# **Preventing or Creating Crises?**

Exploring the Work Process of Managing Challenging Behavior in Canada

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#### **Danish Summary**

Dette specialeprojekt undersøger, identificerer og kortlægger hvordan diskursive og institutionelle processer styrer, former og påvirker måden hvorpå socialarbejdere håndterer konflikter og udfordrende adfærd på en boenhed for voksne personer med en Autisme Spektrum Forstyrrelse i Canada.

Specialet anvender institutionel etnografi (IE) som er en teoretisk and metodologisk tilgang der begynder med individers erfaringer i og omkring deres eget hverdagsliv. Fra dette standpunkt undersøger forskeren individernes handlinger, og ud fra deres erfaringer begynder forskeren gradvist at etabalere en problematik. IE undersøger hvordan vores aktiviteter er kooridineret og formet af komplekse institutionelle processer (ruling relations) der indrammer vores erfaringer i og omkring vores eget hverdagsliv. Vores hverdags erfaringer og hverdags handlinger er organiseret, formet, og indlejret i organisationer og institutioner der går udover dét som vi ved eller direkte kan observere (Smith, 2005). IE tilbyder dermed forskeren at synliggøre den forbindelse mellem individers hverdags oplevelser og de organisatoriske prioteter som er reflekteret i institutionelle tekster. IE lægger særligt vægt på forskellige former for tekster og følger disse tekster for at kunne blotlægge og få indblik i hvordan styrende og magfulde relationer strukturer og koordinerer individers handlinger i en local sammenhæng. Det analytiske mål med IE er at identificere og blotlægge de forbindelser der er problematiske i form af et kort (map) der visualiserer et mere fuldkomment billede af den sociale organisering.

Undersøgelsens empiriske data grundlag bygger på etnografiske interviews med fire socialarbejdere, to interviews med deres leder, ét interview med en trænings instruktør samt tekstanalyse af et specifikt dokument og en træningsmanual der anvendes i den daglige konflikthåndterings proces.

Resultaterne af undersøgelsen blotlægger hvordan det Canadiske sociale arbejde med personer med autisme, er reguleret og standardiseret af en trans lokal Amerikansk trænings organisation hvis institutionelle diskurs objektiviserer de personer den har til hensigt at støtte, og samtidig udelukker (eller misfortolker) de særlige karakteristika ved en autisme spektrumforstyrrelse hvilket får specifikke konsekvenser for beboerne. Ved at anvende de metodiske og kartografiske principper som IE tilbyder, identificerer nærværende undersøgelse en problematik i relation til måden hvorpå socialarbejdere fortolker og håndterer udfordrende adfærd på en måde der ikke altid er støttende eller anerkendende for den enkelte beboer.

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Anthony; your constant source of encouragement, support and understanding is beyond words. Thank you for taking the boys without hesitation when I was working away at the library. And to my three little boys Luca, Noah and Mateo: Mor is finally finished-let's go out and play  $\bigcirc$   $\bigcirc$   $\bigcirc$ .

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#### Foreword

As a former social worker (social pedagogue) with five years of work experience in several Danish residential homes for individuals with developmental disabilities, I have experienced challenging behaviour and conflict situations on a daily basis that I had to deal with. Sometimes individuals would bang their heads on the floor or pull their hair or poke their eye balls, while yelling and screaming. Or sometimes they would hit, kick, pinch, scratch or bite. Simultaneously, I had to implement a pedagogical support practice that framed the way in which I was supposed to interact with the individuals. However, the support practice did not always adequately acknowledge the kind of conflicts that could arise in the everyday "work" of managing challenging behaviour which created an embodied dissonance within me as a social worker. I later re-entered university to pursue a Master degree in Social Work at the Department of Sociology and Social Work at Aalborg University and was fortunate to become affiliated with a large Danish research project investigating the psychosocial risk factors related to occupational health and safety for Danish frontline workers within the ASD area (Høgsbro et. al., 2012). This project inspired me in the development of my own thesis and I began to see possibilities of exploring my study in a different culture as it would open up new ways of learning and understanding the same phenomenon. As a result, I felt compelled to carry out my study in a Canadian context. Comparing and analyzing different ways of doing things is an important sociological approach that allows us to see alternative realities and possibly modify our own culture-bound theories of human behaviour (Spradley, 1979). Being a Danish ethnographic "stranger" in an unfamiliar Canadian culture would force me to reflect upon my own pre-understanding and at the same time, enable me to notice how Canadian social workers are influenced and confined by their current knowledge within their own specialized worlds, the accepted discourses and the premises they take for granted (Høgsbro, 2010). This thesis is a report of a study based upon ethnographic interviews and textual analysis in a residential setting for adults living with an ASD in the province of Ontario, Canada.

# 1. Introduction

The following first chapter of the thesis presents the background of the study, explains the notion of a problematic and introduces the research question. The chapter also defines some key terms, describes the delimitations of the study and finally presents a project design.

#### 1.1 Background of the Study

Assault, abuse or neglect against people with developmental disabilities perpetrated by a care provider in a long-term care facility is not an unknown or a new phenomenon in our society. In fact, research suggests it is widely acknowledged and prevalent in Canada as well as in other countries around the world (Public Health Agency of Canada, 2010; Moore, 2001; Goodridge et al. 1996). Institutional abuse can be defined as any act of violence or rough treatment such as hitting, slapping, forcing body movements and using unauthorized or unsupervised physical restraints in a managed institutional care of human beings that is paid by the government or by other public funds (Ibid).

Simultaneously, frontline support workers endure physical violence from residents. According to Armstrong et al. (2009), physical violence and verbal abuse is a constant and ongoing part of working in Canadian facilities. Their study found that 43 percent of Canadian frontline support workers experience physical violence at work on a daily basis. People with developmental disabilities are dependent on staff, and staff are expected and held responsible for regulating and "controlling" the residents in regards to custodial care. If care is rushed, or worse, if it is forced in terms of when residents are put to bed, woken up, going to the bathroom, when to eat etc., this may leave the residents feeling threatened, fearful, overwhelmed and prone to retaliate violently (Armstrong et al. 2009; Sobsey, 1994).

Research indicates that when frontline support workers are subject to physical violence and verbal abuse from the individuals they support, they subsequently respond in the same way. Few staff can indefinitely work with a individuals who oppose serious challenging behaviour and never use force to defend themselves, protect other residents or staff, regardless of how well-intentioned or caring they may be (Goodridge et al. 1996; Sobsey, 1994). At the same time, lack or inadequate training about how to deal with challenging behaviour is a known fact leading to exacerbating conflict situations and abusive incidents (Public Health Agency of Canada, 2010; Elvén, 2010, Goodridge et al. 1996; Marchetti and McCartney, 1990).

According to Autism Ontario adults with an Autism Spectrum Disorder (ASD) remain among the most vulnerable and poorly served citizens (Autism Ontario, 2008). About one per cent of Ontario's 13 million people have a developmental disability. Out of that number there are an estimated 70,000 people with ASD (Ministry of Community and Social Services, 2012). People with ASD have different characteristics where the core deficits are manifested in the areas of communication, reciprocal interactions, and repetitive behaviours which affect the social interaction with other people (Emerson, 2001). Some individuals with ASD have a need to complete tasks before they can move on to the next and become perseverated or fixated on specific things or processes. If they are interrupted in their thoughts and activities, or if they are feeling overwhelmed, stressed or not being understood, this can easily lead to frustration, self-injurious and/or challenging behavior such as screaming, spitting, kicking, hitting, and putting themselves and/or other people in risk of injury (ibid.). However, as Shuler and Fletcher (2002) points out staff often consider or interpret the lack of communicative competence and understanding of social interaction as "challenging behaviour", but in fact stems from the individuals attempt to get attention, protest against change or avoid uncomfortable situations.

Since the numbers of individuals with various degrees of developmental disabilities continues to grow in Ontario - in a current framework of care that does not seem to

match the complex needs of these people- it is highly likely that conflict situations and abusive incidences will continue to rise, and thus constitute a significant social problem in Canadian society.

As support workers with whom residents have the most daily/nightly contact with, these workers are key players in managing challenging behaviour and dealing with conflict situations. Frontline support workers act the way they think is "right", and what they think is "right" is being governed by the social context in which they are referring to (Høgsbro, 2010). The specific interaction between support worker and individuals with ASD occurs in a complex of institutional processes that are discursively-organized such as policies, ideology, discourses, formalized responsibilities, leadership, resources and/or training that organise frame and influence support workers ability to manage challenging behaviour and conflict situations.

Institutional ethnography (IE) is a sociological method of inquiry that explores and identifies aspects that are "troublesome" by mapping and making visible how translocal institutional processes organise and shape local practices. Hence, I find IE the most suitable approach for my study (DeVault and McCoy (2002) in Smith, 2006).

#### **1.2 Research Question and the Problematic**

In institutional ethnography, the everyday world becomes the problematic which means that questions for investigation arise from the everyday world (Smith, 1987; 2005). Unlike mainstream social science, IE does not begin in theory by formulating a specific research question theoretically; rather it begins with the actualities of people's lives with a focus of investigation that comes from how those people experience, or how they are hooked into institutional relations (Smith, 2005). A problematic is a "…territory to be discovered not a question that is concluded in its answer" (Smith, 2005:41). A problematic organizes the direction of an investigation from the standpoint of those, whose experience, is its starting point and thus, it is larger than a specific question or a problem (Ibid.).

The problematic that I set out to explore arose out of my own experience as a former Danish support worker<sup>1</sup>. In my work, I experienced various organisational disjunctures between the actualities of managing challenging behaviour (with lack of specific training) and the pedagogical support practice that did not adequately take into account the kind of difficulties that could arise in the everyday work of supporting people with developmental disabilities. A disjuncture happens in a local setting when two different versions of reality meet- that of knowing from a ruling perspective, versus knowing from an experiential one (Campbell and Gregor, 2004).

It is this experience of disjuncture that provides an "entry-point" for my inquiry that will however, extend beyond my own work experience, to that of Canadian frontline support workers and the extended social relations that organize the way in which they manage challenging behaviour. Having the opportunity to explore and discover alternative realities about the same phenomenon in a different culture made me wonder about what problematic could be identified in a Canadian context. These questions led me to formalize a main question that I wish to explore;

How is the work process of managing challenging behavior socially organised in a Canadian context and what problematic can be identified in relation to this work process?

By *work process* of managing challenging behaviour I draw on Smith's "generous concept of work" (Smith, 2005: 152). I mean what do support workers do (are required to do) in the sequence/action of managing challenging behaviour both practically and textually. The term *social organisation* refers to when "distinct forms of coordination people's doings emerge that are reproduced again and again". This IE term is explained in the theory chapter.

<sup>&</sup>lt;sup>1</sup> Numerous institutional ethnographers have built their problematic from own experience such as Griffith and Smith, (2004); Ng (1986); de Montigny (1995a) and Rankin (2003).

#### **1.3 Definitions of Key Terms**

*Individuals with ASD:* This study focus on adults with an Autism Spectrum Disorder between the ages of 20-40 living in a Canadian residential home. Throughout the project I will either use the term *individuals with ASD* or simply *the individuals*. The definition of ASD is described in depth in Chapter 2.

*Challenging behavior:* I define challenging behaviour in accordance with Elven (2010) who defines challenging behavior as "behavior that causes problems for people around the person". As I want to explore the work process of how support workers manage challenging behavior, I use the term challenging behavior to direct attention to what support workers do and are required to do when encountering behaviours that they are required to manage and which causes problems for them (Elven, 2010)

#### Social Work:

Since there are no one recognized definition of what *social work* is (Meeuwisse, Swárd and Sunesson, 2007) my definition of social work is shared with that of Payne (2005) who emphasizes how the goals of social work must always be to enhance the clients/individuals identity; as well as the International Federation of Social Work (2012) which definition of social work "…promotes social change, problem solving in human relationships and the empowerment and liberation of people to enhance well-being"

Social worker: In this project I do not use the term *social worker* but the term *support* worker since the informants I spoke to were named *Personal Support Worker* and/or support workers. However, both social and support workers are considered change agents in society and in the lives of the individuals, families and communities they serve and support" (IFSW, 2012).

### **1.4 Delimitations of the Study**

This study focused on capturing detailed accounts of how Canadian support workers manage challenging behavior by moving beyond what could be directly observed or learned in the local setting, and into an exploration of how institutional processes discursively shape and organize their everyday support practice (Smith, 2005). Since it was obviously impossible to explore and map all the of the relations that go into the work process of managing challenging behavior, this study focus only on the intervention approach that support workers use when encountering and manage challenging behaviors. Hence, the study does not explore how custodial responsibilities, leadership and/or staff resources influence the specific interaction between support workers and individuals. Nor does the study investigate and analyse the behaviours, opinions or psychosocial well-beings of the informants. Throughout this institutional ethnographic investigation, the focus has been on the specific intervention approach the design of this project.

#### **Project design**

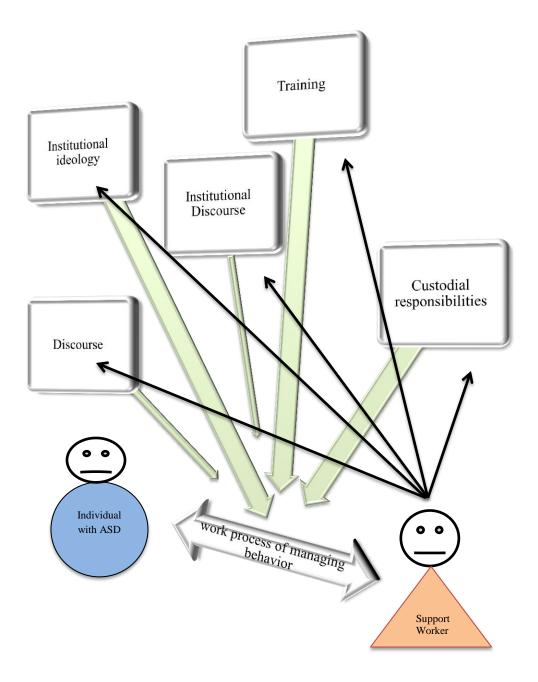


Fig.1.1: The project design is inspired by Smith's diagram (Smith, 2006: p.5). It shows how the work process of managing challenging behaviour is implicated and occurs in a complex of ruling relations beyond their immediate experience. It is from the support workers perspective that my inquiry is taking up and taking aim (the black arrows) into the complex of relations to explore how those institutional processes organise and frame their specific interaction in ways that might not always have a supportive outcome.

# 2. Literature Review

This chapter presents a synthesis of relevant literature and begins by explaining the search strategy. The chapter is divided into four thematic areas that pinpoint the subject matter. The three areas involve 1) ASD and challenging behaviour 2) Factors contributing to a dysfunctional interaction and 3) Institutional ethnography studies. Finally, this chapter summarize and discus how I approach my study and how my research is worthwhile studying.

## 2.1 Search strategy and Literature Review Process

The following literature review was developed through a *three-phase review* of the existing literature. The three-phase review consists of a *broad scan*, a *focused review* and a *comprehensive critique* (Glathorn, 1998). The broad scan of literature review was carried out in the very beginning to increase my knowledge of my topic and to assist me in identifying a research problem background. The focused review was then conducted to help me develop a preliminary sketch of what I was proposing to study (Ibid.). Finally, the comprehensive critique phase involved using my critical judgement in assessing the quality of the collected literature as well as locating the research that had a direct bearing to my research problem (Ibid). This critique involved how I position myself as an institutional ethnographer who does not read the literature for facts or take up the pre-existing discourses, but rather analyse the literatures as *part* of the social organised world of frontline support work (Rankin, (2003); Campbell and Gregor, 2004).

In conducting the broad scan of literature I primarily used the internet to find information about ASD in a Canadian context and came across several autism related websites and key organisations (Autism Ontario, the Canadian National Autism Foundation<sup>2</sup>, the International Autism Foundation Canada<sup>3</sup>). In order to understand the

<sup>&</sup>lt;sup>2</sup> www.cnaf.net/research.html

<sup>&</sup>lt;sup>3</sup> http://internationalautismfoundation.cfsites.org

societal context for Canadian individuals with ASD I also found it relevant and central to explore Canadian social policy and made use of the Canadian Ministry of Community and Social Services website<sup>4</sup>. I then conducting the focused search of literature by using the on-line library of Aalborg University using a RefWorks account to organise the literature I retrieved. The focused review of the literature was carried out in the following data bases: PROQUEST, EBSCOHOST, Academic OneFile, General OneFile and Sociological Abstracts. Using a Boolean search, I developed and combined different combinations of search terms<sup>5</sup>. I also combined the search terms with *institutional ethnography* and found related studies that inquire into the social organisation of knowledge. The following table provides an overview of the different combinations I carried out in my focused review.

Frontline worker	Client/Resident	Location	Торіс
Personal Support	Autism*	Residential*	Abuse* Neglect*
Worker*			
Support Worker*	ASD*	Group home*	Challeng* behav*
Social Worker*	Asperger*	Home*	Conflicts*
Autism Associate*	Developmental*	Facility*	Health and Safety*
	Disability*		
Frontline	Resident *	Institution*	Treatment*
staff/worker*			
Caregiver*	Client *	Independent	Approaches*
		Living*	
Staff*	Individual*		Management*
			Organisation*

<sup>&</sup>lt;sup>4</sup> http://www.mcss.gov.on.ca/en/mcss/

<sup>&</sup>lt;sup>5</sup> A Boolean search uses parentheses to group terms and "operators" such as AND, OR, or NOT to limit the search results.

### 2.2 ASD and Challenging Behaviour

Developmental disabilities are generally used to describe life-long impairments that are attributable to mental and/or physical disabilities. All though there are an innumerable variety of developmental disabilities, Cerebral Palsy, Down's syndrome and Autism are three of the most common examples of developmental disabilities (Volkmar and Wiesner, 2009). Autism is a highly complex disorder that affects the brain's ability to develop social and communication skills. It is one of five developmental disabilities known as autism spectrum disorder (ASD) which is an umbrella category for a range of neurodevelopment disorders in the DSM-IV<sup>6</sup>. The conditions include autistic disorder (usually referred to as autism), Asperger's syndrome, and two severe and rare forms of autism known as Rett's disorder and childhood disintegrative disorder. The fifth type of ASD is pervasive developmental disorder not otherwise specified (PDD-NOS), which is diagnosed when children have autistic symptoms but not necessarily meet all the criteria for autism (ibid.).

Although no two people with ASD exhibit exactly the same symptoms and the severity of symptoms greatly varies, there are some commonalities to their characteristics. Individuals with an ASD have difficulties with verbal and nonverbal language, social interaction and relationships, and they may have restricted, repetitive, and stereotyped patterns of behavior (Volkmar and Wiesner, 2009; Hollander & Nowinski, 2003).

Individuals with autism have difficulty understanding another person's feeling or understanding humor which can affects the relation to other people including staff. If people with ASD are overwhelmed, stressed or not being understood, this can easily lead to self-injurious and/or challenging behaviour such as screaming, spitting, kicking, hitting, smearing and putting themselves and/or other people in risk of injury (Emerson, 2001).

<sup>&</sup>lt;sup>6</sup> *DSM-IV* is a Diagnostic and Statistical Manual of Mental Disorders published by the American Psychiatric Association which defines and describes the diagnostic criteria for mental disorders and provides systematic descriptions of them (Volkmar and Weisner, 2009).

Challenging behaviour is defined in different ways. One acknowledged research definition is the one by Professor Eric Emerson (2001) who defines challenging behaviour as "culturally abnormal behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be put at a risk, or behaviour that probably greatly limits the person in the use of, or results in the person being denied access to, common physical public places or services (Emerson, 2001).

However, as Clinical Psychologist Bo Hejlskov Elvén (2010) points out Emerson's definition is complicated and difficult to master as it does not include what the behaviour may be. Elvén believes that what defines challenging behaviour more than anything, is that it makes other people, such as staff or family, feel inadequate and powerless (Elven, 2010). He defines challenging behaviour as a behaviour "...that causes problems for people around the person" (Elven, 2010). Elven believes that people around the person with challenging behaviours, are the ones defining the behaviour as problematic and as a result the methods used to manage the behaviour, often turn to be inadequate.

Another Clinical Psychologist Andy A. McDonnell (2010), has specialized in working with individuals who exhibit challenging behaviour and is the founder of the international training organization *Studio III Training Systems*. His definition of challenging behaviour focusses, like Elven (2010), on the staffs feelings as he defines challenging behaviour as a "...behaviour that pisses you off" (ibid.).

Although the term is defined differently, challenging behaviour refers to a "difficult" or "problematic" behaviour and the types or severity of challenging behaviour can vary greatly. Some of the behaviours include aggression (hitting, kicking, biting), destruction (ripping clothes, breaking or throwing objects) self-injury (head banging, self-biting, skin picking), tantrums and many other behaviours such as running away, eating inedible objects, rocking and/or other stereotyped movements (Volkmar and Wiesner, 2009; Hollander & Nowinski, 2003). In many cases, however, the term is used to refer to behaviour which does not have such immediately serious consequences but is, nonetheless, very upsetting, disruptive or stressful for the individual as well as the people around the individual (Elvén, 2010).

The causes of challenging behaviour can stem from numerous factors including biological (pain, medication, the need for sensory stimulation), social (boredom, seeking social interaction, the need for an element of control, lack of knowledge of community norms, insensitivity of staff and services to the person's wishes and needs) environmental (physical aspects such as noise and lighting, or gaining access to preferred objects or activities), psychological (feeling excluded, lonely, devalued, disempowered) or simply a means of communication/staff believes (Emerson, 2001, Hasting,1997). Research suggests that challenging behavior is a reaction to the challenging environments that is created around the individual with ASD. Too high demands for which an individual with ASD who does not have the prerequisites to live up those demands can lead to challenging behavior (Harrison, 2005).

There are various approaches, models and treatment used to reduce or manage challenging behaviour for individuals with ASD. As individuals with ASD have difficulties predicting the future and for some individuals they require a clear structure in their daily life, the structure-based autism pedagogy TEACCHH (Treatment and Education of Autistic and related Communication handicapped Children) works with creating structured learning and skills development techniques for people with autism such as piktograms, work systems, structures and lists can help them through daily life (Wall, 1990). However, although this structure-based pedagogy reduces challenging behavior, research indicates that 80 % of conflicts are caused – or worsened- by the way staff manages the situation (McDonnell, 2010). Dr. Andrew McDonnell (BSc, MSc PhD) wanted a method that aimed at avoiding escalating or further stress individuals who is already affected by the uncomfortable situation and thus, he developed the Low Arousal approach in England in 1989. (Studio III, 2012). The Low Arousal approach later resulted in the training program called Studio III. The Studio III approach focus on understanding the handicap or disorder as well as the reactions that people have when they are in conflict (ibid.). The way in which conflicts and challenging behavior are managed therefore takes its point of departure in the actual individual's behavior and his/hers ability to understand. However, the focus is at simultaneously on the behavior of the staff which means that Studio III encourage staff to question their own behavior as well as maintaining an overview in conflict situations and be able to solve the conflict in a respectful and dignifying way (ibid.). Studio III is now the chosen approach in many institutional settings for individuals with developmental disabilities throughout European countries (UK, Ireland, German, Sweden and Denmark).

Some studies indicate that physical as well as medical restraints are often used to treat and manage challenging behavior on the frontline (Enmarker et. al., (2011), Emerson et al. 2000, Feldman et al. (2004). Without formal behavioral guidelines in place staff are more likely to use reactive, controlling and often intrusive methods to manage challenging behavior. The use of inappropriate, inconsistent or reactive intervention strategies may, in turn, act as contributing factors to an increase in challenging behavior (ibid.).

#### **2.3 Factors Influencing a Dysfunctional Interaction**

Research points to various factors associated with and contributing a dysfunctional or difficult interaction between residents and frontline staff (Goodridge et al. (1994), Antonsson et al., (2008), Sobsey (1994), Goffman, 1961).

Sobsey (1994) explains how the physical and psychological aspects of the specific interacting between support worker and residents, are considered within the context of environmental and cultural factors since cultural attitudes, beliefs and ideologies to impact the specific relationship between residents and staff. He says that many organisational philosophies commonly quote the ideals of normalisation and individualization but at the same time the service system that are in place usually or directly, conflict with or undermine the attempt to achieve such goals. Support workers are at the bottom of a complex bureaucracy where they have little real influence or autonomy which might give them a feeling of being powerless within the institution (Sobsey, 1994). The support workers may have too many challenging residents to look after which increases stress, frustration and can subsequently result in mistreatment of the residents. The powerful superiors at the top are far removed from the realities of the

support workers lives and thus, lack basic information and knowledge about the problems they encounter (Ibid).

The specific relationship between carer and residents are further characterised by an asymmetrical relation and power inequity which lead to an unsuccessful interaction, failing to satisfy needs and failing to manage challenging behaviors (Antonsson, et al, 2008, Goffman, 1961). Although the literature pinpoints how the environment in which the care is delivered and organised has significance on the specific interaction, the literature on how the organisation beyond the building affects the actual interaction is scant and needs further studies (ibid.).

Høgsbro et al. (2012) study investigated the correlations between conflict management, pedagogy and mental workload experienced by frontline staff in five Danish residential homes for individuals with developmental disorders including autism. The study investigated how the specific interaction between staff and residents unfolded, and what pedagogical practice and conflict management methods informed their practice. The study showed a direct correlation between the level of mental workload and staff lacking adequate and necessary methods to manage challenging behavior with the individuals they support which created unsupportive situations. Since the majority of research within this field seem to either focus on frontline staffs mental work load or the pedagogical methods used in managing behaviors, this study in particular included both perspectives and focused on the mental workload of frontline staff as well as the problematics in relation to working with individuals who display challenging behavior.

Another related study by Armstrong et al. (2008) investigates the relationship between the quality of care and the quality of working conditions in Canadian long-term residential care compared to Scandinavian care settings (Denmark, Finland, Sweden and Norway). Their findings indicates how a dysfunctional interaction with residents are linked to the working conditions with too much to do, in too little time, limited autonomy and with not enough resources. They are understaffed; do not have time to develop relationships with residents; and may lack appropriate training. The study shows that the working condition not only fosters violence, but the violence is also rendered invisible. Most violent incidents are not reported due to workers fear of being blame. Underreporting is not unusual since a vast majority of violence in long term care goes unreported (Health Canada, 2010; Goodridge et al. 1996). A number of explanations have been suggested for the lack of documentation, including the burden of additional paperwork, the lack of management follow-up, a culture of blame, the desire to avoid conflicts with residents and the general assumption that violence is a part of the job (Ibid).

#### **2.4 Institutional Ethnography Studies**

In my review of the available literature there are two institutional ethnographies that are particular useful both methodologically and substantive in relation to my study. These studies are Gerald de Montigny (1995) and Tim Diamond (1992).

In "Social Working: An Ethnography of Front-line Practice" (1995) de Montigny analyse how social workers makes sense of the everyday reality of social work practice to create organizationally defined problems and cases. De Montigny specifically focusses on the practices that social workers use to produce a universalized professional form of knowledge. This includes their use of ideological practice to produce a specialized professional discourse and their practices of inserting details from client's lives into the discursive order of the hierarchal organization of the agency which are governed by the law (de Montigny, 1995).

Diamond's (1992) institutional ethnography is based on his own direct observation and experience as a caregiver in old age homes for seniors in the U.S. Diamond's ethnographic account portraits what the work is like for the caregivers working in senior homes and what the life is like for the seniors who live there. He explores the physical day-to-day work in which texts (charting, documenting) appear in distinctive work sequences that make his and nursing assistants embodied work accountable within and beyond a wider administrative process.

Other institutional ethnographies have close methodological connection to this study such as Townsend (1998) who identifies the invisible institutional processes that authorize the delivery of community mental health services from the standpoint of occupational health therapists. Turner's (2006) study that maps text-work-text sequences and processes in order to understand how municipal planning organizes land and housing development in ways that subordinates the residents as well as environmental interventions. George W. Smith (1998) investigates the social organization of schooling from the standpoint of young homosexual male students. Although these institutional ethnographies are different from the topic I investigate, they all explore, identify and explicate the social organization of professional and social services from the standpoint of clients/patients, front-line workers, and/or marginalized groups.

### 2.5 Literature Gap

In a review of the available literature, I have not come across a study that explores how Canadian support workers manage challenging behavior and how this work process is socially organised. The purpose of this thesis is therefore to explore aspects of the social organisation of managing challenging behaviour in a Canadian residential home for adults with ASD. The IE approach that I have chosen for my study has not been widely used to investigate the problematic that I set out to explore and thus, my study will likely yield some useful methodological findings. Uncovering the links that might be troublesome between the institutional processes framing the specific interaction between support worker and the individuals they support, is an innovative way to generate knowledge within this field which are beneficial to the individuals with ASD whose voice are not heard.

# 3. Institutional Ethnography - A Theoretical and Analytical Frame

Institutional ethnography (IE) is a sociological approach (a method of inquiry) that is at once theoretical, methodological and analytical. This chapter explains IE, describes its ontology and epistemological position, and presents some of the core concepts from the institutional ethnographic toolkit that I employ in my analysis. The chapter finally includes a scientific discussion between IE as an explorative method versus a hypothetical-deductive method as well as a theoretical discussion.

# 3.1 Institutional Ethnography

Institutional Ethnography (IE) was developed by Canadian sociologist Dorothy E. Smith. Dorothy E. Smith is a professor emerita in sociology and equity studies in education at the University of Toronto and adjunct professor of sociology at the University of Victoria in Canada (Smith, 2005). She is considered one of the most original sociologist and social theorist of our time and has received multiple awards for her work (Campbell and Manicom, 1995.)

Dorothy E. Smith developed IE out of her own experience in and off the women's movement in the 1970s that struggled against the masculine regime in which women were living. In the women's movement, Smith saw a gap of the contradictory modes of her own working existence. Being a single mother of two young children while simultaneously carrying out domestic labour in her home, stood in sharp contrast to the work she was doing as a professor teaching sociology, where the text-based world of sociology had nothing to say about women. Smith saw how her bodily existence, and the knowledge she had as a woman/mother, was not only rendered invisible- it was also completely discounted as a legitimate way of knowing (Frampton et al, 2006; Smith, 2005; Campbell and Manicom, 1995).

Smith realized that the two modes of consciousness/subjectivities of home and university could not be blended or coexists with one another. She struggled with what she came to call her bifurcated consciousness and began to analyse and resolve that *experience of disjuncture* by attempting to reconstruct the sociology that she had learned and was teaching (Smith, 1987: 2005; Campbell and Manicom, 1995). Institutional ethnographers critically investigate those experiences of disjunctures in terms of how they are socially organised. Experience is not to be understood as the "truth" however, beginning with people's social experiences can start us in a place that is in rupture with ruling ideologies and social discourses (Frampton et al, 2006).

The sociology that Smith had been trained in (in a predominantly male discipline) was not designed for exploring those relations of ruling and organisation from the standpoint of women or people. Smith wanted an alternative sociological practice that looked "... at all aspects of a society from where we are actually located, embodied, in the local historicity and particularities of our lived worlds" (Smith, 1987:8). In her long course of trying to find a different way of thinking sociologically, Smith was inspired by several theoretical thinkers, who became important resources in her development of IE. I will not address the work off these thinkers or attempt to trace their connections to Dorothy E. Smith, for that I refer to the writings of Smith (1987; 1990a, 1990b; 1999; 2005) However, in this chapter some of these thinkers will be referred to. The main theoretical thinkers that Smith was inspired by are Karl Marx (materiality; ideology), George Herbert Mead (symbolic interactionism), Harold Garfinkel (ethnomethodology), Michel Foucault (discourse) as well as Mikhail Bakhtin and Merleau-Ponty (Smith, 1987, 2005).

Smith describes institutional ethnography as a method of inquiry that "explores the social relations organising institutions as people participate in them and from their perspectives. People are the expert practitioners of their own lives, and the ethnographer's work is to learn from them, to assemble what is learned from different perspectives, and go beyond what people know to find out how what they are doing is connected with others' doings in ways they cannot see. The idea is to map the institutional aspects of the ruling relations so that people can expand their own knowledge of their everyday worlds by being able to see how what they are doing is coordinated with others' doings elsewhere and else when" (Smith, 2005:225).

Using IE for my study the purpose is to map the social relations that organise the work process of managing challenging. I go beyond what informants know and strive to analyse- through texts and language- just how ruling relations shape this specific work process and what consequences it has for individuals with ASD.

Throughout an institutional ethnographic investigation, the focus is on the social organisation of knowledge rather that interpreting the idiosyncratic behaviour or opinions of informants (Pence, 2011). Since I am interested in making visible how aspects of the work process of managing challenging behavior is socially organized, I make use of IE both ontologically and epistemologically and thus, position myself an institutional ethnographer in this study.

#### **3.2 Perspectives in Social Work- Taking a Standpoint**

Research that investigates the field of social work from a user's perspective, often focus on the user's experiences when interacting with social workers and/or the system. This type of research investigates the kind of consequences the encounter between client and system have for the social work practice (Appel Nissen, Pringle, & Uggerhøj, red. 2007). However, in recent years there has been an increasing interest in how power and power relations affect the specific interaction between users and social workers and/or the authorities within the field of social work (ibid). This thesis is an institutional ethnographic analysis that investigates and focuses on how ruling institutional processes frame and influence how support workers are required to manage challenging behaviors and identify what consequences this has for individuals with ASD.

In an IE project, a specific standpoint is taking up from which to investigate the social and make visible the extraordinary complex of trans-local ruling relations (Smith, 2005). The standpoint taken usually represents those people who stand *outside* the ruling regime such as for example; gay and lesbians in a heterosexual society; people of colour in a racist's society and/or people with disabilities in a society where the disabilities are not accommodated for (Frampton *et al.* (2006). Starting from the standpoint of the oppressed or exploited can reveal aspects of the social that are not wholly visible from other social locations (Smith, 1987, 2005). This study takes the

standpoint of individuals with ASD and thus, represents a user perspective. However, as it was not possible to conduct interviews with them due to the reduced communicative and cognitive limitations, I chose to use frontline support workers as primary informants to critically investigate how relations of ruling frame and regulate their interactions with the individuals they support, and thus be able to identify a problematic which relates to how their interaction is socially organized and what consequences this has for individuals with ASD.

Smith's method of analysis has marked a significant paradigm shift for sociology as her critique of objective knowledge required an ontological and epistemological shift which I will attempt to describe in the following (Smith (1990) in Campbell and Manicom, 1995).

### 3.3 Ontology and Epistemology

Smith (2005) uses the term ontology to denote a theory of how the social exists- how it is real. Rather than treating the social as exiting over and above support workers and determine their behaviour, the ontology of IE views the social as the concerting of people's doings/activities which is the same ontology shared by phenomenologist, symbolic interactionists and ethnomethodologist (DeVault and McCoy (2002) in Smith, 2006). However, Smith expands this through the concept of *social relations* which refers to the *coordination* of people's activities within and across a local and translocal, wider institutional context (Smith, 2005). The forms of coordination always occur in and through language and go beyond language to text. The ontology of IE can be illustrated with the following mnemonic<sup>7</sup>:

# AI + D + C = S

**A**[ctual] **I**[ndividuals] + [their] **D**[oings] + [how] **C**[oordinated] = [the] **S**[ocial]

Figure 3.1: The ontology of IE

<sup>&</sup>lt;sup>7</sup> Sited from Smith's presentation at an intensive IE workshop at the University of Toronto, June, 2010

To translate IE's ontology of the social into a general framework for my study, I view (actual) support workers and the way in which they manage challenging behaviour (their doings) to be discursively coordinated within and across a wider institutional complex of relations beyond the support workers immediate view.

When Smith designed the ontology of IE, she made a major ontological shift from how we used to look at the world (ibid.). Making an ontological shift meant changing from a generalized world of theoretical and conceptual explanations to a world of people's actual activities and practices. Transferring agency from concepts to the experiential way of knowing something, Smith designed a modest ontology that focus on explaining *how things happen the way they do* instead of *why things happen the way they do* (Ibid.).

The term epistemology means a "theory of knowledge" and refers to a way of understanding and explaining how we know what we know. Since institutional ethnographers turn away from positivist epistemologies that assume we can know the social world by using the same "objective" methods, I take a reflexive epistemological position that begin in and from support workers experiential work knowledge (Smith, 2005; Frampton et al. 2006). It is through a mutual dialogical interviewer-informant interchange that my epistemological position is constituted as reflexively (ibid.). Smith defines the term work knowledge as "...what people know of and in their work and how it is coordinated with the work of others" (Smith, 2005:229). As the different work knowledges were produced and collected in my empirical field work (from support workers, the manager and a training instructor), I gradually began to jig saw them together in a way that enabled aspects of the social organisation of managing challenging behaviour, to begin to emerge (Ibid). Using IE's theorized cartographic principles (mapping) enables me to explain what actually happens when support workers manage challenging behaviour and make visible, how translocal ruling institutional discourses frame and shape this specific work process in ways that might not always have a supportive outcome for the individual with ASD (ibid).

Institutional ethnographer, Susan Turner (Turner, 2011) has developed specific mapping codes and symbols as a reference guide in how to map institutional processes.

In the box below I introduce and describe some of them and how I employ them in my analysis.

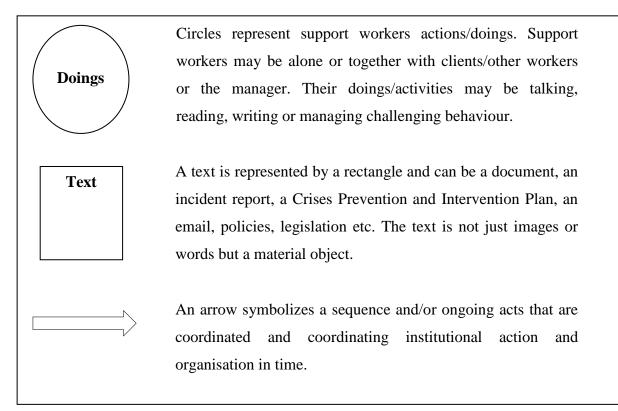


Figure 3.2: Mapping codes for exploring institutional relations (Turner, 2011)

As Smith describes "A map assembles different work knowledges, positioned differently, and should include, where relevant, an account of the texts coordinating work processes in institutional settings (...). Institutional ethnography's project of mapping (...) always refers back to an actuality that those who are active in it know" (Smith, 2005:226).

## 3.4 Social Relations and Social Organisation

Smith's concept of *social relations* refers to social processes or sequences of action that hook people and their doings in a particular local setting into what others are doing elsewhere and elsewhen (Smith, 2005). The concept is different from how it is frequently used in social science because it does not refer to a relationship or interaction between two people such as a father-son, teacher-pupil or husband-wife relationship

(ibid.). Rather, social relations are *actual practices* and *activities* through which people's lives are socially organised, and it is the interplay of social relations that constitute the social organisation (ibid.). Smith saw the benefits of being able to make visible- as social relations- the complex practices that coordinate people's actions across separations of time and space (Campbell and Gregor, 2004). This theorizing of connections makes it possible for social analysts to explore what are otherwise mysterious aspects of people's lives.

Analytically, I therefore view support workers doings (managing challenging behaviour) in a *sequence of action* that somehow hooks their doings into to what other people are doing, or have been doing, elsewhere and else when (Smith, 2005). The concept of social relations will guide me through my data collection and subsequent analysis of how social relations concert and coordinate the way in which support workers manage challenging behaviour (ibid.)

#### **3.5 Ruling Relations**

The institutional ethnographic project is one of exploring the ruling relations from within the support workers experience and there are lots of different ways of doing that (Smith 2005; 2006). Like Marx (Marx and Engels, 1970) Smith views class and ruling relations as being produced by people but she updates Marx's analysis since class and ruling relations were governed through different practices in the earlier capitalist era than they are today (Smith, 1987, Rankin, 2003).

The concept of ruling relations directs specific attention towards;

"...the distinctive translocal forms of social organisation and social relations mediated by texts of all kinds (...). [Ruling relations] are objectified forms of consciousness and organization, constituted externally to particular people and places, creating and relying on textually based realities" (Smith, 2005:227).

A prominent aspect of IE is the recognition that text-based forms of discursive practices and knowledge are central to large-scale organisation and relations of ruling in our contemporary society (Campbell and Gregor, 2004). Texts are nearly always implicated in ruling as ruling relies on complex forms of documenting, reporting and selecting particular aspects of people's work/lives. In the next section, I introduce how institutional ethnographers view texts and discuss why texts are specifically integral to IE.

### **3.6 The Role of Texts**

Institutional ethnographers recognise and view texts as *coordinators* and *organizers* of people's everyday lives because texts are present in our everyday world, and at the same time they are tied into translocal social relations and organisation that permeate, shape and control our everyday world (Smith, 2005). Institutional ethnographers consider texts to be a *material* thing that carries a message. A text can be a document, a file, protocols, reports, adds, film and/or electronics such as computers or TV. Smith (2001) wants us to understand that when phenomena formulated in the lexical forms of sociology, suppress and *objectifies* the presence of subjects, texts and documents are essential to this objectification and thus, they must be examined in terms of how the mediate, regulate and authorize how support workers manage behaviors (Smith, 2001:1).

Institutional ethnographers believe that texts are not isolated from *courses of action* and thus, it is possible for me to go *beyond* the limits of observation in the residential home and into exploration of what institutional ethnographers call the "ruling" or translocal relations that extend way beyond, and yet organize, the way in which support workers manage behaviors with the individuals they support (Smith, 2001, Smith and Turner, 2012: Forthcoming).

As Smith puts it:

"Texts are of central importance to institutional ethnography because they create this essential connection between the local of our (and others') bodily being and the translocal organisation of the ruling relations" (Smith, 2005:119)

In order to implement this in practice, institutional ethnographers always recognize, examine and analyse texts in a *sequence of action* as well as analyzing how they are *activated* by people (Smith, 2001). This means that when a support worker reads a specific text, he/she activates and responds to the text, engages with its language, acts from it and becomes its "agent" (Smith, 2005). Institutional ethnographers would say that the support worker engages in a *text-reader conversation* (Smith, 2006:228).

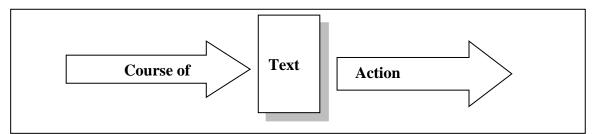


Figure 3.3: Conceptualizing Texts in Action (Smith, 2005:167)

When texts are activated by support workers, they *are* support workers doings, because the text-reader conversation takes place in real time, in an actual setting and in a sequence of action (Ibid.). When a text has been located in action, the next step is to analyse the text in a *work-text-work sequence* (Turner, 2011). The work-text-work sequence of action makes visible how the supports workers doings (managing challenging behaviour) are coordinated and text-mediated with the work/doings of other people elsewhere and else when.

The term *intertextual* means that texts are situated in a complex of sequences, including discourses and regulatory texts. The concept intertextuality insists that a text cannot be

read in detachment from other texts that it addresses, refers to, relies on etc. (Smith, 2005; Fairclough, 1992).

Some texts are regulatory which means they regulate other texts. Smith explains that "...higher-order texts regulate and standardize texts that enter directly into the organisation of work in multiple settings" (Smith, 2006:79). This is referred to as *intertextual hierarchy*. The texts which support workers use in their support practice are thus regulated and standardized trans-locally by higher-order texts such as training programs, policies, government directives, laws etc.

My textual analysis will therefore not be limited to analysing the texts used on the frontline but furthermore analyse the texts as intertextual and thus, explicate how the text is regulated and standardized by trans-local levels of ruling institutional organisation. The text I will be analysing is presented in the methodology chapter (Chapter 4).

As discourse and language are central to these forms of organization, language "...must be brought into the scope of institutional ethnography's ontology so that it and the variety of what gets done in language can be incorporated into ethnographic investigation" (Smith, 2005: 69). The role of discourse and the concept of institutional discourse will be described next.

#### **3.7 Discourse and Institutional Discourse**

The term *discourse* refers to a field of relations that includes not only texts but the *activities* of people in actual sites who produce them, use them and take up the conceptual frames they circulate (Smith, 2005). Building from Michel Foucault's (1970) conception of discourse, and his notion of discourse as a regime of disciplinary power, Smith too identifies the discursive practices of contemporary society as important elements of the ruling relations that governs individuals.

Foucault's (1984) conceptualizing of knowledge/power is for Smith social relations that come into play as actual people participate in knowing and acting knowledgeably (Campbell and Gregor, 2004). Smith turns discourse "…in the directions of the social

relations of text-mediated language in our society, whereby texts are used to mediate and coordinate social relations" (Frampton *et al.*, 2006): 30) For Smith the conception of discourse therefore refers to translocal relations that *coordinate* the practices of support workers talking, writing, and reading in a particular residential home at a particular time (Ibid.). As described, she maintains an interest in the presence of subjects who activate the text, in language, in a moment of reading, writing and understanding a text.

I follow Smiths conception of discourse and understand language and discourse to be generated within dialogical social processes that can be traced from the doings of support workers into, and within, trans-local ruling relations. Support workers *participate* in discourse because discourse constrains what they can say and write, and thus support workers reproduce and modify discourse in the work process of managing challenging behaviour (Ibid).

Regulatory (textual) frames of institutional discourses structure what is relevant and select the concepts, methods and categories that organise institutional representations (Smith, 2005). Smith explains that local *actualities* are converted into textual realities that operate to structure institutional action<sup>8</sup>. In creating textual realities, there is a dialogue happening (which is work that somebody does) between the institutional discursive frame (anchored in a boss text) and the actuality that produces the textual reality. The boss text controls how actualities are inscribed and "fitted" into the text and as a result, it is only *aspects* of actualities that are being selected while others are excluded or neglected (ibid.).

As institutional discourse provides categories and concepts under which what people do becomes institutionally accountable, institutional discourse *objectifies* because it displace and subdue the presence of subjects and agents. When actualities are selected and fitted into the categories and concepts of the regulatory frame, a perspectiveless and "empty" account is produced. Regulatory frames are "discursive procedures that

<sup>&</sup>lt;sup>8</sup> Smith does not give the term *actuality* content as it is always directing us to the world to be explored outside the text. Actualities are always more than can be named, categorized or described (Smith, 2005:223)

organize how something is to be interpreted" (Smith, 2005; 227). According to linguists *shells* are nouns that don't seem to refer to anything (Schmid (2000) in Smith, 2005). Smith adopts the concept of utterances or words that function as shells in the text-reader conversation of institutional discourse. The shells of institutional discourse are "empty" and waiting to be "filled" with something to make their sense (Smith, 2005). This will be explicated in my analysis.

My theoretical approach for understanding the relation between theory and practice which I encounter in the empirical data material is thus, discursive analytic. In the following, I discuss how the methodological approach in this study is an explorative approach that proceeds rather differently.

#### **3.8** An Explorative versus a Hypothetical-Deductive Approach

The *inductive* approach moves from specific observations to broader generalizations and theories. The point of departure lies in the empirical where the observed phenomena are described as they appear to the researcher. The researcher must be as objective as possible as the pre-understanding is put "aside" (Riis, 2001). The inductive approach is a more open-ended and exploratory approach, especially at the beginning, than the deductive approach. The *deductive* approach works from general to the more specific and is concerned with testing or confirming hypotheses (ibid). The hypothetical-deductive method (HD method) is commonly referred to as the scientific method for testing theories and hypotheses. The HD method proceeds by formulating a specific research question or hypothesis that is then theoretically tested or interpreted in ways that either confirm or falsifies the hypothesis (Ragin, 1994). The researchers pre-understanding plays a significant role since the researcher formulates the hypotheses and also tests them. However, most research involves both inductive and deductive methods at some point in the research project (ibid).

Unlike the HD method, exploratory research seeks to find out how people get along in the setting under question, what meanings they give to their actions, and what issues concern them (Shutt, 2012). The goal is to learn "what is going on here?" and to investigate social phenomena without explicit expectations. IE provides a conceptual framework towards *exploring* and *discovering* the everyday world which becomes the problematic (Smith, 1987). IE investigate the social world from outside the frameworks of ruling (theoretical) discourse and not by formulating a specific research question that is then theoretically interpreted or tested. The questions for investigation arises from people's actual experiences or struggles which leads to an investigation of how those experiences/struggles are influenced and organised by trans-local ruling relations (Smith, 1987; 2005).

Institutional ethnographers understand an ethnographic setting to be constituted locally by people's work but do not theorize that work and those understandings, as symbolic interactionists or grounded theorist do (Campbell and Gregor, 2004). The analytic goal for IE is to get an ethnographic account that identifies, traces, and describes the social relations of the local setting by explicating how trans-local ruling relations organises and controls the local (ibid). The interest in explication is materialist and empirical which means that in order to explicate and "make something" of the data, institutional ethnographers return to the research field to discover actual connections which is how I simultaneously proceeded in my fieldwork.

According to Hans-Georg Gadamer (1900-2002) being a researcher in a foreign field requires continuous reflection and awareness of one's own background and preunderstanding (Hammersley, 2007). Since this study arose out of my own background and experience as a former support worker, I continuously reflected upon my preunderstanding throughout the research process. Being a Danish ethnographic "stranger" in an unfamiliar Canadian culture forced me to be open-minded to what I discovered and not reject data that was inconsistent with my own pre-understanding. Committed to learn from informants would mean, in classic hermeneutic terms, my understanding might change. While the researcher of the inductive approach strives to be objective by putting his/hers pre-understanding "aside", the institutional ethnographer's experience and pre-understanding plays a significant role throughout the whole research, interpretation and mapping process which I am aware influence the findings (Riis, 2001; Smith, 2005). Rather than using theory to analyze the empirical data, interpretation is disciplined by IE's theorized way of exploring power and knowledge, and by the materiality of the empirical data (Campbell and Gregor, 2004). The findings of an IE project is a social map that illustrates the text-mediated social relations that reveal how ruling relations operate, intrude and organize local social practices beyond people's everyday knowledge (ibid.). The map provides knowledge that can be used by people to better understand the social practices of how things are put together.

Unlike IE, theorists within the German traditions of the Frankfurt School of Critical theory<sup>9</sup>, theorize about the ideal speech situation that stresses the need for adequate opportunity for individuals to speak; adequate opportunity to challenge the rules or the topic of discussion; adequate opportunity to acquire the skills of discourse and adequate opportunity to be free of violence and other forms of coercion (Habermas, 1981). As my theoretical approach for understanding the relation between theory and practice is institutional ethnographic, I have found it useful to include a brief discussion with the Frankfurt school tradition; in particular Honneth's recognition theory which will briefly be presented next.

### **3.9 Recognition Theory**

Axel Honneth is an internationally renowned social theorist who has continued the legacy of the Frankfurt School's Critical Theory. Like Smith, Honneth is inspired by Hegel and Mead who both developed theories about individuals need for recognition. Honneth believes that recognition of every member of society is a precondition for a fully integrated and sustainable society and thus, he has developed critical, normative social theory about the human need for recognition (Honneth, 2006).

Honneth draws on Hegel's assumption that individual's identity are dependent upon mutual recognition relations in three spheres such as 1) family/love life, 2) rights, 3) solidarity in which the individual enters (Høilund and Juul, 2005). According to

<sup>&</sup>lt;sup>9</sup> 1. generation (Adorno, Horkheimer), 2. Generation (Habermas), 3. Generation (Honneth).

Honneth the recognition relations are created and constituted through these various forms of recognition. However, if these forms of recognition are not met individuals with ASD will experience violation in terms of: 1) physical violations, 2) refusal of rights and 3) degradation of life forms (Honneth, 2003, Høilund and Juul, 2005)<sup>10</sup>. Hence, recognition and good social judgment ought to be the normative ideal in social work practice especially when interaction and working with the marginalised groups or clients who are dependent upon the social workers (ibid.)<sup>11</sup>.

While Smith (2005) theorizes the relationship between subject-ruling practices, Honneth (2003) theorizes the relationship between subject-subject as he believes that recognition is vital for every individual's self-realization of self-confidence, self-respect and self-esteem to obtain and maintain a good life (Honneth, 1996; Høilund and Juul, 2005). In my analysis I refer to Honneth's recognition theory to substantiate my social critique of the ruling relations that regulate and organize the specific interaction between support worker in such ways that seem to subordinate and exclude the individual's need of recognition (ibid.).

In this chapter I have presented and explained the institutional ethnographic framework for my analysis. Next, I present the methodology chapter.

<sup>&</sup>lt;sup>10</sup> My own translation from Juul and Høilund's (2005) Danish book: Anerkendelse og Dømmekraft i Socialt Arbejde.

<sup>&</sup>lt;sup>11</sup> Peter Høilund is a professor at the Department of Social Sciences at Roskilde University, Denmark.

Søren Juul is cand.mag. in history, sociology and lecture at Roskilde University center as well as the Department of Social Work and Aalborg Universitet.

# 4. Methodology

Various methods are used in IE including interviews, observation, textual analysis and mapping techniques. My fieldwork aims at studying what the "world is like" to Canadian support workers who have learned to see, hear, think and act in ways that are culturally different from Danish support workers (Spradley, 1979)<sup>12</sup>. However, the aim of my project is not limited to – in Spradley's sense- writing up an ethnographic description of Canadian frontline support practice and thus "remaining" at the local level. My interest focused on capturing detailed accounts of how support workers manage challenging behavior by moving beyond what can be directly observed or learned in the local setting, and into an exploration of how institutional processes discursively shape and organize support workers everyday work practice (Smith, 2005).

There are two levels of data collection involved when using IE. *The local level data collection* seeks to explicate what actually happens in a local setting where individuals interact and this data offers an entry into a problematic of the everyday world (Ibid.). *The translocal level data* seeks to make visible the missing organizational details of how the broader setting works<sup>13</sup>. The two levels of data are connected and the purpose of establishing such linkages is to explicate the relations of ruling as described in Chapter 3 (Ibid). In this study, I make primary use of individual ethnographic interviews with four frontline support workers, two interviews with their manager and one informal interview with a training instructor. I also make use of textual analysis of a specific document that support workers are required to implement when they encounter and have to deal with challenging behaviour. Finally, I investigate textual material from the training program which the organisation uses. The design of my empirical field work has been inspired by various principles from Spradley's book *The Ethnographic Interview* (1979) in combination with institutional ethnographic data collection methods, which will be described ongoing in this chapter.

<sup>&</sup>lt;sup>12</sup> James P. Spradley was a professor of Anthropology at Macalester College (1969-1983) and is well known for his additions to the literature on ethnography and qualitative research.

<sup>&</sup>lt;sup>13</sup> These two levels are also referred to as "*entry-level data*" and "*second-level data*" (Campbell and Gregor, 2004)

### **4.1 Interviews**

Using interviews in IE can be described as "talking to people". The interviews are always an open-ended inquiry where the interviewer is oriented towards sequences of interconnected activities (DeVault and McCoy (2002) in Campbell and Gregor, 2004). Driven by the search to discover "how it happens" IE sets out to provide analytic description of such processes in an actual setting. The researcher is investigating the institutional and discursive processes in which the researcher is located as well as the informants which mean that opportunities to talk with people about institutional ethnographic interviews is to maintain an institutional focus by keeping the "institution in view" and by paying specific attention to the institutional discourses that the informants might practice (McCoy (2001, 2004) in Smith, 2006).

Institutional ethnographer Liza McCoy (2001, 2004) offers some strategies for working with interview accounts in a way that maintains those focuses and lays the groundwork for further research and analysis<sup>14</sup>. She explains how a researcher's first step is to explore *what* the informants are talking about in regards to their own work and the work processes of other people. The next step involves paying specific attention to *how* they talk about their work for the purpose of identifying institutional processes (ruling relations) that needs further investigation.

Pence (2011)<sup>15</sup> also emphasizes that learning from practitioners themselves about how they put things together and how their work is coordinated with the work of others, is a key point to consider when collection data for the analysis. Building on institutional ethnography, Pence has developed a scientific research method called Institutional Analysis (IA) to disclose aspects of how institutions operate that directly or indirectly produce negative outcomes for the people they are dealing with (Pence, 2011; Smith and Pence, 2011). Depending on the person to be interviewed and the information sought, the ethnographer interview people that is being "processed as cases", frontline

<sup>&</sup>lt;sup>14</sup> Liza McCoy- is a professor in sociology at the University of Calgary, Canada, and a former student of D.E Smith

<sup>&</sup>lt;sup>15</sup> Ellen Pence was also a student of D.E Smith and received her PhD from the University of Toronto

practitioners working with the "cases", managers, advocates and local or national experts on the problem being explored (Ibid.). Not all interviews are alike as they seek different understanding and require different methods of asking. IA operates with four kinds of interviews: *The work practice interview, the text-based interview, the macro Interview* and/or *Focus groups*. I make use of the first three mentioned interviews which will be described further on in this chapter.

### 4.2 The Role and Competence of the Ethnographer

One of the great challenges in doing ethnography is to initiate, develop, and maintain a productive informant relationship (Spradley, 1979). The ethnographer-informant relationship is fraught with difficulties and the specific interaction has a profound influence on the interviews (Ibid.). As Spradley explains, interviewing informants depends on interpersonal skills which include asking questions, listening instead of talking, taking a passive rather than an assertive role, expressing verbal interest in the other person by eye contact or other nonverbal means (Ibid). Building rapport and conducting interviews is a complex process but according to Spradley, this process is facilitated by the following principles; keep informants talking, make repeated explanations, restate what informants say, and don't ask for meaning, ask for use.

As Smith (2005) describes, the ethnographer is one "...who is looking, asking questions, wanting to discover what people are doing and how people are putting things together (Smith, 2005:145). However, since institutional ethnographers are interested in learning from people's experiences or work knowledges, this constitutes a certain barrier. As discussed in Chapter 3 institutional discourses select those aspects of what people do, that are accountable to the institution and as a result subsumes descriptions based in actual experience which is what the researcher is specifically interested in (Ibid.). Support workers are trained in using institutional concepts and categories and they are accustomed to speaking within a ruling institutional discourse. The problem for institutional ethnographers is therefore to go *behind* that barrier of institutional discourse to learn what people actually do. The researcher must avoid being subject to, what institutional ethnographers call "institutional capture" that occurs "... when both

informant and researcher are familiar with institutional discourse, know how to speak it, and hence can easily lose touch with the informant's experientially based knowledge" (Smith, 2005:225).

DeVault and McCoy (2002) emphasize that the researcher must find ways of moving the talk *beyond* institutional language to "what actually happens" in the local setting (DeVault and McCoy (2002) in Smith, 2006). Being Danish with English as a second language became a benefit in regards to "unpacking" the institutional discourse. The discourses which Canadian support workers practiced were entirely foreign to me and as a result, I was compelled to have them explain to me step-by-step what they do when encountering challenging behavior, and how they do it.

### **4.3 Ethical Principles**

In regards to ethical considerations, I adopt Spradley's (1979) ethical principles which involve five set of standards namely; *Informants considered first; Safeguard informant's rights interest, and sensitivities; Communicative Research Objectives; Protect the privacy of informants; Don't Exploit Informants; Make Reports Available to Informants.* 

By *considering informants first* Spradley describes that all ethnography must include inquiries to discover the concerns or interest of informants which must be always be considered first. As an institutional ethnographer I took this into account by listening to the support workers experiences of what they found problematic in the work process of managing challenging behavior. Considering informants first, their experiences gave me a sense of direction in how this work process is coordinated and embedded within a complex of institutional relations beyond their view.

Ethnographic research always pries into the lives of informants and thus, the ethnographer must be committed to *safeguard informant's rights, interest, and sensitivities*. Ethnographic interviewing represents a powerful tool for invading other people's way of life and it reveals information that can be used to affirm or violate their

rights, interests and sensitivities. In interviewing my informants I ascertained my informant's protection by assuring them that everything they said was considered completely anonymous. I offered them to read my transcription in order to give them the opportunity to accept or take out parts/aspects of the interview. None of the informants expressed interest in reading the transcriptions.

Another important element to consider is how *to communicate research objectives* since each informant has the right to know the aim of the study. I made sure I communicated my research objectives by incorporating this principle into my interview guide where I explained, prior to the interview, what the aim of my study was (see appendix). However, as an institutional ethnographer (which Spradley also simultaneously emphasize) the ethnographer is always in a dialogue with the informants and must be willing to direct the investigation into paths suggested by the informants. As a result the research objectives can change along the way. I took this into consideration by creating an open-ended interview guide that opened up to a dialogue with informants.

In order to *protect the privacy of informants* I informed them prior to the interview, that all names, places and/other identifying features mentioned in the interview, would be changed in my field notes as well as in my thesis. I further explained that my empirical data collection would be deleted and destroyed after writing up my thesis. Spradley stresses that the ethnographers must *not exploit informants* by making sure that the informants receive some form of a personal gain from participating in my study. In considering a "fair return" I brought coffee and muffins for the interviews to show my gratitude for their time. I also assured them that I would *make my report available* upon return once I was done writing my thesis.

### **4.4 The Recruitment of Informants**

The recruitment of informants was organized through an internet search of agencies and organisations that provide services for individuals with ASD. I chose one of Canada's largest service provider for individuals with ASD who provides services for more than 5000 people with ASD within the province of Ontario. The organisation is a non- profit

organisation under the Ministry of Community and Social Services. I contacted the organisation by sending an email asking if they were willing to assist me in my project (Appendix A). I received a positive response from a Clinical Director who informed me about their willingness to participate. However, before they could allow me further access, they requested I forwarded my proposed study including the questions I had for staff as this has to be discussed with the Chief Executive Officer of the organisation. If there were no concerns, my request would be forwarded to 15 managers in the region. Hence, it would be up to them to participate and assist me with my study (Appendix B). I received responses from three managers. As my search criteria were support workers who specifically encounter challenging behaviours on a daily/nightly basis, I chose the manager who informed me that all her clients had various degrees of challenging and/or self-injurious behaviour including aggression. We arranged for a telephone meeting where we made further arrangements for my first visit which purpose was to get acquainted with the manager; inform more in-debt about my study; get a tour of the residential homes and to meet some of the support workers, in order to prepare for my interviews (Spradley, 1979).

### **4.5 First Visit**

The research setting was located in a community in the Northern West region of Ontario. On the first visit I met with the manager in her office where she gave me detailed information about her role as a manger, the residential homes she oversees, the individuals who live there and the support workers who work there. I had previously explained in our telephone conversation that I was interested in textual materials that go into the work of managing challenging behaviour and thus, she provided me documents that support workers use in the work process of managing challenging behaviour. I finally signed a confidentiality form to ensure that all the information I received would be strictly confidential. Before I left, I got a tour of the two residential homes where I met five of the individuals who live there as well as the support workers on shift. The manager informed me that since most of her staff had expressed interest in participating in my study, it was up to me to select potential informants from either houses or just one of the houses. In order to get accounts from two different houses, I decided to interview four support workers (two from each house). I returned the following week to conduct the interviews with the primary informants: frontline support workers.

### 4.6 Creating an Interview Guide

Being a novice institutional ethnographer, I decided to develop an interview guide. Having an interview guide "by my side" reduced the sense of apprehension I experienced and provided me with guidance in how to present myself, how to formulate myself, what to say next, and above all guide me in directing the conversation towards what I was interested in exploring. My interview guide was organized and developed out of my research interest in the work process of managing challenging behaviour. To ensure that I obtained a detailed description of how support workers engage in this specific process, I decided to make use of Spradley's (1979) strategy for asking descriptive questions. According to Spradley, there are various types of ethnographic questions and several subtypes and the precise form depends on the cultural scene selected for investigation. When asking descriptive questions, Spradley explains that the researcher is "...offering informants a frame and canvas and asking them to paint a word-picture of their experience" (Spradley, 1979:85). In formulating my questions in my interview guide, I primarily made use of grand tour questions including typical, specific and guided grand tour questions<sup>16</sup>. I also incorporated experience questions since these types of open ended question specifically asks informants for experiences they have had in some particular situation or setting (Ibid). Descriptive questions form the basis of all ethnographic interviewing and lead directly to utterances that are expressed in language by the informants (Ibid.). In my interview guide I also developed a "Probe list" to assist me in getting more in debt with certain topics (Appendix C).

### **4.7 The Local level Data Collection**

For purposes of confidentiality the residential homes- where the interviews were conducted- will be referred to with fictitious name such as House A and House B. In House A there are nine full/part-time staffs that support two females and one male

<sup>&</sup>lt;sup>16</sup> To read more about what these entails, I refer to Spradley, 1979: 86)

individual. In House B there are seven full/part-time staffs that support one female and two male individuals. All individuals are between 22-40 years of age and have been diagnosed with High-Functioning Autism (HFA) - some of which have other mental disorders such as skitzofrenia, Tourette syndrome or Post-Traumatic Stress syndrome. The first two individual interviews were conducted in House A followed by the last two interviews conducted in House B. The informants will be presented and referred to as following:

*Informant 1:* A male support worker who works full-time in House A. He has worked in this house for three and a half years. Educated as a DSW (Developmental Service Worker). The interview lasted 71 minutes and took place in the staff room in House A.

*Informant 2:* A female support worker who works full-time in House A. She has worked in the house for 9 years. Educated as a PSW (Personal Support Worker). The interview lasted 58 minutes and took place in the staff room in House A.

*Informant 3:* A female support worker who works full-time in House B. She has worked there for 5 years. Educated as a DSW (Developmental Service Worker). The interview lasted 51 minutes and took place in the staff room in House B.

*Informant 4:* A female support worker who works full-time in House B. Educated as a PSW (Personal Support Worker)The interview lasted 58 minutes and took place in the staff room in House B.

During the interviews I would pay specific attention to *how* they talked about managing challenging behaviour as well what documents they referred to. When documents were mentioned, I would ask them to explain their use and go through the documents stepby-step. I would also ask if I could obtain a copy in order for me to map how the texts operate in a sequence of interconnected activities. Since all informants recursively mentioned or referred to the CPI plan (which I had already obtained during my first meeting with the manager) I became analytically interested in this specific document. Two other documents such as the PRN Protocol and the Incident Report were also recursively mentioned. These documents will be presented and explained in my analysis.

However, as an institutional ethnographer (and limitation of this thesis) it is impossible to follow and map all the institutional "trails" identified for further investigation. I specifically chose to follow and explore the "CPI trail" as there was something problematic re-occurring when support workers referred to CPI. CPI (Crises Prevention Intervention) is an intervention approach that support workers use when managing challenging behavior.

After the interviews were conducted and recorded with my IC Recorder, I met with the manager to briefly discus and clarify any issues that might have arisen during the interviews. Since I expressed interest in learning more about what CPI consist of, she provided me with a "Refresher Workbook- for review of the Nonviolent Crises Intervention Training Program". This book explains and describes the CPI principles and a specific "Crises Development Model" that (what I later came to discover) frames and organizes the CPI plan which support workers follow and implement on the frontline. The CPI approach will be explained in depth later on.

Although transcribing tape-recorded interviews is time-consuming and tedious, it represents one of the most complete expanded accounts of field notes (Spradley, 1979). I transcribed all interviews as an essential part of identifying a problematic as well as developing detailed interpretation of my collected data. After transcribing the interviews, I did another "interview" with the data collected and posed questions such as: what is the work that these informants are describing or alluding to? What does it involve for them? How is their work connected with the work of other people? What particular skills or knowledge seems to be required? What does it feel like to do this work? What are the troubles or successes that arise for people doing the work? What evokes the work? How is the work articulated to institutional work processes and the institutional order? (McCoy (2004) in Smith, 2006: 111). By doing so the problematic began to emerge.

### **4.8 The Emerging Problematic**

In talking with support workers, there seemed to be unanimity that the CPI approach works "better in theory than in practice" and it is "a lot harder to use than what they teach you". Although the approach supposedly teaches support workers "...how to restrain people without hurting them" most support workers found the CPI techniques inadequate and difficult to master because the individuals are heavier, taller, stronger and/or "too hard to control". Below I present some examples. All names have been changed for the confidentiality of the individuals.

"We all have to have the course in CPI but I don't like to use it. When I first started working here I had to do it a couple of times but it's hard and it takes two people so because I often work one-on-one with clients so I wouldn't do it on Peter because he is too strong and I wouldn't do it on Alex either so instead I just try to get out of there and close the door, call our manager or dial 911. For Martin and Maria we call 911 because it is their [CPI] protocols" (Interview with support worker)

Below is another example that illustrate a disjuncture between how CPI organises the way in which conflicts should be managed, and how the actual work of supporting individuals means doing things that are not appropriate in terms of the formalized CPI guidelines;

"One particular occasion I came in to work in the morning and he was upset and you could tell because he was sitting on the floor naked and pulling at his toenails so he was already very agitated (...) so this particular time he kicked his cupboard doors so hard that they shattered and a splinter went in his eye and then he tried to hit me with the broken pieces of wood so I just basically tried not to get hurt by holding his hands away from me so he eventually calmed down but we have had to take courses on how to restrain people without hurting them but it takes two people to do it so you can't do it by yourself, so I mean it's better in theory that in practice because it's a lot harder to actually use it than what they teach you. I see why they teach it and it can work but for example when you are trying to restrain a very large person it's difficult and with him that weighs up to 270 pounds, it can be long, you know. Well, you are not supposed too but I have had to wrestle with him by myself but just long enough until I can get away and not get hurt but if he keeps going and you have reached the maximum dose of PRN's then... I don't like to have to restrain him so instead of restraining I just try to keep him from hurting himself or if I know he is going to get upset I basically try to stay away from him until someone can come help because CPI is always last resort...well, police is the last resort. CPI is something we try to rarely use but with him it would happen more" (Interview with support worker).

As the problematic related to the CPI approach began to emerge from my data, this problematic was now organising the direction of my investigation into a translocal level of obtaining more data collection. Since each individual has a CPI Plan that organises and frames how support workers are required to manage an individual's behavior I found it essential to conduct an interview with the manager about the CPI plan and the CPI training. I specifically wanted to learn what significance the CPI Plan has in practice and how this text is a component of translocal ruling relations. As Campbell and Gregor (2004) emphasize an IE research project is not done, until such linkages between the two levels of local and translocal level of data, has been exposed.

### **4.9 Translocal Level of Data Collection**

In returning to conduct an interview with the manager, I made use of a *macro-picture interview* and a *text-based interview*. The two forms of interviews were combined and took place with the manager in her office and lasted approximately two hours. The *macro-picture interview* is conducted with experts and administrators to document the issues that are influencing the local practice, and to ascertain what the informants sees as the causes of the problem under investigation (Pence, 2011). The purpose of conducting a *macro-picture interview* with the manager was to make sure that what I

had seen, heard and read was understood "correctly". The macro-picture interview guide was therefore organised around three major themes such as the CPI Plan and the CPI training and the Incident Report process (Appendix D). A *text-based interview* is conducted with informants to discover how a particular text is produced and used (Pence, 2011). I did not create an interview guide for this purpose as I simply wanted the manager to take me through a CPI plan and explain it to me step-by-step in order to discover the significance of this plan and how it relates to the emerging problematic. In conducting the text-based interview I specifically asked how and by whom the CPI plan is produced. What is the purpose of this plan? And, how does it operate and organise the work process of managing challenging behaviour? By doing so- my aim was to identify the ruling relations that organise the way in which support workers manage behaviors.

After the interview was over, the manager introduced me to a CPI instructor who teaches CPI to staff. Although I was not prepared to interview him as a potential informant, having the opportunity to talk with him became very useful for my understanding as well as my analysis. After 3 weeks I finally returned to conduct one day of participant observation, however due to the limitations of this thesis my observation will not be accounted.

### 4.10 Textual Analysis

As explained each individual has a CPI Plan that organises and frames how support workers are required to manage an individual's behavior and hence, I analyse an individual's CPI Plan. The CPI Plan will be analysed in terms of (1) how the text carry a discourse that defines the way in which support workers ought to manage challenging behaviour; (2) how the text coordinates the way support workers talk; (3) how the text coordinates the support workers actions in relation to the individuals they support; (4) and how the text select those occurrences that are significant to the institution and may not accurately reflect the individuals behaviors (Pence and Smith, 2011). The aim of my textual analysis is furthermore to identify how the CPI Plan is intertextual connected and a component of translocal ruling institutional organisation. In this chapter I have presented the methods used in this study. Next, I briefly reflect critically upon my chosen methodology.

### 4.11 Methodological Reflections

Participant observation is a research strategy that takes places 'in the field' and aims at getting an intimate familiarity with a specific group of individuals and their practices through an intensive involvement in their natural settings (Hammersley et al., 2007; Spradley, 1979). Initially I set out to conduct three days of participant observation to observe how support workers interact with clients as an ideal supplement to textual analysis and interviews. The strength of participant observation is that through observations and interactions over a long time of periods, the researcher can discover hidden details and discrepancies between what informants say and what actually happens (Hammersley et al., 2007). However, due to the scope and time limitation of this thesis I later decided to only carry out one day of observation which however, is not accounted for in this thesis.

Before I present my analysis strategy and begin my analysis I briefly include the concepts of validity, generalizability and recursivity in order to establish whether the findings of this study are reliable and trustworthy (Kvale, 1997; Campbell and Gregor, 2004).

### 4.12 Verification

Validity refers to whether a method investigates what it proposes to investigate (Kvale, 1997). The scientific validity of the research results is therefore established when the methodological procedures are logically consistent, are followed demonstrably and with an adequately described theory of knowing (Campbell and Gregor, 2004). Throughout this thesis, I have attempted to generate validity by describing and explaining how I have built my institutional ethnographic account. I provide a solid explanation of the theoretical, methodological and analytical framework of IE. By doing so I offer the reader the possibility to critically judge whether my methodological way is transparent and the findings I present, are considered valid. Generalizability in IE relies on demonstrating how

relations of ruling operate in and across local settings, organising the experiences that the informants talk about (Campbell and Gregor, 2004). I have therefore specifically been interested in the *recursion* of how support workers manage challenging behaviour. Recursion refers to the "...social process through which the same, or similar, forms of social organization are held in place through texts and concepts in ruling forms of social organization" (Frampton *et al.* 2006). When something is organized to recur, it shows a pattern in the world which is the organization that institutional ethnographers explore. In my analysis I explicate and identify how the work process of managing challenging behavior is a recurring process being produced the same way over and over again. The claim of validity and generalizability of the findings is thus established when the recursivity of how support workers manage challenging behaviour with the individuals they support, becomes explicit (Campbell and Gregor, 2004).

### 4.13 Analytic strategy

Analytic strategies vary across different traditions within ethnography depending on the ontologies. Because the ontology of IE views the social as the concerting of people's activities and investigates how these activities are coordinated, connected and shaped by a local or translocal institutional context, the social ontology of IE becomes analytically important (Smith, 2005).

The first level of analysis (the local level) begins in the actualities of the everyday world (smith, 2005). I here describe what support workers do/are required to do when encountering challenging behaviour with the individuals they support. In the second part of my analysis (the translocal level) I make visible how discursively-organised relations organise and frame this specific interaction in ways that might not always have a supportive outcome. The empirical data used here consists of the interview with the manager, a training instructor and the textual training material used in the everyday work of supporting individuals with ASD (Smith, 2005).

# 5. Analysis Part One: The Local Residential Setting

The analysis begins in an actual conflict situation that will underpin the whole analysis as I gradually attempt to identify and resolve the problematic related to the CPI approach that specifically organizes and authorizes how support workers are required to respond to individual's behaviors. All names in the analysis have been changed to protect the confidentiality of the individuals, staff and organisation.

A few months ago, we were sitting in the backyard...myself, another staff and one of the individuals who lives here so Peter began to get anxious and started to whine. And the common thing he would say is "Are you mad at me?" so I just tried to de-escalate the situation and I said to him: "Why don't we go inside and I will get you a PRN and when you are calm, we can come back outside" and he said "Okay". So we were walking to the backdoor and I was about 10 feet or so away and he looked at me and he just bolted and ran across the street and started punching a lady's car but then the lady came out and she tried to intervene so he bit her finger and this all happen in 10 seconds. When I came around the corner he was screaming "I didn't mean too...I didn't mean too" so he came running across the street and he went to punch me so I grabbed both his hands and got him inside the house (...) So he was charged with Aggravated Assault and went to jail for a few days but the problem with him is that he doesn't even understand why or the consequences that goes with that...I mean he has autism...

### 5.1 Managing Challenging Behavior

Depending on the situation, the individual and the behavior, support workers manage challenging behavior by using the CPI approach and/or by administering PRN (Prescription Rendered when Needed) which is medication that addresses aggression, anxiety and/or other behavioral concerns (Appendix E). Although this study do not focus on how behaviors are managed with PRN, I do find it essential to briefly account

for the use of PRN here because it is after all the primary way in which challenging behavior is managed in the residential homes used in this study. A support worker explains the use of PRN this way;

"So Peter can have a maximum dose of 75 mgs of Loxapine and that's the most PRN he can have in one day. Each pill is 10 mg. So if he is anxious, I would give him the first dose but if he is still upset 30 minutes after that and hasn't started to calm down I would give him another one and if that hasn't worked after 30 minutes, I give him another one and so on. So it tells you right here [in the PRN protocol] what you have to do. But some of the medication can sedate them quite a bit, so if they are just a little bit anxious, you don't want to give them the highest ones. Peter used to get one medication and it went up and up and up until you would give him Haldol which is just a really nasty drug that knocks...basically it's so nasty that you have to take another pill with it to fight the side effects, but he doesn't get that anymore- thank god. But I have seen him fight through more drugs that you can knock out a horse with and he is still going so I guess they get used to the drugs too" (Interview with a support worker)

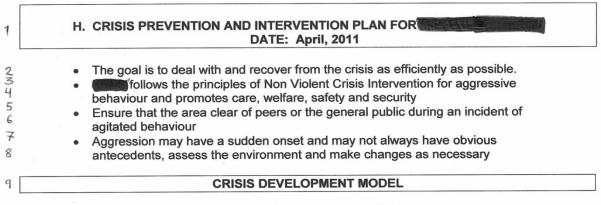
As this support worker indicates there is a maximum dose that an individual can have in one day. If the medication is not adequate or efficient, support workers rely on the CPI approach and its specific methods to physically intervene and manage individual's behaviors. The CPI approach is outlined in the CPI Plan which the manager explains this way;

"Basically the PRN protocol goes together with the CPI Plan so if the medicine doesn't work, we got trained ways of physically getting people to safe areas. You give PRN when the client shows certain signs of anxiety but for someone else you might start your PRNs when he is defensive. You would probably never start with PRNs if the client is already acting out so the two plans cross over and work together" (Interview with manager).

As the CPI plan is a document that defines individual's behaviors as well as authorizes how and when support workers must address challenging behaviors with the use of the CPI approach, Peter's Plan is introduced next.

### **5.2The Crises Prevention and Intervention Plan (CPI Plan)**

Each individual with ASD has a Behavior Support Plan which aims to "…provide a planned approach to prevent (and if necessary, manage) crises situations". The CPI plan is a part of the Behavior Support plan and the goal is to "deal with and recover from the crises as efficiently as possible" [2].



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### Stages of Behaviour Upset and Corresponding Responses

11	ANXIETY/SUPPORTIVE		
12	DESCRIPTION	STAFF RESPONSE	
13 14 15 16 17 18 19 20 22 23 24 25 6	<ul> <li>ANXIETY: Any combination of these behaviours may be present for any amount of time</li> <li>Whining <ul> <li>"Are you mad at me?"</li> <li>Staring at a person</li> <li>Placing his hands over his ears</li> <li>Laughing for no apparent reason</li> <li>Saying he misses his parents</li> </ul> </li> </ul>	<ul> <li>BE SUPPORTIVE:</li> <li>Scan environment for items that may be a source of his anxiety; remove the item from the environment (if necessary or possible)-he may be obsessing</li> <li>Staff should be calm, firm, clear and easy to understand</li> <li>Increase personal space between yourself and the source of his anxiety; remove the item from the environment (if necessary or possible)-he may be obsessing</li> <li>Staff should be calm, firm, clear and easy to understand</li> <li>Increase personal space between yourself and the source of the reelings/needs and tell staff what's bothering him (e.g. "If there's something on your mind, you should tell staff.")</li> <li>Remain calm and supportive</li> <li>Attempt to find the source of the problem and find a remedy for it</li> <li>Go downstairs and be available for support</li> <li>Continue with positive language and encourage verbal communication</li> </ul>	

#### DEFENSIVE/DIRECTIVE

DESCRIPTION	STAFF RESPONSE
DEFENSIVE: Any combination of the following behaviours:	BE DIRECTIVE:
<ul> <li>Verbal threats to others</li> <li>Reaching out in an attempt to aggress</li> </ul>	<ul> <li>Be clear and direct</li> <li>Set appropriate limits</li> <li>Follow-through with limits and expectations</li> <li>Be firm and confident</li> <li>Use minimal language-leave the apartment</li> <li>Return to find apartment when he requests that you do so</li> </ul>

#### PHYSICALLY ACTING OUT/NON-VIOLENT PHYSICAL CRISIS INTERVENTION

38	DESCRIPTION	STAFF RESPONSE
3901234456749951	DESCRIPTION ACTING OUT: Any combination of the following behaviours may be present: - Aggression - Property destruction - Self-abuse (attempting to pull teeth out)	STAFF RESPONSE  NON-VIOLENT PHYSICAL CRISIS PREVENTION:      Remain calm and confident      Ensure environment is safe by removing other individuals and any objects that can be harmful in the room <u>or</u> leave the room altogether      Keep the verbal interaction to a <u>minimum</u> . Do not attempt to sooth him at this point      Use CPI training to block any possible strikes      Staff facial expressions should remain neutral      Call another staff for back-up support if necessary      Use physical redirection if necessary      Refer to the list of 'Behaviour Management'' section in this report
52		Refer to the list of Benaviour Management section in this report     emergency services (police, etc.) as needed, with direction     from manager

### TENSION REDUCTION/THERAPEUTIC RAPPORT

DESCRIPTION	STAFF RESPONSE
TENSION REDUCTION: Any combination of these behaviours	THERAPEUTIC RAPPORT:
may be present	Allow (and staff) to have some time alone
	<ul> <li>Demonstrate that you are still calm and available to talk</li> </ul>
<ul> <li>Sitting down</li> </ul>	Debrief with your team mates, manager or BT-learn from the incident
<ul> <li>Takes some space</li> </ul>	Do not lecture
<ul> <li>Demonstrating a calm, normal tone</li> </ul>	<ul> <li>Move on with the day</li> </ul>
and cadence	<ul> <li>Remove any items that may be broken or harmful to but leave and</li> </ul>
<ul> <li>Accepting staff requests</li> </ul>	disorganization for her to clean on his own time
<ul> <li>Increase in verbal communication</li> </ul>	Complete appropriate documentation
	Praise every time he communicates verbally

### **5.3 The Four Stages of Behavior Upsets and Corresponding Responses**

In the above CPI plan, there are four different "Stages of Behaviour Upsets" [11] referred to as "Anxiety"," Defensive", "Acting Out" and "Tension Reduction" [13, 27, 30, 35]. These four stages are categorized under the headline called CRISES DEVELOPMENTAL MODEL [10]. On each stage, Peter's behaviours are defined and inscribed in the boxes on the left columns below "Description" [13]. The corresponding staff responses are described and outlined in the boxes on the right column below "Intervention to Support" [13].

That means if Peter is showing "Anxiety" at the first stage [13], he may ask the staff "are you mad at me?" or have any combination of the following behaviours such as "whining; staring at a person; placing his hands over his ears; laughing for no apparent reason" or "saying he misses his parents"[13-22]. When Peter shows "anxiety", support workers must respond by being "supportive" and "scan the environment for items that

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may be a source of his anxiety; remove the item from the environment; staff should be calm, firm, clear and easy to understand; increase personal space between yourself and Peter; encourage to verbalize his feelings/needs and tell staff what's bothering him... (And so on)" [15-26].

However, if Peter becomes "Defensive" at the second stage [27] and shows any combination of the following behaviours such as "verbal threats to others" or "Reaching out in an attempt to aggress" the support workers must be "Directive" by setting "appropriate limits; follow-through with limits and expectations; be firm and confident; use minimal language-leave the apartment; return to apartment when he request that you do so" [31-36].

If Peter then begins "Acting Out" at stage three [39] and shows any combination of the following behaviours: "Aggression; Property destruction; Self-abuse (attempting to pull teeth out)" [43-45] support workers are now authorized to respond by using "Nonviolent Physical Crises Intervention" such as "CPI training to block any possible strikes" and/or " Use physical redirection if necessary" [40-50]. According to the CPI Plan, Peter will eventually calm down in the final stage of "tension reduction" [57] which support workers respond to by offering "therapeutic rapport" [57].

As it appears the CPI Plan does two things. It operates as a discursive frame which;

- Organizes how an individual's behaviors are defined and interpreted as *anxiety*, *defensive*, *acting out* and *tension reduction* through the "Four Stages of Behavior Upset" [13, 27, 30, 56]
- Coordinates a matching staff response by authorizing support workers to act supportive, be directive, using Non-violent Physical Crises Intervention and by offering therapeutic rapport [13, 27, 30, 56].

In the following section I analyze how the CPI Plan coordinate support workers talk as well as actions.

### **5.4 Activating the CPI Plan**

When support workers read a CPI Plan their consciousness is coordinated with the words of the text (Smith, 2005). Support workers who enter into a text-reader conversation with a CPI Plan activates the plans authoritative and regulatory potential of when and how to manage the individuals behaviors (ibid.). When Peter's support worker was talking about the incident with Peter I noticed how the discursive practices of the CPI plan was reproduced in his talk which seem explicit in the following excerpts (my emphasis added);

So Peter began to get anxious and started to whine. And the common thing he would say is "Are you mad at me?" so I just tried to de-escalate the situation and I said to him: "Why don't we go inside and I will get you a PRN and when you are calm, we can come back outside" and he said "Okay" (Interview with support worker).

When Peter begins to "whine" and saying "Are you mad at me?" this is immediately interpreted by the support worker as Peter beginning to get anxious. According to Peter's CPI Plan, this is precisely what Peter does when having "anxiety" [17-18]. Peter's "whining" and his question is interpreted and considered the common thing he would say when having "anxiety" and anxiety requires medication (PRN). The possibility that perhaps Peter's "whining" could be signs of Peter feeling sad is disregarded. Although support workers are also required to encourage Peter to verbalize his feelings/needs when he shows any combination of the above behaviors [20] this support worker offers medication as soon as Peter begins to "whine". However, since Peter "bolted and ran across the street and started punching a lady's car" the medication is never given to him until he is taking away by the police. When I later asked the support worker what he thought might have triggered Peter's behavior he replied;

S: We have no idea and I have thought about that a million times because you always think "What could I have done differently?" but I wouldn't have done anything differently because based on the information I had that is the way I would handle it...

C: When you say "based on that information you had"- what do you mean?"

S: Just the signs he was showing...he was showing minor agitation but to explode like that...I guess that's why we are paid to support them (Interview with support worker).

The way in which this support worker manage Peter's behavior is organized and regulated by the CPI Plan that specifically structure institutional action in terms of how the support workers are required to respond when Peter "whines" and/or asks those questions. As a result, this support worker would not have done anything differently because this is how he is required to respond based on the *information he had*.

Most of the support workers that I talked with often referred to those "signs" or "warning signs" which are written down in the CPI Plan so that support workers know what to "look out for". As one support workers explains;

The best way to avoid incidents is to recognize the signs that someone is getting upset and those signs are all written down in their CPI plan and the PRN protocols and the signs are pretty consistent once you get to know them (Interview with support worker).

Another support worker says;

The warning signs are the first thing we tell new staff when they come in and it's written down in their plans and they have key points of what the individuals like to do and these are things that upset her and these are things you do when she gets upset. We have all that written down so if it is a new staff that just started; they can go here and check it (Interview with support worker).

It seems explicit how support workers consciousness is coordinated with the CPI Plan. The discursive practices of the CPI Plan and/or the PRN protocol permeate their everyday language as well as coordinating their actions. This support worker explains; Basically if Thomas is **defensive**...for example if there are too many people around him and if you are talking about him with another staff even in a positive way- he doesn't like that and then there is a good chance he might do something silly like pulling someone's hair or something like that. If he is **acting out**, his **aggression** is biting or scratching or kicking and he throws things at other people (Interview with support worker).

This support worker says;

It all depends on the levels of agitation how I would handle things. If he is unable to return to his daily activities, I would give him a PRN at Level 1. But let's say you come in and he is already acting out, I would handle it right there but the best way to prevent crises is to get to them when they are still a little agitated and calm them down before they get out of control (Interview with support worker).

The discursive practices of the CPI Plan are re-produced by support workers when referring to individual's behavior as *anxious, defensive* and/or *acting out*. The purpose of the CPI plan is to "*deal with and recover from the crises as efficiently as possible*" [2] which institutional discourse explicitly permeate their talk and coordinate their actions as they attempt to *prevent crisis* before the individuals *get out of control*.

If an individual is "acting out", the CPI Plan authorizes support workers to respond with the use of "Nonviolent Physical Crises Intervention" [30] which can be illustrated in an ongoing sequence of action in the figure below;

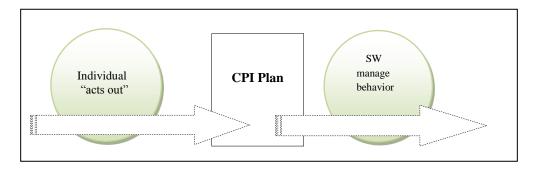


Figure.5.1: The CPI Plan in action

In Peter's CPI Plan [3] it states that the organization follows the principles of the *Non Violent* Crises Intervention which the manager explains this way:

M: It's based on those principles because we are governed, right? We can only use Nonviolent Crises Intervention to manage behaviour...
C: How come?
M: Because CPI is the training that the Ministry and our organisation have picked.
CPI is kind of intrusive but it is safe ways of helping people gaining control so you have to have training in CPI. If you don't have CPI, you can't work until you get the course done (Interview with manager).

Next, I describe more in depth what the CPI's Nonviolent Crises Intervention training consist of and how support workers get the training.

### 5.5 The Nonviolent Crisis Intervention<sup>®</sup>

The Nonviolent Crisis Intervention<sup>®</sup> training program is described as a "holistic and safe, non-harmful behavior management system designed to aid staff members in maintaining the best possible Care, Welfare, Safety, and Security <sup>SM</sup> for agitated or out-of-control individuals even during their most violent moments"(CPI, 2005:26). In talking with the CPI training instructor, I discover how this training program comes from the U. S when I ask;

C: Where do you as an instructor get this training?
T: From the people...it is a US company...
C: So this US Company comes to Canada and teaches you?
T: Yes. So we are actual managers that are trained from this company so then we set up at course for the staff here at our training room and then we go through the CPI refresher workbook. So the support workers take a two days program and then every year they have a five hour refresher (Interview with a CPI training instructor)

The two day training program involves teaching support workers how to use "safe nonharmful control and restraint positions to safely control an individual until he can regain control of his behavior" (CPI Inc. 2005:26). The manager explains the training this way:

M: So basically the program teaches staff safe holds and blocks so that individuals don't end up getting broken bones and such... CPI teaches strategies on how to bring people down but worst case scenario it teaches you how to get out of a choke, bite or a hair pull...

C: So which techniques would you say the support workers here use the most? M: So we do the block for kicks...the hair pulls we do. The bites are more if they bite you, you must try your best not to pull away but shove your hand towards them, to get them to open their mouth and we do the Team Control position which takes two people. That position is a new way of holding them because years ago you would get them in this position but then kick their legs out so they would be flat down and you would be on the ground with them but there have been deaths with that, so it has been revised. So this is the most intrusive hold you have. And then there is the Transport. We use that too if someone wouldn't leave the common area and it was too hard to get the rest out, then we use a little transport to take them into their bedroom to calm down but restraints are always used as last resort (Interview with manager).

The various CPI techniques which the manager describes are used by support workers such as the Team Control position. According to CPI Inc. (2005) the Team Control position is used to "manage individuals who have become dangerous to themselves or others. Two staff members hold the individual as the auxiliary team member(s) continually assess the safety of all involved and assist, if needed" (CPI Inc.2005: 9-13). The Team Control position is illustrated below. All content herein used with permission of Crisis Prevention Institute. ©CPI 2011. All rights reserved.



The figures illustrate how the staff members who are holding the individual should;

- Face the same direction as the acting-out person while adjusting, as necessary, to maintain close body contact with the individual.
- Keep their legs in front of the individual. Bring the individual's arms across their bodies, securing them to their hip areas.
- Place the hands closets to the individual's shoulders in "C-shape" position to direct the shoulders forward." (CPI Inc. 2005: line.).

The "control dynamics" of this position reduces the individuals "upper body strength by controlling the arms as weapons: Reduce lower body strength by controlling the back incline: Reduce the mobility by close body contact" (CPI Inc. 2005:20-29). However, when talking with the training instructor about this technique he says;

T: That is the worst thing we ever, ever have to do. We don't like it because it's long, it's tiresome and what happens when you get really, really tired and you can't do it anymore? You basically let the person go because you have to get out but it would always be used as a last resort because it depends on the house. I mean a lot of the individuals we support have behavioral protocols [CPI Plan] so in that protocol it may state to use it but even if it doesn't and the situation is getting quite dangerous to the person or to the people, then a "Team Control position" would probably be used, so it would be a discretion of the staff. So the team would decide unless there is a protocol in place (Interview with the CPI training instructor). Although this position is always used as last resort the training instructor explains that this position is the worst thing support workers have to do because it can be tiresome and support workers don't like to use it. At the same time this position might be outlined in the CPI Plan which explicate a dominating institutional judgment that frame the way in which support workers can act and think in the concrete situation (Høilund and Juul, 2003). This form of institutional judgment regulates the support workers actions in ways that lead to inappropriate barriers for recognition as well as exclude the ethical consideration of an individual's adequate opportunity to be free of violation (Honneth, 2003).

At the same time it becomes apparent in the following excerpt that the CPI approach is not specifically developed towards individuals with ASD which seems to be a significant part of the problematic that I attempt to identify. The training instructor says:

T: The other instructors who work in the prison systems said sometimes they can have problems with that position [Team Control position] but for them they always have that third person to come in and take over if they get too tired...

C: So CPI is used in the prison systems?

T: They have to...well, I don't know if every prison has to but I think so because at the training sessions that I attend some of the people who were there came from the prison systems and last time I took the training- there were security guards from the casinos who use CPI on their customers...

C: Oh really? So CPI is actually very generic?

T: Yes- it's right across the board. It's not just for people with autism. It's for everybody. It's for the whole general public (Interview with the CPI training instructor).

The Nonviolent Crisis Intervention<sup>®</sup> is developed by an American training organisation called the Crisis Prevention Institute Inc. (CPI Inc.) based in Wisconsin<sup>17</sup>. The CPI Inc. is the self-proclaimed largest provider of crisis prevention and intervention training in the worldwide training industry. According to the organisation, more than six million

<sup>&</sup>lt;sup>17</sup> www.crisesprevention.com

human service professionals, organizational leaders, mental health facilities, hospitals, schools, businesses etc. around the world have participated in the CPI behavior management training (CPI Inc., 2009).

Although CPI espouses an ideological training program that "provides the best possible Care, Welfare, Safety, and Security for staff members and those in their care" those individuals are at the same time discursively constructed as "aggressive, hostile, violent, agitated and out-of-control individuals" (CPI, 2005:26).

CPI seem to show positive politeness by claiming to provide the best possible care, welfare, safety and security for those in their care but at the same time the discourse shows negative politeness towards the individuals they claim to support (Fairclough, 1992). The substantives such as *hostile, aggressive* and *violent* define the individual's behaviors as intentional and aimed at causing harm to others which indicates that the behaviors seem to be problematic for the training organisation rather than the individual in need of support (Elven, 2010; Fairclough, 1992). Such use of particular politeness conventions implicitly embody, and acknowledge, asymmetrical power relations (ibid.) This perhaps explains why the arms of the individuals must be controlled as weapons (CPI Inc. 2005:20-29). 2010).

Analyzing and recognizing the CPI Plan as an institutional coordinator it becomes visible how the local support practice is organized and regulated by the translocal ruling relation of CPI Inc. that extend beyond the local support practice. The next step in my analysis will therefore move *beyond* the local to explicate how individual's "warning signs" (such as Peter's "whiny" behavior) are inscribed into the CPI Plan that organizes and structures institutional action in terms of how support workers are required to respond. Next, I therefore analyze how the CPI Plan selects only those behaviors that are significant to the CPI institution and make visible what consequences this has for individuals with ASD.

# 6. Analysis Part Two: Reaching into translocal ruling relations of CPI

### 6.1 The Crises Development Model

In the intertextual hierarchies of institutions the frames of higher order texts regulate those produced at lower levels (Smith, 2001; Fairclough, 1992). Taking a closer look at Peter's CPI Plan, the reader will notice a bold headline called the *Crises Development Model* [9]. The Crises Development Model is directly text-mediated with the Nonviolent Crises intervention training program which educational system provides staffs with *"easy-to-understand models to use when confronted with anxious, hostile, or violent behavior"*. (CPI Inc. 2009:3). This model operates as the regulatory text that organizes the actual CPI Plan which enters directly into the local residential home where support workers and individuals with ASD interact. The model teaches support workers how to recognize behavior levels which an individual may go through and how to match these behaviors with a corresponding staff response (CPI Inc., 2005). The recognizable behavior levels are defined and categorized to occur at four levels such as;

- <u>ANXIETY</u>: A noticeable increase or change in behaviour. A nondirected expenditure of energy; e.g., pacing, finger drumming, wringing of hands, or staring. It is the first level in the CPI Crises Development Model <sup>SM</sup>
- <u>DEFENSIVE</u>: The beginning stage of loss of rationality. At the stage, an individual often becomes belligerent and challenges authority. It is the second level in the CPI Crises Development Model <sup>SM</sup>
- 3. <u>ACTING-OUT:</u> The total loss of control which results in a physical acting-out episode. Individuals in this level are presenting a danger to themselves or others. It is the third level in the CPI Crises Development Model <sup>SM</sup>

 <u>TENSION REDUCTION</u>: A decrease in physical and emotional energy that occurs after a person has acted out, characterized by the regaining of rationality. It is the fourth level in the CPI Crisis Development Model <sup>SM</sup>

These defined behaviors provide support workers a way to recognize when and how to intervene with matching and corresponding staff responses which are described below. Support workers must respond by being;

- 1. <u>SUPPORTIVE</u>: An empathetic, nonjudgmental approach attempting to alleviate anxiety. It is the recommended Staff Attitude/Approach to an individual at the Anxiety Level
- 2. <u>DIRECTIVE</u>: An approach in which staff member takes control of a potentially escalating situation by setting limits. It is the recommended Staff Attitude/Approach to an individual at the Defensive Level.
- <u>NONVIOLENT PHYSICAL CRISES INTERVENTION</u>: Used only as last resort when a person is a danger to self or others. This involves the use of safe, nonharmful control and restraint positions to safely control an individual until he can regain control of this behavior.
- 4. <u>THERAPEUTIC RAPPORT</u>: An approach used to re-establish communication with an individual who is experiencing Tension Reduction. (CPI, 2005:pg.26:1-41).

The *Crises Development Model* is the regulatory frame/text that governs and organizes how individual's behaviors are selected and inscribed into the actual CPI Plan. In the following I explicate this intertextual hierarchy of converting behaviors into the CPI Plan.

### 6.2 Converting Behaviours into the CPI Plan

When asking the manager about how the CPI Plan is produced, the institutional hierarchy seems to emerge as she explains;

M: The CPI Plan is made by a Behavior Therapist, the manager and staff during team meetings where the individuals are discussed. So basically it's a generic document that the clinical department of the organization produce and it provides some of the bullet points that we need to highlight through the form so the Behavior Therapists actually have to apply the form to each person on their case load so she puts stuff in there and at the end of the day you get all these signatures from the individual, the parents, the manager, the BT, the psychologist and the CEO....

C: So the Behavior Therapist is required to fill out the CPI plan?

M: Yes, well she is giving a basic... she is just interjecting the specifics to him so the BT [Behavior Therapist] does rely heavily on the manager and the team to get these plans done...

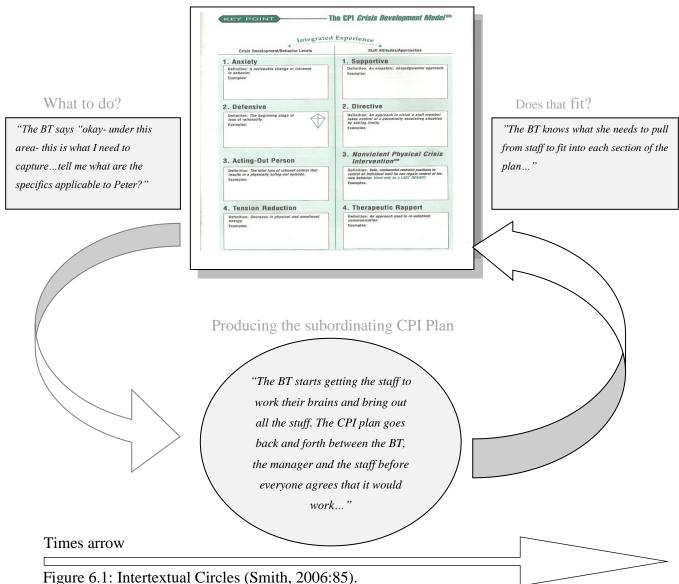
C: I see- so what is the information that she puts in the CPI Plan based on? Is that through data collection of the clients or..?

M: That is basically the BT coming and saying "okay- what is relevant information for this? She knows what she needs to pull from staff to fit in to each section of the plan. So she might come to a team meeting and say "okay- under this area- this is what I need to capture"

C: And she receives that information from you and the staff?

M: Yes- we would pull the whole staff in because everybody works with the clients so all the staff in the house and then we would have a team meeting and the BT would say " okay- tell me what are the specifics applicable to Peter?" so then she starts getting the staff to work their brains and bring out all the stuff. Now this can go back and forth between the BTs and staffs two times before we all agree that it would work (Interview with the manager).

When producing the CPI Plan the behavior therapist creates a particular description of the individual's behaviors as *she knows what she needs to pull from staff to fit in to*  *each section of the plan.* When *interjecting the specifics to him* the work of the behavior therapist is guided by the regulatory text (*the Crises Development Model*) which organizes her interest towards getting the *relevant information* of what she *needs to capture.* The shells of the CPI institutional discourse (*anxiety, defensive* and *acting out*) are "empty" - waiting to be "filled" with something to make their sense (Smith, 2005). In this textual work-up the behavior therapist "*fits*" (rather than *describes*) Peter's behaviors into the CPI Plan which is an intertextual circular process illustrated below;



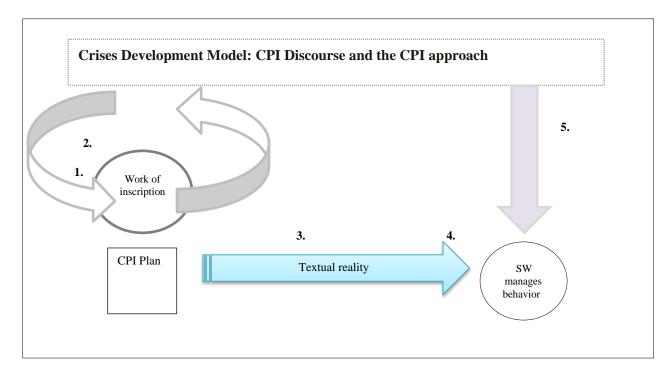
## The Regulatory Text

According to Smith (1990) ideological practices are methods of constructing stories out of the "real world". However, ideological practices are distinctive in that they select *only* what will fit the regulatory frame and exclude what does not fit. The CPI Plan therefore selects only those behaviors that are significant to the *Crises Development Model* while other behaviors are subsequently excluded or neglected.

Once the inscription is done, the CPI Plan is now a textual reality that represents individuals' behaviors as well as structures institutional actions in terms of how support workers manage these behaviors which appears in the interview with the manager;

What the BT [Behavior Therapist] is trying to do is to put it into some groups, so that staff knows "okay, that is that group where he is defensive; I better do this right?" So although these guys can bounce from here to there [points on the paper], the purpose of this document [the CPI Plan] is so that staff can say "Right, Bobby defensive: banging head against window- better do this" so it helps the staff to keep up so things don't get rolling on so fast, right? But what is missing in his is that he cries...when he is done he cries" (Interview with manager).

This standardized and institutionalized work process of producing the CPI Plan and making it actionable in the local residential home can be illustrated in an ongoing sequence of action in the following map (circles are "doings" and rectangles are texts).



The map illustrates how 1) the team gather to create the CPI Plan and the work of inscribing individual's behavior into the CPI Plan begins. 2) Individual's behavior must "fit" the categories of the Crises Development Model and CPI discourse. 3) Then the CPI Plan eventually enters into the local residential home where it becomes a "textual reality" that not only represents individuals' behavior but also 4) structures, shapes and authorizes how support workers are required to manage their behaviors. 5) The whole process is governed and framed by the regulatory texts (Crises Development Model), the CPI discourse and the CPI approach. However, in the following I make visible the consequences this ideological practice seems to have for individuals with ASD.

## **6.3 The Consequences**

I think one of the biggest incidents I have experienced was with a nonverbal larger woman. We were in a store when another client accidently bumped into Maria so she started screaming and acting out. I just kept talking to her and trying to calm her down. When the other staff had secured the other clients in the van, she came back in the store so we twoman teamed her to get her outside. We pretty much had to carry her which was so awful because she didn't want to walk so we got her outside and I just held her against the wall and held her hands because she was beating herself in the head and face at that point. After she attacked me, and you could tell she didn't want to attack me because she was crying and screaming, so we had to take her to the hospital and that is where we found out she had a bladder infection. So it all happened because she had a bladder infection. But everything was by the book and we did all the proper steps of managing the situation. I filled out the incident report and the manager did a Serious Occurrence because the incident happened in the community" (Interview with support worker).

This incident shows how the support worker uses a CPI restraint<sup>18</sup> when Maria begins to "act out" in the store. As the support worker explains she and her colleague are doing *all the proper steps of managing the situation* which explicitly indicates how their actions are authorized and coordinated with the CPI approach and the CPI plan. However, since Maria's behavior is interpreted by the support worker as "acting-out", the possibility that she might be in pain is discounted. As a result Maria is restrained although her "acting-out" behavior is due to a (properly painful) bladder infection.

In the incident with Peter, his behavior is simultaneously interpreted in accordance with the CPI Plan as signs of "anxiety" rather than perhaps signs of feeling sad. The utterance of "whining" has at some point been "fitted" into the "anxiety" level in his CPI Plan by the behavior therapist to inform the support workers on the frontline how to respond

<sup>&</sup>lt;sup>18</sup> The "two-man team" position (see page 72)

when Peter gets anxious. However, in the following excerpt in becomes explicit how Peter's behavior was in fact due to him feeling sad, frustrated, upset, and perhaps abandoned. The support worker explains:

Actually the reason we think he got upset was because the day before this happened, his parents told him he couldn't come home on home visits anymore and his parents kind of threw the key away on him. They didn't visit him once, didn't do nothing because they were having problems with his sister and his sister would throw things at him when he came home to visit and she would call him a retard and I don't like you so his parents said "You can't come home anymore" so that is actually why we thought he got upset the next day and his dad is his idol... (Interview with support worker).

Since the goal of the CPI approach is to "deal with and recover from the crises as efficiently as possible" (CPI Plan, [2]) the CPI approach disregards the fact that individuals with ASD exhibit challenging behaviours when in pain, fear, stress or trying to protest against change. Their behaviors are therefore not "intentional", violent or aggressive acts. A change in a familiar routine can be very difficult for individuals with ASD because they find it hard to predict what might happen next (Harrison, 2005). If staff who support them do not find ways of helping the individual adapt to change, such changes can cause panic attacks which can results in serious self-injurious and challenging behavior (Ibid).

When Peter's behavior is interpreted in accordance with the CPI Plan and being offered medication rather than perhaps emotional comfort he is - in Honneth's perspective- not recognized though a mutual relation with the support workers which seem to cause further insecurity and frustration that eventually causes him to aggress on the neighbor's car. As the manager points out:

But the thing is he went over there to bang on the car. The neighbor walked up to him, pointing her finger in his face...well, then it went from banging to grabbing. He did not go over there to hurt her. He went over there to hit the car...clearly he was doing that because he was upset and mad and he couldn't bring it out to talk about it (Interview with the manager).

Since support workers are required to fill out an incident report whenever they have managed challenging behavior with CPI or PRN, I briefly account for the incident report process to highlight how the actuality of Peter's incident remains invisible.

## **6.4 Incident Report Process**

The support worker says;

So Peter was screaming that he didn't like me and it wasn't his fault...just screaming, so the police told him to lie on the ground and luckily for him he did because the police had their Tasers out that pumps you with electricity so you can't move. It hurts like hell but it's a non-lethal way that they use now. It shoots two wires out with gropes in it and then it zaps you with 100.000 volts. So they handcuffed him and took him away and then I had to go into the police station and give them my account of what had happened. When I got back here I filled out the incident report and then the manager did a Serious Occurrence... (Interview with support worker).

After support workers fill out an incident report on the computer, they send it to their manager who reads it, comments on it and sends it off to the head office within the organization. If the incident happens outside in the community, the incident report is considered a "serious occurrence". If other community members were involved in the incident- like the neighbour in the incident with Peter- then the incident report becomes an "Enhanced Serious Occurrence" which is sent to the Ministry of Community and Social Services within one hour. The manager explains Peter's incident report this way:

So the staff filled out this first page in "Events leading up to" he wrote: Peter was in backyard with staff. Began whining, was asked to go inside. "Description of Incident": Peter ran across the street and allegedly bit the neighbour's hand. Staff then escorted Peter back into his apartment. "Actions taking to resolve": Neighbours called the police, the police came and arrested Peter. Peter was given PRN before he left the house. He was handcuffed and taken by police to the station. So then I have to fill out the Manger Part and I just kept it quick and wrote "Peter was taken into police custody, and held for the night. He will appear in court on x and then I clicked "yes" for serious and sent it to head office and to the Ministry (Interview with the manager).

Since I was not given permission to reproduce Peter's actual incident report, I account for what it stated in the following way:

## Events leading up to the incident:

Peter was in backyard with staff. Began whining, was asked to go inside.

## **Description of Incident:**

Peter ran across the street and allegedly bit the neighbors' hand. Staff then escorted Peter back into his apartment

### Actions taking to resolve

Neighbors called the police. The police came and arrested Peter. Peter was given PRN before he left the house. He was handcuffed and taken by police to the station.

**Managers Comments/Action** 

Peter was taken into police custody, and held for the night. He will appear in court on [date].

As it appears in the incident report, the utterance of "whining" has been reproduced while the actuality is not in there- it is left out and the voice of Peter remains silent. Filling out the incident report not only shows how support workers are accountable to the authorities but also how the actuality of Peter's behavior- in this whole incident process- has become subdued by the magisterial forms of the objectifying ruling relations (Smith, 2005; Diamond, 1992). When talking with the manager I ask (my emphasis):

C: If we look at the incident report is there anywhere in here where it actually says what possibly triggered Peter's behavior?

M: No, because we can't. That is my assumption...it is his primary support workers assumption but in "Events leading up to the incident" is just right before it happened. You have to write just what you saw. You can't really write what you are thinking because then it wouldn't be as objective, right? **The reports have to be factual**. What did you see and what happen. We can't be putting out personal opinions into it. That can be discussed with doctors later on and the higher ups **but for the reports sake, it has to be factual...** 

C: So in the actual incident report it looks as if he just bolted for no reason...

M: Right... because that is just my thought and I can't prove it. All we can prove is that he was in the backyard and he was whinny (Interview with the manager).

As the documenting processes are "for the reports sake" they seem to have little to do with the actual individuals similar to the charting and documenting processes in Diamond's (1992) ethnography. Social workers affirm their power to account for client's lives through "factual" statements that they write in records or documents (de Montigny, 1995). However, their text-mediated practices remove clients as subjects to the objectified version and to the ruling relations when support workers construct "reality" that can be ordered, regulated and administered (ibid).

C: So Peter was in a regular jail that night?

M: Yes- a normal jail for criminals. He was supposed to leave for his bail hearing which is where you go and they will tell you if you are guilty or not and then pay 500 dollars until you get your court hearing but in Peter's case the crown attorney who is representing the people didn't want to have that, so they believed that if he had mental health he is not getting out, so he was supposed to go to the [mental hospital] the next day after bail hearing but they couldn't arrange it so he actually stayed 5 days in jail. They didn't give him his medicines because when I called they said; "no- we don't give medicines here" and we weren't allowed to go visit...

C: So he was there in jail by himself for 5 days? M: Yes...

C: How do you think he....

M:Oh he was scared...he was really scared...

(Interviewwith manager).

In the following I use IE's cartographic principles to map the incident with Peter and thus, make visible an aspect of the social organization of managing challenging behavior.

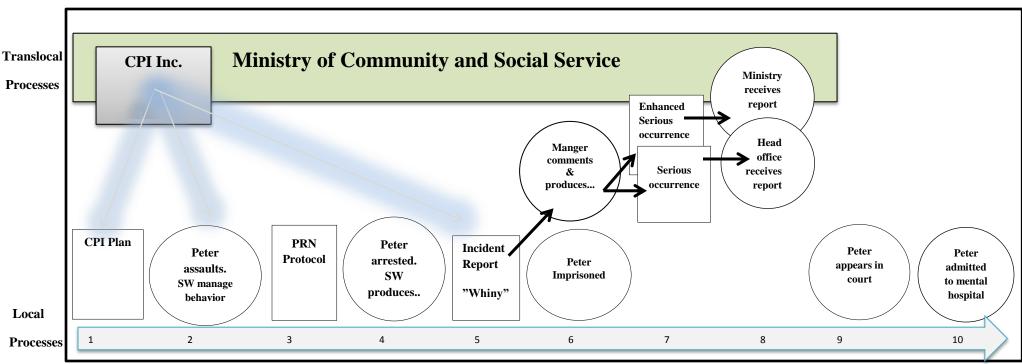


Figure 6.3: The text-mediated social relations of managing challenging behavior

1) The map explicates how the translocal ruling relations of CPI Inc. is aligned with the Ministry of Community and Social Services and operates in and across the local setting. The map illustrates how CPI Inc. organizes the local support practice through the CPI Plan 2) and by coordinating and authorizing support workers management of challenging behaviors. 5) CPI Inc. also intrudes the incident report by reproducing the utterance "whining" from the CPI Plan which completely objectifies the actuality of Peter's behavior. Although the map makes visible what consequences Peter's "whiny" behavior has for him, the map is generalizable as it demonstrates how one aspect of the social organization of managing challenging behavior is held in place through text-mediated practices and through the ruling relations of CPI Inc. Hence, the map makes visible how the work process of managing challenging behavior is actually put together through social relations and organization based in and mediated by texts.

# 7. Conclusions

This final chapter restates the research question; reviews the methods used and summarize the findings. This study set out to explore the following research question:

# How is the work process of managing challenging behavior socially organised in a Canadian context and what problematic can be identified in relation to this work process?

Employing institutional ethnography I made use of individual ethnographic interviews with four frontline support workers; two interviews with their manager and one informal interview with a training instructor. I also made use of textual analysis of a CPI Plan and the CPI's training manual. Beginning from the experiences of Canadian support workers the problematic related to how they manage challenging behavior was yet an unknown territory to be discovered. As I gradually learned how support workers text-mediated practises coordinated their actions in ways that appeared to be problematic, this emerging problematic was soon organising the direction of my investigation. The aim of my analysis therefore focused on exposing the linkages between the local support practice and the translocal levels of institutional processes in order for me to identify the problematic and explain just how Canadian frontline support workers manage challenging behavior the way they do.

The findings of my study show that Canadian support workers manage challenging behavior either by administering medication (PRN) and/or by using the CPI approach (Nonviolent Crises Intervention training). The Nonviolent Crises Intervention training program is developed by the American training organisation, CPI Inc. which teaches support workers how to use control and restraint positions when medication no longer work or seem adequate. Since each individual with ASD has a CPI Plan that defines individual's behaviors as well as authorizes how support workers are required to respond to their behaviors, my study shows how the discursive practices of the CPI Plan explicitly frames and shapes support workers language as well as actions.

The findings of my study makes visible how the local support practice is regulated and standardized by the translocal ruling relation of CPI Inc. who construct the individuals they claim to support as aggressive, hostile, violent and out-of-control. This institutional discourse permeates the text-mediated practices of CPI which subsequently defines individual's behaviors as having anxiety, being defensive and/or acting out. Such institutional discourse not only objectifies individuals in need of support, it simultaneously excludes, subordinate and misinterpret the specific characteristics of an Autism Spectrum Disorder and the possible triggers of individuals behaviors. This identifies the problematic in relation to the work process of managing challenging behavior because it has significant consequences for the individuals.

In the incident with Maria, my findings show that the support worker interprets and manage Maria's behavior as per CPI Protocol. The actual trigger of her behavior (a properly painful bladder infection) is therefore excluded. Simultaneously, in the incident with Peter- his behavior is interpreted as "the common thing he would do" when having "anxiety" which exclude the possibility that perhaps his "whiny" behavior is due to him being sad. When Maria and Peter are not being recognized or understood for their actual behavior, the CPI approach seem to be counterproductive which will highly likely maintains, a self-perpetuating process.

As the CPI Plan authorizes how support workers are required to respond and think in a concrete situation, this seem to shape support workers actions in ways that lead to inappropriate barriers for recognition in the interaction with the individual they support. As Peter's support worker explains, he would not have managed the behavior any differently.

My findings further shows that Peter's incident report removes him as a subject and his voice remains silent. The incident report does not benefit him in any way and the possibility of modifying or reorganizing the support practice for the better is not possible as long as the account of what actually happen is never made visible.

By using IE's theorized cartographic principles enabled me to explain and make visible how the work process of managing challenging behavior is actually put together in a Canadian context. My map (figure 6.3) illustrates how the translocal ruling relations of CPI frame and shape this specific work process in ways that does not always have a supportive outcome for the individuals. Although the CPI Inc. aims at "preventing crises"- my findings suggest that it paradoxically seems to create one.

# 8. Reference List

Antonsson, H., et al.(2008): Caregivers' reflections on their interactions with adult people with learning disabilities. *Journal of Psychiatric and Mental Health Nursing* 

Armstrong et al. (2009): They Deserve Better. The long-term care experience in Canada and Scandinavia. Canadian Centre for Policy Alternatives.

Autism Ontario (2008): FORGOTTEN: Ontario Adults with Autism and Adults with Aspergers.

Blaxter, L, Hughes, C. & Tight, M. (2006): How to research. England. Open University Press

Campbell, M.L & Gregor, F. (2004): Mapping Social Relations. A Primer in Doing Institutional Ethnography. Toronto: Garamond Press.

Campbell, M. L & Manicom, A. (1995): Knowledge, Experience, and Ruling Relations: Studies in the Social Organization of Knowledge. Toronto: University of Toronto Press.

Campbell, M.L. (1998a): Institutional ethnography and experience as data. Qualitative Sociology 21 (1): 55-73.

Church, K., Diamond, T., & Voronka, J. (2004). In profile: Personal Support Workers in Canada. Toronto: RBC Institute for Disability Studies, Research and Education.

CPI's Nonviolent Crisis Intervention<sub>®</sub> training program General Information and empirical support, (2009)

DeVault M. & McCoy, L. (2006): Institutional ethnography: Using interviews to investigate ruling relations. In D.E. Smith, Institutional Ethnography as Practice (2006) Toronto: Rowan & Littlefield Publishers, Inc.

Deveau, J.L. (2008). Examining the Institutional Ethnographer's Toolkit. Socialist Studies, 4(2): 29-47.

de Montigny, G.A.J. (1995a): Social working. An Ethnography of Front-Line Practice Toronto, On.: University of Toronto Press.

Diamond, T. (1992): Making gray gold: Narratives of nursing home care. Chicago: University of Chicago Press.

Emerson, E. (1995): Challenging Behaviour. Analysis and Intervention in People with Learning Difficulties. Cambridge: Cambridge University Press.

Emerson, E. (2001): Challenging Behavior: Analysis and intervention in people with learning disabilities. Cambridge University Press.

Emerson et al., 2000: treatment and management of challenging behaviors in residential settings. Journal of Applied Research in Intellectual Disabilities, Vol 13.

Enmarker, I, Hellzen, O., Olsen, R. (2011): Management of person with dementia with aggressive and violent behaviour: a systematic literature review." *International Journal of Older People Nursing*.

Furey, E. M. & Niesen, J. J. and Strauch, J. D. (1994). Abuse and neglect of adults with mental retardation in different residential settings. Behavioral Interventions, 9: 199–211. Volume 9, Issue 4, pages 199–211.

Glathorn, Allan A. (1998). Writing the Winning Dissertation. A Step-by-Step Guide. Corwin Press, Inc.

Goodridge, Johnston & Thomson, 1994: *Conflict and Aggression as Stressors in the Work Environment of Nursing Assistants: Implications for Institutional Elder Abuse*"

Goffman, E (1961). Asylums: Essays on the social situation of mental patients and other inmates. New York: Doubleday.

Goodridge *et al.* (1996): Conflict and Aggression as Stressors in the Work Environment of Nursing Assistants: Implications for Institutional Elder Abuse. Journal of Elder Abuse & Neglect, Vol. 8 (1).

Griffith, A. & Smith, D.E (2004): Mothering for schooling. New York: Routledge.

Hastings, R.P (1997); Staff beliefs about the challenging behaviors of children and adults with mental retardation. Clinical Psychology Review.

Honneth, A (1996): The struggle for recognition. The Grammar of Social Conflicts. The MIT Press, Cambridge, Massachusetts.

Høilund, P. & Juul, S. (2005): Anerkendelse og dømmekraft i socialt arbejde. Hans Reitzels Forlag. København.

Høgsbro, K. & Eskelinen, L. Arp Fallov, M., Mejlvig, K., Permin Berger, N (2012): Når grænserne udfordres- Arbejdsbelastninger og pædagogiske udfordringer i specialpædagogiske boenheder. AKF, Anvendt KommunalForskning.

Høgsbro, K. (2010): SIMREB –towards a systematic inquiry into models of rehabilitation. Scandinavian Journal of Disability Research, 12 (1), 1-18.

Kvale, S. (1997) Interviews: An Introduction to Qualitative Research Interviewing.

Marchetti, A. G. & McCartney, J. R. (1990): Abuse of Persons with Mental Retardation: Characteristics of the Abused, the Abusers, and the Informers. Mental Retardation (6).

McCoy, L. (2001): Keeping Social Organization in View: Data Analysis in Institutional Ethnography. In Smith, D.E (2006).

McCoy, L. (2004): Interview Accounts of Everyday Experience. In Smith, D.E (2006).

McDonnell, A.A. (2010). Managing Aggressive Behaviour in Care Settings: Understanding and Applying Low Arousal Approaches. Chichester: Wiley-Blackwell.

Ng, R. (2006): Exploring the globalized regime of ruling from the standpoint of immigrant workers. In Caelie Frampton, Gary Kinsman, A.K. Thomson & Kate Tilleczek (Eds.) Sociology for Changing the World: Social Movements/Social Research. Halifax: Fernwood Publishing, p. 174-188.

Ng, R. (1986): Politics of community services: Immigrant women, class, and state. Toronto, Ont.: Garamond Press.

Payne, M. (2005): Teorier I Social Arbejde. Hans Reitzels Forlag.

Public Health Agency of Canada (2001): Stand by Me: Preventing Abuse and Neglect of Residents in Long-Term Care Settings. National Clearinghouse on Family Violence. ON.

Rankin, J. (2003): How nurses practice health care reform: An institutional ethnography. PhD diss., University of Victoria.

Ragin, C. (1994) Constructing Social Research: The Unity and Diversity of MethodPine Forge Press. Schutt, R. K.:Investigating the Social World: The Process and Practice of Research" 7th ed. Sage Publications, 2012.

Smith, D.E (2006): Institutional Ethnography as Practice. Toronto: Rowan & Littlefield Publishers, Inc.

Smith, D. E. (2005): Institutional Ethnography: A sociology for People. Lanham, MD: AltaMira Press.

Smith, D. E. (1990b): The conceptual practices of power: A feminist sociology of knowledge. Toronto, Ontario, Canada: University of Toronto Press.

Smith, D.E. (1987): The everyday world as problematic: A feminist sociology. Toronto: University of Toronto Press.

Smith D. E and Pence, E (2011). Institutional Analysis. Making Change from Below.

Smith, D. E. (2010). Institutional Ethnography. A Week Intensive Summer Workshop. Toronto, On: Ontario Institute for Studies in Education - University of Toronto.

Smith, D.E & Turner, S.M (2011) Institutional Ethnography Textual Workshop. Toronto, On: Ontario Institute for Studies in Education - University of Toronto.

Smith, D. E. (1999). Writing the Social: Critique, Theory, and Investigations. Toronto: University of Toronto Press.

Smith, G. W, Mykhalovskij, E. & Weatherbee, D. (2006): A research proposal. In Dorothy E. Smith (Ed.) Institutional Ethnography as Practice. Lanham: Rowman & Littlefield Publishers, Inc.

Smith,G.W. (1990): Political Activist as Ethnographer. In Caelie Frampton, Gary Kinsman, A.K. Thomson & Kate Tilleczek (Eds.) Sociology for Changing the World: Social Movements/Social Research. Halifax: Fernwood Publishing.

Sobsey, D. (1994): Violence and abuse in the lives of people with disabilities: The end of silent acceptance? Baltimore: Paul H. Brookes Publishing Company.

Spotlight on Transformation. A developmental Services Bulletin from the Ministry of Community and Social Services: Issue 13, 2009.

Spradley, J. (1997): The Ethnographic Interview

Townsend, E.A. (1996). Institutional Ethnography: A method for analyzing practice *Occupational Therapy Journal of Research* 16: 179-199.

Turner, Susan M. Texts and the Institutions of Municipal Government: The power of Texts in the Public Process of Land Development, in Lindsay Prior (Ed.) Using Documents and Records in Social Science Research, Sage Publications Ltd. New Delhi. Vol 4.

Volkmar, F.R & Wiesner, L.A. (2009). A Practical Guide to Autism. John Wiley and Sons, Inc., Hoboken, New Jersey.

Walby, K. (2007). On the social relations of research: A critical assessment of institutional ethnography. *Qualitative Inquiry*, 13 (7), 1008-1030.

http://www.mcss.gov.on.ca: Ministry of Community and Social Services (2011)

http://www.phac-aspc.gc.ca: Public Health Agency of Canada (2010)

# **Appendix A: Letter to Organisation**



Dear \_\_\_\_\_

I hereby send you a summary of my proposed study, the methodology and questions.

As Your organisation is one of Canada's largest service provider and committed to enhancing the quality of life of people with an Autism Spectrum Disorder, I hope you can assist me with your valuable knowledge and expertise that we, in Denmark, can learn from, and be inspired by.

If you are willing to participate in my study, I kindly request:

- To meet the supervisor/manager and staff in the residential home to inform about my study
- To interview 3 to 4 frontline support workers
- To carry out 1-2 days of observation

If you have any questions, please feel free to contact me anytime at xxx-xxx-xxx or email me: xxx@xxx. You are also welcome to contact my supervisor at Aalborg University; Prof. Kjeld Høgsbro at xxx@xxx

Sincerely,

## Cecilia Bonnevie

*Graduate Student of Social Work* Department of Sociology and Social Work University of Aalborg Denmark

# **Appendix B: Email correspondence with Agency**

From: XXX Sent: September 15, 2011 3:51 PM To: XXX

## Subject: Request by Graduate Student - Denmark

The clinical department has had a request by a graduate student from Denmark that I am forwarding to residential managers in Central East, XXX and Central West. I have attached a cover letter and project summary for the study for your information. She is requesting to spend a couple of days at one of the residential sites to gather information for her study. If you think that you will be able to accommodate this student please respond to her email directly by Friday September 23rd. Her contact information is in her cover letter. Your participation is completely voluntary. I know that she is more than willing to come in and meet with any manager about the plan for her research for further clarification. This opportunity may be an interesting experience for both you and your team.

Thanks very much,

XXX XXX, R.S.W., Clinical Director Department of Clinical Services Xxx Xxxx xxx xxxx Ontario Tel. (000) 000-000-0000 Fax. (000) 000-000-0000 Email:xxx@xxx.xxx

## **Appendix C: Information Letter to staff**



# Looking for support workers...

My name is Cecilia and I am a graduate student from Aalborg University in Denmark completing my Master's degree in Social Work.

I am looking for Canadian frontline support workers who would share your valuable knowledge with me about your experience of supporting individuals with an Autism Spectrum Disorder. The purpose of my study is to learn and understand what the world is like for Canadian frontline staff when encountering challenging behaviour in a Canadian residential home.

I would need a recorded interview of maximum one hour, conducted at your convenience. Participating in this study is entirely voluntary, completely anonymous and consent can be withdrawn up to writing of thesis. The recorded interview will be transcribed for analytical purposes- any identifying information will be deleted. I hope you will choose to participate in my study.

If you have any questions or concerns, please contact me at xxx-xxx-xxx or email me: xxx@xxx or feel free to contact my supervisor Prof. Kjeld Høgsbro at xxx@xxx.

Thank you for your time and cooperation.

Cecilia Bonnevie,

Graduate Student, MA of Social Work Department of Sociology and Social Work University of Aalborg Denmark

# Appendix D: Interview Guide for Primary Informants: Support Workers

1.	My name is Cecilia and I am graduate student from	Introduction
	Denmark doing a master degree in Social work. I am	
	writing my thesis that explores Canadian frontline	
	practice of Managing Challenging behaviour.	
2.	The purpose of my study is to explore and understand	Explicit purpose
	what the world is like for Canadian frontline staff when	
	dealing with challenging behaviour and conflict situations	
	with individuals with ASD in a residential setting	
3.	As a Danish student, I am specifically interested in	Ethnographic project
	learning and understanding what you do, or what you are	explanation
	required to do, when you encounter challenging	
	behaviour with clients (both practically and textually) I	
	would like to learn from your experience and give you a	
	voice of what that work is like	
4.	Before we start I would like to ask you if I can record our	Recording explanations
	interview so I can go over it later. I will delete the	
	recordings once I am done my analysis	
5.	I also want to inform you that participating in my study is	Confidentiality
	completely anonymous. Your name or any names that	
	you mention will be deleted. You are free to refuse to	
	answer any of my questions or end the interview at any	
	time.	
6.	Do you have any questions for me before we begin?	Allow for questions
		Begin Interview:
7.	So to start off I would like to ask you:	Informants background
	<ol> <li>What is your educational background or training?</li> <li>How long have you worked here?</li> </ol>	and responsibilities
L		

8.	<ul> <li>3. Is there any specific reason that you chose to work here or within the ASD field?</li> <li>4. What are your main responsibilities?</li> <li>Could you describe a "typical day" on the job and sort of take me through your day from the moment you arrive</li> </ul>	Grand tour Question: General overview of the
	and until you leave work?	informants work
9.	How many residents do you work with during a shift? How much time are you directly together with residents during a shift? Can you tell me about the individuals that you work with? How would you describe them? What do you do as a part of your job with the individuals you work with?	Relation to clients
10.	If you think back the past month or so, can you think of any challenging situations that you have experienced with residents? (If yes) Could you describe to me what you did/do in such a situation? How are these situations experienced on a daily basis?	Challenging behaviour
	Thank you for sharing your experiences. I have really learned a lot today and can hear you know a great deal more so if I think of more questions that I would like to ask you later on, would you be okay with me contacting you again? Thanks for talking to me.	Interview closing and taking leave

# **Appendix E: Macro-Picture Interview Guide for Manager**

The purpose of this interview is to clarify and make sure that what I have learned is understood correctly and the questions I have regard; The CPI Plan, The CPI training and the Incident report process. Before we begin I would like to ask permission to tape record our conversation to so I can go over it later. The recordings will be deleted after writing my analysis.

## Theme: The CPI Plan

- 1. From talking with the support workers, I have come to understand that if they experience challenging behavior with clients, they are specifically required to follow and implement the Crises Prevention & Intervention Plan that is outlined in the Behavior Support Plan. Is that correct?
- 2. Could you take me through this Crisis Prevention and Intervention Plan here for X and explain it to me step-by-step as if I had to learn how to do this tomorrow? (How is it used? And what is the purpose of the plan?)
- 3. How are the Crisis Prevention and Intervention Plan created? (Who makes this document?)
- 4. What is the information based on? How is the information collected?
- 5. What is the role of the Behaviour Therapist? What is she required to do?
- 6. To sum up in short: Who reads it? Who acts on it? Who makes the plan?
- 7. Is says the Crises Prevention Intervention Plan is based on the principles of CPI?
- 8. Is the Crises Prevention and Intervention Plan a ministry requirement?
- 9. We have talked about the actual Crisis Prevention and Intervention Plan. Could you describe to me –sort of in a sequence of action- what happens step-by-step from the moment support workers experience an incident with a client until the incident is over?

## **Theme: The CPI training**

- 1. Could you begin by describing to me what CPI is?
- 2. Is all staff required to get CPI training?
- 3. Can you tell me about the actual training? How and where is staff trained?
- 4. How long is the training program?
- 5. How often is the training updated?
- 6. The training manual I got- can you explain some of the pictures to me?
- 7. Which ones would you say is being used here?
- 8. In X's Crises Prevention and Intervention Plan it says "Use CPI training to block possible strikes. How do the support workers know which CPI technique to use?

- 9. Do you find the CPI training program useful and adequate?
- 10. Is there something in the CPI training program that is not adequate?
- 11. Have this agency always used CPI? What approach was used before?

## **Theme: The Incident Report**

- 1. In talking with the support workers, I have heard of a "Serious Occurrence" and an "Enhanced Serious Occurrence when they talk about making an incident report. Could you begin by explaining to me these two types of incidents?
- 2. Could we go through an actual incident report (either on the computer or on paper) step-by-step?
- 3. What is the purpose of the incident report?
- 4. Who creates the incident report? Where does it go afterwards? And then?
- 5. Who reads it? Who acts on it?
- 6. How is it used? (After it is filled out and sent away?)
- 7. What is adequate info? (Is there anywhere in this incident report where the support worker can register possible triggers or note the warning signs?)

## Probes:

-Can you tell me more about that?

-Let's see if I have grasped what you describe correctly...

-Could you describe to me what that involves?

-What do you do next?

-Oh that's interesting... (Express interest)

-I never thought of that... (Expressing cultural ignorance)

-I'd like to know what you do when you encounter challenging behaviour and conflict situations"

-Let's go back to my earlier questions. Could you describe to me what that involves?

## **Appendix F: PRN Protocol**

#### PRN for

For High Anxiety & Aggression towards others

#### Medication:

Loxapine (with a maximum total dose of 75 mgs in any given 24 hours period)

### REMINDER: Watch for sedation that may result in an unstable gait that could result in a fall

Staff is reminded that the PRN is a proactive strategy for addressing behavioral concerns. The following guidelines have been implemented to support **Concerns** while in crisis.

<u>Calming Strategies</u> - to be used as preventative measures, at the first signs of anxiety

- Remove from the situation and put him in an isolated area/room
- Offer him his balls to play with
- Put music on for
- Offer food such as cookies, soup or pop
- Offer a bath
- Give him space

#### Level 1 Intensity

- Anxiety (pacing becomes a stomping)
- Dumping food onto floor and not wanting to eat
- increased Vocalizations (more intense chirping)
- Pretending to spit at an individual
- Saying no to all request made by staff
- Stimming excessively (with an increase in frequency and intensity from baseline levels)

\*\*If remains at Level 1 for 5 minutes and does not respond to redirection the PRN should be administered\*\*

#### Level 1 initial dose: Loxapine 10 mgs

Additional Level 1 Dosing:

If the above Level 1 behaviors 30 minutes after initial dose of Loxapine (10 mgs), a 2<sup>nd</sup> dose PRN should be administered.

The 2<sup>nd</sup> dose is: Loxapine 10 mgs

If after 30 minutes from the 2<sup>nd</sup> dose, where the continues to display the above Level 1 behaviors and he is unable to return to his daily activities, a third dose PRN should be administered.

The 3<sup>rd</sup> dose is: Loxapine 10 mgs

If after 30 minutes from the 3<sup>rd</sup> dose, Minutes is still displaying the above Level 1 behaviors and he is unable to return to his daily activities, a fourth PRN should be administered.

#### The 4<sup>th</sup> dose is: Loxapine 10 mgs

After the forth dose, the manager must be contacted for approval of subsequent doses.

#### Level 2: Self Injurious or Aggressive Behaviour

- Spitting directly from his mouth one someone
- Making loud sounds like an owl "HOOTING"
- Throwing away his medication
- Making physical contact with an individual in the motion of a stabbing punch, grabbing or jumping on their back
- Jumping high in the air and landing on his knees
- Forceful rocking when in the vehicle
- Running extremely fast back and forth and smashing body into the wall or furniture
- Requesting a bath or food items and refusing when given
- Saving NO forcefully to all request made by staff

If any of the Level 2 behaviours listed above are observed administer a Level 2 PRN immediately.

#### Level 2 initial dose: Loxapine 25 mgs

#### Additional Level 2 Dosing:

 If **Contract** is unable to return to his daily activities and continues to display the above Level 1 or 2 behaviors **30 minutes** after initial Level 2 dose of Loxapine 25 mgs, a second PRN should be administered.

#### The second dose is: Loxapine 10 mgs

 If subset is unable to return to his daily activities and continues to display the above Level 1 or 2 behaviors 30 minutes after second Level 2 dose of Loxapine 10 mgs, a third PRN should be administered.

The third dose is: Loxapine 10 mgs

 If simple is unable to return to his daily activities and continues to display the above Level 1 or 2 behaviors 30 minutes after third Level 2 dose of Loxapine 10 mgs, a fourth PRN should be administered.

The fourth dose is: Loxapine 10 mgs

After the fourth dose, the manager must be contacted for approval of subsequent doses.