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Revealing disjunctures: Making tensions between fetal alcohol spectrum disorder diagnoses and institutional supports visible

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ABSTRACT

Institutional ethnography (IE) is a method of inquiry that offers emancipatory possibilities. This paper reveals how IE's emancipatory value is linked to identifying and examining *disjunctures*, which are discrepancies and disconnections between what is understood to be happening versus what is actually being experienced. Using examples from an IE study that examined the social organization of supports and services for children medically diagnosed with fetal alcohol spectrum disorder (FASD) in an urban community in eastern Canada, four specific disjunctures are revealed and discussed. These disjunctures make various disconnections between school-aged children diagnosed with FASD and institutional supports visible. Furthermore, I illustrate how the ambiguity of institutional policies and communication makes it difficult for children living with FASD to thrive. This study also reveals how caregivers are required to be FASD experts while not being seen or treated as experts. By uncovering and making disjunctures visible, I argue that IE studies can draw evidence-based attention to specific institutional policies and practices that are missing or require change.

1. Introduction

In institutional ethnography (IE), one of the goals is to analyze *disjunctures*. Disjunctures refer to the discrepancies and disconnections between what is understood to be happening versus what is actually being experienced. This paper reveals how using IE is useful for identifying and examining disjunctures that occur when children are diagnosed with fetal alcohol spectrum disorder (FASD). To provide context, the first section of this paper reviews key aspects of FASD: what it is, how it is unique, why people seek early diagnostic assessments, how it affects the work of parenting, and its currency as a medical diagnosis. The methodology section details recruitment, data collection, and data analysis for this IE study.

Later, I discuss disjunctures between (a) medical professionals' positions on the utility of a FASD diagnosis and the available supports; (b) eligibility criteria for supports and recognized exceptionalities; (c) requested support and the actual organization of the support; and (d) parenting work and the parental work that counts for institutions. By making the disconnections between the realities of living with FASD and the institutional supports visible, it becomes clear that ambiguity of institutional policies and communication makes it difficult for children with FASD to thrive. It also becomes evident that parental figures are required to be FASD experts while not being seen or treated as experts.

1.1. Getting acquainted with FASD

1.1.1. What is FASD?

Fetal alcohol spectrum disorder (FASD), caused by prenatal exposure to alcohol, permanently impairs cognitive, behavioural, social and emotional development. When exposed to alcohol, a fetus can develop growth deficiencies, central nervous system dysfunctions and unique facial anomalies (Astley & Clarren, 2000; Clarren & Smith, 1978). Jones and Smith (1973) wrote the first published paper on fetal alcohol syndrome that made the connection between prenatal alcohol exposure and growth, brain development, and joint malposition explicit. Teratogens, found in alcohol, can interfere with fetal development that is occurring around the time of consumption—making the central nervous system most vulnerable since it is in constant development in utero (Clarren & Smith, 1978). Currently, FASD is the umbrella term coined in 2000 to represent a range of diagnoses related to prenatal alcohol exposure (Astley & Clarren, 2000; Streissguth & O'Malley, 2000).

Knowing that a diagnosis does not determine a specific course of treatment or intervention, however there is an inventory of approaches and strategies that have been documented as effective with children diagnosed with FASD. Child development and FASD literature agree that early interventions, birth to age 6–7 years, help mitigate potential challenges that children and youth living with FASD face as they move into adulthood (Abrams, 2010; Astley, Bailey, Talbot, & Clarren, 2000; Carmichael Olson, Rosalind, Gelo, & Beck, 2009; Paley & O'Connor, 2009). One current and major diagnostic challenge is that diagnostic testing is designed for children approximately age 7 and older, excluding

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adults, which is past the point of "early" intervention (Astley & Clarren, 2000; Benz, Rasmussen, & Andrew, 2009; Canadian Association of Paediatric Health Centres, 2010).

1.1.2. What is unique about FASD diagnoses?

FASD is frequently cited as being the "leading preventable cause of neurodevelopmental disability" (Bryanton et al., 2014, E121) and is unique in several ways. First, it is a medical diagnosis for a developmental delay from birth that is considered both behaviourally preventable and irreversible (Abel & Sokol, 1987; Coles, 1993). Mothers who give birth to children with FASD are often subjected to moral judgment to the extent that some pregnant women in North America have been held against their will in custody such as prison or treatment centres for the sake of their fetus—sending the message that the state is more invested in the fetus' well-being than that of the pregnant woman herself (Lester, Andreozzi, & Appiah, 2004; Paltrow, 1990; Winnipeg Child and Family Services (Northwest Area) v. G.(D.F.), 1997).

Second, it is a medical diagnosis that is not recognized by all health professionals as legitimate. The Canadian diagnostic guidelines were last revised in 2005 (Chudley et al., 2005a). One of the most stigmatizing aspects of the diagnosis is that it requires doing a complete history that confirms maternal consumption of alcohol during pregnancy (Armstrong, 2003; Armstrong & Abel, 2000; May et al., 2009).

Third, the way FASD manifests in children living with FASD can greatly vary depending on a multitude of variables such as the volume, frequency, and timing of the alcohol consumption; living conditions and access to good prenatal care; early childhood environment; and co-existing mental health among other determinants of health (Abel, 1995; Chudley, 2008; Chudley et al., 2005b). The implications of this variability are that the appropriate interventions and supports for people living with FASD are diverse and poorly understood (Carmichael Olson et al., 2009; Fast & Conry, 2011; Kalberg & Buckley, 2007; Lutke, n.d.).

1.1.3. Why get diagnosed?

It is widely understood that there are many more people living with FASD than are diagnosed (Bell et al., 2015; Elliott, Payne, Haan, & Bower, 2006; May & Gossage, 2001). Prevalence data does not exist for most populations worldwide for several reasons. At the individual level in the U.S. and Canada, the impetus for getting a FASD diagnosis is often made to gain access to supports and services as well as confirm or legitimize observed behavioural or developmental concerns (Carmichael Olson, Jirikowic, Kartin, & Astley, 2007; Koren, Fantus, & Nulman, 2010b; Streissguth, Bookstein, Barr, Sampson, O'Malley, & Young, 2004).

The overwhelming majority of parents who pursue a FASD diagnostic assessment are adoptive or foster parents, compared with birth parents (Astley et al., 2000; Brown & Bednar, 2004). Unlike birth parents, adoptive or foster parents do not have the fear of being blamed or shamed for their child's potential FASD diagnosis. There are no studies that examine why parents do not pursue a FASD diagnostic assessment for children; however, scholars have made some conjectures about possible reasons (Badry, 2010; Brown, Sigvaldason, & Bednar, 2005; Carmichael Olson et al., 2007; May et al., 2009). Conjectures include the lack of FASD awareness and screening among health care professionals; lack of diagnostic assessment services; misreading behaviours as symptomatic of other diagnoses such as attention deficit disorder (ADD), attention deficit hyperactivity disorder (ADHD), oppositional defiance disorder (ODD), or poor parenting skills; and the fear of stigma attached to the birth mother if a FASD diagnosis is made. Table 1 lists a range of possible reasons why parents may seek, or not seek, a FASD diagnostic assessment.

1.1.4. Parental work of children with FASD

Literature on the work of parents has largely focused around foster and adoptive parent experiences, expressions and sources of parent stress, and the importance of early interventions that parents need to facilitate (Brown & Bednar, 2004; Brown, Bednar, & Sigvaldason, 2007; Caley, Winkelman, & Mariano, 2009; Carmichael Olson et al., 2009; Michaud & Temple, 2013; Paley & O'Connor, 2011; Pelech, Badry, & Daoust, 2013; Swart, Hall, McKee, & Ford, 2014). Parents are responsible for many aspects of supporting a child with FASD. In addition to the "usual" parenting responsibilities, they are subject to scrutiny of people who do not know about or understand FASD and how it is expressed in a child's appearance, cognition, and behaviour (Brown & Bednar, 2004; Brown et al., 2007; Giunta & Streissguth, 1988).

1.1.5. The emphasis on early interventions

There has not been extensive research done in the field of early interventions for children with FASD, in part because most diagnoses do not occur until children are school-aged (Carmichael Olson et al., 2007; Streissguth et al., 2004). Early interventions refer to intentional efforts made to optimize the development of children ages zero to five that have developmental delays or challenges. The emphasis on early interventions grew when a book by Streissguth, Barr, Kogan, and Bookstein (1996) highlighted common *secondary disabilities* of adults living with FASD. Secondary disabilities refer to challenges that a person was not born with but live with due to adverse childhood events and circumstances. Literature suggests secondary disabilities for individuals living with FASD include mental health issues, disrupted school experience, trouble with law, inappropriate sexual behaviour, alcohol and drug addictions, dependent living arrangements, and problems with employment (Badry, 2010; Clark, Lutke, Minnes, & Ouellette-Kuntz, 2004; Gary Roberts and Associates, 2008; Streissguth et al., 1996). The main argument for early interventions is that secondary disabilities can be mitigated if children had early interventions and appropriate supports throughout their childhood.

Even for children that already have a diagnosis, their behaviours and academic performances are frequently mislabeled or mistaken for something other than FASD since children with FASD can present themselves as having a learning disability, attention deficit hyperactivity disorder, oppositional defiance disorder; or as simply being a non-compliant child (Carmichael Olson et al., 2009; Clark, 2012; Koren, Fantus, & Nulman, 2010a). The education system, where child spend a lot of "awake" time, is organized in a way that expects teachers to

Table 1
Reasons for pursuing versus not pursuing a FASD diagnostic assessment.

Possible reasons to seek a diagnostic assessment (Carmichael Olson et al., 2007; Koren et al., 2010b; Streissguth et al., 2004)	Possible reasons to *not* seek a diagnosis (Badry, 2010; Carmichael Olson et al., 2007; Carmichael Olson et al., 2009; May et al., 2009)
• Clarity on the nature of the exhibited behaviours; • Want to provide appropriate interventions, supports, and services; • Proof of "disability" for access to resources or services; • Rule out other possible explanations for challenges or behaviours; and • Participate in a prevalence study that may lead to better services.	• Parents and service providers alike are unfamiliar with FASD; • Medical professionals are unfamiliar with FASD screening tools or other flags that may lead to a referral; • No local diagnostic team/capacity; • Lack of trained interdisciplinary team (where assessments are possible but diagnoses are not); • Women may not disclose prenatal alcohol consumption (e.g., fear of judgment, blame, stigma, uncertain of outcome etc.); • Symptoms are diagnosed with other labels such as attention deficit disorder (ADD), attention deficit hyperactivity disorder (ADHD), oppositional defiance disorder (ODD); and • Behaviours are interpreted as the effects of poor home environment or parenting skills.