treatment, care and support that will be made available. The diagnosis of autism in children is notoriously ambiguous, yet receiving such a diagnosis is the only means of access to sources of support that are otherwise unavailable. Because of its ambiguity, standardizing the diagnosis of autism presents a problem when it is an essential step for parents who have children with problems that could be ambiguously identified as autism in securing help and support. 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 of the processes involved in going from the actualities of parents' experiencing a child's problems to the formalized and standardized diagnosis that gives access to services made available in the health care system. 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 autism 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 texts.

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Introduction:

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). 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 unique to 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, during, 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 help both children with ASD and their families. Originally, I felt 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 or shifted to include exploring the institutionally coordinated everyday doings of mothers and others[3] involved in the process of diagnosis.

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[2] I use the terms ASD and autism interchangeably.

[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, practitioners, teachers, therapists, social workers, family, 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.

The focus of this paper is on the institutional processes that translate the experience of caregivers of children who exhibit the kinds of behaviours that may lead to a diagnosis of autism into a standardized textual representation of autism. The focus of this inquiry is not the individuals involved in the process 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 work of professional practitioners and parents in arriving at a diagnosis of autism, and on the textually mediated sequences that produce a particular situation and particular experience as a standardized representation of 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 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 conceptualizations[4]. 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

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[4] 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).

"virtual reality" (Rankin, 2002). 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 the line. The **fourth** section briefly discusses the implications of this analysis in the context of the process of diagnosing autism and the broader implications to health relations. I discuss the limitations of the process of diagnosing autism based on the standardization of a disability that is not so clear-cut.

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, 1994). While ASD broadly consists of five related disorders[5], 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 have 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 contact[6] 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 regulate social interaction, difficulty making friends, limitations in shared enjoyment of interests with others, and a general lack of social or emotional reciprocity" (APA, 2000 cited in Seltzer et al., 2004: 237). The last core area of deficits includes restricted,

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[5] Autistic Disorder, Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder, and Pervasive Developmental Disorder-not otherwise specifice (PDD-NOS).

[6] 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.

repetitive behaviours and interests, primarily in three overlapping domains: behavioural (such as perseverations, aggressions, tantrums, head banging, and self-injurious behaviors[7]), 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 Seltzer et al., 2004; Duchan, 1998; Gray, 2003). ASD is also often accompanied by mental retardation (Gray, 1994) and other co-occurring disorders (see Fombonne, 2003). Furthermore, 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 (Nessenbaum et al., 2002). Autism is therefore diagnosed primarily through observing the child over a period of time, often in different settings (Nessenbaum et al., 2002) and by speaking to those who know the child best, with the help of standardized texts (discussed below).

The Process of Diagnosis in British Columbia:

The process of diagnosing autism can be a significant source of stress for families, whether the outcome is a diagnosis of autism or not (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 (Grogan and Knussen, 2003).

In a separate institutional ethnography, I described 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

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[7] Some behaviours can be termed "tap behaviours" – these are behaviours such as "repetitive behaviour, lack of eye contact, self-injurious behaviour that are characteristic of children with autism" (Tomanik et al., 2004: 17).

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 my work of speaking to this and other mothers about the diagnostic process of autism, I was drawn to explore the process 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.

In 2004, British Columbia (BC) experienced a "restructuring practice" whereby diagnostic services for autism spectrum disorders (autism) for children six years of age and under were transformed to a standardized process based on principles of evidence-based medicine. This reform process deployed one master text that governed the entire process of diagnosing autism. 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 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, ending with the assessment stage of the process, which I focus on later. Based on the *Standards and Guidelines*, assessments for individuals under the age of six who might have an ASD need to be conducted by a "multi-disciplinary" team consisting of an intake social worker[8], psychologists (an autism specialist[9] and a psychologist), speech-language pathologist, and a pediatrician[10]. The team "must meet (at the end of the assessment) to discuss the findings of their assessments and agree upon a proper diagnosis" (Standards and Guidelines, 2003). For children six years old and over, the ASD assessment needs to be completed by a single discipline practitioner who is deemed to be a "Qualified Specialist".

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[8] Responsible for coordinating the process of diagnosing autism once the child is referred to the Autism Assessment Network (BCAAN).

[9] Responsible for conducting the Autism Diagnostic Observation Scale and the Autism Diagnostic Interview-Revised. This individual is often the leader of the assessment team.

[10] Responsible for conducting a medical consultation and ruling out any other problems that might explain the child's current behaviours/impairments.

During the assessment stage of the process, as outlined by the *Standards and Guidelines*, “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 individuals suspected of having ASD] are necessary components of a diagnostic 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”. 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 B). While I focus 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.

Embedded within the *Standards and Guidelines*, the ADI-R and ADOS is the *Diagnostic and Statistical Manuel of Mental Disorders*, Fourth Addition (DMS-IV) (American Psychiatric Association, 1994). 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 concept of intertextuality[11] 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 A for the criteria of Pervasive 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 them and their caregivers throughout the individual’s life course (see Table 1). In fact, a diagnosis on the spectrum enters the child with a diagnosis and

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[11] “…[H]igher level texts establish the frames and concepts that control and shape lower level texts” (Smith, 2005: 226).

their caregivers into other institutional processes as both age throughout the life course[12]. The point is that in the context of contemporary health care institutions, diagnoses are no longer a way of communicating to doctor and patient what may be wrong and what course of treatment might be applicable; diagnoses may make available specialized services and supports for persons with a disability and those who provide care.

Table 1:

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

Autism services:

0-6 years of age:
- $20,000 annually to purchase autism intervention
- Early Intensive Behavioural Intervention Program
- Family focused support
- Other services

6-18 years of age:
- $6,000 annually to purchase autism intervention services
- Educational program – special education services

19+ years of age:
- Community Living BC services if IQ is 70 or less
- Mental health services if individual qualifies

The reform practice discussed above 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 the disability and their caregiver(s) being entered into a text-mediated and text-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 a multi-disciplinary team administering tools to create a “textual representation” of the child suspected of having ASD, via textually mediated relations[13]. In doing so, I explore and explicate an aspect of what Rankin and Campbell (2006: 15) call “textual representation of health care”, whereby, in this case, services are allocated based on the textual

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[12] This aspect of caregivers and care receivers experience has not been investigated.

[13] These are relations between individuals that are mediated by texts.

coordination and representation of people's experience and doings. My hope as an institutional ethnographer is to explicate the process of diagnosis in order to explain how things work. The following section briefly describes how I intend on exploring 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[14], 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, it would not offer a unique lens for social inquiry[15].

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" (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[16] (psychologist), a general psychologist, and a social worker. In addition, I spoke with mothers of children with ASD. All the individuals interviewed are or have been a part of the process of diagnosing autism at one point in time. Interviews with the practitioners took place at an autism assessment centre in BC. Interviews with mothers took place in BC and Alberta at their homes. It is important to note that the inserts of mothers discussed below are taken from interviews I had in multiple settings for either my master's thesis or this study. Furthermore, I did not sit in on practitioners diagnosing children with autism; rather, I asked practitioners to teach me how they do

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[14] Smith uses the term actuality to describe where people are actually located (outside of the text(s)); this is the location where exploration begins as set out by the study's problematic.

[15] The alternative is to begin in a world already penetrated by discursive ways of knowing and doing.

[16] 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".

their work as if I were to do it[17]. By exploring different perspectives and experiences of individuals who are a part of institutional processes, 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[18] knowledge (Smith, 2005:29). In order to explore how things work and are discursively organized, exploring texts[19] and how they mediate social relations is key to IE. The hope is to move beyond the "objectified subject of knowledge" (Smith, 2005:10) to explore and examine how people's experiences are connected to extended social relations that are textually mediated[20] (Smith, 2005:24; 1990).

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 and

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[17] This was suggested by Dorothy Smith.

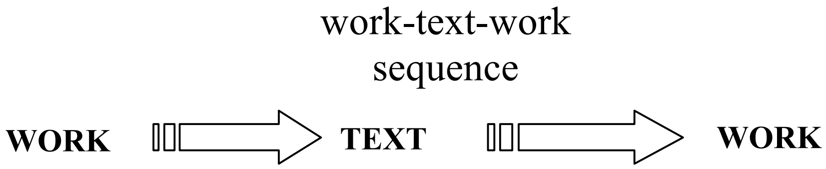
[18] Ordinary refers to individuals' everyday knowledge located in their local actualities of their lived experience.

[19] Anything that is replicable across time and space, from forms (medical charts, referral forms, etc), media, music, documents.

[20] Smith describes extra local or translocal relations of ruling as mediated relations that occur out of sight, but can be made ethnographically visible, often mediated by texts. For further discussion, see Smith (1990).

intertextual[21]. Through the work[22]-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. 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 "central to everything that happens" (Campbell and Gregor, 2002: 79). 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 peoples everyday doings. Multiple texts were identified in this study. For the purposes of this paper, I use three of them in my analysis. They include 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 autism spectrum disorders in BC. In doing so, I shed light on restructuring practices in BC and ethnographically describe how this ruling standpoint enters into and mediates peoples everyday doings (Rankin and Campbell, 2006). By making use of texts that process and reformulate peoples' experiences at the local setting and translate them into virtual realities at the institutional setting, IE provides a way to address hidden dangers in restructuring practices. As Rankin and Campbell (2006: 18) write, my analysis "enters water that looks calm and troubles it". In saying that, I show the dangers in taking virtual realities as "truth".

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[21] Intertextuality is a term that describes how texts do not stand alone from other texts. In other words, higher-level texts interact with lower level texts, organizing and coordinating the frames of lower level texts; they are essentially intertextual. For further discussion, see Smith 2005.

[22] Institutional ethnographers apply a "generous" concept to work. Work for institutional ethnographers is not understood in the traditional sense of paid work. Work for institutional ethnographers is anything that people do that takes time, effort, and intent (see Diamond, 1992; Smith, 2005).

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 process of diagnosis in BC. My overview begins with the point in time described by mothers and others when concerns arose about a child in the area of social interactions, communication, and stereotypical 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, parents, or anyone else who expresses concerns to parents might also raise a perception of a problem. I interviewed Cindy, a mother of a child with autism (Cam), who started having concerns about her child at around the age of two years old. She explained,

> …We kept going to our doctor saying that she wasn't talking very much, she's not talking, she's not talking, she's not putting words together, she could only say, one word here and there. She couldn't really put it together, and being that she was our third child, that wasn't normal, or it wasn't normal from the other experiences with my two sons… I finally said to him, 'she's not talking, she can't put the sentences together; if she wants a cookie, she'll stand at the cookie jar and 'aaahh aaahhh (inaudible)'…So yeah we just kept going to him and finally, I have to think back here, probably at about three I went to my doctor, just my regular family doctor, and I said, you know this is the day and life of me and my daughter, this is what she can do, this is what she can't do, this is how she communicates. I said 'there's something wrong'. And at that point, let me think back here, what was our first step? We went to see uh, uh, a pediatrician...

During these early years of her child's development, a perception of a problem emerged for Cindy when she compared her child's development to the development of her two older sons and other “normal” developing kids her child’s age. Knowing something was wrong, Cindy continuously went to her family doctor for “regular checkups”, expressing concerns about her child. While the diagnosis process began for Cindy during the beginning years of Cam’s life, the “clinical pathway” did not start until Cam fit within the discourse of medicine – this process of fitting in consisted of struggles between Cindy’s beliefs and knowledge as a mother and the beliefs and knowledge of those who were in charge of making Cindy’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 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 see, the *Standards and Guidelines* gives these individuals 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 Tammy’s experience is one of many different pathways that may lead to the assessment centre where the parent(s) and the child are seen by a multidisciplinary team, 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, through textually mediated relations, (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 [parent(s) and child] everyday worlds into shapes that fit the topic-assigned spaces provided” (Smith, 2005:226)[23]. This process is indicative of the assessment process described and

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[23] 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 (see Diagram 2).

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, in which the work of mothers complement the work of practitioners. This sequence leads the actuality of mothering a child suspected of having autism 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"

Due to the confines of this paper, I focus specifically on the social relational sequence between a mother and psychologist that 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 or not. 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 are sent to the Centre, ensuring the referrals are filled out correctly by the correct practitioners that "we can accept", and sending the referrals to the appropriate team throughout the jurisdiction.

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 by whom and when over the assessment period. The schedule not only orients mother and child to the work to be done by practitioners, but also orients 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.

Table 2 – Assessment Schedule:

One-day Assessment:	Two-Day Assessment:
Gather all referral and supporting documentation prior to the assessment (Intake Coordinator)	Gather all referral and supporting documentation prior to the assessment (Intake Coordinator)
9:30 to 11:00am: medical consultation with (Developmental Pediatrician). 11:00-1:00pm: ADI-R with (Psychologist: Autism Specialist) 11:00-1:00pm: ADOS with (Psychologist) 1:00-2:00pm: team meeting 2:00-3:00pm: family conference	Monday: 9:30-12 noon: ADI-R with (Psychologist: Autism Specialist) 2:00-3:00pm: Psychology assessment (Psychologist: Autism Specialist) 3:00-4:00 pm: Pediatric Consultation (Developmental Pediatrician) Tuesday: 9:30-12 noon: ADOS & SLP assessment with (Psychologist) 12noon to 1:00pm: team meeting 1:00-2:00pm: family conference

At a point during this time of the process, in an attempt to "promote the application of evidence-based[24] practices in the identification, assessment and diagnosis of children with ASD" (*Standards and Guidelines*, 2003:2), the clinical Autism Specialist (psychologist) who 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 both parent(s) of a child suspected of having autism and the Autism Specialist into a dialogue. The other tool is the Autism Diagnostic Observation Scale (ADOS), 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 by the ADI-R. I exemplify the work involved in making the

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[24] 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".

mother's actuality as a caregiver for a child with autism (textually) actionable to practitioners, which are aligned to the ruling apparatus.[25]

I begin by illustrating the complementary and complex work-text-work sequence between a practitioner and a parent, where the ADI-R is used to assist the practitioner in diagnosing a child with autism based on a mother's actuality[26]. This is illustrated in Diagram 1. This diagram shows the practitioner being guided extralocally by the ADI-R, which further guides the social relational sequence between himself and the parent(s).

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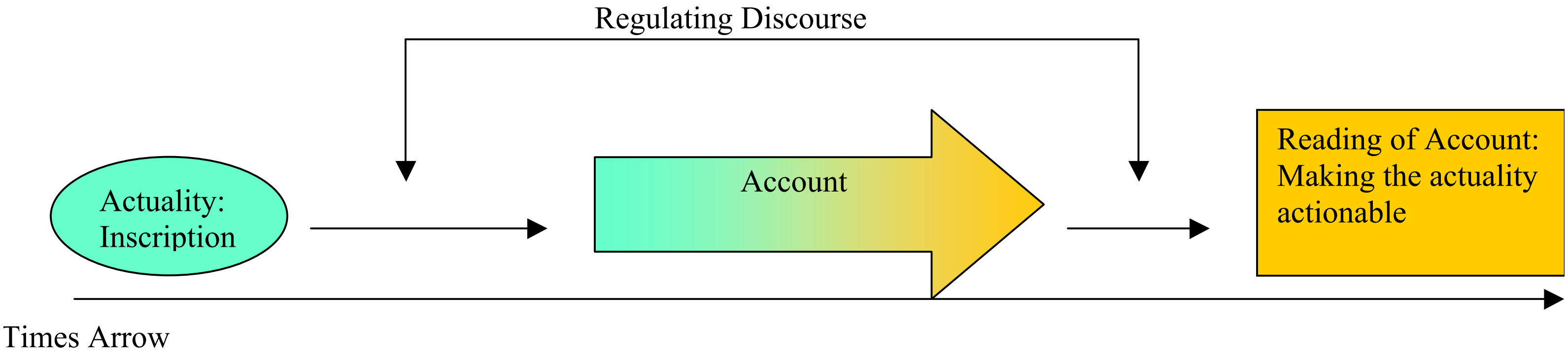
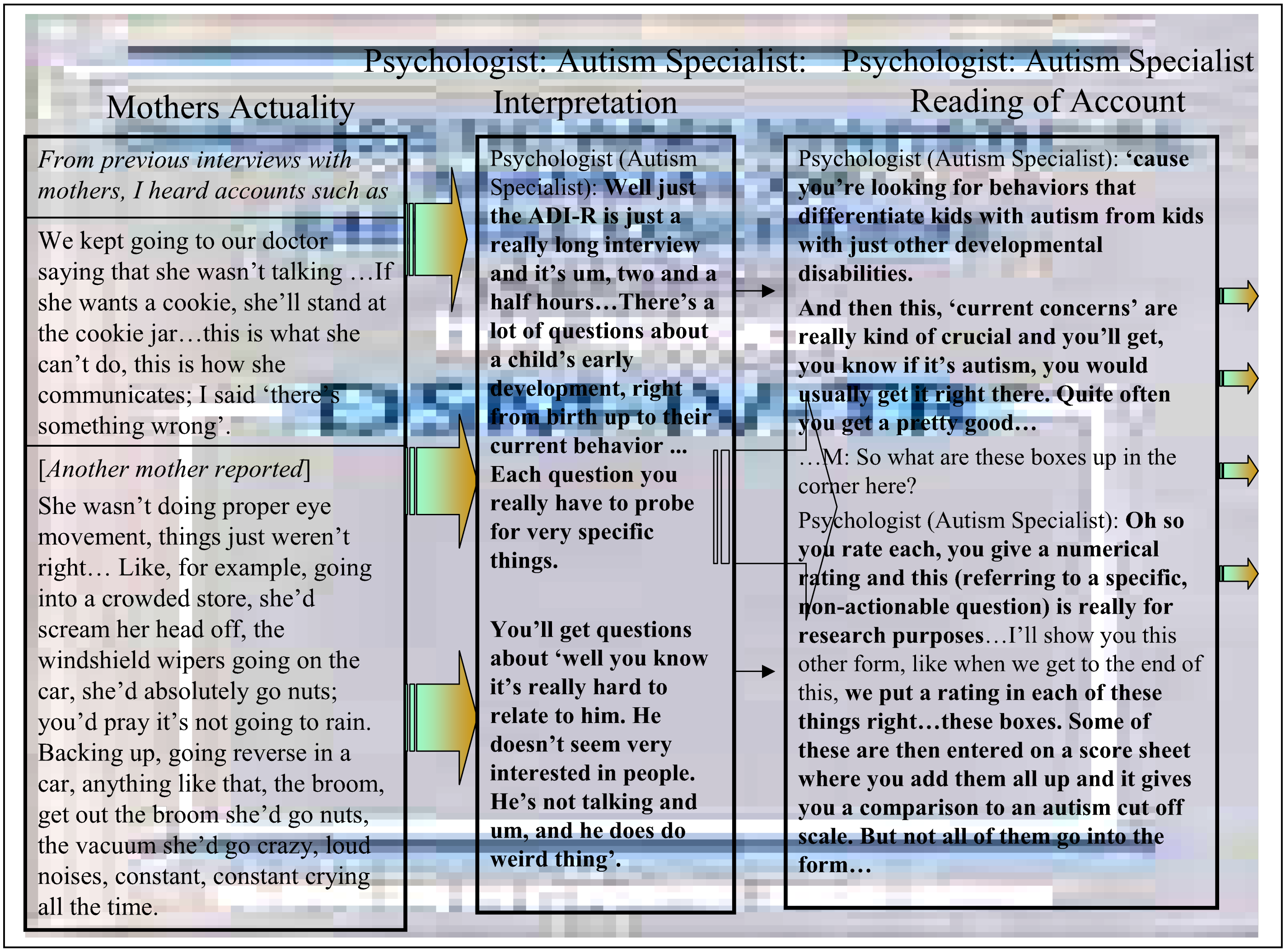
[25] I focus on this sequence because of the nature of the work involved in this parent-practitioner interaction. Also, as mentioned above, this sequence is a microcosm of other social relational sequences throughout the process of diagnosing autism, and exemplify the work involved in making the parent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

[26] This diagram is just a portion of a larger diagram not included in this paper.

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





From previous interviews with mothers, I heard accounts such as

We kept going to our doctor saying that she wasn't talking …If she wants a cookie, she'll stand at the cookie jar…this is what she can't do, this is how she communicates; I said 'there's something wrong'.

[*Another mother reported*]

She wasn't doing proper eye movement, things just weren't right… 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, 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.

Psychologist (Autism Specialist): **Well just the ADI-R is just a really long interview and it's um, two and a half hours…There's a lot of questions about a child's early development, right from birth up to their current behavior ... Each question you really have to probe for very specific things.**

You'll get questions about 'well you know it's really hard to relate to him. He doesn't seem very interested in people. He's not talking and um, and he does do weird thing'.

Psychologist (Autism Specialist): **'cause you're looking for behaviors that differentiate kids with autism from kids with just other developmental disabilities.**

And then this, 'current concerns' are really kind of crucial and you'll get, you know if it's autism, you would usually get it right there. Quite often you get a pretty good…

…M: So what are these boxes up in the corner here?

Psychologist (Autism Specialist): **Oh so you rate each, you give a numerical rating and this (referring to a specific, non-actionable question) is really for research purposes**…I'll show you this other form, like when we get to the end of this, **we put a rating in each of these things right…these boxes. Some of these are then entered on a score sheet where you add them all up and it gives you a comparison to an autism cut off scale. But not all of them go into the form…**

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 work[27]. This diagnostic interview focuses on "getting maximal information from the parent about the three key areas that make up autism: (1) reciprocal social interaction; (2) communication and language; and (3) repetitive, stereotyped behaviors"[28] and is an essential component of the assessment process.

Diagram 1 shows how this social relational sequence is textually mediated with the intent of quantifying[29] 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 is further organized by the DSM-IV[30][31]. 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 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"[32] 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

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[27] Similar to a mother's work being mediated by this text, my work in interviewing the practitioner was also mediated by the ADI-R.

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

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

[30] Notice behind the scenes of Diagram 1, the DSM IV is present, representing the coordinating of work processes.

[31] 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).

[32] Probing is similar to "pressing", a technique used for the ADOS.

> 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 would stand in front of the fridge and fuss' or 'he would drag me by the hand' or 'he would get it himself'. 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 (based on the ADI-R). In the process of probing via the regulating discourse, 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, which guides this textually mediated relational sequence. 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"[33]) 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.[34] 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 criteria, and thus the filling of autistic shells is complete. 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: like reading a road map, mapping allows individuals to locate themselves within the terrain of the ruling apparatus; mapping also assists individuals in gaining more knowledge about the

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[33] 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.

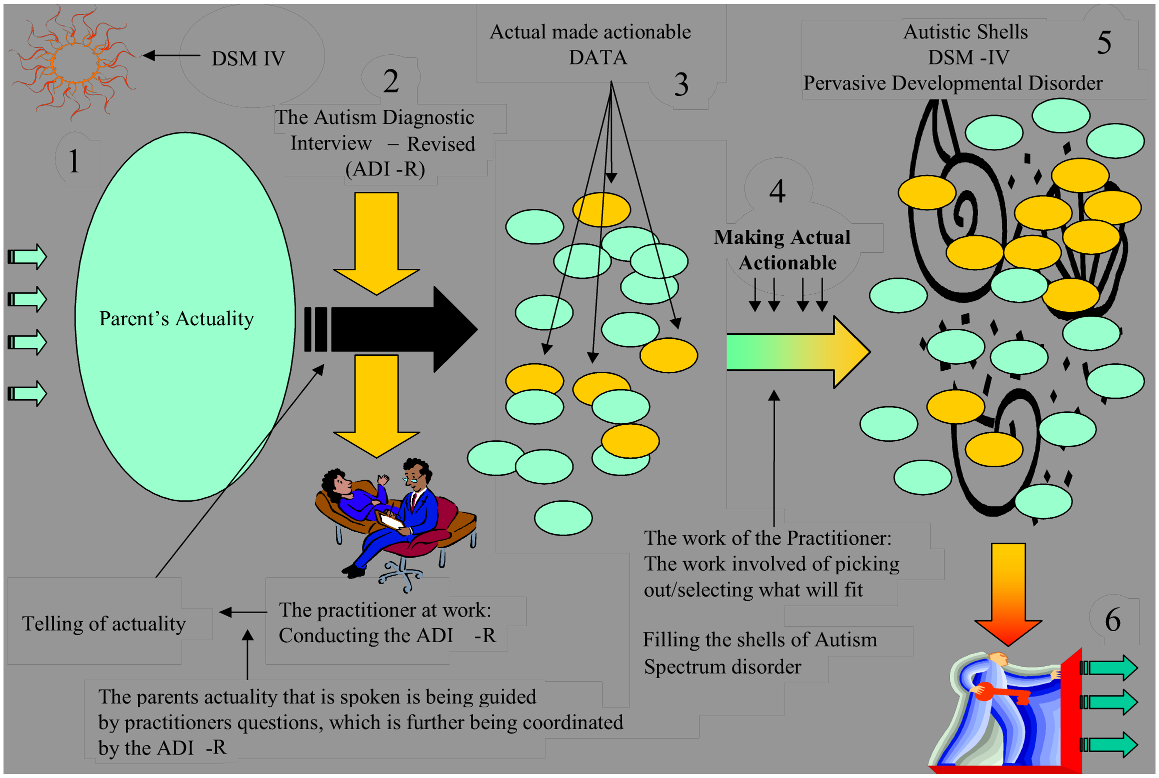
[34] Some questions from the ADI-R are scored while others are not. The questions that are scored are the ones that activate and refer back to the DSM-IV criteria, for the purposes of making the mother's actuality actionable. Other questions might activate and inform social relational sequences down the line.

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 (mother'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 in Diagram 2) 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, "autistic shells" (5) and the social relational sequences that may or may not follow (6), making the mother's actuality actionable in some way. This point of Diagram 2 is represented in Diagram 1, column 3.

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

Times Arrow



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 the complementary work of a parent and a practitioner, and how their work 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, DSM-IV and *Standards and Guidelines*. 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; a sequence of actions is further being framed by the DSM-IV in an attempt to fulfill requirements outlined in the *Standards and Guidelines*. 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:

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. In the course of the practitioners work in observing the child's behaviours, and similar to the work of probing activated by the ADI-R, the ADOS produces standardized descriptions of behaviour that can then be fitted to the diagnostic shells. The purpose of this tool is to observe the child who is suspected of having autism in different types of situations and settings, with the focus on observing social and communicative behaviours. This tool orients a practitioner's work[35] to look for very specific behaviours associated with autism[36], and 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 (Diagram 3, 4) and the team meets[37] to determine whether the child meets the required criteria for a diagnosis of autism based on the *Standards and Guidelines* (Diagram 3, 5).

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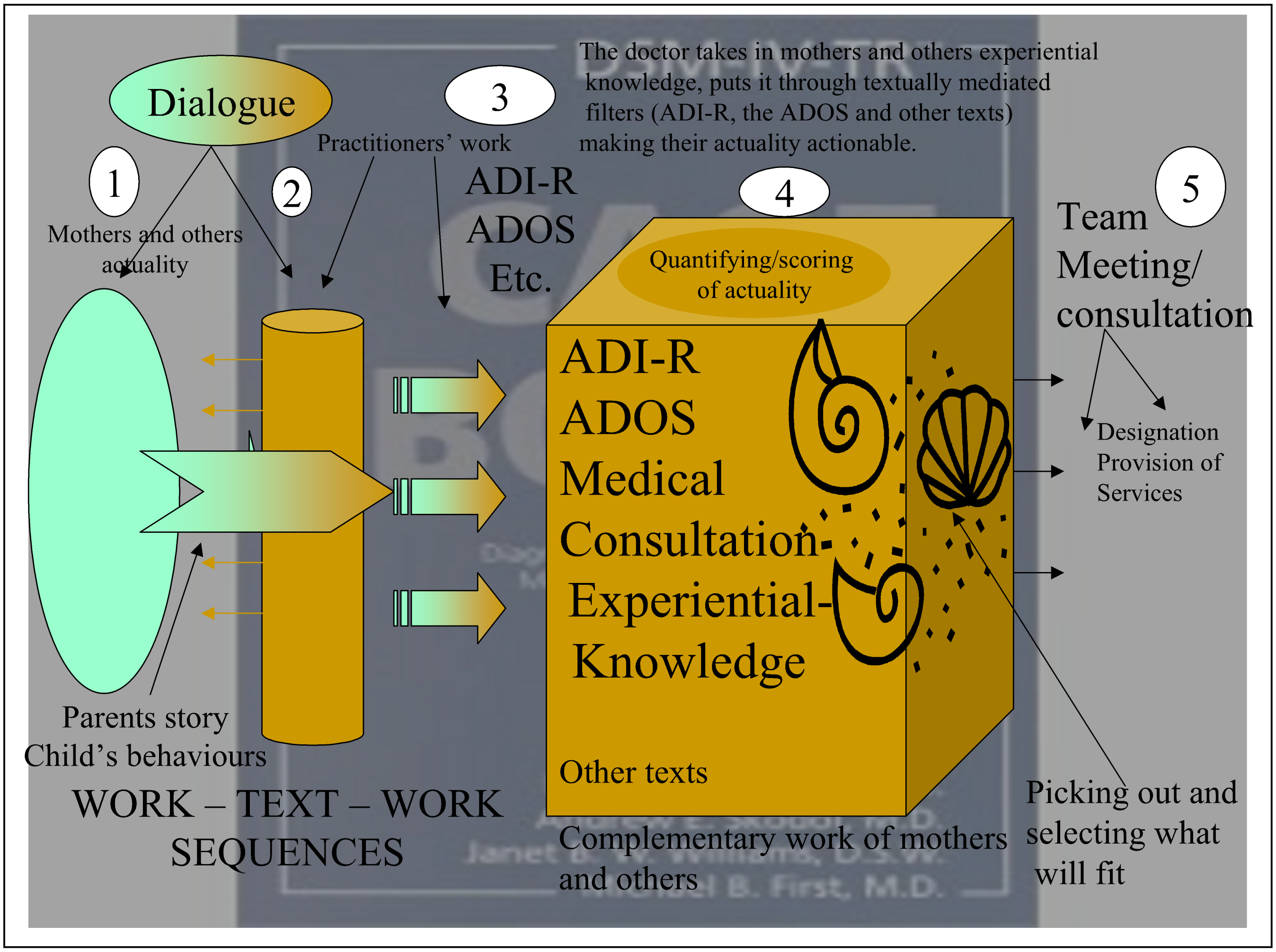
[35] With the intent of organizing and coordinating the practitioners experiential knowledge with a standardizing effect.

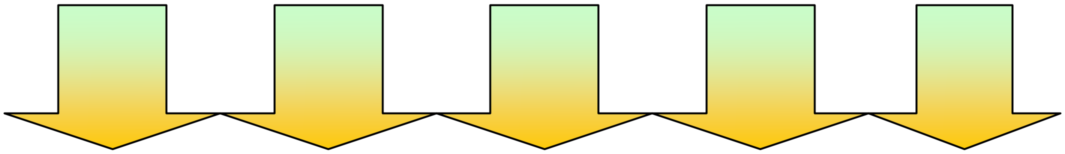
[36] This is accomplished through the work of the practitioner in observing and "pressing" the child's behaviours, similar to the work of probing described in the ADI-R

[37] Because "the *Guidelines* now call for a team-based diagnosis" (Pediatrician).

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



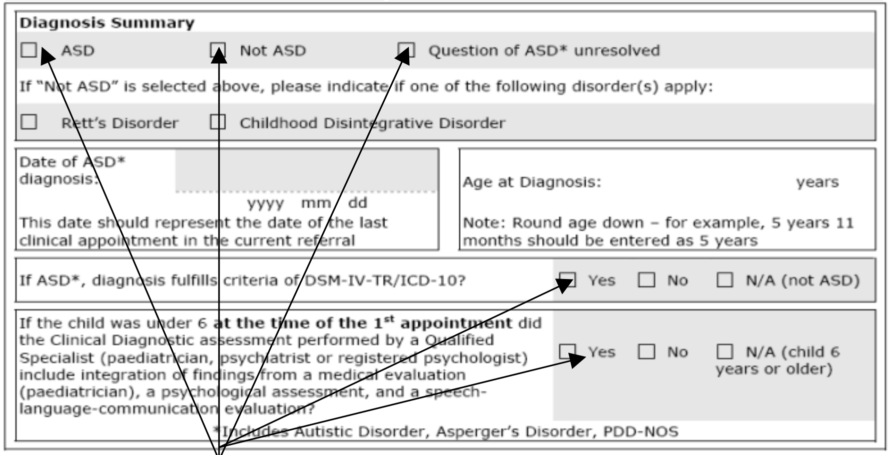
The doctor takes in mothers and others experiential knowledge, puts it through textually mediated filters (ADI-R, the ADOS and other texts) making their actuality actionable.



6

BCAAN Clinical Outcome Form

(**P**rovincial **A**utism **N**etwork **T**esting **E**valuation **R**eport)
Application for British Columbia Ministry of Children and Family Development Autism Funding



Part Four: Assessment Summary

Diagnosis Summary

☐ ASD ☐ Not ASD ☐ Question of ASD* unresolved

If "Not ASD" is selected above, please indicate if one of the following disorder(s) apply:

☐ Rett's Disorder ☐ Childhood Disintegrative Disorder

Date of ASD* diagnosis: yyyy mm dd

This date should represent the date of the last clinical appointment in the current referral

Age at Diagnosis: years

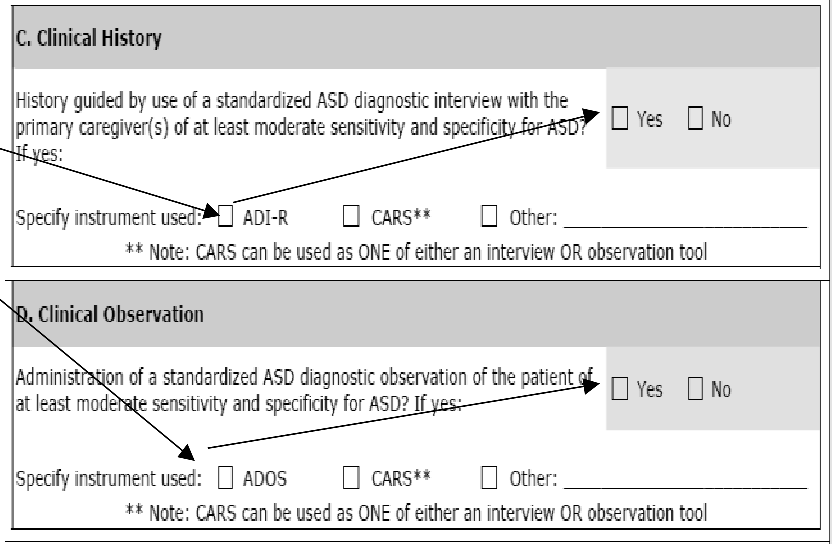
Note: Round age down – for example, 5 years 11 months should be entered as 5 years

If ASD*, diagnosis fulfills criteria of DSM-IV-TR/ICD-10? ☐ Yes ☐ No ☐ N/A (not ASD)

If the child was under 6 **at the time of the 1st appointment** did the Clinical Diagnostic assessment performed by a Qualified Specialist (paediatrician, psychiatrist or registered psychologist) include integration of findings from a medical evaluation (paediatrician), a psychological assessment, and a speech-language-communication evaluation? ☐ Yes ☐ No ☐ N/A (child 6 years or older)

*Includes Autistic Disorder, Asperger's Disorder, PDD-NOS

Actual Made Actionable



C. Clinical History

History guided by use of a standardized ASD diagnostic interview with the primary caregiver(s) of at least moderate sensitivity and specificity for ASD? If yes: ☐ Yes ☐ No

Specify instrument used: ☐ ADI-R ☐ CARS** ☐ Other: ____________________

** Note: CARS can be used as ONE of either an interview OR observation tool

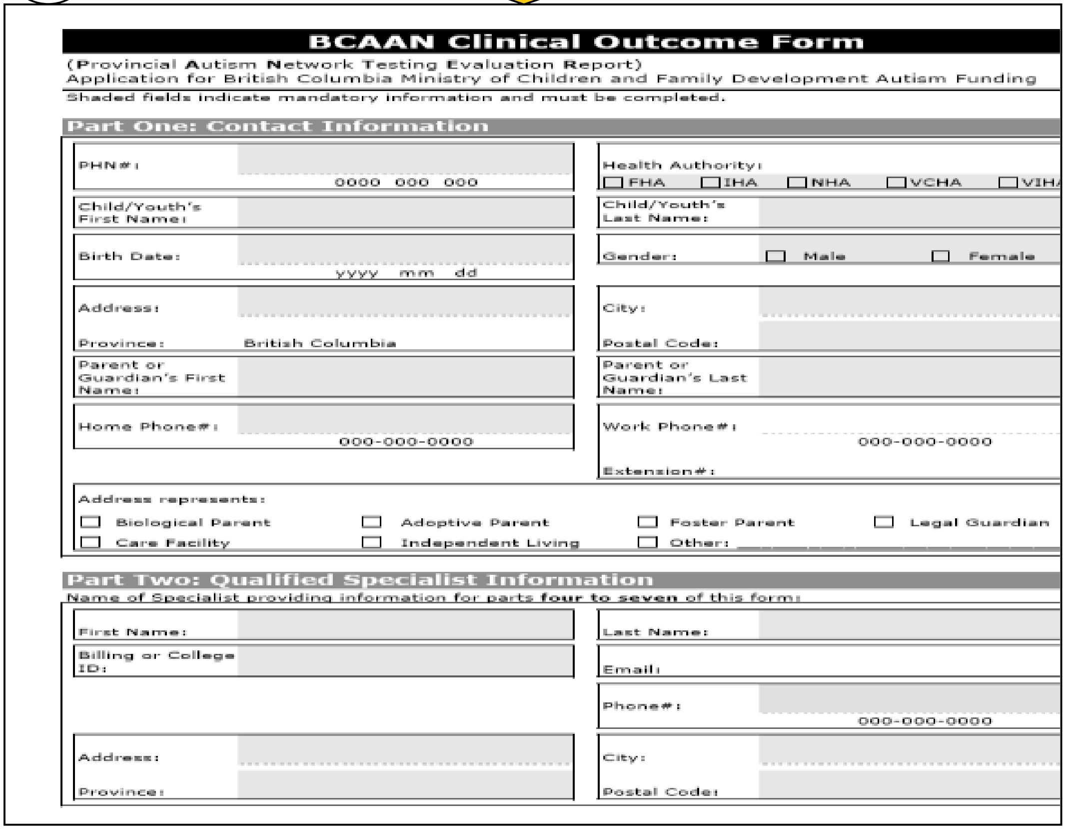
D. Clinical Observation

Administration of a standardized ASD diagnostic observation of the patient of at least moderate sensitivity and specificity for ASD? If yes: ☐ Yes ☐ No

Specify instrument used: ☐ ADOS ☐ CARS** ☐ Other: ____________________

** Note: CARS can be used as ONE of either an interview OR observation tool

7



BCAAN Clinical Outcome Form

(Provincial Autism Network Testing Evaluation Report)
Application for British Columbia Ministry of Children and Family Development Autism Funding

Shaded fields indicate mandatory information and must be completed.

Part One: Contact Information

PHN#: 0000 000 000
Health Authority: ☐ FHA ☐ IHA ☐ NHA ☐ VCHA ☐ VIH
Child/Youth's First Name:
Child/Youth's Last Name:
Birth Date: yyyy mm dd
Gender: ☐ Male ☐ Female
Address:
Province: British Columbia
City:
Postal Code:
Parent or Guardian's First Name:
Parent or Guardian's Last Name:
Home Phone#: 000-000-0000
Work Phone#: 000-000-0000
Extension#:

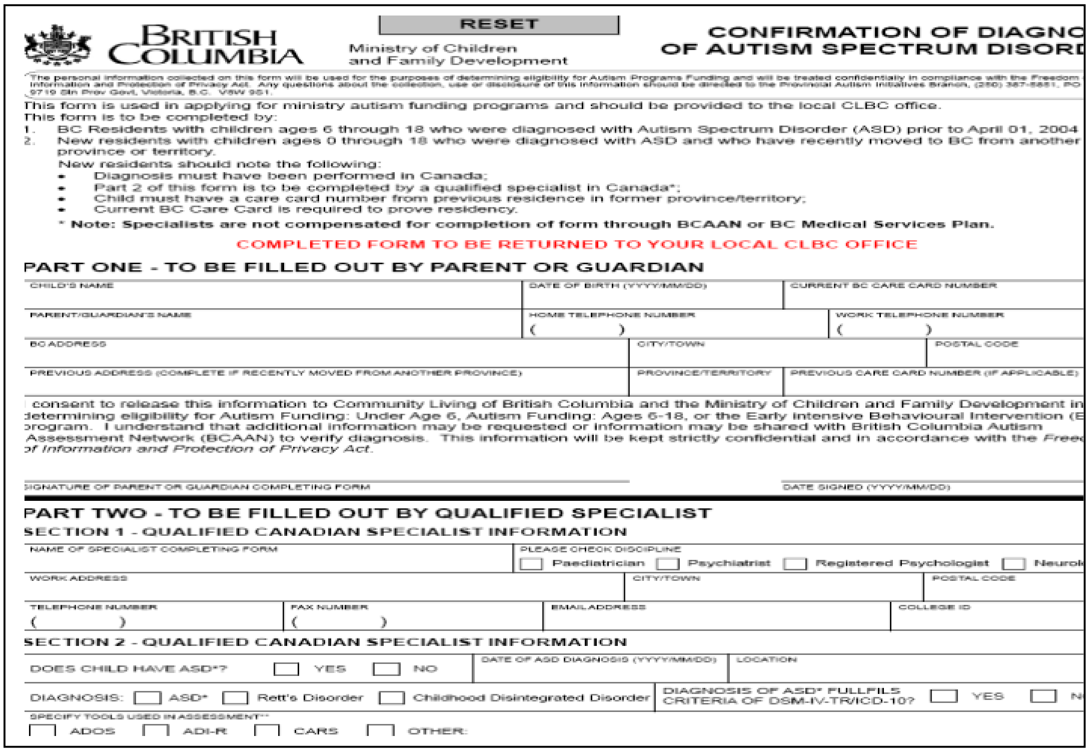
Address represents:
☐ Biological Parent ☐ Adoptive Parent ☐ Foster Parent ☐ Legal Guardian
☐ Care Facility ☐ Independent Living ☐ Other: ______

Part Two: Qualified Specialist Information

Name of Specialist providing information for parts **four to seven** of this form:

First Name:
Last Name:
Billing or College ID:
Email:
Phone#: 000-000-0000
Address:
Province:
City:
Postal Code:

BC Autism Assessment Network (BCAAN)



BRITISH COLUMBIA
Ministry of Children and Family Development

RESET

CONFIRMATION OF DIAGNO
OF AUTISM SPECTRUM DISORD

The personal information collected on this form will be used for the purposes of determining eligibility for Autism Programs Funding and will be treated confidentially in compliance with the Freedom of Information and Protection of Privacy Act. Any questions about the collection, use or disclosure of this information should be directed to the Provincial Autism Initiatives Branch, (250) 387-5851, PO 9719 Stn Prov Govt, Victoria, B.C. V8W 9S1.

This form is used in applying for ministry autism funding programs and should be provided to the local CLBC office.
This form is to be completed by:

1. BC Residents with children ages 6 through 18 who were diagnosed with Autism Spectrum Disorder (ASD) prior to April 01, 2004
2. New residents with children ages 0 through 18 who were diagnosed with ASD and who have recently moved to BC from another province or territory.

   New residents should note the following:
   - Diagnosis must have been performed in Canada;
   - Part 2 of this form is to be completed by a qualified specialist in Canada*;
   - Child must have a care card number from previous residence in former province/territory;
   - Current BC Care Card is required to prove residency.

* **Note: Specialists are not compensated for completion of form through BCAAN or BC Medical Services Plan.**

COMPLETED FORM TO BE RETURNED TO YOUR LOCAL CLBC OFFICE

PART ONE - TO BE FILLED OUT BY PARENT OR GUARDIAN

CHILD'S NAME
DATE OF BIRTH (YYYY/MM/DD)
CURRENT BC CARE CARD NUMBER
PARENT/GUARDIAN'S NAME
HOME TELEPHONE NUMBER ( )
WORK TELEPHONE NUMBER ( )
BC ADDRESS
CITY/TOWN
POSTAL CODE
PREVIOUS ADDRESS (COMPLETE IF RECENTLY MOVED FROM ANOTHER PROVINCE)
PROVINCE/TERRITORY
PREVIOUS CARE CARD NUMBER (IF APPLICABLE)

I consent to release this information to Community Living of British Columbia and the Ministry of Children and Family Development in determining eligibility for Autism Funding: Under Age 6, Autism Funding: Ages 6-18, or the Early intensive Behavioural Intervention (E program. I understand that additional information may be requested or information may be shared with British Columbia Autism Assessment Network (BCAAN) to verify diagnosis. This information will be kept strictly confidential and in accordance with the *Freed of Information and Protection of Privacy Act.*

SIGNATURE OF PARENT OR GUARDIAN COMPLETING FORM
DATE SIGNED (YYYY/MM/DD)

PART TWO - TO BE FILLED OUT BY QUALIFIED SPECIALIST

SECTION 1 - QUALIFIED CANADIAN SPECIALIST INFORMATION

NAME OF SPECIALIST COMPLETING FORM
PLEASE CHECK DISCIPLINE ☐ Paediatrician ☐ Psychiatrist ☐ Registered Psychologist ☐ Neurol
WORK ADDRESS
CITY/TOWN
POSTAL CODE
TELEPHONE NUMBER ( )
FAX NUMBER ( )
EMAIL ADDRESS
COLLEGE ID

SECTION 2 - QUALIFIED CANADIAN SPECIALIST INFORMATION

DOES CHILD HAVE ASD*? ☐ YES ☐ NO
DATE OF ASD DIAGNOSIS (YYYY/MM/DD)
LOCATION
DIAGNOSIS: ☐ ASD* ☐ Rett's Disorder ☐ Childhood Disintegrated Disorder
DIAGNOSIS OF ASD* FULLFILS CRITERIA OF DSM-IV-TR/ICD-10? ☐ YES ☐ N
SPECIFY TOOLS USED IN ASSESSMENT**
☐ ADOS ☐ ADI-R ☐ CARS ☐ OTHER:

ASD Intervention Services: Activating Specific Social sequences

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, 1-5). Through the complementary work of mothers and others[38], 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.[39] During this time, the work of picking out and selecting what fits in the autistic shells is written in texts and made actionable in some way. Based on the team meeting/consultation (Diagram 3, 5), forms are filled out that specify the outcome of the process, assuring the *Standards and Guidelines* were followed (Diagram 3, 6). 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, 7). Notice how the DSM-IV is in the background of Diagram 3, representing how this master text governs the entire process of autism diagnoses.

The interview insert below represents how the actualities of mothers and others and their complementary work are made official and thus actionable. 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…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 (PANTER[40]) 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).

At the end of the assessment process, the practitioner, based on the work knowledges of the multidisciplinary team, fills out a form that is 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 actionable. If the metaphorical autistic shells are filled based on specific criteria outlined in texts, the PANTER form activates other social

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[38] Work here includes the work of practitioners in following the *Standards and Guidelines* and their work of implementing the assessment tools as discussed above. The mother's work is talking about her actuality and waiting during the assessment process. The work of the child suspected of having autism is doing the tasks involved in the ADOS.

[39] The child might need further assessment, be diagnosed with autism or be reevaluated. These outcomes represent different pathways that might be activated as an outcome of the assessment process.

[40] Provincial Autism Network Testing Evaluation Report (PANTER).

relational sequences for the family and child, whether in the form of services, access to funding, education support or interventions for areas of concern. In addition, a "longer version" of the PANTER form is sent to BCAAN for administrative purposes (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 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 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 unaccountable actualities that fall through the cracks, resulting in individuals being left outside the scope of services and supports.

Autism <u>Spectrum</u> 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: 94-95) 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.

As such, the characteristics of autism are unique to each person who has the disability in addition to the individual(s) doing the work of describing or measuring the disability. It is a disability with many gray (immeasurable and uncertain) 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 standards[41] 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[42], 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.[43]

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. A sifting process similar to panning for gold facilitates this representation. In order to do so, what has been referred to as "new" methods of accounting logic are put in place to formulate and reformulate, calculate, and enumerate people's experiences, which are then

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[41] Procedural standards are one of four types of standards discussed by Timmermans and Berg (2003:25) 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, 2003:26).

[42] The practitioners interviewed described the ADI-R and the ADOS as tools "that are generally accepted worldwide as being the gold standard…it's a gold standard of behaviour disorders" (Pediatrician).

[43] "…[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).

made into a textual representation ("they are worked up and worked on as virtual realities"). There is a problem inherent in this process. Ian Hacking explains:

> '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 points of view while silencing others. The implications are drastic; displacing people's everyday doings into standardized processes where their actualities are forced 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 perpetuates un-accounted for areas of autism where individuals are left outside the purview of services and supports in a funding-driven system like BC[44].

Another difficulty brought on by the process is that in some cases, assessment tools/instruments 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 edge of the "autistic shells".

Research further suggests that the instruments required by the *Standards and Guidelines* are restrictive in their requirements needed to diagnose children with autism.

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[44] This is exemplified in the case of Cindy and her child Cam. Through the work of Cindy and others, Cam was eleven years old when her and her mother's actualities were made to fit within autistic shells prescribed. An actionable diagnosis was the outcome. This provided the key to services and supports. It is important to note that the mother, child, and family missed out on years of services and supports, including early intervention therapy.

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: 213) 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.

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"[45]. 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.

Conclusion:

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

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[45] "So you give the diagnosis and the child receives funding. The family receives funding. The diagnosis, 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" (Pediatrician).

BC, services and supports become available based on actionable “designations” and are not based on need. However, families of children who have some but not all characteristics of autism are also in need of services[46]. 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.

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 (whether in the form of services or not).

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. I problematized and interrogated this process, showing how a pile-up of unaccounted for actualities is produced when a process to diagnose 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.

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[46] “ …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” (Pediatrician).

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.

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 ethnography provides an ethnographic look "inside Canada's health care reform" (Campbell and Rankin, 2006) and adds 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:

DSM-IV Criteria for Pervasive Developmental Disorders:

Disintegrative Disorder299.00 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

299.80 Rett's Disorder:

(A) All of the following:

1. Apparently normal prenatal and perinatal development
2. Apparently normal psychomotor development through the first 5 months after birth
3. Normal head circumference at birth

(B) Onset of all of the following after the period of normal development:

1. Deceleration of head growth between ages 5 and 48 months

2. Loss of previously acquired purposeful hand skills between ages 5 and 30 months with the subsequent development of stereotyped hand movements (e.g., hand-wringing or hand washing)
3. Loss of social engagement early in the course (although often social interaction develops later)
4. Appearance of poorly coordinated gait or trunk movements
5. Severely impaired expressive and receptive language development with severe psychomotor retardation

299.10 Childhood Disintegrative Disorder:

(A) Apparently normal development for at least the first 2 years after birth as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior.
(B) Clinically significant loss of previously acquired skills (before age 10 years) in at least two of the following areas:

1. Expressive or receptive language
2. Social skills or adaptive behavior
3. Bowel or bladder control
4. Play
5. Motor skills

(C) Abnormalities of functioning in at least two of the following areas:

1. Qualitative impairment in social interaction (e.g., impairment in nonverbal behaviors, failure to develop peer relationships, lack of social or emotional reciprocity)
2. Qualitative impairments in communication (e.g., delay or lack of spoken language, inability to initiate or sustain a conversation, stereotyped and repetitive use of language, lack of varied make-believe play)
3. Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, including motor stereotypies and mannerisms

(D) The disturbance is not better accounted for by another specific Pervasive Developmental Disorder or by Schizophrenia.

299.80 Asperger's Disorder:

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

1. Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, 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.

(B) Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one 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, non-functional 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

(C) The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
(D) There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years)
(E) There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.
(F) Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

299.80 Pervasive Developmental Disorder Not Otherwise Specified (Including Atypical Autism):

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction or verbal and nonverbal communication skills, or when stereotyped behavior, interests, and activities are present, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder. For example, this category includes **atypical autism** --- presentations that do not meet the criteria for Autistic Disorder because of late age of onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

Appendix B:

Autism Diagnostic Interview-Revised (ADI-R)[47]

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

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

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.

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.