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## **Abstract**

This is an ethnographic study of the Open Door School, a specified school for children's with ASD in the capital of India, New Delhi. The aim of the study is to study how contextual and cultural factors affects the way in which social workers understand and manage challenging behaviour displayed by their students, children's with ASD at the Open Door School.

The parties of the study are a Danish master student in Social Work and the Open Door School. Based on the writers ethnographic field work at the Open Door School and the material gained and produced at the course of it (e.g. ethnographic field notes and interviews) the study maps and explicate how social workers at the Open Door School understand and manage challenging behaviours in their everyday work processes. The study also maps how local and trans-local contextual and cultural factors affect social workers understanding and management of challenging behaviours.

The study shows that the everyday work processes at the Open Door School is organized by the principles of Structured Teacching which is an American evidenced based program administrated by the TEACCH Division in North Carolina. The study shows that social workers understanding and management of challenging behaviours is referring to and is consistent with the philosophy and principles of Structured Teacching.

The mapping of the local and trans-local contextual and cultural factors shows that the social workers understanding and management of challenging behaviours is generated and thus affected by the social movement of three mothers of children with ASD who in 1994 founded the Open Door School. This was a part of the parent organization 'Action for Autism' (AFA) the mothers had constituted in opposition to the oppressive aversive methods and structural exclusion their children's were exposed to in a high-profile special school in New Delhi.

The study explicates and shows how the social movement of AFA founded the Open Door School and generated of a non-violent teachings policy where the use of any aversive methods at the Open Door School was prohibited. Accordingly, the study explicates how Merry Barua took up training at the TEACCH Division in North Carolina in the United States and accordingly introduced the philosophy and principles of the Structured Teaching as a non-violent teaching intervention at the Open Door School. It is trans-local and local processes of the non-violent teaching policy, Merry Barua' training in Structured Teacching at the TEACCH Division in North Carolina in 1995 and the later commitment with the AACTION team training the social workers in the intervention method of Structured Teacching that concertedly affects social workers understanding and management of challenging behaviours at the Open Door School.

The mapping of the trans-local and local processes shows further that it is the norms and standards of the non-violent teaching policy and commitment of practicing the philosophy and principles of Structured Teaching that generated AFA as a training center of the semi-professional education the Diploma course in Special Education in ASD. With the generation of the professional education, the study shows that AFA transformation of the amateurish approach at the Open Door School to a professional expertise in ASD has a significant influenced on the social workers understanding and management of challenging behaviours in terms of being institutional accountable and role models in respect to the norms and standards of the discursive practice of the Open Door School.

The contextual and cultural factors that surround the Open Door School and affects the social workers understanding and management of challenging behaviours are throughout the study being discussed and reflected upon from the perspective of the writer' cultural premises of the Danish welfare system.

## **1.0 Introduction**

Most people with Autism Spectrum Disorders (ASD) have expressive communications problems (Mitchells et al., 2006) and are at risk to develop challenging behaviors such as physical aggressions, self-injury, property destruction, inappropriate social and sexual conduct, hyperactivity, defiance, tantrums, bizarre mannerism etc. (Horner et al., 2002; McClintock et al., 2003; Prizant & Whetherby, 2005). Having expressive communication problems people with ASD are assumed not to be able to take care of their own health and safety and are some of the most exposed people in the society (Høgsbro, 2010).

Not being able to take care of themselves people with ASD in institutional settings are not only depended on social workers willingness to treat them well (Høgsbro, 2010). They are entrusted social workers assessments of their needs and are being exposed to social workers definitions of their problems and accordingly social workers way of managing their problems (Høgsbro, 2010). Social workers way of understanding and managing challenging behaviours are some of the most significant factors in the process of treating people who display challenging behaviour well and give them the best opportunities in life (Emerson, 2001; Hastings, 1997).

In the process of understanding and managing challenging behaviours social workers are influenced by the contextual and cultural factors which makes an institutional setting (Emerson, 2001). It means, social workers in institutional settings have different cultural premises for caring out social work and consequently, social workers within and across cultures are most likely to have different social rules for defining inappropriate behaviours as challenging behaviours as well as different intervention approaches for managing challenging behaviours (Emerson, 2001; Hastings, 2007).

This study is focusing on how social workers working in institutional settings for people with ASD understand and manage challenging behaviours. Empirical the study is an ethnography of the Open Door School, a school for people with ASD

placed in the Indian capital, New Delhi. Based on my (the writers) ethnographic fieldwork at the Open Door School, the study is mapping how contextual and cultural factors affects the way in which social workers at the Open Door School understand and manage challenging behaviours. The data collected is being mapped and discussed from my subject position as a Danish social worker within the Danish Welfare System. Through my reflective process of the data, a translation of my Danish way of understanding and managing challenging behaviour is made. The analytical approach is hermeneutic interpretation.

## **2.0 Issues, Concepts, and Methods**

This chapter begins with a conceptual clarification of the terms Social Work, Autism Spectrum Disorders and Challenging Behaviour. These conceptual clarification forms the basis of the subsequently issues and research question.

### **2.1 Social work**

This study is a social work study focusing on social workers working in institutional settings for people with ASD. The study understands social work in accordance with Malcolm Payne as; ‘...an activity that happens among human beings, and is to be understood as being culturally constructed and bound to time, place and its doers’ (Payne, 2005b in Ratu -Tyrkkö, 2010:21). For Payne social work is understood as a social construction that must be understood within its cultural, political and economic context (Payne, 2005a). Hence, social workers activities, understandings and beliefs in how to treat people well and give them the best opportunities are understood as the cultural, political and economic factors that makes a particular social context. In other words, this study is built on the belief that social work in institutional settings for people with ASD are carried out with differences within and across cultures.

## 2.2 Autism Spectrum Disorders

The focus of this study is people with ASD. ASD is a set of neurodevelopmental disorders that covers the lifespan of a person's life (Hollander & Nowinski, 2003; Volkmar, 2005a; Volkmar & Klin, 2005b; Matson & Rivet, 2008). Even though ASD is not the official diagnostic term, ASD is the term autism researchers and clinicians have recognized as the internationally term synonymous with the official term, Pervasive Developmental Disorder (Grinker, 2007; Hollander & Nowinski, 2003; Volkmar, 2005a; Volkmar & Klin, 2005b). Pervasive Developmental Disorder is the official classification and diagnostic term used by the two major classifications systems; The American Association's', *Diagnosis and Statistical Manual of Mental Disorders* (DSM-IV-TR), and the World Health Organizations, *Internationally Classification of Diseases* (ICD-10) (Hollander & Nowinski, 2003; Volkmar, 2005a; Volkmar & Klin, 2005b). Throughout this study Autism Spectrum Disorders is abbreviated as ASD and the term ASD is used synonymous with the official term, Pervasive Developmental Disorders.

In consensus DSM-IV-TR and ICD-10 characterizes ASD as a set of disorders<sup>1</sup> with severe and pervasive impairment of development in the three core areas of '*...reciprocal social interaction skills, communication skills, and by a restricted, stereotyped, repetitive repertoire of interests and activities*' (American Psychiatric Association, 2000; WHO, 2007)

According to DSM-IV-TR and ICD-10 these abnormalities are pervasive features of individual's functioning in all situations and "... has been present from as early as it could be detected reliably and will diminish progressively as the child grows older, although milder deficits often remain in adult life" (WHO, 2007).

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<sup>1</sup> With little variation, DSM-IV-TR and ICD-10 outline some of the different disorders which lie on the spectrum as

Childhood autism, Infantile autism, Atypical autism, Autistic disorders, Kanner Syndrome, Rett's Disorders, other Childhood Disintegrative Disorders, Asperger Syndrome, Pervasive Developmental Disorders Not Otherwise Specified (PDD-NOS)" (American Psychiatric Association, 2000; WHO, 2010).



With references to DSM-IV-TR & ICD-10, ASD is understood as a broad spectrum with a wide set of different neurodevelopmental disorders. People with ASD are people sharing the commonalities of abnormalities in the core area of social interaction, communication and repetitive behaviors.

### **2.3 Challenging Behaviour**

Most people with ASD are having communication problems and are displaying challenging behaviours in some degree (Mitchells et al, 2006). Challenging behaviour is a new term that has replaced terms as behavioural disturbance, problem behaviour, maladaptive, dysfunction, aberrant and abnormal behaviours (Emerson, 2001; Murphy et al., 2001)<sup>2</sup>. These terms used to describe unusual behaviours which can be harmful to the individual who display challenging behaviours<sup>3</sup>, challenging for social workers and/ or objectionable to members of the public (Ibid.).

A widely internationally accepted definition of challenging behaviour is the definition formulated by Eric Emerson, Professor of Clinical Psychology at the Institute of Health Research at Lancaster University (Bell & Espie, 2002; Stevens, 2006; Murphy et al, 2001). Whereas other definitions of challenging behaviour (Bell & Espie, 2002; Ager & O'May, 2001) emphasizes challenging behavior as an interaction between a person with challenging behaviour and others mainly focusing on social control and the means of communication, Emerson goes beyond these definitions by placing the focus on the importance of social and cultural expectations as well as the contextual factors in defining behaviours as challenging (Emerson, 2001). Emerson defines the term challenging behaviour as

*'...culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious*

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<sup>2</sup> The term challenging behaviours was introduced in the 1980s by The Association for People with Severe Handicaps in North America (Emerson, 2001; Murphy et al., 2001).

<sup>3</sup> For the person who display challenging behaviours the consequences may include abuse, inappropriate treatment, exclusion, deprivation and systematic neglect (Emerson, 2001).

*jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities' (Emerson, 1995).*

With his definition Emerson re-conceptualized challenging behaviour as a social phenomenon; a socially constructed concept which can '...only be fully understood when viewed as a social construction, a position which is highly consistent with the 'contextualist' world view of behaviour analysis' (Emerson, 2001:7). Being viewed as a socially constructed concept, culturally abnormal behaviours<sup>4</sup> deemed to be challenging behaviours is not specified within the definition. Culturally abnormal behaviours are being understood and deemed as challenging behaviour with references to the social rules that constitute appropriate behaviour within a social context. Furthermore, challenging behaviours are being managed with respect to the intervention paradigm that exist' within a social context (Emerson, 2001; Morris & Midgley, 1990; Murphy et al., 2001).

## **2.4 My Personally Journey to the Open Door School**

I'm a social worker and in my professional context in Denmark, I have experienced how challenging and what a strain it can be to work with people with ASD displaying challenging behaviours. Through eight years of practice in diverse institutional settings for people with ASD, I have been exposed to and experienced some of the various ways challenging behaviour can be displayed. I have been hit, spit, screamed and kicked at, I have experienced children's, adolescents and adults throwing and destroying properties, I have experienced self-injurious behaviours such as hitting, biting, cutting etc., I have experienced stereotyped repetitive behaviours such as repeated vocalizations, body movements and object plays. As a professional social worker, I have faced various situations displayed by people with ASD which has within the particular institutional settings been defined as challenging behaviours.

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<sup>4</sup> Emerson does note '...that abnormal cultural behaviours embraces serious physical aggression such as destructiveness and self-injury'. In addition to these serious behaviours, Emerson notes, '...that less serious behaviours as physical and verbal aggression in the forms of spitting, pinching etc. and possibly minor self-injury and stereotype behaviours might lead to significant levels of avoidance by members of the public' (Emerson, 2001:4).

Having to face challenging behaviour the subject of how we as social workers understand and manage challenging behaviour within institutional settings have preoccupied my professional interest throughout my career. The subject did not just preoccupy my interest because I have felt helpless in dealing with 'challenging' behaviours – which I did at times. However, throughout my career I have experienced that different social rules existed within different institutions regarding how specific behaviours were defined as challenging behaviours and how these unusual 'challenging' behaviours were thought to be managed. Some deemed a little bit as challenging behaviour others didn't. Some believed setting up more and more rules and structure was the best way to prevent and manage challenging behaviour others didn't.

According to Emerson challenging behaviour is a challenge for any institution as it can create '...conflict between service ideologies, personal beliefs and beliefs about the nature of behavioural practice' (Emerson, 2001:146-147). This is my experience within the institutional settings I have worked. I have experienced that challenging behaviour has been a complex issue which led to endless discussions and disagreements about how to define inappropriate behaviours as challenging behaviours. How challenging behaviours are to be managed? Different beliefs in what causes challenging behaviour? Whether to use physically restrain or not, when, the safety of the person itself or others were in jeopardy? Whether to set up more and more structure to manage and then prevent challenging behaviours or not? Whether our way of managing challenging behaviours recognized - or violated - the individual whom displayed any form for challenging behaviours etc. In all, I have experienced that challenging behaviours is an issue which among social workers creates different beliefs in how to understand and manage challenging behaviours within and across institutional settings in Denmark.

I no longer work as a social worker in the practical field. I needed further training to fulfill my professional dream for doing internationally humanitarian work and yet, I started this Master degree in Social Work at Aalborg University. Leaving the practical field, I initially thought, I also left my professional interest which had

preoccupied and frustrated me throughout my career. I did leave it for a while. But by chance I was offered the opportunity to become a student assistant at Aalborg University. I was offered to be attached to the Work and Safety project<sup>5</sup> studying social workers work and health issues in respect to managing 'challenging' behaviours in residential homes for adults and young persons with various degrees of developmental disabilities (Feb, 2012). This offer was an opportunity I could not reject and yet again, my professional interest for understanding and managing challenging behaviours gained my preoccupation – this time from a scientific and theoretically perspective.

As a master student, you have the opportunity to obtain practical experiences through an internship nationally as well as international. Having travelling experiences, I decided to go abroad. In my search for a placement I contacted the Disabled Peoples Organization Denmark through which I got in contact with and affiliated at the Research Center Division at the Indian National Center for Autism in New Delhi. It is through my placement at the Indian National Centre, I got in contact with and had the opportunity to observe the Open Door School - a second division of the Indian National Centre for Autism.

## **2.5 North and South: A Danish social worker and the Open Door School**

In India the government did not recognize ASD as a disorder until 1999 and has failed to provide appropriate services and socially support for people with ASD (Grinker, 2007). Hence, there are no governmental services, schools or treatments available for people with ASD (Grinker, 2007). With no services available, Merry Barua, a mother of a child with ASD, founded in 1994 the Open Door School for children's with ASD on an experimental basis with just one teacher and two students (Action for Autism, 2011). Today, with 60 students, the Open Door School is recognized by the Indian Ministry of Social Justice &

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<sup>5</sup> The Work and Safety project mentioned is the 'Psychosocial Risk Factors at Work and Handling of Conflicts in Residential Homes for Adults and Young Persons'. The research project is led by Professor Kjeld Høgsbro, Aalborg University and Docent Leena Eskelinen, Danish Institute for Governmental Research (AKF).

Empowerment and the National Trust as a modeling school for teaching children's with ASD in India. ([www.autism-india.org](http://www.autism-india.org)).

The Open Door School is a non-governmental and parent run organization and hence, social workers at the Open Door School are having other culturally, economically and educationally premises for carrying out social work in regard to people with ASD than social workers within the Danish Welfare State. Having the opportunity to observe the Open Door School, I became aware of the significance of these contextual and cultural factors differences. These differences were a challenge to my own premises to understand how challenging behaviours should be managed.

For instance, at the Open Door School I observed situations where social workers were restraining the wrist of their students to avoid students to run away or simply to guide the student's to the toilet. As a social worker within the Danish Welfare System you are not allowed to restrain the wrist of a person with ASD to guide the person to the toilet or other places, if, the person is not able to do it by her/himself (The Danish Act on Social Services § 123 & 124). Often thinking that the Indian social workers were violating the students by restraining his/her wrist, I found myself reflecting upon which contextual and culturally factors that determents my own understanding and belief in how to understand and manage challenging behaviours. Have the Danish Act on Social Services confined my understanding and belief in how to managed challenging behaviours?

According to Kjeld Høgsbro, Professor of Social Work at Aalborg University, Denmark '...professionals are confined by the current knowledge within their own specialized worlds, the accepted discourses and the premises that are taken for granted' (Høgsbro, 2010:2). It means, social workers acts the way they think is 'right', and what they think is right is being governed by the social context they are referring to (Høgsbro, 2010), Observing the Open Door School made me reflect on my own knowledge; how do I, a Danish social worker, actually understand challenging behaviour? How do I actually believe challenging behaviour ought to be managed? Contrasting my own

understanding I started questioning which contextual and cultural factors affects the way in which social workers at the Open Door School understand and believe how challenging behaviours should be managed. In other words, I became interested in the cultural premises for carrying out social work at the Open Door School.

## **2.6 Research Question**

Through the case of the Open Door School, my aim with this study is to identify and map how contextual and cultural factors affect the way in which social workers at the Open Door School understand and manage challenging behaviour displayed by their students, children's with ASD.

My research question is:

**How do contextual and cultural factors affect the way in which social workers understand and manage challenging behaviour displayed by people with Autism Spectrum Disorders at the Open Door School in India?**

As it becomes clear in the theoretically and methodologically discussion this question cannot be fully answered without being conscious of the context of the researcher, in other words, being conscious of my own cultural premises and expectations.

To identify and map means to explicate and draw up a map that visualizes how contextual and cultural factors that surround the Open Door School concertedly affect social workers understanding and management of challenging behaviours displayed by people with ASD.

### ***2.7.1 Conceptual Clarifications***

In the following a conceptual clarification of the concepts used within the research questions are defined.

### ***2.7.2 Contextual factors***

With reference to Smith, a context is referring to an institutional setting. An institutional setting is something within social workers practices and activities are socially organized (Campbell & Gregor, 2004; Smith, 2005). Therefore, contextual factors are characterized as those ruling relations<sup>6</sup> (i.e. local and trans-local policies, professional standards, institutional ideology, resources, training etc.) that rules, shapes and socially organizes social workers practices, activities and ability to carry out social work (Ibid.).

### ***2.7.2 Cultural factors***

With references to Geertz, culture ‘... consists of socially established structures of meaning’ (Geertz, 1973: 13) and with references to Bateson, the premises of culture are linked into a coherent ‘logical’ and structural system (Bateson, 1958). Therefore, culture is understood as an interworked system of cultural premises and meanings linked in a structural system; it is a context, something within which social events, behaviours, institutions or processes can be intelligibly (Geertz, 1973). However with references to Spradley, cultural factors is referring to the cultural premise of ‘... the acquired knowledge that [social workers] use to interpret experience and generate social behavior’ (Spradley, 1979:5). Therefore, culturally factors are the characteristics of a shared system of meanings or beliefs which have, according to Spradley, been ‘... learned, revised, maintained and defined in the context of people interacting’ (Spradley, 1979:6).

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<sup>6</sup> Ruling Relations is the concept Smith uses to name the socially-organized exercise of power that shapes social workers behaviours and work within an institution (Campbell & Gregor, 2004; Smith, 2005).

### ***2.7.3 Open Door School***

The Open Door School is a direct school service for children's with ASD providing training in communication skills, building basic interaction skills, pre-reading and writing skills and vocational skills ([www.autism-india.org](http://www.autism-india.org)). The Open Door School is a training service provided by the Indian National Centre for Autism<sup>7</sup> and is physically placed in the four-story building of the Indian National Centre for Autism located in the urban district of Jasola Vihar in New Delhi (Ibid.).

The Open Door School is placed on the first floor of the building where six classrooms divides the school into six classes in which about 60 children's in the age of 3 - 18 are placed depending on their abilities, needs, and chronological age (Ibid.). The abilities and needs of the children' attending the Open School range widely from a mild learning and social disability to a severe impairment (Ibid.).

Each of the six classes is associated with a social worker and a different number of care-aids, caregivers, trainees and volunteers. Care-aids are teacher-assistants having courses in teaching children's, but not specified in teaching children's with ASD. Caregivers are unskilled employees with no education in ASD. Being a non-governmental organization the Open Door School makes use of volunteers who offers their daily help to the school. The focus of this study is social workers.

### ***2.7.4 Social workers***

Social workers at the Open Door School are professional social workers having a graduation in the semi-professional Diploma course: Special Education in Autism Spectrum Disorders. Through the Diploma course, social workers have obtained the dual qualification to teach people with ASD educational work skills and to socially support the need of people with ASD to be included within the educational environment. With the dual qualification social workers take up the

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<sup>7</sup> See further description in chapter 7.3.2



dual role at the Open Door School. They are both teachers and social workers. As this study is a social work study focusing on the social problems children's with ASD in India are facing in regard to educational exclusion, I will throughout the report distinguish between the professions of teachers and social workers. I refer to teachers in regard to educational goals and teaching educational skills such as academics and vocational skills. I refer to social workers as those who provide people with ASD socially support in regard to obtain inclusion within the educational teaching environment of the Open Door School as well as the Indian Society.

Each social worker at the Open Door School is in charge of each their respective classes. More specifically, the role of the social worker is to set up a teaching environment in the classroom that socially support the need of the children's to be included in the educational activities of the class despite the inappropriate behaviours the children's might display. As teachers, the social workers are as well responsible for the educational activities and goals of the class. As professional in charge of each classroom, the role of the social worker is also to instruct the care-aids, caregivers and volunteers attending the classroom about the work processes of the class. Also, the role of the social workers is to supervise the trainees who are attending the Diploma course in Special Education in Autism Spectrum Disorders provided by the National Centre and are doing their practical training on daily basis at the Open Door School.

Social workers at the Open Door School are not just social workers having a Diploma in Special Education. They are first and foremost mothers of children's with ASD who have given up their careers and dedicated their lives for their children's with ASD (Grinker;2007). In their struggle to give their children's the best opportunities in life and in their struggle to find the best appropriated educational setting for their children's, they have taken a Diploma in Special Education and have become social workers at the Open Door - a position that gives their children's direct admission as a student at the Open Door School (Ibid.).

### ***2.7.5 To define challenging behaviours***

With references to Emerson, defining challenging behaviours is referring to the '... social rules regarding what constitutes appropriated behaviour' within an institution (Emerson, 2001:7). To define challenging behaviours is accordingly understood as an identification of those social rules that constitutes inappropriate behaviours within the Open Door School and gives them the label challenging behaviours.

### ***2.7.6 To understand challenging behaviours***

With references to Emerson, understanding challenging behaviours is referring to '... the beliefs held by social workers regarding the causes of the person's 'challenging' behaviour' (Emerson, 2001:7). To understand challenging behaviours is accordingly in this study understood as identifying social workers belief in the causes of the inappropriate behaviours.

## **2.8 The process of the cultural translation**

In the process of answering the research question I use institutional ethnography. a frame of reference to explore, discover and learn about the contextual and culturally factors which frames the social knowledge of an institution (Smith, 2005). Through interviewing and observations, institutional ethnography is driven by the search to discover and map what people actually do; what they experience and how what they do is coordinated within a social context of contemporary society, local practices and experiences (Smith, 2005). With references to institutional ethnography, I answer my research question by identifying and mapping those contextual and culturally factors which affects the way challenging behaviours are being understood, defined and managed at the Open Door School.

In accordance with institutional ethnography, I interact with and observe the social workers to discover and 'learn' firsthand how challenging behaviour is understood and managed within the social context of the Open Door School. It

is through a reflective process of my observations and my questions it becomes a translation - a thick description - of the significant contextual and cultural factors which affects the way in which social workers at of the Open Door School understand and manage challenging behaviors (Geertz, 1973). It is also in this reflective process, a translation of my own cultural premises within the Danish Welfare System for understanding and managing challenging behaviors is made. In the analytical description I involve the theoretically perspective of the social theory of Alex Honneth' and Michel Foucault' theory of power/knowledge.

## **2.9 Delineation**

It is important to clarify that this study is a social work study focusing on social inclusion of children's with ASD in Indian educational school environments. The focus of the study is not on the educational goal and activities at the Open Door School as such. The focus is on how social workers socially support the need of children's with ASD to be included within an educational environment of the Open Door School without the harmful use of aversive methods. Aversive methods are harmful methods which children with ASD in ordinary Indian schools have and still are using to manage challenging behaviours children with ASD displays.

It is also important to clarify that the purpose of this study is not to study the different types or prevalence of challenging behaviour people with ASD might display.at the Open Door School. Neither it is to study what impact challenging behaviour has in regard to stress and burn outs among social workers. Moreover, the purpose of the study is not to evaluate the intervention programmes used at the Open Door School or discuss what is 'best practice in regard to understand and manage challenging behaviours.

It is my frame of references to institutional ethnography which is marking out the frames and delineation of this study. Hence, the purpose of this study is neither to generalize about the individual social workers at the Open Door School (Smith, 2005) nor make an assessment of the individual social workers ability to

understand or manage challenging behaviours. The purpose of the study is to identify and map how contextual and cultural factors have a generalizing affect in how social workers within institutions beliefs challenging behaviours are to be understood and managed in terms of intervention approaches (Smith, 2006).

Most importantly, it is essential for the reader to notify that this study is not a comparative study between The Open Door School and a specific Danish institution for people with ASD. Nor is it a comparative study between the Indian social workers and Danish social workers understanding of challenging behaviours. However, doing ethnographic work is an intensive work where the reflection of the researcher is central to grasp the foreign (Spradley, 1979). In fact doing ethnographic work requires, according to Geertz, that the researcher work critically with his/hers pre-judgment' and fore-understandings in the process of grasping and writing up a cultural description of a foreign culture (1973). Therefore, the reflection of the researcher is included when doing ethnography, not just to understand a foreign culture. It is '... a fundamental tool to understand ourselves' and our own cultural premises (Spradley, 1979: III).

## **2.10 The purpose of the study**

This study is made for social workers working with people with ASD in institutional settings and other interested. The purpose is to produce social knowledge for how certain contextual and cultural factors of an institution that affects the way in which social workers understand and manage challenging behaviour. Such knowledge is needed in the process of developing better services and intervention for people with ASD displaying challenging behaviour (Smith, 2005).

### 3.0 Literature Review

Institutional ethnography is an 'alternative' sociology that does not begin in theory, but in people's experiences (Smith, 2006). It is a method that differs from conventional research studies as it does not take set in conventional research reliance on library search (Campbell & Gregor, 2004, Smith, 2005). Even though this study begins in my professional experience as a social worker, it is essential for an institutional ethnographic study to be linked to the scholarly literature (Campbell & Gregor, 2004). It is essential to discover what is already known about the subject and how researchers take on an issue in relation to what others have said (Campbell & Gregor, 2004). In the following the literature search framing this study will be reviewed in regard to what is already known within the focus of the study as well as why this study is required.

Linking the terms 'Autism Spectrums Disorders'<sup>8</sup> and 'Challenging Behaviour'<sup>9</sup> the following search engines<sup>10</sup> have been searched for papers in English: Psychinfo APA, Web of Science, Cambridge Scientific Abstracts, Academic Research Library, Proquest, Google Scholar and Academic Search Premier. The search showed a remarkable gap of empirical research in studies meeting the focus of this study. For instance, the result of the Psychinfo APA search engine resulted in 31 papers where 6 papers were marked for a further review. Similar results appeared among the other search engines but most notably, papers marked for further review were virtually the same papers. Altogether the amount of papers marked was 20 and following the subsequent review of the marked papers only one paper met the focus and interest of this study. Altogether, the literature review showed an international gap of empirical research on how contextual and cultural factors affect the way in which social workers understand and manage challenging behaviours in institutional settings for people with ASD.

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<sup>8</sup> Autism Spectrum Disorders was also replaced with the terms: ASD, autism, Pervasive Developmental Disorders and PDD.

<sup>9</sup> The American spelling of 'behavior' was also adopted throughout the search.

<sup>10</sup> The search engines used are the search engines which I have had access to through Aalborg University Library. Searching in other search engines such as Scopus may have given another result.

Viewed with a critical eye, the target group, people with ASD displaying challenging behaviours, may have been empirically researched in a larger extent than the results of the literature search carried out. As Dailey (2002) stresses, research in the field of ASD have only received limited attention regarding the influence of cultural factors within cultural contexts such as institutional settings and addresses that '...perhaps [ASD] has fallen between the cracks of the disability literature and mental health fields, viewed by one as a problem to schizophrenia and by others as more related to mental retardation' (Dailey, 2002: 532). No matter what the reason is, it is important to note that people with ASD displaying challenging behaviour may, most likely, have been studied under other terms such as people with intellectual disabilities, people with mental retardation, and people with developmental disabilities. Because of the time limit of this study, the extent of people with ASD displaying challenging behaviours studied under other terms than people with ASD have not been reviewed further and will in this study remain as unidentified.

A follow up of the references cited in the papers marked indicates that the subject of challenging behaviour within the field of all developmental disorders is a broadly explored research field. Particularly, it has been widely identified that the presence of challenging behaviour is associated with lower well-being (e.g. Blacher & McIntyre, 2006) as well as one of the major causes of stress and burn outs among social workers (e.g. Bersani & Heifetz, 1986; Jenkins et al, 1997; Hatton et al, 1995). Likewise it has been identified that people displaying challenging behaviour are at greater risk of abuse from their social workers (Rusch et al, 1986; Zirpoli, 1987); that social workers engage in fewer social interactions with people displaying challenging behaviour (Hastings & Remington, 1994) and that people displaying challenging behaviour are likely to be perceived more negatively by social workers (e.g. Jones et al., 1990). As it has been widely found that people displaying challenging behaviours are at greater risk for being abused by social workers as well as social workers are at risk of burning out due to challenging behaviour, there seems to be a valid reason to study the social relation between people displaying challenging

behaviour and social workers understanding and management of challenging behaviours in institutional settings.

By reviewing the references cited in the marked papers, the names of Eric Emerson<sup>11</sup> and Professor Richard P. Hastings, School of Psychology at Bangor University in England appears frequently regarding the subject of challenging behaviour. It appears that both researchers over the last 15 - 20 years have taken on the majority of research – independently but also in collaboration - within the field of people with intellectual disabilities and mental retardation displaying challenging behaviour in institutional settings. Based on their empirical research as well as Emerson's (2001) comprehensive overview of the current findings about the nature, epidemiology, causes and treatment outcomes of challenging behaviour, and Hastings (1997) overview of staff belief about challenging behaviours of children and adults with mental retardation, both Emerson and Hastings issues the knowledge gap which appears to exist within the subject of social workers understanding and management of challenging behaviour in institutional settings.

Hastings stresses that social workers beliefs are likely to have a significant impact on the process of care for people displaying challenging behaviour and that, social workers understanding of challenging behaviour may be a key factor in designing successful behavioural interventions (Hasting, 1997: Hastings & Brown, 2000). According to Hastings, there is a close inseparable relationship between the behaviour of social workers and the behaviour of the person displaying challenging behaviours (Hastings, 1997; Hastings, 1999; Hastings & Brown, 2000). This because, challenging behaviours '...typically is maintained as access to attention or tangibles mediated by others or they are maintained by escape or avoidance of social interactions or certain activities' (Hastings & Brown, 2000: 234). According to Hastings the majority of situations regarding challenging behaviours are therefore related to the experiences and consequences of social workers behaviours and even more important, social workers belief of causal attribution for displaying challenging behaviours

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<sup>11</sup> See chapter 2.3

(Hastings, 1997; Hastings, 1999; Hastings & Brown, 2000). However, Hastings et al. have found that social workers behavior is very often depended on 'rules' that may govern social workers behavior rather than contingency-shaped responses (Hastings & Remington, 1994; Hastings, 1997; Hastings & Brown, 2000) and hence, Hastings notes that; to fully understand challenging behaviour '...we need to analyze [social workers] behaviors'(Hastings & Brown, 2000: 234) in the process of understanding how social workers define certain behaviours as a social problem (Emerson, 2001) and why social workers behave in particular ways (Hastings & Brown, 2000).

Emerson agrees that social workers understanding and management belief of challenging behaviour have a significant impact on the social relation between the person displaying challenging behaviour and the social workers (Emerson, 2001). However, Emerson notes, it is culture that sees something as abnormal or wrong, names it and does something about it and therefore, the social context is significant in giving meaning to any behaviour as behaviours can only be defined as challenging within particular contexts along with the surrounding cultural beliefs and general role expectations (Emerson, 2001). In other words, in their process of understanding and managing challenging behaviours social workers are influenced by the contextual and cultural factors surrounding institutional settings. According to Emerson, social workers understanding, behaviours and management belief regarding challenging behaviours are likely to be influenced by environmental factors ranging from public policy to local fluctuations such as social workers health conditions, training as well as social workers ability to manage any social disruption caused by challenging behaviours (Emerson, 2001). On this basic, Emerson points out that '...unless we acknowledge the importance of social and cultural factors in defining challenging behaviours, we may be tempted to search for ever more refined mechanical and physical definitions of an inherently social process. Such a course of action would of course be doomed to failure' (Emerson, 2001:10).



### 3.1 A Knowledge Gap

Both Hastings and Emerson stresses that very little is known about contextual and culturally factors affecting social workers understanding and management of challenging behaviour and we need to explore the contextual and cultural factors of institutional settings to gain an awareness of how culture may affect the outcome of social workers training as well as social workers behaviour (Emerson, 2001; Hastings & Brown, 2000). As Hastings and Brown puts it; there is a need to establish a control of those contextual and cultural factors which may affect the way social workers understand and manage challenging behaviour in their social relation with people displaying challenging behaviour (Hastings & Brown, 2000).

Having completed a review of cross-culturally research on ASD until the year 2002, Tamara Daley, Ph.D. in clinical Psychology at the University of California – Los Angeles found that the research field of ASD within cultural contexts and developing countries has only received limited attention (Dailey, 2002). Daley found that only a few researchers have attempted a comparative approach and / or explicit addressed the influence of cultural factors (e.g. Probst, 1998; Tungaraza, 1994)<sup>12</sup>. Hence Dailey stresses that more detailed cross-cultural studies discussing the influences of cultural factors within the field of ASD are warranted (Daley, 2002).

However, the one paper the literature search found to meet the focus of this study is the recent cross-culturally study by Hsu-Min Chiang, Ph.D. in special education, Macquarie University, Australia (2008). Chiang studied Australian and Taiwanese children's with ASD with severe speech impairments using challenging behaviour in institutional school settings. Observing 32 children's (17 Australians and 15 Taiwanese) by videotaping two hours of challenging behaviour during the children's school routines, Chiang found a significant difference between Australian and Taiwanese children's on the amount of challenging behaviour. Australian children' were found to be more requesting

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<sup>12</sup> None of the studies Dailey found involved or met the focus of this study.

and directing challenging behaviours more towards adults than Taiwanese children's. But most remarkable, Chiang found that challenging behaviours occurred most often during structural academic activities than during free time. According to Chiang these findings may be affected by the social workers who work with the children's. Likewise, the findings may indicate that the occurrence of challenging behaviour is associated with structural activities and structural settings (Chiang, 2008). Based on her results Chiang stresses that structure is a significant factor to study further in regard to social workers understanding and management belief of challenging behaviour displayed by people with ASD. In relation with her research Chiang found that there still exists a lack of research studying cultural factors within and across two countries and yet, more research are needed to confirm the findings of the structural significance (Chiang, 2008) - particularly taking Chiang' small sample into consideration.

Being an institutional ethnographic study of the Open Door School, an additional literature search of the linking terms 'Autism Spectrum Disorders' and 'Institutional Ethnography' has been completed by using the earlier mentioned search engines. The search did not provide any English papers in the search engines sought, which indicates that previous studies using the method of institutional ethnography for exploring institutional settings for people with ASD has not been applied. A subsequently search was carried out by replacing the term 'Institutional Ethnography' with just 'Ethnography'. By linking 'Autism Spectrum Disorders' and 'Ethnography' the search provided a total result of 4 papers. None of the papers met the focus of this study. Altogether, the literature search indicates there is no tendency among researchers applying institutional ethnography or ethnography as a research methods within the field of ASD.

In sum, the literature review carried out indicates a remarkable knowledge gap within the research aimed at challenging behaviours in institutional settings for people with ASD and no tendency of using the research method of institutional ethnography within the research field of ASD. There appears to be a knowledge gap and a requirement of research focusing on, how contextual and culturally factors affects the way in which social workers understand and manage

challenging behaviour - within and across culturally contexts. Based on the literature search carried out, this study appears to be required to identify contextual and cultural factors affecting social workers understanding and management of challenging behaviour in institutional settings for people with ASD.

## **4.0 Researching the Open Door School**

In this chapter my methodologically way of tracing the understanding and management of challenging behaviour at the Open Door School is explained. I try to explain the research design in the most possible transparent way. Transparency aspires to verify my footing and thus allow the reader an opportunity to judge whether my work appears consistent with my statement of methodology (Campbell & Gregor, 2004). In the following institutional ethnography will be explained followed up by how institutional ethnography is being used in this study including the ontologically and epistemologically viewpoint of the study.

### **4.1 Institutional Ethnography**

Institutional ethnography is an 'alternative sociology' developed by the Canadian sociologist Dorothy E Smith. By combining Marx's materialist method, Garfinkel's ethnomethodology and feminism Smith created institutional ethnography as a sociology to explore the social relations that structures people's everyday lives in those forms we call 'institutions' (Smith 2005; 2006). Institutional ethnography is a methodology to explore how institutions are put together and how those who work within them are ruled by the trans-local social relations i.e. contextual and cultural factors that makes the institution (Ibid.). It is a method for mapping the social relations that coordinates and constitutes social workers work and social knowledge within their particular institutional settings (Smith, 2005; 2006). In institutional ethnography social relations' does not refer to an interaction between two people or more (Campbell & Gregor,

2004). Social relations refer to the social processes that coordinate actually practices and their activities in interconnection with the contextual and cultural factor of the institutional discourse (Smith, 2005; 2006). In fact, it is the interplay of social relations that constitutes the social organization of an institution (Campbell & Gregor, 2004).

Through the conception of social relations, Smith created social relations as a research 'tool' to map how the practice of an institution is concerted and coordinated between the local setting of everyday life and the trans-local processes that organize and shape the organization (Campbell & Gregor, 2004). Using social relations as an investigation tool, Smith made it possible to 'visualize' how complex local practices are coordinated by trans-local ruling relations and accordingly, how individual's actions are ruled by the social knowledge that exists within the institution (Campbell & Gregor, 2004).

In institutional ethnography trans-local relations are seen as the ruling relations who control the organization of an institution (Campbell & Gregor, 2004). Ruling relations are the objectified forms<sup>13</sup> of social organization that consciousness constitutes and controls people's actions and social knowledge (Smith, 2006). They are the forms of ruling who rely on people knowing how to take them up and act in an appropriated manner (Campbell & Gregor, 2004).

According to Smith the objectified form of ruling is mediated by text (Smith, 2005). Texts (paper/print, film, and/or electronics such as computers or TV) are components of social relations as they enter into peoples' life' by coordinating their actions and hence gets things done in a specific way (Campbell & Gregor, 2004)<sup>14</sup>. According to Smith, texts carry power as they create the connection between the behaviour of an individual in a local setting and the trans-local organization of the ruling relations. Although Institutional ethnographers rely on

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<sup>13</sup> Objectified forms '... are those forms that we know as bureaucracy, administration, management, professional organizations and the media (Smith, 1990:6).

<sup>14</sup> 'In this view, a text can be any kind of document, on paper, on computer screens, or in computer files; it can also be a drawing, a photograph, a printed instrument reading, a video or a sound recording' (DeVault & McCoy in Smith, 2006:34).

textual analysis I am not using textual analysis in my analysis (cf. Methodological reflections.)

Institutional ethnography identifies texts as those who objectify and coordinate people's doing as an actual interchange between a reader' 'activation' of a text and the reader's response to it (Smith, 2005; 2006). For instance, as a Danish Social worker I am governed by the Danish Act of Social Services. By following the act, I activate the act it. Smith calls this a text-reader conversation. When texts (as the Danish act) are activated, they are people's doings because the text-reader conversation takes place in real time, in the actual local setting and as moments in sequences of action (Smith, 2005; 2006).

Institutional ethnography shares with Foucault (c.f. chapter 5.2) an interest in texts, power and governance (Campbell & Gregor, 2004). However there are some differences which are particular significant for empirical research (Campbell & Gregor, 2004). In Foucault's work the notion of discourse designates a kind of large-scale conversation in and through texts (Ibid.). In extension of Foucault's conception, Smith' conception of discourse refers to a field of trans-local and local social relations that includes not only texts and their intertextual conversation, but the activities of people in actual sites who produce them and use them and take up the conceptual frames they circulate (DeVault & McCoy in Smith, 2006).

Smith wants us to understand that people participate in discursive activities and discourses constrain what people can say or write or act (Ibid.). In fact, Smith uses the term institutional discourses to explain how people's doings and actions within an institution makes them 'institutional accountable' - or as she notes '...make them integral with the production of the institution' (Smith, 2005:120). According to Smith, people actively constitute social relations and '...participate in social relations, often unknowingly, as they act competently and knowledgeably to concert and coordinate their own actions with professional standards or family expectations or organizational rules' (Campbell & Gregor, 2004:31). Hence, institutional discourses are distinctive because they displace and subdue the presence of subjects (Ibid). This means, people within an

institution are objectified by the power that emerges within an institutional regime, power that is mainly formed by political text-processes (Campbell & Gregor, 2004). It is the power of the peoples text-reader conversation that make people express and act in accordance to the institutional discourse's frames, concepts and categories (Ibid.). It is this textual representation of an institutional discourse – in this study the intervention approach - that is objectifying social workers as institutional accountable because social workers 'disappear' as subjects (Smith, 2005).

However, in according to Smith, a discourse does never lose' the presence of the subject who activates the text in any local moments of its use (DeVault & McCoy in Smith, 2006). This means, that the subject' inner experience in activating a text cannot be objectified. This is why institutional ethnography is said to begin in personal experiences (Campbell & Gregor, 2004). Also this is why institutional ethnography is all about clarifying how subject's actions and experiences are actually being objectified and most often taken for granted (Campbell & Gregor, 2004).

#### **4.2 Institutional ethnography in this study**

In this study I use Smith' research tool of social relations to identify how the contextual and cultural factors affect social workers understanding and management of challenging behaviours at the Open Door School. I use trans-local ruling relations synonymously with cultural and contextual factors. By using my field notes, transcribed interviews, photo' and documents which I have collected within the institutional discourse of the Open Door School, I identify and map those trans-local ruling relations that are shaping the actions and beliefs of the social workers at the Open Door School in terms of understanding and managing challenging behaviours.

In the process of selecting methodology for me an important aspect of choosing institutional ethnography was that the researcher's background is bound to be a part of the picture (Smith, 2005). However, I remind the reader I only use aspect

of institutional ethnography combined with traditional ethnography which I explain in the following.

#### ***4.2.1 Traditional ethnography***

Traditionally ethnography is the study of culture (Spradley, 1979, Geertz, 1973, Hammersley, 2007). It is a systematic approach for understanding how other people see their experiences and understand their culture, '... the acquired knowledge that people use to interpret experience and generate social behavior' (Spradley, 1979:5). Traditional ethnography is the study of people's way of life within their own culture and according to Spradley, a method to understand another culture from the native point of view (Spradley, 1979). Through ethnographic field work the essential core of traditional ethnography is to understand the system of meanings / the social rules that constitute the culture and accordingly describe the culture (Geertz, 1973; Spradley, 1979). Traditional ethnography is with the words of Geertz to write out the systematic rules that exist within a social culture (Geertz, 1979).

With references to Hammersley, Geertz, & Spradley elements of traditional ethnography is referring to the elements of travelling to a distant country immersing oneself, learning to navigate in a new cultural context and producing a culturally embedded interpretation (Geertz, 1973; Spradley, 1979). Combining Institutional ethnography with these elements of traditional ethnography involves in other words my own personhood in the process of learning how to navigate as a social worker at the Open Door School and accordingly map the social knowledge and organization of the Open Door School (Hammersley, 2007). Most importantly the combination gave me the opportunity to use my own reflections in the interpretation process for understanding the behaviours of the social workers and the contextual and cultural factors which coordinates and affect their understanding and management of challenging behaviours (Geertz, 1973, Hammersley, 2007, Spradley, 1979).

Even though my methodological approach is institutional ethnography combined with elements of traditional ethnography, institutional ethnography is

to be seen as my main frame of reference in terms of answering my research question. I consider Institutional ethnography as the appropriated method to conduct knowledge of how the Open Door School is socially organized and likewise, how social workers behaviours, doings and beliefs are coordinated and ruled by the contextual and cultural factors which surround the Open Door School. Additionally, I consider the mentioned elements of traditionally ethnography as a 'translation tool' for me to learn the distant culture of the Open Door School as a basic to understand my own understanding and management belief of challenging behaviours within my Danish context. Together I found this combination as the appropriated research method to answer the need of my research questions.

#### ***4.2.2 A qualitative research study***

Due to my methodological combination, this study is to be viewed as a qualitative research method where data is collected in terms of ethnographic interviews and participant observation. In this study participant observation is my method to interview, observe and describe the social workers work at the Open Door School in their natural surroundings and to collect naturally occurring, non-biased data (Campbell & Gregor, 2004). The strength of participant observation as a qualitative research method is that through observations and interactions over a long time of periods, I can discover hidden details and discrepancies between what informants say – and often believe - should happen and what actually does happen (Hammersley et al., 2007). These discrepancies would be hard to grasp by other means of qualitative research methods and unobtainable by quantitative research (Hammersley et al, 2007).

One of the limitations in connection with ethnographic work is, according to Hammersley et al, that representativeness in a single case or small number of cases is always in doubt (Hammersley et al., 2007). However, Hammersley et al. notes that ethnographic research is sometimes concerned with a case that has an intrinsic interest and hence, generalization is not the primary concern



(Hammersley et al., 2007). This involves this study. This study is a study with an intrinsic interest in studying the Open Door School for understanding my Danish way of understanding and managing challenging behaviours and hence, generalizability – the extent that findings in one situation can be transferred to other situations- is not a concern in this study (Kvale et al, 2007).

However doing ethnography is, according to Pink, ‘... a process of creating and representing knowledge (about society, culture and individuals) that is based on ethnographers’ own experiences. It does not claim to produce an objective or truthful account of reality, but should aim to offer versions of ethnographers’ experiences of reality that are as loyal as possible to the context, negotiations and intersubjectivities through which the knowledge is produced’ (Pink, 2007: 22). Hence, writing up the ethnography of this study is not an acknowledgement process in terms of finding the final truth of how to understand and manage challenging behaviours as a social worker (Hastrup, 1992). The purpose of writing up this ethnography is to describe how social workers within diverse cultures have learned to see, hear, speak, think and act on the basis of my reflexive approach (Hastrup, 1992).

#### **4.3 A Multidimensional study**

Fundamental to the approach of institutional ethnographic is an ontology<sup>15</sup> that views the social as the concerting of people’s activities (Campbell & Gregor, 2004; Smith, 2005; 2006). Through the concept of social relations Smith refers to Marx’ work, the coordination of people’s activities on a large scale (Smith, 2006). She refers to the coordination that occurs in and across multiple sites of the society, involving the activities of people who are not known to each other and who do not meet face-to-face (Smith, 2006). Smith’s believes that the social being in the contemporary ‘everyday world’ is being socially constructed and organized in a powerful way by the trans-local ruling relations that pass through local institutional settings (Ibid.). She believes that institutional settings are

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<sup>15</sup> The study if ‘being’ and ‘becoming’; it is concerned with the fundamental nature of existence (Kvale et al., 2009)

shape according to the dynamic of a transformation that begins and gathers speed somewhere else (Campbell & Gregor, 2004). Smith ontologically viewpoint is in other words that institutional settings are organized by the specific historically and culturally factors surrounding the institutional setting and that the social knowledge within the institutional setting is taken for granted by the people who are objectified by the knowledge (Smith, 2005; 2006). With this ontologically viewpoint, institutional ethnography is in this study considered to undertake a scientifically position within the premises of social constructionism.

With references to Vivien Burr, social constructionism is a shared belief of the following premises: a critical stance towards taken-for-granted knowledge; that all knowledge is historically and culturally specific; that the way in which we understand knowledge is sustained by social processes; and that knowledge and action goes together (Burr, 1995: 3-5). Social constructionist, views the social world as a product of social processes and hence, social constructionist's focuses on social processes when explaining social phenomenon' (Burr, 1995). They focus on the interactive social processes that take place routinely between people as they share the belief that social phenomenon' is constructed by human actions and that a social phenomenon is transformable by human actions (Burr, 1995).

In terms of social constructionism the social world gets constructed by our use of language. In fact, our use of language is seen as a form for action, and some constructionist's such as Foucault take this 'performative' role of language as their focus of interest (Burr, 1995). Language is according to Smith central in terms of forming organizations and 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 investigations' (Smith, 2005: 69).

As Smith emphasizes in her book 'Institutional Ethnography – A Sociology for People', she is not concerned about the epistemological<sup>16</sup> issues (Smith, 2005).

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<sup>16</sup> Epistemology is the nature of knowledge and justification (Kvale et al. 2009). The belief in what knowledge is, how it is acquired and how do we know, what we know (Dascal, 2003).

In terms of her interest on social action the epistemologically position of institutional ethnography does not just undertake an epistemologically position of social constructionism where the realization is seen as a relation between the language and what the language is about (Burr, 1995). As Smith ascribes the researcher an important role in the interpretation and mapping process, the ontologically and epistemologically framework of institutional ethnography is in this study considered as a combination of social constructionism and hermeneutic.

Hermeneutic in its tradition means interpretation, the study of interpretation of written text (Schmidt, 2006). Modern hermeneutic is an extended ontological philosophy which encompasses not only issues involving the written text, but everything in the interpretative process (Ibid.). This includes verbal and nonverbal forms of communication as well as prior aspects that affect communication, such as the interpreter's presuppositions and pre-understandings (Dascal, 2003). The perception in hermeneutic is that the interpreter is always a part of the social world and understands the social world through its presuppositions and pre-understandings (Ibid.). Hence, an interaction among the interpreter and the social world being interpreted will in the perception of hermeneutic always exist in terms of seeking meaning of the text being interpreted (Schmidt, 2006).

The interpretation of meaning occurs in modern hermeneutic within the hermeneutical circle<sup>17</sup> (Schmidt, 2006). The hermeneutic circle describes the methodologically process for understanding a text hermeneutically (Dascal, 2003). However, this circular character of interpretation does not make it impossible to interpret a text; rather, it stresses that the meaning of a text must be found within its cultural, historical, and literary context (Ibid.). In the philosophy of modern hermeneutic, you are as a researcher always a part of the hermeneutic circle in terms of our being in and understanding of the social world which forms the way we understand and interpret the social world (Ibid.).

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<sup>17</sup> With the hermeneutic circle, hermeneutic is both a method for interpretation and a philosophy of the human being and the reality and the human beings understanding of the reality.

Despite the fact that Smith doesn't take up the epistemologically issue, she does note that writing up an ethnography is the researcher's interpretation process '...for finding conceptual links in order to make sense of the data' (Campbell & Gregor, 2004:98). In the interpretation process, Smith emphasizes that the researchers experiences, presupposes and fore-understandings plays an important part in the interpretation in terms of understanding how the social organization of a setting actually are concerted (Smith, 2005). This means, I view the social world as being socially organized by trans-local ruling relations and that I do not view a discourse as being historically and culturally voided. I believe human beings within any discourse understand and interpret the social world from a perspective formed by our past experiences and their interest for the future.

Referring to various theoretically perspectives and levels of analysis my ontologically and epistemologically framework is built on what Podgórecki calls a multidimensional sociology. Multidimensional sociology represents a multidimensional methodological and conceptual framework designed by the researcher '...to grasp more comprehensively the variety of faces of social reality' (Podgórecki and Los, 1979: 332).

In terms of electing a multidimensional viewpoint, I must state the awareness of the ongoing debate regarding criticism of the results of multidimensional studies for not being accumulative and progressive (Burger, 1986). This criticism is raised by scientist who argues that a prolific variety of approaches is not reconcilable (Burger, 1986). Being aware of this criticism and ongoing debate, I choose to have a multidimensional framework as I find it the most appropriated approach for answering the need of my research questions. The debate however will not be discussed further due to the limitation of this study.

#### **4.4 Participant Observation – the Method for Data Collection**

According to Smith, institutional ethnographers uses whatever method is practicable and appropriated in opening up those aspect of institutional processes with which they engage (Smith, 2006). The most common methods

are interviewing, participant observation, focus groups and the researcher's reflections on her or his experiences (Smith, 2006). All serve to generate a thick description of what people do and how what they do are coordinated in their everyday lives (Ibid.). This study uses participant observation and my own reflections on my own experiences. In the following participant observation as a method for data collection will be explained.

Participant observation is a strategy that aims to gain a close and intimate familiarity with a given group of individuals and their practices through an intensive involvement with people in their natural settings (Hammersley et al., 2007; Geertz, 1973; Spradley, 1979). According to Hammersley, participant observations involves the researchers participating, '...overtly or covertly, in people's daily lives from an extended period of time, watching what happens, listening to what is said and/or asking questions through informal and formal interviews, collecting documents and artefacts – in fact, gathering whatever data are available to throw light on the issues that are the emerging focus of inquiry' (Hammersley et. al, 2007:3). Participant observation is a research strategy which takes places 'in the field' and which makes it possible to transform all the data under analysis into text in form of transcribed interviews, field notes, photography etc. (Geertz, 1979; Hammersley et al., 2007; Spradley, 1979).

Participant observation is a relatively 'unstructured' way of collecting data (Hammersley et al, 2007; Spradley, 1979). Firstly it does not, according to Hammersley, involve a fixed and detailed research design specified at the start (Hammersley et al, 2007). Secondly, the categories that are used to for interpreting what people say or do are not built into the data collection process through the use of observation schedules or questionnaires (Ibid.). Instead they are generated out of the process of data analysis (Ibid.).

Doing ethnographic fieldwork in relation to the theoretical frame of institutional ethnography is likewise, according to Campbell & Gregor, an open-ended research method that is not fully planned in advance. The process '...is rather grabbing a ball of string, finding a thread and then pulling it out. That is why it is

difficult to specify in advance exactly what the study will consist of...[...]...the researcher knows what she wants to explain, but only step by step does she know who she needs to interview or what texts and discourses she needs to examine' (Campbell and Gregor, 2004:?). Conducting an institutional ethnographic study inquires for this reason an adequate explanation of the methodology way of the study (Campbell & Gregor, 2004). In the following I outline my methodology footing, beginning with how the researcher's reflections are a significant feature in doing ethnographic work. Not just in terms of reflecting on one's own experiences but also in the terms of the researcher's awareness of how the researcher's personhood plays a significant role in his /her way of being and relating with the informants involved (Hammersley et al., 2007; Pink, 2007).

#### **4.5 Ethnographic field work as a way of Being and Relating**

According to Spradley, ethnography means 'learning from people' rather than studying people and thus, doing ethnographic fieldwork is a learning process where the researcher is taught by the people they are studying to understand the meanings of those actions and behaviours that constitute their culture (Spradley, 1979). The researcher must relate with the native people in form of a student / teacher relationship as it is the natives who are the gate way for the researcher to learn and grasp the language of the natives and the meanings of the native's behaviours (Hammersley et al, 2007). Hence, the researcher must act ignorant in her way of being and relating with the natives to grasp the social structure of the foreign culture (Ibid.).

However, the relationship between the researcher and informant is not just a one-way learning relationship. The relationship is, according to Spradley, a mutual learning relationship where the ethnographer does not only learn to understand the meanings of the native language and behaviours (Spradley, 1979). The native's also '...learn to translate [their own embedded culture] when communicating with outsiders' (Spradley, 1979: 19). Relating with the researcher the native learns to view and in question its own culture from the

perspective of the researcher (Spradley, 1979). However, being an outsider in a foreign culture is the strength in doing ethnography because the researcher as an outsider views the culture from another perspective than the natives who are embedded within the culture (Geertz, 1973).

When doing ethnographic fieldwork you are as an ethnographic researcher placed in the middle of the field using your own personhood, experiences and reflection to gain understanding and knowledge of the particular culture/institution you are exploring (Geertz, 1973; Hammersley, 2007; Spradley, 1979). As an ethnographic researcher you cannot avoid relying on 'common-sense' knowledge and you cannot avoid having an effect on the social phenomena you study (Geertz, 1973; Hammersley, 2007; Spradley, 1979).

Within the philosophical hermeneutic tradition<sup>18</sup> of ethnography, the tradition Spradley and Geertz represents, understanding social worlds is inevitably reflecting the 'prejudices' and the pre-understandings of the interpreter (Spradley, 1979; Geertz, 1973). Understanding a foreign social world and interpreting a social world is in, accordance with Gadamer, writing up an ethnographic description produced on constructions that inevitably reflect the socio-historical position and background of the interpreter (Hammersley, 2007). An ethnographic description is with the words of Gadamer, '...a re-creation of the text guided by the way the translator understands what it says' (Gadamer, 2004:388)<sup>19</sup>. The researchers 'prejudices' and fore-understandings plays in other words a significant role in the researcher's process of interpreting and understanding a foreign culture. Being an outsider placed in the middle of a foreign field requires thus a conscious reflection and awareness of the ethnographers own background and pre-understandings (Ibid.).

Throughout my ethnographic fieldwork at the Open Door School I have tried to be conscious and reflected upon my professional background. Being self-conscious of my background, the interpretation from my subject position does

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<sup>18</sup> Developed by Gadamer

<sup>19</sup> With the words of Geertz '...that we call data is really our own constructions of other people' constructions of what they and their compatriots are up to' (Geertz, 1973:9).

not, according to Allaine Cerwonka, have to reject all notions of objectivity of the study:

*‘To say that understanding is always a situated practice is not simple to acknowledge that we always bring personal “bias” (conceptual and personal fore-understandings and prejudgements) to our research. It is to say that we always understand through a set of priorities and questions that we bring to the phenomenon/object we are researching (...) ...how one’s personhood is also a condition for knowledge claims, rather than a deterrent to understanding. (...) ... far from being a deficiency, the sustained contact and negotiation between the ethnographer and the phenomenon she researchers is really ethnography’s creative center’ (Cerwonka, 2007, 28-31).*

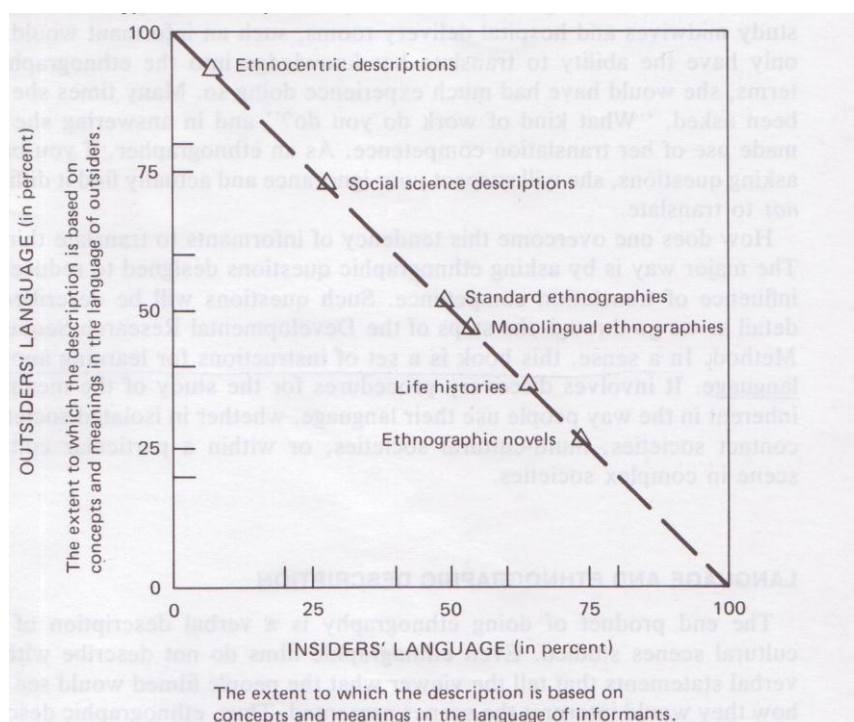
Doing ethnographic fieldwork is in other words the process of acknowledgement where the researcher’s fore-understanding and pre-conceptions plays an important role in both the field work, theoretically interpretation, and not to forget the analytically translations process when writing up an ethnography (Hammersley, 2007). Doing ethnography is intensive work, where the ethnographer not only must grasp the meaning of a foreign culture (Hammersley et al). Doing ethnography requires critical reflections regarding the ethnographer own fore-understandings and pre-conditions (Hastrup, 1992). Reflections that can lead to new understandings and critical perspective on his/hers own cultural setting (Hastrup, 1992).

#### **4.6 Writing up a Thick Description**

Writing up an ethnographic description – a thick description - is according to Geertz a translation, a communication of the cultural meanings the ethnographer has discovered to readers who are unfamiliar with the culture and cultural scene (Geertz, 1973). In terms of writing an ethnographic description it is, according to Spradley, essential for the researcher to learn the language of the natives to use the native terms and meanings in your writing as well as the researchers own terms (Spradley, 1979). If not using native terms and the terms of your own, the ethnographic description becomes either ethnocentric by not



using the terms of the native and ignore what things means, or, it becomes an ethnographic novel providing a rich description by only using the language of the communities (Spradley, 1979). A standard ethnographic description using both the native terms and meanings and the ethnographers own constitutes, according to Spradley, a faithful description to the concepts of the informants. Figure 1 (Spradley, 1979:22) provides a comparison of the different types of descriptions in terms of the language used to describe the culture.



**Figure 1: Types of Descriptions**

The figure illustrates that the productivity of writing an ethnographic description lies in the relationship between the informant and ethnographer (Spradley, 1979). It is the ability of the native to translate and describe its own culture for the ethnographer and the ethnographer's ability to grasp, translate and write up an ethnographic description by using the natives terms as well as the ethnographers own that forms the production of a thick description (Spradley, 1979). However, it is as a whole the researcher's observations and the

researchers reflections upon the observations that forms the production of the final thick description. In the following, I outline my footing at the Open Door School. I outline my footing in terms of grasping and translating how contextual and cultural factors are affecting social workers understanding and management of challenging behaviours displayed by people with ASD.

#### **4.7 Components of the study**

In this following chapter the most essential components of my ethnographic fieldwork is outlined. These components 'visualizes' my footing in terms of collecting data at the Open Door School. This includes the premises for collecting data and my reflections and choices in regard to the premises for collecting data. The chapter begins with the progression of the study.

##### ***4.7.1 The progression of the study***

As mentioned this study was founded during my internship at the Research Division at the Indian National Centre for Autism where I was given the opportunity to observe the Open Door School with a specific focus of my own choice. Being deeply involved in the Work & Safety project (c.f. chapter 2.4) combined with my cultural interest of studying cultural similarities and differences, I chose to focus on and observe the same subject as the Work & Safety project i.e. the link between social workers work and health issues and their way of managing conflicts in regard to challenging behaviours. Hence I observed the social organization of the Open Door School and the way social workers managed conflicts on the basics of the observation and interview guides elaborated by the Work and Safety project<sup>20</sup>.

While observing the Open Door School I gained a specific interest in institutional management of challenging behaviours and after my return to

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<sup>20</sup> As I have been a part of the elaboration process of the guides as a student assistant, I was fully acquainted with these guides and had as well been given permission to use the guides by the Work & Safety project management.

Denmark, I was determent to make this institutional ethnographic study of the Open Door School. In line with the Work & Safety project my interest was to focus on social workers management of challenging behaviours. However in contrast with the Work & Safety project I was not interested in how challenging behaviours adversely affects social workers health and safety and personally well beings. I was interested in the way social workers understand and manage challenging behaviours in terms of intervention approaches.

With my slightly change of focus a discrepancy among my collected ethnographic fieldwork and the focus of this study arose. Particular a lack in interviewing the social worker about how they understand and what they believe causes challenging behaviours. To deal with this discrepancy I travelled back to the Open Door School in spring 2011 to collect further qualifying data in regard to the focus of this study. Thus in the terms of collecting data for this study, the data has been collected during two visits to The Open Door School. First visit as an intern in spring 2010 and second visit during a private visit to India in spring 2011. My mainly ethnographic fieldwork has been carried out during my three months internship at the Research Division in spring 2010. During my second visit I re-observed the Open Door School for 6 days and re-interviewed my informants in regard to the research questions of this study. Data collected during both my visits are being used within this analysis.

#### ***4.7.2 Ethics***

A consideration of the ethical implications of ethnographic research and representation should underpin any research project (Pink, 2007). In terms of getting access and doing ethnographic fieldwork at the Open Door School, the access was given through the Research Division where I was placed as an intern. To conduct research and get access to the Open Door School required a letter of interest and a full application in terms of a research proposal. These applications were to be reviewed and approved by the Institutional Review Board of the Research Division to ensure that the project met the important ethical standards and was based on a sound theoretical background. My

applications for doing ethnographic fieldwork as an intern on the basis of the Research project (appendix 9A) got approved by the Institutional Review Board. Likewise did my second application for collecting further data in terms of the focus of this study (appendix 10A).

According to Spradley it is important to explain the informants what ethnographic field work is (Spradley, 1979). My ethical approach towards the social workers at the Open Door School was to be open about who I am and what I was doing at the Open Door School. Hence, on the very first day as I entered the Open Door School, I introduced myself for the staff at the daily staff meeting. I not only introduced myself personally, but also I explained and describe what ethnographic fieldwork is, what the focus and purpose of my study is. I explain that I was at the Open Door School to observe and interview their way of working in regard to managing challenging behaviours. I particular made it clear that my study was based on a voluntarily basis. This meant that it would be okay for anyone to say no for me to observe them in their particular classes or interview them. I also made it clear that no names would be mentioned in the finally report and this finally report would be available for them to read. I selected this overtly role in collaboration with the Director of the Research Division<sup>21</sup> who wanted the social workers to be aware of why I as a foreigner was at the Open Door School. Further ethical reflections are to be read in appendix 1.

#### ***4.7.3 Informants and engagements***

According to Spradley, ethnographic researchers work together with informants to produce a cultural description (Spradley, 1979). Informants provide a model of the researcher to imitate. In fact an ethnographic researcher hopes to learn to use the native language and acts as the informants do (Spradley, 1979). The informants are according to Spradley ‘...a source of information; literally, they become teachers of the ethnographers’ (Spradley, 1979:25).

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<sup>21</sup> Same procedure happens during my second visit. I explained why I was back, my change of focus and that all studies are done on a voluntarily basis.

The Director of the Research Division was my gatekeeper in terms of getting in contact with and in terms of selecting what Spradley calls 'productive informants' (Spradley, 1979). Not everyone makes according to Spradley a good informant and hence, the challenges were to select informants who could teach me the culture of the Open Door School (Spradley, 1979). In this process, there was one certain criterion to be conscious about. The informants had to be a social worker with a diploma in Special Education as well as a mother of a child with ASD. At the Open Door School there are few social workers employed who are not mothers or fathers of a child with ASD - these were deselected.

Another essential criterion was the language. In doing ethnography, language plays an important role and enters every phase of the research project (Spradley, 1979; Hammersley, 2007). Language structures our field notes and enters in every analysis and insight. Language permeates our encounters with informants and the final ethnography takes shape in language (Ibid.). Language is according to Spradley, more than '...the means of communication about reality: it is the tool for constructing reality' (Spradley, 1979:17. It is the tool for description (Ibid.).

Travelling to a distant country a researcher must deal with at least two languages – their own and the languages spoken by the informants (Spradley, 1979). Travelling to India I had to deal with my natively speaking language, Danish and the official spoken language at the Open Door School, English<sup>22</sup>. Speaking English fluently collecting data in English has not been an issue for me. However, even though English is one of the official languages<sup>23</sup> spoken in India, English was not the spoken language among the social workers at the Open Door School. It turned out that the social workers either spoke English fluently, spoke it brokenly or neither spoke or understood English at all. To avoid a language barrier between me and the informants, the director and I

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<sup>22</sup> Websites, teaching materials, general information, schedules and visuals for the students were all written in English. In the relation between the Social workers and the students the spoken language was mainly English.

<sup>23</sup> In India the official spoken languages are Hindi and English.

negotiate five social workers and classes to observe and to interview formally throughout my internship as well as my second visit. Thus the social workers selected as informants for this study were all educated social workers as well as mothers with a child with ASD; they either spoke English fluently or brokenly, they were all class teachers of one of the six classes at the Open Door School and they have all voluntarily accepted to become informants and hence be a part of this study.

When doing ethnographic fieldwork it is essential for the researcher to establish, maintain and sustain a good relationship with the informants (Spradley, 1979). Where participant observation is involved the researcher must find some role in the field being studied. This will usually have to be done at least through implicit, and probably also through explicit, negotiation with the people in the field (Hammersley, et al., 2007, Spradley, 1979). Access may need to be secured through gatekeepers, but it will also have to be negotiated with the people being studied (Spradley, 1979; Hammersley et al., 2007).

Throughout my fieldwork I have tried to be conscious about my way of relating with the informants and have with every social worker negotiated my role as a participant observant. As a consequent of being short of staff all social worker's had an expectation off me to fully participate as a participant observant. Hence, in terms of maintaining my good relation with the informants, my role at the Open Door School has been fully participation. Fully participation means, according to Hammersley, that I have participated and been doing the work like any other staff member in the class rooms at the Open Door School (Hammersley, 2007). To read more about my role as a participant observant see appendix 5.

#### ***4.7.4 An open – ended study***

In accordance to institutional ethnography my approach for collecting data was an open-ended undertaking in terms of observing and interviewing to learn 'first handed' how social workers managed challenging behaviours at the Open Door School (Smith, 2005). Despite my open – ended aspect for collecting data, I did

use the observational guide elaborated in accordance to the Work & Safety project and likewise I did set up a thematically guide for interviewing the social workers during my second visit. I used the observational guide and made the interviewing guide to validate the study i.e. that I through my method of institutional ethnography investigates what this study is purport to investigate (Kvale et al., 2009). Accordingly this study is built on an awareness that this study is not to be reproduced or generalized, as the interactions I have had with the informants, are not to be replicated (Kvale et al., 2009). However, to make the most consistent, trustworthy and reliable study as possible, I try to describe my methodologically way as transparent as possible for the reader to judge my footing in terms of collecting data. In the following the components of observing and interviewing will be outline.

#### ***4.7.5 Interviewing***

Interviewing in institutional ethnographic fieldwork range widely from spontaneous informal causal conversations to formally arranged meetings (DeVault & McCoy in Smith, 2006). In institutional ethnography interviewing also takes up an open-ended inquiry better described by Smith as 'talking with people' (Smith, 2006). Through 'talking with people' an institutional ethnographic researcher use informants' accounts not as a window to the informant's inner experience, but in order to reveal the 'relation of ruling' that shape experiences (Smith, 2006). Hence it is through informant's stories and descriptions that I can identify the trans-local relations, discourses and institutional work processes that are shaping the informants everyday work (DeVault & McCoy in Smith, 2006). In the process of collecting data in form of interviewing I have made use of both causal conversations and formally interviews.

My purpose for interviewing was to identify how social workers at the Open Door School believes challenging behaviours is to be understood, defined and ought to be managed. Likewise to identify their belief in what causes the reason why people with ASD display challenging behaviours. To make this

identification I developed, an interview guide elaborated on the theoretically basics of Emerson's four fundamental factors for understanding social processes that makes an institutional settings. The four factors and the interview guide developed have been in my mind throughout my observational time and are to be read in appendix 3.

As my approach for collecting data undertook an open-ended aspect, the interview guide was not used as a tightly structure for an informal interview. The interview guide was developed with references to Kvale as so called thematically research questions formulated in line with the theoretically language of Emerson (Kvale et al., 2009). Formed as thematically questions, the questions were not formulated as interviewer questions ready to question the informants' - few suggested questions were made. However, setting up thematically questions gave me, according to Kvale, the possibility to obtain rich and varied information by approaching the theme from different angles (Ibid.). It also gave me the possibility to ask thematically questions doing casual conversations doing the everyday work. This happened often and is, as mentioned, a part of doing ethnographic field work.

Overall, my way of interviewing has been an ongoing process throughout my observational period. While observing my informants I have continuously asked my informants research questions based on my interview guide and I have continuously asked new and more structural and contrast questions from different angles to confirm that my understanding and conclusions were consistent (Kvale, et al. 2009; Spradley, 1979). However thematically questions not answered or understood doing the observational time were taken up doing the formal interviews in the end of my observational period. Hence, thematically research questions asked before informal interviews were either discussed further doing formal interviews or not discussed. It all depended on the qualitative and extension of the casual conversations I had made during my time of observing.

Methodologically, both my casual conversations and formal interviews are built up as ethnographic interviews. With references to Spradley' and Kvale'



definitions of doing ethnographic interviews, I have encourage my informants to describe as precisely as possible what they experience and how they act and why the act as they do in accordance to managing and understanding challenging behaviour (Kvale et al, 2009; Spradley, 1979). All formal interviews have been recorded on my iPod and subsequently transcribed word by word into text by myself. Informal interview in terms of casual conversations have been described and written down as ethnographic field notes.

#### ***4.7.6 Observing***

The purpose for my observations was to identify the organizational structure of the Door School i.e. to identify the everyday work, organizational structure and intervention approach of the Open Door School in relation to how social workers manage challenging behaviors. More specifically, to identify which contextual and culturally factors affected the choice of intervention approach and to identify whether there were any link between the intervention approach and the way social workers belief challenging behaviours are to be understood and managed.

The observation guide of the Work & Safety project has, as mentioned, been the overall framework of my observations. However, because the observation guide of the Work & Safety project embraced part that was of no relevance of this study, I developed my own observation guide before returning to the Open Door School in 2011. This means the observations made during my internship were made by following the whole framework of the Work & Safety guide (appendix 8) and the observations during my second visit took set in my own developed observation guide. I elaborated my own guide by combining the four factors of Emerson (like the interview guide) and with the elements from the Work & Safety guide I found appropriated. The observation guide is to be studied in appendix 4.

However, in accordance with the Work & Safety guide, I took on the role as a participant observant to 'shadow' the individual informants for a certain time of period to namely observe how the individual managed challenging behaviours

as well as learned how challenging behaviours were thought to be managed. To 'shadow' the informants implied a lot of consideration and reflections in terms of my own acts. My reflections regarding my footing as a fully participant observant are to be read in appendix 5.

#### ***4.7.7 Ethnographic notes***

Field notes are the traditional means in ethnography for recording observational and interview data (in this study causal interviews which have not been recorded) (Hammersley, 2007). Field notes are originally handwritten notes covering the problematic of the study (Ibid.). According to Spradley there are different kinds of field notes and hence, each researcher will develop a unique way in accordance with the setting the fieldwork occurs and the role taken by the researcher (Hammersley et al, 2007; Spradley, 1979).

Having to fully participate as an observant gave me a lot of challenges in writing field notes as it was not possible to write everything down that goes on or everything that informants said. Not having time to write down field notes shortly after any observations my kind of field notes became what Spradley calls the condensed account (Spradley, 1979). This mean I always carried pen and paper in my pocket to write down phrases, single words, and unconnected sentences. As soon as possible after each field session I would fill in details and recall things that were not recorded on the spot. In other words, I used my condensed notes to write, according to Spradley, expanded field notes with fully details (Spradley, 1979). See appendix 6 for further descriptions.

#### **4.8 Data overview**

All in all, data I have collected in forms of observations, interviews and photo' have been converted into text – written words and constitutes my analytical material for answering the research questions. For the reader to get a clear overview of the total data, see table 1 for a data overview.

<b>Data collected at the Open Door School</b>	<b>Spring 2010 (Internship):</b>	<b>Spring 2011:</b>	<b>Data converted into text</b>
<b>Observations</b>	<p>1 week participant observation in the respective four classes where my informants were the class teachers.</p> <p>Each class consists of app. 6 students and all students display 'challenging' behaviours in some ways.</p>	2 days follow up observations in the same classes as in spring 2010.	Ethnographic field notes
<b>Interviews</b>	<p>Causal conversations</p> <p>One formal interview with one social worker</p>	<p>6 formal interviews with social workers</p> <p>1 formal interview with Merry Barua, the founder of the Open Door School and Director of the National Centre for Autism.</p>	<p>Transcribed interviews</p> <p>&amp;</p> <p>Ethnographic field notes</p>

**Table 1: Data overview**

The amount of formal semi-structured interviews in this study is altogether seven – six interviews with the social workers I have been observing and one interview with Merry Barua, Founder of the Open Door School and Director of the Indian National Centre for Autism. In addition to the collected data I do use documents to verify public policies and the institutional philosophy of the Open Door School. When documents are used it will be mentioned within the analysis.

Three of the social workers have been interviewed after observing them for two days and the three interviews have been arranged separately after finishing my observations. The interviews have all taken place in the classroom after the

children's have taken of from school or in the Library of the National Centre. During some interviews trainees and caregivers have been present in the classrooms doing other work, but not commenting on the questions asked or the statements said. Throughout my observational time it was a challenge to find time and nevertheless room to fulfill formal interviews as all classrooms and others throughout the day were occupied with other intervention programmes etc. However interviewing the two directors took place in a quiet room with nobody else present.

I have been given permission of Merry Barua to mention her name and quote her sayings (IF). Merry Barua is one of the three mothers who founded the Open Door School and is today director of the Open Door as well as the National Centre for Autism. The six social workers appear anonymous.

#### **4.9 The Analysis**

With references to DeVault & McCoy '...there are no 'one way' to conduct institutional ethnography investigation; rather, there is an analytic project that can be realized in diverse ways' (DeVault & McCoy, 2002: 755). The only main analytic notion to hold on to is the idea of social relations as the heart of the analysis (Ibid: 85). Hence, getting to a written account that explicates the actually social relations of a setting is the analytical work in institutional ethnography (Ibid.).

The analytical work in institutional ethnography is what Smith calls for interpretation. Interpretation is the analytically process '... for finding conceptual links in order to make sense of the data' (Campbell & Gregor, 2004: 98.) and is disciplined first by the analytical framework of social organization of knowledge (the analytical 'tool' of social relations and the notions of ruling relations) and then by the materiality of the data (Campbell & Gregor, 2004). 'But when it comes to interpreting data, institutional ethnography relies on, explores and explicates linkages that are lived, brought into existence in time and space by actual people doing actual things' (Ibid.:98). In terms of explicating the linkages / the social relations the researcher must, according to Smith, 'map them'

(Campbell & Gregor, 2004). In institutional ethnography a map is essential as it should assemble and visualize the linkages of the trans-local social relations that are positioned differently but together constitutes the social organization and social knowledge of a particular setting (Smith, 2005). To draw up a map of the social relations allows according to Smith, the analysts to identify how things are organized and how people's lives are ruled (Ibid). A written analytical account in institutional ethnography involves in other words an interpretation and '...map' that can serve as a guide through a complex ruling apparatus' (DeVault & McCoy, 2002: 754; Smith, 2005).

As mentioned I consider Smith's interpretation process synonymous with the interpretation process of the hermeneutical circle (c.f. chapter 4.3). Hence, I make use of Gadamer's hermeneutical circle to grasp the meaning of how the contextual and culturally factors constitutes social workers understanding and management of challenging behaviours. The hermeneutical circle is an analytical tool where the researcher's understanding of the text i.e. the data collection as a whole is established by reference to the individual parts and the researcher's understanding of each individual part by reference to the whole (Schmidt, 2003). Neither the whole text nor any individual part can be understood without reference to one another, and hence, the interpretation process becomes a circle (Ibid.). So through the iterative process of the hermeneutical circle, I explore the local and trans-local processes to develop an understanding and meaning of how the social organization and work is concerted at the Open Door School and how the social workers are ruled in terms of understanding and managing challenging behaviours.

#### ***4.9.1 Analytical strategy***

My analytical strategy for explicating and writing up my analytical account is divided into two parts.

The first analytical part, The Discursive Practice, explicate the everyday work processes of how social workers understand and manage challenging behaviours at the Open Door School. This analytical part forms the foundation

for interpreting and explicating how contextual and cultural factors which surround the Open Door School have affected social workers understanding and management of challenging behaviours.

The second analytical begins with an introduction of the map, the Social Context of the Open Door School. This map is the map I have in terms of institutional ethnography drawn up to visualize the linkages of the individual contextual and cultural factors that together constitute the trans-local relations that affect how social workers at the Open Door School understand and manages challenging behaviours. Based on the analytical tool of the hermeneutical circle I explicate how each individual contextual and cultural factor together have affected social workers understanding and management of challenging behaviours.

Throughout the second analytical part I embed my reflections upon my own cultural premises for understanding and managing challenging behaviours. In terms with Gadamer my reflections identifies my social history and thus my pre-judgment and fore-understandings for interpreting and mapping the Open Door School. Throughout the second analytical part I also embed the theoretical perspectives of Honneth and Foucault.

## **5.0 Theory**

In this chapter Honneth' theory of Recognition and Foucault's theory of power/knowledge will be outlined. I use Honneth to identify the social critique of the social movement of mothers of children with ASD. I use Foucault to identify and discuss how knowledge within a discourse shapes the power relations between social workers and people with ASD. The theories will be described shortly followed up by a discussion of the different ontologies of Honneth and Foucault is made.

## **5.1 Alex Honneth – The struggle of Recognition**

The German philosopher Alex Honneth has developed the theory 'Struggle of Recognition' which is a critical, normative social theory about the human need of recognition (Honneth, 1996). Honneth considers recognition as vital for every individual's self-realization of self-confidence, self-respect and self-esteem to obtain the good life (Honneth, 1996). In fact he considers recognition of every member of the society as a precondition to obtain a fully integrated and sustainable society (Honneth, 2003). However, Honneth's work is not just a theory about individuals identify-formation and having their broadly 'moral' expectations violated (Anderson in Honneth, 1995). It is also a theory regarding the society and its conflicts, development and stability which is the part I make use of in this study (c.f. methodological reflections). Honneth's theory is a continuation of Frankfurt School's attempt to locate the motivating insight for emancipatory critique and struggle within the domain of ordinary human experience (Ibid.). In accordance to Honneth the society is founded on a normative ideal and hence, he follows the normative ideal of the critical theory, i.e. the intersubjective relationships already exist (*are*) within the frames of the modern society and can at all the time be transcended to a new idealized level in terms of what (*should*) be characterized as more justified (Honneth, 1995). (See Appendix 12 for further description)

## **5.2 Michel Foucault – Power/knowledge**

The French philosopher Michel Foucault was one of the most influential thinkers in the contemporary world (Heede, 2007). As a philosophical historian and an observer of human relations, his work focused on the dominant genealogical and archaeological knowledge systems and practices, tracking them through different historical eras, including the social contexts that were in place and that permitted change - the nature of power in society (Foucault, 1977; Heede, 2007).

In Foucault's early archeological phase the subject is reduced to a function of discourse which means an individual unconsciously is governed by the rules of the systems and thoughts that exists within a given historical domain and period (Jørgensen & Phillips, 1999). In this early phase Foucault covers the rules for which statements there are bound to be meaningful and true with a particular discourse (Ibid.). Thus, Foucault takes up the premise as a social constructionist, i.e. that knowledge is not a reflection of the reality, but a discursive construction as every discourse has its own regime of knowledge (Ibid.). The purpose for Foucault is, in this early phase, explicitly to identify how the structure of a discourse is governing what is to be said within a regime of knowledge and nevertheless what is unlikely to be said (Heede, 2007).

Particular Foucault's writing on power, knowledge and discourses in his late genealogical phase has been influential in academic circles (Heede, 2007). In this late phase Foucault believed that freedom is understood as the power to question what is currently taken for granted, plus the capacity to change oneself and, perhaps, one's milieu (Heede, 2007). Foucault stated that power '...reaches into the very grain of individuals, touches their bodies and inserts itself into their actions and attitudes, their discourses, learning processes and everyday lives' (Foucault 1980:30). He believed that knowledge is always a form of power, but he took it a step further and told us that knowledge can be gained from power, producing it, not preventing it (Foucault, 1977).

In Foucault's view, knowledge is forever connected to power, and he often wrote them in this way: power/knowledge (Heede, 2007). Foucault's theory states that knowledge is power:

*'Knowledge linked to power, not only assumes the authority of 'the truth' but has the power to make itself true. All knowledge, once applied in the real world, has effects, and in that sense at least, 'becomes true.' Knowledge, once used to regulate the conduct of others, entails constraint, regulation and the disciplining of practice. Thus, there is no power relation without the correlative constitution of a field of knowledge, nor any knowledge that does not presuppose and constitute at the same time, power relations' (Foucault 1977:27).*



For Foucault power exists everywhere and comes from everywhere, and was a key concept because it acts as a type of relation between people, a complex form of strategy, with the ability to secretly shape another's behaviour (Heede, 2007). However, Foucault did not see the effects of power as negatives that exclude, repress, censor, mask, and conceal, but rather, as a producer of reality: "it produces domains of objects and rituals of truth" (Foucault 1977:194). The importance for Foucault always lay in the effect that power has on entire networks, practices, the world around us, and how our behaviour can be affected, not power itself (Heede, 2007). In view of Foucault, it is not possible to reach the universal 'truth' as you cannot speak from a position outside the discourses (Foucault, 1977). Effect of 'the truth' is shaped within discourses (Foucault, 1980).

Even though Foucault stresses that 'the truth' is shaped by the power/knowledge of a discourse, Foucault also stresses that discourses operates by 'rules of exclusion' i.e. what is prohibited for subjects to say. Subjects are controlled in terms of *objects* (what can be spoken of), *rituals* (where and how one may speak), and *the privileged or exclusive right to speak of certain subjects* (who may speak). In the Discourse on Language (1971), Foucault more specifically explicates that 'rules of exclusion' i.e. to oppose the power/knowledge of the discourse creates a fear to speak about the discourse, a fear for exclusion (Foucault, 1971; Høgsbro, 2009). In accordance to Høgsbro, Foucault introduces an existential dimension where we as subjects are placed between discourses and thus faces an existential choice of whether to be institutional accountable or to oppose 'the truth' of the discourse and thus abolish the order of the discourse - an existential choice between inclusion and exclusion (Høgsbro, 2009).

The subject is according to Foucault objectified through the discourses and hence he does not ask – in contrast to Honneth - the universal question of 'who am I', as a unique ahistorical individual. He asks the questions 'what am I', as a historical product (Anderson in Honneth, 1996). In accordance to Jørgensen &

Phillips we may say that Foucault reject the widely believe of the western world, that the subject is an autonomous and self-determining entity (Jørgensen & Phillips, 1999).

### **5.3 Honneth & Foucault – a discussion**

As the ontology<sup>24</sup> of Honneth's and Foucault's theories differs from each other, I will in the following discuss these differentiated ontologies. The discussion is essential as Foucault is social constructivist of thinking and Honneth theory is a social theory as well as a scientific theory within the field of critical theory. Critical theory is a social theory oriented toward critiquing and changing the society as a whole (Honneth, 1995). The critique of the social actuality is anchored on a normative ideal which is founded on the idea of people's inherency of the emancipatory interest (Honneth, 2003). Honneth's normative ideal is recognition and the moral forms of violations in the three spheres of recognition constitute the heart of the justification and argumentation for the social critique of the societal conditions (Ibid.). As the theory of recognition can not only be determined by legal criteria, Honneth's criterion of social philosophy is ethical (Honneth, 1995).

The ontology of Honneth's is based on the fact that an actual historical world exists independent of our theories of this and hence, Honneth argues, that recognition is the universal condition for developing a successful identity (Honneth, 1995). People's ability to act as a social individual in an actual world dependent on recognition is the basis for autonomy and individuality (Ibid.). Autonomy and individuality is according to Honneth established in the mutual relations between to individuals and in terms of Honneth's subject position - a subject is 'shaped' in the mutually relations between two individuals (Ibid.). Thus Honneth's ontological view is that an individual is 'brought' into an actual historical world, where the identity of an individual is developed in the mutual relations with the surrounding world (Honneth, 1995).

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<sup>24</sup> The nature of being, existence and reality.

As mentioned Foucault deems the discourse to be the one which objectifies the subject. The subject has no basis in itself as it is 'decentered' by the existing discourse (Heede, 2007). Foucault perceives the actual world subjected to historical processes, which means, that the subject is reduced to the function of the discourse (Heede, 2007). In contrast to Honneth, Foucault's view is that an actual historical world does not exist. The reality is a construction (Foucault, 1977). For Foucault the subject - or you may say, the body of the subject - is perceived as an empty 'frame' where diverse historical events inscribe themselves (among this language and patterns of imaginations) (Heede, 2007). Within the ontology of Foucault the subject does not have a natural existence in the real world. The subject is a specific size as it is shaped and produced by the surrounding world / discourses it enters (Heede, 2007). In other words, when an individual enters a particular discourse he or she is subconsciously being objectified by the discourse and concurrently shaped as a specific subject (Foucault, 1980). Thus, it is the discourse which speaks objectively through the subject, and it is the discourse which appeals to the individual as subjects (Heede, 2007).

Power is according to Foucault the ontologically fundamental basis of the society (Foucault, 1980). It means that acts power other acts. Hence a society without power or relations is seen by Foucault as an abstraction (Heede, 2007). Power is in other words the ruling of other people's possibilities which unfolds in endless chains of unequal and mobile relations (Foucault, 1980). For Foucault 'the truth' of people's reality is not a prerequisite for people's emancipation - it is the object of research (Heede, 2007).

Ontologically, Honneth takes set in a subject – subject relation where the subject is 'shaped' through its mutual relations with other subjects from the surrounding world (Honneth, 1995). In contrast to Honneth, Foucault takes set in a subject - object relation. In Foucault's perspective subjects are being objectified by the ruling regime of truth which sets up the framework for what is possible for individual subject to say and act (Jørgensen & Phillips, 1999). Thus, the ontologies of Honneth and Foucault take set in two different perceptions of

the reality as well as individual's social position in the modern society. Consequently of their different ontologies they also take set in two different forms of epistemology.

Despite the different ontologies of Honneth's and Foucault's I do not find it problematical to apply Honneth's theory of recognition in association with Foucault's theory of power/knowledge. You may say that Honneth with his framework of self-realization sets up a social structure for recognition. A structure we can use within any particular discourses as Honneth is not interested in the contextual content of the good life. Thus, I use Honneth's social structure for recognition in what Foucault calls two independent discourses - The Open Door School and my Danish context - with each their regime of truth. This despite the fact there is no space for Honneth's normative ideal of recognition in the universe of Foucault where everything is a matter of power and power relations.

## **6.0 Mapping the Open Door School**

The analytical description is divided into two parts. The first part, the Discursive Practice, identifies the intervention paradigm that constitutes the norms and standards for how social workers understand and manage challenging behaviours at the Open Door School. The Second part, The Ruling Relations of the Open Door School, maps how the trans-local contextual and cultural factor that surrounds the discursive practice are linked together and accordingly affects social workers understanding and management at the Open Door School.

## 6.1 The Discursive Practice

My starting point in terms of mapping the discursive practice of the Open Door School begins with the following ethnographic note that describes how Jack<sup>25</sup>, a higher function student with ASD is displaying aggressive challenging behaviours.

*I was walking in the hallway between the office and library when Jack, one of eldest students at the school, approached me with Jill (social worker) walking right behind him. As he passed me, he started hitting me with his left hand. Jill came from behind instructing Jack by saying 'hands quiet' while grabbing Jacks hitting arm. Jack stops hitting me. Instead he grabs the t-shirt of Jill with both his hands. Jill repeats herself, 'hands quiet', while holding on to the arms of Jack for him to let go of her t-shirt. I put my hands on the top of Jacks hands for him to let go of the t-shirt. Jill keeps repeating herself by saying 'hands quiet'. After a while Jack lets go of the t-shirt and accordingly Jill and I loosen our grips of Jacks hands. Jack asks for something in another language than English and Hindi. Jill replies in English asking him what he wants. Jack asks for something particular in Hindi. Jill replies to Jack that, that is something he has to ask his parents for. Afterwards Jack says that he wants to go home. Jill replies that she wants to speak to him, when he has calmed down. She asks him to go and sit at the stairs 20 meters behind. Jack does not act and Jill repeats herself after where Jack moves towards the stairs and sits down. Jill follows Jack. As she stands by the stairs she repeats herself saying: 'I want to talk to you, when you have calmed down. Count to 20'. Jack repeats that 'I want to go home'. Jill starts counting 1, 2, etc. Jack follows until the number of 8. Jill repeats herself: 'I want to talk to you when you have calmed down'. Jack counts to 20. Jill asks Jack whether he has calmed down. Jack says yes. Jill asks what he wants and listens to Jacks request and reply Jack by saying: 'that is something you have to ask your parents for'. Jack keeps his sitting position on the stairs. Jill says to Jack, 'it is time to go to class to check schedule and continue class. Are you ready to go to class?' Jack asks for more but after a few minutes he agrees to*

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<sup>25</sup> All names throughout the analytical description have been changed.

go to class to check schedule. Jack gets up and starts his walk towards the classroom. In a quick move Jack changes his direction and runs towards the waiting room in the reception area where his mother sits. While Jack sat on the stairs Jill had asked me to go to the reception area to ask the mothers in the waiting room to lock the reception door from the inside. When Jack reached the reception door, the door was locked. He hammers his knits on the door and shouts 'open it, open it' repeatedly. In the meanwhile, Jill grabs a pen and paper in the office area. She writes on the paper 'go to class and check schedule'. After a short while Jack stops hammering the door and runs out of the front door towards the entrance gate. Jack tries to pass the security guard who stands in front of the gate by hitting him with his hands. The guard holds his position. Jill approaches Jack and gives him the paper she wrote in the office. Jack takes the paper and reads it loudly: 'go to class and check schedule'. After reading the paper he repeats 'I want to go home'. Jill repeats herself too: 'you have to go class to check schedule to see when you are going home'. Furthermore she says that she wants to talk to him when he has calmed down and he has to go to the stairs and sit down. After a few minutes Jack walks back to the stairs and sits down. Jill asks him to count to 20 which he does straight away. While he sits on the stairs Jill writes a new paper with the instruction that he has to go to class to check schedule to see when he is going home. Jack reads the paper loudly. After reading the paper Jack says that he wants to go to class to check schedule. Jill repeats his words and asks Jack the question: Are you ready to go to class to work? Jack says 'yes'. Jill asks him to stand up and go to class. Jack stands up and walks to his class. He checks his schedule and begins his next lesson.

Accordingly I spoke to Jill about what had happened since Jack was upset. Jack was upset because he was one hour late for school due to a horrible traffic jam. He had arrived at 10 o'clock and had missed two lessons which frustrated him. In his frustration, he wanted to hit his mother who sat in the waiting room in the reception area (EN).

Jack displayed one among a various type of challenging behaviours which social workers at the Open Door School are facing in their daily relation with the students. The situation can be analyzed from different perspectives and hence, I will throughout this analytical description refer back to the situation with Jack. Based on the situation with Jack, I jump into the identification of which intervention approach Jill is referring to in her management of the inappropriate behaviours Jack displayed.

### ***6.1.1 Structured Teacching***

Throughout the situation with Jack, Jill is instructing Jack to calm down by using few verbal prompts and written visuals. She uses the verbal prompt and written visuals to instruct Jack go back to class to check schedule and thus follow the structure of his daily schedule. Using written visuals and using the term 'check schedule' are intervention instructions referring to the intervention method of Structured Teacching.

Structured Teacching is an intervention approach developed by Eric Schopler in the late 1970s and is administrated by the TEACCH<sup>26</sup> Division of the University of North Carolina at Chapel Hill in the United States. The TEACCH program is an evidence-based service, training, and research program for individuals of all ages and skill levels with ASD. The program is built on research and experience that indicates that people with ASD are predominant visual learners and that structure fits the 'Culture of Autism' (Action for Autism, 2008; Schopler et al., 1995). "Culture of Autism" is a concept TEACCH developed for understanding the characteristic patterns of the behaviours of individual with ASD as well as the way individual with ASD are seen to think (Schopler et al., 1995; [www.teacch.com](http://www.teacch.com)). More specifically the TEACCH program defines the 'Culture of Autism' as ([www.teacch.com](http://www.teacch.com)):

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<sup>26</sup> Treatment and Education of Autistic and related Communication handicapped Children's

- Relative strength in and preference for processing *visual* information (compared to difficulties with auditory processing, particularly of language)
- Frequent attention to *details* but difficulty understanding the meaning of how those details fit together
- Difficulty *combining* ideas
- Difficulty with *organizing* ideas, materials, and activities
- Difficulties with *attention*. (Some individuals are very distractable others have difficulty shifting attention when it is time to make transitions)
- Difficulty with concepts of *time*, including moving too quickly or too slowly and having problems recognizing the beginning, middle, or end of an activity
- *Communication* problems, which vary by developmental level but always include impairments in the social use of language
- Tendency to become *attached to routines*, with the result that activities may be difficult to generalize from the original learning situation and disruptions in routines that are upsetting, confusing, or uncomfortable
- Very strong *interests and impulses* in engaging in favored activities, with difficulties disengaging once engaged
- Marked *sensory* preferences and dislikes

The long-term goal of the TEACCH programmes is both skill development and fulfillment of fundamental human needs such as dignity, engagement in productive and personally meaningful activities, feelings of security, self-efficacy, and self-confidence ([www.teacch.com](http://www.teacch.com)). The dual goal means that the TEACCH programmes has a dual functioning i.e. teaching skill development such as academics and vocational skills and socially supporting the needs people with ASD have to be fully included within the institutional setting as well as the society. To accomplish these long-term goals, TEACCH developed the intervention approach called 'Structured TEACCHing'.

In terms of managing challenging behaviours, the intervention strategy of Structured Teacching does not work directly on challenging behaviours, but



addresses challenging behaviors in a proactive manner by creating an appropriated physically Structured Teacching environment that reduces the stress, anxiety and frustration which people with ASD may experience (Ibid.). To reduce the stress people with ASD may experience, the philosophy of Structured Teacching is to create a physically structured teaching environment that accommodates the needs of students with ASD i.e. make the daily activities predictable for the individuals with ASD to understand what he or she is expected to do and what is going to happen next (Action for Autism, 2008; Schopler et al., 1995).

In accordance with the principles of Structured Teacching, the following four components form a physically structured teaching environment (Schopler, 1995). In an analytical perspective, the components form the identification of whether an institution makes use of Structured Teacching as an intervention method for teaching children's with ASD. The four components are:

1. *Physical organization.* Physical organization refers to the physical layout of the classroom or the area for teaching. Physical organization helps or hinders a student's independent functioning and his recognition of and compliance with rules and limits. It is designed to provide students with visual information to direct their activities in a predictable manner (Ibid.).

2. *Scheduling.* Since students with ASD have problems with sequential memory and organization of time, they need schedules. Visual schedules let the students know what activities will take place and in what sequence and assist them in predicting events, lessening their anxiety (Schopler et al., 1995).

3. *Work systems.* Students with ASD have problems in organizing activities and work independently. To learn student's with ASD to work independently. Work systems refer to the systematic and organized presentation of tasks/materials in order for students to learn to work independently, without instructions/prompts. Work systems tells the students what activities must be completed in independent work areas by visually specifying what and how much work must

be done and indicating when each task and the work session are completed (Schopler et al., 1995).

4. *Task organization.* Similar to work systems, task organization determines what work students should do independently, what needs to be done within a task, how many items must be completed, and final outcomes (Schopler et al., 1995).

By setting up a physically structured teaching environment for people with ASD the intervention approach of Structured Teaching believes that visual support helps people with ASD to express their needs and feelings by means other than challenging behaviour (Ibid.). A physically structured teaching environment reduces, in according to the philosophy of Structured Teaching, the stress of people with ASD by giving them the possibility to express themselves through visuals and thus prevent and decrease challenging behaviours. By setting up a physically structured teaching environment for people with ASD and help the student's to express themselves structured teaching is an intervention approach that provides compensational support related to the specific deficits of ASD and thus reduces the stress of people with ASD and prevents as well as decrease challenging behaviours.

#### ***6.1.2 Social Workers Management of Challenging Behaviours***

When I entered the Open Door School in March 2010, it was observable that the Open Door School practices the principle of Structured Teaching and that Structured Teaching is the intervention approach that constitutes the everyday work processes at the Open Door School. I observed that the physically organization was systematically structured.

*'...each classroom is systematically divided into different work areas marked with visual cues that illustrate the use of the work areas such as: work on your own-, play-, group-, tiffin-, teacher's area etc. Also in each classroom, each child have an individual schedule that visualizes the daily structure of the child'*

*lessons and activities i.e. computer-, sensory-, art-, and vocational lessons as well as the child's work time; play time; tiffin time, etc. Even toilet visit and 'time to drink water' is put into some of the children's schedules. The individual schedules, which are made by written words, visuals or objects depending on the individual's ability, indicates a predictability where every minute and small activity of the day is systematically structured and visualized. Even the common areas of not only the Open Door School, but the entire building of [the National Centre] is systematically structured and marked with visual cues that illustrate the purpose and structure of each area / room. [However] it wasn't just by observing the classroom that it became obvious that the intervention approach is Structured Teaching. When I was introduced to [one of the social worker's, the social worker] explicit said to me that '...here at [the Open Door School] we use Structured Teaching. In fact, we use structure for everything' (EN)*

The physical organization of the Open Door School is in accordance with the principles of Structured Teaching, a structured organization where the use of personally schedules and visuals constitutes social workers work processes in terms of preventing as well as managing challenging behaviours.

*'It is the social worker that instructs the individually child to check schedule. This happens either by given the child the verbal prompt to check schedule or give the child its transmission card without verbally prompts. A transmission card is a written card, visual or object connected with the schedule which indicates that the child has to check schedule i.e. approach its personally schedule to check what to do next. When the child approach its schedule it must first put the transmission card in the folder attached to the schedule before he or she takes the next visual and moves on with the next activity. Does the next visual indicate a computer, the visual instructs the child to walk to the computer room. When the child enters the computer room he/she must match the visual card from the child's personally schedule with the matching folder in the computer room. After matching and putting the visual card into the matching folder in the computer room the child starts its computer lesson. All depending on the abilities of the child, the computer lesson is structured and scheduled with work*

*task the child has to make. When the computer lesson has finished, the social worker gives the child its transmission card and thereby instruct the child to walk back to the classroom to check schedule and move on with the next activity. This process happens repeatedly (EN).*

In accordance with the principles of Structured Teaching the Open Door School makes use of scheduling i.e. visual schedules that structures and predicts the activities of the students. Each child has an individually developed schedule made by words, visuals or object all depending on the ability of the child. The schedule instructs the child what to do in the present moment and what is going to happen next. The schedules form the predictability they need in terms of preventing stress and accordingly challenging behaviours.

The third and fourth principle of the structured teaching, work systems and task organizations, is also a part of the physically structured teaching environment of the Open Door School. Every classroom has work areas where each child has its own work system made with an individually task organization in terms of vocational work, academics, matching games etc. that visualizes how much work the individual child needs to do. The work system and task organization will not be described further as they are not essential in terms of the focus of this study, namely the social support social workers carries out in terms of including children's with ASD in educational activities and accordingly how they manage challenging behaviours. The work systems and task organization are however mentioned for explicating that it is the intervention approach of structured teaching that constitutes and organizes the everyday work processes at the Open Door School.

In accordance with the philosophy of Structured Teaching, the social workers train the children's to express themselves when the educational activities become too challenging:

*S: We give them working or communication skills that help them to relax and make them calm down. This so they know how to communicate with us, and that is important for us because they cannot communicate a proper way. They*

*don't know how to express themselves, so then we give them some ideas or we give them some ways to communicate so they can communicate. All this is a part of improving their communication skills. When they know how to communicate, they don't stress up. If they want a break, they can say 'I want a break' so I need to go out. We teach them that.*

*I: Like you teach them to tell that 'I have finished my work'...*

*S: Yes, or If they need any help. Sometimes they got challenging work and they start hitting or start crying. Then we give them the cards of 'I need help' (ID).*

Besides from practicing the four principles of Structures Teacching social workers learn in line with the philosophy of Structured Teacching the children's to communicate by using visuals card, picture exchange, that enables the children's to express that they either need help with my work, need to go to the toilet, need a break, I have finished my work etc. The communication cards are visual cards marked with symbols that visualizes that I for instance need help. This card, 'I need help', symbolizes two hands reaching towards each other. The communication card of 'I need to go to the toilet' symbolizes a toilet.

The communication cards are placed around the classrooms so they are reachable and visible for the children's or visualized by the social workers, if, the social workers asses that they might need help, need the toilet etc. Then the cards are being shown to the student and the student can take up the card he needs help for. The cards 'I need help card' and 'I have finished my work' are lying on the table when the students are working independently on educational activities or pre-vocational work so those who have learned to use the communication pictures can ask for help when needed. Due to the different functional levels of the students attending the Open Door School not all students manage to use the communications card as a communication system. However those who manage to grasp the function of the communication cards are taught the system as a way of preventing and managing challenging behaviours.

The following quotation verifies that Structured Teaching is the intervention approach that constitutes and organizes social workers way of managing challenging behaviours at the Open Door School – or in the terms of the Open Door School to control the inappropriate behaviours the students display:

*I: Technically, you use structure here at the Open Door School for controlling the behaviours?*

*S: Yes, absolutely. That is the first thing we do. It happens automatically, it is so within us that it happens automatically. So the first thing we do is structuring to avoid behaviours. If there are certain children' who we know, like we know Thomas, we know Joe and we know Daniel. We know they have intense behaviours, we know what could trig does behaviours... so we are kind of preparing them in advance by using schedules, so they know what is up. They know what is happening doing the day, what to follow next or what is expected from them. That is only made by using a lot of structure. So once, a behaviour starts again structure is what we do. Structure is something we always use (IA).*

The quotation clearly indicates that Structured Teaching is the intervention approach social workers at the Open Door School uses to manage or in the terms of the social worker to avoid challenging behaviours. By following the principles of Structured Teaching social workers at the Open Door School work to include children's with ASD within the teaching environment by provide compensating support of their communicative and social deficit. The quotation: 'it is so much within us' indicates that Structured Teaching is an embedded part of the culture of the Open Door School i.e. something they take for granted.

However when a child is displaying challenging behaviours, the actions of the social worker is to make the child follow its personally schedule to make it calm down and thus limit the stress of the child. Following the schedule decreases the stress and anxiety of the child and helps it to calm down and do the activity which is expected of him / her. This is what Jill did in the situation with Jack. She used the principle of scheduling to instruct Jack to go to class to check schedule by giving him basic verbal prompt and written visuals. By giving Jack

written visual and verbally instructions Jack did calm down when he finally shifted his attention from the disruption of his delay to check his schedule and continue his lessons. By using the principle of scheduling Jill supported Jack in transforming his focus from aggressive challenging behaviours to a calm behaviour which made it possible for Jack to attend the educational activities of his schedule.

In terms of institutional ethnography Structured Teaching is the intervention approach that organizes the everyday work processes at the Open Door School and accordingly is the intervention methods social workers at the Open Door School uses to manage challenging behaviours or in their own terms controlling the behaviours of their students. Structured Teaching is in the view of Spradley the acquired knowledge – intervention approach - social workers at the Open Door School use to interpret experiences and generate social behaviour (Spradley, 1979). Structured Teaching is the culture, the shared intervention system of meanings and beliefs social workers at the Open Door School have learned, revised, maintained and defined as the appropriated intervention approach for socially supporting the need of people with ASD to be included in educational activities (Spradley, 1979).

### ***6.1.3 Social Workers Definition of Challenging Behaviours***

In accordance to Emerson social workers define challenging behaviours in respect to the social rules that deems inappropriate behaviours as challenging behaviours (Emerson, 2001). At the Open Door School the social rules for deeming challenging behaviours are very explicit:

*S: You see, any behaviour that is unsafely for the [social workers] and all the students around is challenging...it is indicating, that doing learning it may expand and that is something we won't let them do. So anything that is interfering in learning, anything that is disrupting the entire class room. Anything that is not good for the child or the [social workers] is a behaviour problem (IA).*

Inappropriate behaviours that are unsafely for both the child and staff members around the child and any behaviours that are interfering and disrupting the teaching environment of the classrooms is deemed and label as challenging behaviours at the Open Door School.

*I: What is an appropriated behaviour when you are here [at the Open Door School] and what is a challenging behaviour?*

*S: I prefer to say that appropriate behaviour is something we expect them to do and challenging behaviour are when it becomes difficult to make them learn, make them a good life. Challenging behaviours is something that comes in the way of learning of the child, also in the way of the people ... the mental piece of people in understanding the problems.*

*I: You said that appropriated behaviour is the way we ask them to behave.*

*S: Yes*

*I: Observing the classes and observing your class as well, I have observed that phrases such as: 'Sit down', 'hands to yourself', 'sit smartly'...*

*S: ...that is all acceptable, appropriate behaviours, safety behaviours ... but if somebody is doing this (shaking hands in the air) it is not going to harm the people around him. But many people would not like that happen. Again, we have to put in perspective about how we take the behaviours when they are present in different ways (IB).*

In accordance to Emerson, inappropriate behaviours can only be defined as challenging behaviours within an institution along with the surrounding cultural beliefs and general role expectations (Emerson, 2001). The two quotations explicate unambiguously that social workers at the Open Door School are affected by the culturally intervention belief of Structured Teaching where the expected behaviour of the students is to follow the instructions of their individually schedules and thus not disturb the teaching environment of the class. The social rules for appropriated behaviours at the Open Door School is then to follow the social workers instruction of the schedule the social workers



have set up for each individual child. Does the child not follow its schedule or other instructions given by the social workers the behaviours of the child is deemed and label as challenging behaviours.

In the situation with Jack, Jacks inappropriate behaviours were clearly deemed and label as challenging behaviours in terms of social workers definition of challenging behaviours. Firstly, he was interrupting the classroom and the entire hallway of the National Centre. Secondly his aggressive behaviour was unsafely for me, Jill, the guard and his mother. By unsafely behaviours I mean hitting me, hitting the guard, wring Jill t-shirts near her neck and threatening his mother in the waiting room by hammering the door.

#### ***6.1.4 Social Workers Understanding of Challenging Behaviours***

In extension of the social workers definition of challenging behaviours the question is how the social workers at the Open Door School understand challenging behaviours i.e. what their belief is in regard to the causes of the 'challenging' behaviours the students display (Emerson, 2001).

*I: What do you basically think causes challenging behaviours? Do you think it is attention seeking as you mentioned before?*

*S: I think communication. Some is attention, but I see a great deal is because they cannot communicate. They cannot tell, if, they have a tummy ache. They cannot tell, if, they have a headache. I feel like vomiting, you know. I need or want water. It's too hot. It causes a lot of stress... so I think it is of huge importance that we make them learn to communicate and then attention. Because they do not know how to get attention, I mean, in India and properly also in your country, when someone is throwing a bottle, they will wonder why he is doing this. If the child is bringing the bottle they won't be thinking of it...*

*I: ...people would understand...*

*S: ...yes, and they will not give it attention (IA).*

The social workers basic belief what causes challenging behaviours is the difficulties in communication. As the social worker explicate, the communicative impairment makes it difficult for people with ASD to communicate and having difficulties in communicating evolves challenging behaviours.

*I: What do you think causes challenging behaviour?*

*S: Lack of motivation, social motivation, difficulties in communication and sensory difficulties. These all together gives us difficulties in many ways. Like learning for them, the way of living life, living life in respect of other people. Not in respect for them only, but also for the people living with them. Because, if, it becomes difficult for them that is challenging behaviours [for us]. Communication is the basic for challenging behaviours. Lack of motivation, to teach them what you want them to learn is very difficult. Those behaviours are a kind of challenging and those behaviours comes out of the autism.*

*I: When you say difficulties in communication, is that about misunderstanding? Do you think the children's are communicating, trying to communicate to us, something we kind of misunderstand or do you think they just behave because they do not really know...?*

*S: Yes, the kids are impairment in communication. The way they communicate is different from what we do and also difficult for us to understand and many times, if, we understand it is it about attitude. It's about getting attention. They may hit and they may pull your hair. All of this is challenging. Why? Because this is a lack of communication, so it is the communicative impairment that is difficult for them. They are communicating, but their ways of communicating is not appropriated to us, to the world (IB).*

The social workers belief in what causes challenging behaviours is explicit communication problems as well as lack of motivation and sensory issues. However, the communicative deficit, the core feature of ASD, is the basic cause social workers at the Open Door School explicit believe causes challenging behaviours. It is the communicative deficit in not being able to communicate in

an appropriated manner that is believed to evolve challenging behaviours including attention seeking behaviours.

The social workers belief is explicitly referring to the seventh point of the 'culture of autism' namely communication problems (cf. page X). In line with the 'culture of autism' the social workers believes it is communication problems and accordingly deficiency in the social use of language that subsequently causes challenging behaviours. It means, it is the communication deficit that makes it difficult for people with ASD to express their needs and feelings and it is the communicative deficit that makes it difficult for the social workers to understand the communicative behaviours of people with ASD. Even if the social workers understand the inappropriate communicative as attention seeking behaviours, the social workers belief is, that the attention seeking behaviours is a consequence of the communicative deficit the students have.

Lack of motivation is another belief held by the social workers in terms of what is causes challenging behaviours. By lack of motivation the social workers means lack of motivation for following the instructions social workers are giving them. Lack of motivation for doing the educational activities and work task they have been given. Lack of motivation that among others can be caused by different favored interest the students might have:

*David is not participating in the classroom together with the other children's. Sarah (the social worker) explained that David is only coming for a few lessons every day, because the school is not motivating for him. David is a higher functional boy that is able to communicate verbally. Sarah teaches David in a separate room, but finds it difficult to teach him because of his obsession of bike-rickshaws. He only talks about bike-rickshaws and is not motivated to always follow Sarah's instructions. As she said, 'I take him on rickshaw rides around the block and he is happy as ever. I ask him to do some work and he starts winding up spitting, hitting himself or something else. But we can't spend every lesson in a rickshaw so I have to find something that can motivate him' (IE).*

Unfortunately the quotation does not explicitly clarify what lack of motivation explicitly indicates. However, the ethnographic observations clarify that lack of motivation can be very strong interests and impulses in engaging in favored activities such as David's obsession with bike-rickshaws. David's strong interest in bike-rickshaws causes difficulties for Sarah in getting David's attention to participate in the daily scheduling and educational activities she has set up for him. Not following Sarah's instructions David is displaying challenging behaviours as he is disturbing the teaching environment (cf. social workers' definition of challenging behaviours). You may say that student's lack of motivation is believed to cause challenging behaviours because of the difficulties the social workers are facing in regard to motivating the student to join the teaching environment of the classrooms.

Beside communication problems and lack of motivation the social workers believe challenging behaviours can also be caused by sensory difficulties. With reference to the TEACCH concept the social workers understand that marked sensory preferences and dislikes are causing challenging behaviours. My focus throughout the study has not been on sensory issues and will not unfold this further. However, I find it important to clarify that students at the Open Door School are provided with sensory therapy on a daily / weekly basis and the social workers are instructed by the occupational therapist in terms of managing particular sensory behaviours.

The social workers' belief held in regard to what causes challenging behaviours is basically a communication problem as well as lack of motivation and sensory issues. The causes are referring back to the TEACCH concept of the 'culture of autism' i.e. the way of understanding the behavioural patterns that are seen as characteristic for individuals with ASD. These behavioural patterns are among others communication problems, difficulties in attention, strong interest in favored activities and difficulties in disengaging from the strong activities and marked sensory preferences and dislikes. Hence, the social workers' belief in the causes of challenging behaviours takes set in an understanding of the specific patterns that characterize the individuals with ASD. The social workers have in

other words an understanding of the difficulties individuals with ASD is facing, but also, they have a clear understanding of the difficulties they as social workers are facing in terms of supporting the needs of the students. The following quotation explicates very warmly the difficulties in understanding the characteristic patterns of individuals with ASD, patterns that most often develops into challenging behaviours:

*S: I think it is so difficult to understand them. They are a sort of a puzzle. They are like a piece of a puzzle. They keep you thinking what is next. It's really difficult. To understand autism is to experience only. I mean, that each child is different. The more you see, the more you find out how different each child is and then you come to the conclusion that these are the few things which are bond to them, but still each child is different. He or she has its own set up patterns, rituality's. Its own set of behaviour and intellectual level of functioning, so again, the more you see, the more you work with children's with autism, the more vast autism becomes to you (IC).*

Throughout my ethnographic fieldwork at the Open Door School I was repeatedly told by the social workers that to manage challenging behaviours - in the terms of the social workers - it's all about understanding autism'. I repeatedly asked the individual social workers to explicate to me what they meant by the saying and what they were referring to. Everyone referred back to the core feature of ASD which I already knew. I kept thinking that there must be more to it, but never got to terms with the understanding of the saying. However writing up this analytical description and particular this chapter of social workers understanding of challenging behaviours it becomes clear that the social workers are referring to the characteristic patterns of individuals with ASD, i.e. are referring to the TEACCH concept 'culture of autism'. It is the characteristic patterns of communication problems, difficulties in attention, strong interest in favored activities and difficulties in disengaging in the strong activities and marked sensory preferences and dislike that is affects social workers belief in what causes challenging behaviours. Even Jill's understanding of why Jack was

upset and displaying aggressive challenging behaviours is referring back to the concept of 'Culture of autism':

*'Jill explains further that Jack loves to do his work. He follows his schedule punctually but is having difficulties in changing the structure of the day as he is very attached to his schedule. When Jack checks his schedule in the morning he remembers it and, if, there have to be made any changes he gets upset and may react like today. As Jill explained, Jack was not coming from the morning as he usually does, so she thought Jack was absent for the day and for this reason did not remove the visuals on his schedule. When Jack turned up one hour late the visual cards for the two first lessons was still on his schedule. Unfortunately Jack managed to check schedule before Jill, so Jill had to remove the visual cards for the first two lessons in front of him while explaining that he was late and that is why she was removing them. Jack did not approve of the removal and got very upset on his mum for being late (IE).*

Jill' belief that the aggressive behaviour Jack displayed was explicit caused by Jack' tendency of being attached to routines and consequently, any disruption in his routine makes Jack upset. This tendency to become attached to routines and any disruption of the routines are upsetting, confusing or uncomfortable for the individual is one of the 10 points of the 'Culture of Autism'. The characteristic behavioural patterns that are seen in individuals with ASD - in terms of the 'culture of autism' – are difficulties individual with ASD are facing. It is the difficulties individual with ASD are facing in according to the 'culture of autism' social workers at the Open Door School believed causes challenging behaviours. Thus, to understand the term 'it's all about understanding autism' is to understand the difficulties individual with ASD are facing in terms of the philosophy of Structured Teaching the 'culture of autism'. The identification of the social workers understanding of challenging behaviours are like social workers definition and management of challenging behaviours social workers affected by the philosophy of structured teaching.

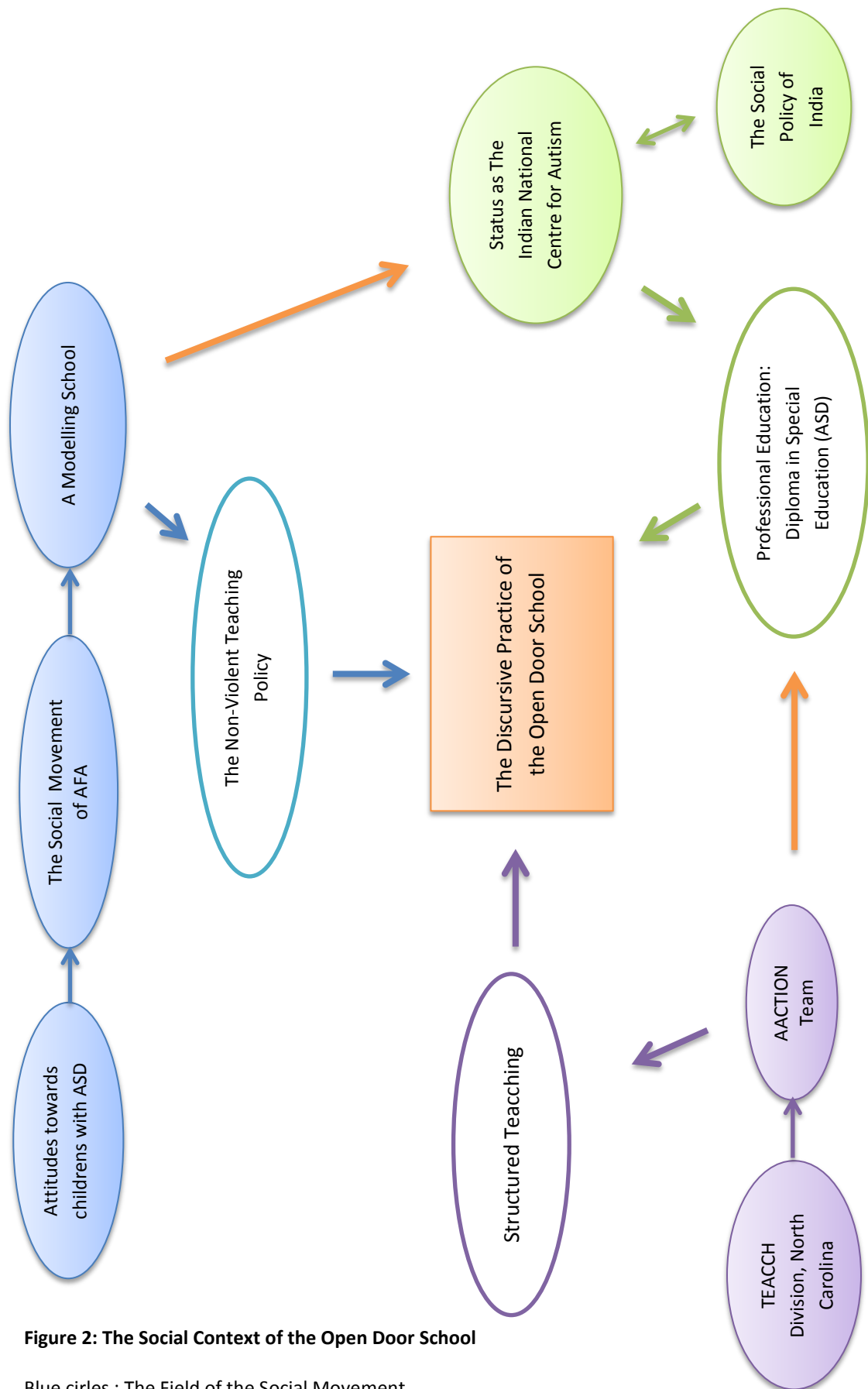
### **6.1.5 Summary**

Challenging behaviours are in accordance to Emerson being understood according to the social rules that deem inappropriate behaviours as challenging behaviours and challenging behaviours are managed with respect to the intervention paradigm that exists within in a social context. The identification of the Open Door School shows that challenging behaviours are being defined, understood and managed in accordance to the principles of the intervention approach of Structured Teaching. Structured Teaching is with references to Spradley the acquired knowledge – intervention approach - social workers at the Open Door School use for defining, understanding, and managing challenging behaviours (Spradley, 1979). Structured teaching is the shared intervention system of meanings and beliefs social workers have been learned, revised, maintained and defined as the appropriated intervention approach to socially support the need of people with ASD within the institution of the Open Door School (Spradley, 1979). Thus it is the cultural belief in and practicing of structured Teaching that determents inappropriate behaviours as wrong and deems them as challenging behaviours at the Open Door School and accordingly constitute social workers management of challenging behaviours (Emerson, 2001). For Foucault Structured Teaching is the power/knowledge of the Open Door School which objectifies the social workers management, understanding and definition of challenging behaviours displayed by the student's (Foucault, 1977). Structured Teaching is the cultural factor that has an significant impact on the discursive practice of everyday life at the Open Door School and accordingly have a significant impact on the social workers understanding and management. In the following I map the ruling relations – the local and trans-local contextual and culturally factors – that shape and sustain the discursive practice and accordingly shape and sustain social workers understanding and management of challenging behaviours at the Open Door School.

## **7.0 Mapping the Rulings Relations of the Open Door School**

It is in this following chapter I map how contextual and cultural factors affect social workers understanding and management of challenging behaviours. In terms of institutional ethnography it is in this chapter I map how the practice of the Open Door School is concerted and coordinated between the local setting of the everyday life at the Open Door School and the trans-local ruling relations that organize the organization of Open Door School. My analytical description takes set in the map, the Social Context of the Open Door School (figure 2), I have drawn up to visualize the ruling relations that carry and control the discursive practice of the Open Door School. The map visualizes the individual trans-local contextual and cultural factors concertedly shape the discursive practice of the Open Door School. The local factors are marked with light colors and the trans-local factors are marked with dark colors. Throughout my description, the map serves as a guideline for explicating how the ruling relations of the contextual and cultural factors of the Open Door School affects social workers understanding and management of challenging behaviours. The map is divided into three fields: The Field of the Social movement, the Discursive Field and the Institutional Field. These three fields represent the disposition for the following description of each individual and cultural factor and how they concertedly constitute the discursive practice of the Open Door School. My starting point on map is the Field of the Social Movement.





**Figure 2: The Social Context of the Open Door School**

Blue circles : The Field of the Social Movement  
 Purple Circles: The Discursive Field  
 Green Circles: The institutional Field

## 7.1 The Field of the Social Movement

In accordance to institutional ethnography, an institution is shaped according to the dynamic of a transformation that begins and gathers speed somewhere else (Smith, 2005). This means social workers work and social knowledge of Structured Teaching is socially constructed and ruled by the specifically historical contextual and cultural factors surrounding the institution (Ibid). The Field of the Social Movement, maps how the specific historical social factors of disrespectful attitudes towards children's with ASD in traditional Indian special school generated the non-violent teaching policy of the Open Door School, a policy that have an significant influence on the implementation of Structured Teaching and accordingly social workers understanding and management of challenging behaviours.

### 7.1.2 Attitudes towards Children's with ASD

The social construction of the Open Door School began in the late 1980's in opposition to the social condition children's with ASD were exposed to:

*'In the 1980's a diagnosis of autism in India was rare. The majority of children with autism routinely received a diagnosis of mental retardation. A handful was diagnosed as having Minimal Brain Dysfunction and others received diagnoses of 'slow learner' and 'behaviour problem.' If, at all, children with autism attended school, they attended schools for the mentally retarded, where the same intervention techniques were given to all. Without knowledge about the specific ways autism affect a child, schools and parents alike were unable to address the children's needs. Even the very basic facts about children with autism were absent. Knowledge of these facts all have direct implications for teaching techniques, but in the absence of understanding, appropriate intervention did not occur.*

*In 1988-1989 a group of three concerned parents got together in Delhi. Two of these children had received a diagnosis from the same psychiatrist, who was trained in North America, and the mother of the third had found the diagnosis*

*herself. These three children all attended the same high-profile special school, but none were making any progress. The children were often left to do whatever they pleased, or were included in singing time and other non-specific activities. With thirteen kids and one teacher, the students who were autistic received the least attention, and these children began to show an increasing amount of challenging behaviours. Parents were not able to observe their child during class, and the teachers did not offer any guidance for management at home. Furthermore, two of the children began to report that they were being punished by being hit and pinched by their teachers. The children didn't want to go to school' (The History of Action for Autism: [www.autism-india.org](http://www.autism-india.org)).*

With no knowledge of the disorder ASD teachers within the traditional Indian schools had no professional knowledge of how to understand the characteristic behaviours children's with ASD might display. Also they did not have any specified training techniques to manage challenging behaviours and accordingly no knowledge of how to socially support the needs of the children's with ASD to be included in the educational activities and peer-activities. Without knowledge of the specific characteristic patterns individuals with ASD have, teachers were most often using aversive methods to teach or in other words control the behaviours the children's display. Aversive methods are defined as:

*'There is yelling at the child. There is hitting, there is slapping, there is pinching, there is pulling being done to them. [Aversive methods are also] confining them in a room, depriving them of their lunch, and in extreme cases tying to chairs, and in rare cases much worse things. And then of course expelling the child (telling the parent - take your child out of this school) (IF).*

Due to the lack of knowledge of the disorder ASD in India, families with ASD experienced a systematical neglect and exclusion within the traditional Indian schools. Neglect in terms of structural exclusion of the children's by not including the children's in the educational activities and neglect in terms of physical violation caused by the teacher's use of aversive methods. No one had questioned the use of aversive methods until the three mothers of children' with

ASD in 1989 got together and started questioning the teaching techniques the teachers of their children's school' were using.

As loving mothers, the mothers started, in terms of Foucault, questioning the teaching techniques social workers at the high-profile school were using (Foucault, 1977). Foucault would say, that they did not fear questioning the appropriateness of the aversive methods and structural exclusion teachers were taking for granted. Honneth would say it was the three mother's experiences of the physical violation that generated the mother's social critique of the structural exclusion their children's were exposed to and accordingly bounded up the mother's social movement for facilitating an including educational school services for people with ASD in India (Honneth, 1995).

### ***7.1.2 The Social Movement of AFA***

It was the mother's experiences of the structural exclusion of their children's in the traditional Indian special schools that activated their social movement for fully inclusion of children's with ASD within educational settings. Led by the parent Merry Barua, the three mothers founded in 1991 the parent organization Action for Autism (AFA) with the goal '... to provide support and services to persons with autism and their families, and to create an environment in India in which people with [ASD] are able to grow to their full potential' ([www.autism-india.org](http://www.autism-india.org)). As a part of their social movement for including educational services, AFA founded in 1994 The Open Door School, the first special school for autistic children's in India (Ibid.).

With the activation of the social movement the three mothers (in the following AFA) founded the Open Door School and generated the remaining contextual and cultural factors that organize the discursive practice of the Open Door School. AFA generated the contextual and cultural factors that today surrounds the Open Door School and accordingly generated the way in which social workers at the Open Door School understand and manage challenging behaviours.

### 7.1.3 A Modeling School

In opposition towards the use of aversive method and lack of knowledge to socially support the need of children's to be included with in the educational activities in ordinary special schools, AFA founded in 1994 the Open Door School with the dual purpose to provide direct training for children's with ASD without the use of aversive methods and to be a modeling school.

*I: Could you describe what it means that the Open Door School is a modeling school?*

*S: What it means is that when we started this organization there was nothing for autism, there were no schools and stuff like that. So when the Open Door started we didn't want to have this large school with 200 kids and with boarding and all that. The idea was to start a small place, because when I started the school people would say, '...oh you will hit the children's. How would they ever learn?' I actually had workshops, training workshop where they went back to say that they have a school where they don't punish. Have you ever had a school like that? This was the feedback and this is for real, okay. They thought we were stupid and having no ideas of what the children's wanted. That's how it was received. So in that environment we started the school. It was meant to be a place where people would see and learn and understand that, this is how to teach kids with autism. We hoped that this would help people to start schools like this and that is what ended up happening. So we are a school of modeling, a school people visit and - even you have seen how many people comes to visit - to see how we are teaching, to observe. So what we ended up doing was that more and more people wanted to start up a school for autism, so this is a model people can come to see how we teach and how we don't teach. We don't hit, we don't yell, and we don't beat them up while we teach them. And you don't just let them in the corner to sit flap and say: it is okay, I am teaching a kid with autism. So that is how it is a modeling school (IF).*

The purpose of the Open Door School was to start a specified school for children's with ASD without use of aversive methods such as yelling, hitting,

excluding the children's in the everyday teaching environment. AFA wanted the Open Door School to be a modeling school, a pioneering school that would transform the lack of knowledge of how to include people with ASD in an educational teaching environment without the use of oppressing aversive methods. Honneth would say that with the foundation of the Open Door School, AFA generated new idealized norm and standards for what *should* be characterized as more justified way of teaching people with ASD (Honneth, 1995). As a modeling school, AFA generated new norms and standards for how to socially support the needs of children's with ASD to be included in educational settings, a methodology teachers in the general disability sector, mainstream schools, parents and others can learn by observing the social workers daily working processes at the Open Door School (Honneth, 1995).

Being a modeling school means that social workers at the Open Door Schools are role models for not using any aversive methods in terms of managing challenging behaviours. The social workers are pioneers in how to socially support the need of children's with ASD to be included within a teaching environment without the use of aversive methods. They are pioneers in regard to generate knowledge within the non-autistic disability sector as well as the general public in how to understand and manage challenging behaviours displayed by children's with ASD. The trans-local processes of the three contextual factors described generated together the local contextual factor of the non-violent teaching policy. The non-violent policy forms the policy of how social workers are not allowed to use any aversive methods in terms of managing any type of challenging behaviours the children's might display.

#### ***7.1.4 The Non-Violent Teaching Policy***

The following quotation explicates the social policy of how social workers at the Open Door School are not allowed to manage any inappropriate behaviour deemed as challenging behaviours.

*I: What kind of rules have you set up here at the Open Door School? I don't know if you have anything written down? I mean, how are the [social workers]*

*allowed to behave towards the children's or the adults? Are they allowed to restrain them? Are they allowed to - I don't see that - but are they allowed to hit them?*

*S: We have a policy and the policy is that, when a person shows any kind of behaviour there is always a reason behind. It is not a bad behaviour. We do never use aversive, and I also must add that there might be people that do it and I don't know, right? But the policy is... and we try to keep track on it also. But the policy is that you never use any forms of aversive and the [social workers] know why, because that is a part of the training. The aversive are not going to help the child learn anything. If we do at all use a punished procedure, it would be something like a three minutes time-out from something. But we don't do anything like yelling at the kids, raising the hand or locking them up and that kind of stuff.*

*I: Is the policy written down?*

*S: Ken was working on that, but he had to leave early (IF)*

The non-violent teaching policy of the Open Door School is very explicit: any use of aversive methods such as hitting, pinching, yelling etc. is strictly prohibited at the Open Door School. Even though the policy is not written down, social workers at the Open Door School is according to Merry familiar with the policy as they have been trained in the policy during their diploma education (cf. chapter 7.3.1). Yet, Merry is aware that incidents might happen, but they try to keep a track on it does not happen. Merry trust the social workers:

*I: If I understand you correct, you trust the social workers in what is the right behaviours to do within any situation?*

*S: See we try to keep the training and understanding updated. We want them to come to a place where...even I sometimes buffer and so do the [social workers]. I have been doing it for so many years and have dealt with some of the most complex skills. Any human makes mistake, but a mistake should never be an extreme violation of human rights. It should never be that and to the best of my*

*knowledge it has never happened. I know there has been one caregiver who has hit a couple of children's and we found out immediately and this is never going to happen again. And I know, it will happen again with new trainees, but we have to be rigid. Like we are visionary with people in the community, we have to be visionary with people with autism also. (IF)*

Merry have trust in her people so that the use of aversive methods will not happen, but as she states, we have to be rigid as new trainees are coming in i.e. trainees who at the beginning of the Diploma course might not understand the characteristics patterns of the disorder ASD and who might not know how to manage challenging behaviours without the use of aversive methods. Merry is aware of this risk and hence all employees at the Open Door School has to be rigid towards the social policy of the non-violent teaching policy.

Being a modeling school as a part of AFA' social movement for transforming an including teaching environment for children's with ASD, the non-violent teaching policy affect social workers in terms of being role models not using aversive methods in their daily management of challenging behaviours.

My question to the founder Merry Barua clearly indicates my focus and prejudices of managing challenging behaviours with the use of physical restrain. As mention in the introduction, I found myself reflecting upon my own cultural premises for judging when social workers are acting violating towards the children's. I found myself being confine by the Danish Act on Social Services § 123 & 124 which indicates that you as a social worker is not are allowed to restrain the wrist of a person with ASD to guide the person to the toilet or other places, if, the person is not able to do it by her/himself. More specific, you are not allowed to restrain a person unless the safety of the person or others is in jeopardy.

Being involved in the situation with Jack reminded me of the time when I was working in the practical field and often experienced similar situations, particular from my time working in residential homes for people with ASD.



*'The situation today reminds me of how simple social work can be and how complicated social work is at home [with institutional settings of the Danish Government]. If a similar situation happened at home I could not, like Jill, just continue work without documenting the situation. I would have had to report the use of force to the Social Service of the Municipality (cf. X), where a counselor would judge whether I acted ethically acceptable by using the force to let go of Jacks grip on Jill' t-shirt. The counselor would later report back whether the forcing has been approved or not. If not approved I would get a reference and taken in for an interview. Beside I would have had to fill in another report to the Work and Health Department (Arbejdstilsynet) for the hits Jack gave me. All this documentation would take at least 45 min up to an hour as the procedures are comprehensive. Jill did not have to report anything, she could move on with her work straight away. Merry trust that her social workers do not act violating towards the children's in any ways. Within the Danish Welfare System, the trust of us social workers has gone into several stages of governmental control in terms of documentation that takes up most of our working time. No wonder why colleagues do not report all incidents. No wonder why we, the passionate social workers, leave the field in large flows. Our professional judgment has drowned in an huge amount of documentation and has taken us away from the children's, youngster and adults who needs our help and whom I entered the field to help (IE.).*

My reflections indicates there is a vital difference in how we as social workers within institutional settings of the Danish Government and social workers at the Open Door School are being regulated in terms of using physically restraints towards children's with ASD. Being governed control Danish social workers must document every simple situation to be judge by the social services of the local municipality. Social workers at the Open Door School regulate each other within the institution of the Open Door School which demands a self-discipline attitude among the social workers to regulate each other behaviours morally (Foucault, 1971). However, all social workers are confined with the norms and standards of the Open Door School for how – in terms of Honneth - to morally and ethically manage challenging behaviours.

*I: I am trained in the Danish Welfare System where we have this law saying nobody is allowed to violate a person with a disability ...*

*S: Violate how?*

*I: We are not allowed to hold a person wrist. We are not allowed to hold the wrist or elsewhere unless the safety of the person is in danger.*

*S: So you are not allowed to do this (hold on to the arm) ..*

*I: Only if the person safety is in danger. Let me give you an example, we are not allowed to hold a person wrist, if, the person is going to the toilet or somewhere else*

*S: ...you see that is also not allowed here...see it's not a kind of rule as such. It is not forbidden but you don't do it. It is not appropriated. They are human beings. You don't do this. Instead you can do this...*

*I: Hold their hands properly*

*S: If someone is doing it then that person is doing it wrong. They are not something non-living. They have emotions, all the feelings....so how would I feel if someone would drake me like this? I would feel very bad and they ...it should not be done, even if you are doing your best. They should be treated like us.*

*I: Like we would like to be treated ourselves?*

*S: Yes, but we don't have rules that you can't, but sometimes we have to do it. But as you are saying in your country it is not allowed to force them or...*

*I: No, it is not allowed to hold them on the for example the upper arm. Holding hand to hand is allowed. However, it is all about interpretation isn't it? Because when is it holding hands and when is it forcing and hurting the person ...*

*S: That is the thing because if someone is holding or hurting a person, the person is not able to tell it. Only you can see.*

Social workers at the Open Door School is according to the quotation familiar with the non-violent policy, but they are also aware that they –in the perspective of my Danish understanding - sometimes have to hold on to wrist of a child even though it is not acceptable. But as the quotation indicates, it is the interpretations of the individual social workers whether her/his way of holding/behaving towards the child is to be judge , in terms of Honneth as a physical violation or not. Recognition of the individual with ASD happens in according to the social in the intersubjective relation between the social worker and the individual with ASD. It is the judgment of the individual social worker that judges whether he or she acted ethically acceptable or not.

In Denmark it is the individually social worker that judges whether he/she will report an incident which has happened between the social worker and the individual with ASD. Even though we are obliged to, a lot of incidents are not reported and yet, oppression of people with ASD happens despite of the rights of protection (e.g. Strandvænget I 2007, [www.nyhederne.tv2.dk](http://www.nyhederne.tv2.dk)).

In terms of any regulations of aversive methods we are as social workers, according to Foucault, demanded to speak up – not fear to speak up – if we observe colleagues or others use oppressive methods to towards individual with ASD. To speak up is for Foucault significant for regulating the violating behaviours of any social worker. To regulate the use of aversive methods is for social worker to not to fear to speak up if a child is being oppressed with any use of aversive methods. To regulate the use of aversive methods demands that social workers are good role models in terms of managing challenging behaviours without use of aversive methods – no matter whether you are an Indian or Danish Social worker.

## 7.2 The Discursive Field

Foucault developed the concept of the 'discursive field' as a part of his attempt to understand the relationship between language, social institutions, subjectivity and power (Heede, 2007). In this chapter I map how the trans-local relationship with the TEACCH Division, North Carolina and AACTION Team have constituted as well as sustain structured teaching as the power/knowledge of the Open Door School and thus have objectified social workers understanding and management of challenging behaviours. My starting point on the map is to describe the trans-local relation of the TEACCH Division, North Carolina.

### 7.2.1 The TEACCH Division, North Carolina

In the process of setting up an including teaching environment that socially support the need of the children's and was consistent with the non-violent policy of the Open Door School, Merry Barua, went to the TEACCH Division in North Carolina and took up training in the philosophy and principles of structured teaching.

*I: So within the modeling school you have somehow chosen or committed to use structured teaching as a method, technique and ABA....*

*S: yes, yes, because....one of the first things we realized, when we started, was that we were using methods I had brought out of my head, okay. But I found that a lot of my use is a part of these methods. When you look at a child, trying to understand, you come up with ideas that are exactly this. Then I did the course in Structured Teaching in 1995 in North Carolina, with the TEACCH. So then we introduced [Structured Teaching], and then in the meantime, when we introduced [Structured Teaching], we realized that a lot of ABA' stuff, particular what we call VBA, which is particular teaching Pics and signs and all of that focusing on communication. We found that [VBA] is very useful for very young children's, so we use that. We use a lot of VBA with the young children's because it has a really big impact. But we also know, and we learned from my experiences that you got to have structure. While [ABA] is something you can*

*use for a certain period, Structured Teacching is something we call a lifespan approach. That is what we call it. We call structure a lifespan approach, because structure is something my son needs, the little boy needs it, we all need it'. (IF)*

Unfortunately it doesn't appear in my empirical data how Merry got in contact with and got the funding to travel to take up the training at the TEACCH Division Center. However, with Merry' training at the TEACCH Division the Open Door School took up the intervention method of Structured Teacching and in conjunction a specific understanding of the disorder of ASD and thereby the characteristic behaviours people with ASD might display. Merry' training at the TEACCH Division in North Carolina is the trans-cultural factor that introduced and implemented Structured Teacching as the intervention method at the Open Door School, a trans-local factor which we learned in the mapping of the Discursive Practice have affected social workers understanding and management of challenging behaviours as their understanding and management is referring directly to the philosophy and principles of Structured Teacching.

I must raise the awareness that structured teacching is not the only intervention approach used at the Open Door School. The Open Door School is also making use of the positive reinforcing element of Applied Behavioural Analysis (ABA). This includes edibles<sup>27</sup> and positive phrases such as smartly sitting, good working, waiting smartly, hands to your-self, sit down stand up, wait, hands out, legs down etc. These reinforcing elements are intervention elements social workers use in terms of behavioural modifications and not in terms of organizing their daily work processes. Structured teaching is the intervention approach which organizes the daily teaching environments of the social workers which is the focus of this study. Hence, elements used in accordance to the behavioural based methods of ABA will not be identified due to the limitation of this report.

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<sup>27</sup> Edibles are something eatable such as crisps, chocolate, Pepsi etc.

### **7.2.2 The AACTION Team**

To sustain the knowledge and practice Merry took up at the TEAACH Division and implemented at the Open Door School, Merry was for years sending some of her people to the TEACCH Division, North Carolina to obtain training. Later on the Open Door School entered into a partnership with the American AACTION Team who travels to Delhi to update the social workers training in structured teaching.

*I: What kind of connection, do you have with the AACTION Team? Do you have a cooperation?*

*S: Yes, yes, yes. See, the AACTION Team is a volunteer thing that got in touch with us several years back. They wanted to do something volunteering in the developing countries which were very nice of them. So we just pay for the airfare and we don't pay them anything for their time. In fact their sponsoring is not too much, but we have to do all the arrangements for their stay. We do all that and they come and give us all the training. What happens is that...you know, I have done the TEACCH training in 1995, and then, I had another couple of people who did the TEACCH training and they were working here for many years... I have been out of this for quite a while, but they have got themselves a little bit confused so some of the stuff which was happening was not appropriated. When the AACTION team came and they did...and see earlier, I would send one person and the person might come back with a wrong understanding and that was it. Here the whole team is getting the training, and we are discussing it, and we could see our mistakes. Then they went to our classes and gave us feedback on that and it really help to put eye on the stuff. The AACTION team doesn't do the ABA and VBA. They are completely against it which is okay with us...*

*I: They are totally into Structured Teaching.*

*S: Yes, that is fine with us. Because what do we want? We want training in a methodology, so we can use it accurately to benefit our children's. I don't care*

*what your belief is. You teach us, you are good with it, and we are very lucky that they come and train us'. (IF)*

The American organization, AACTION<sup>28</sup> Autism, is a humanitarian organization dedicated to develop worldwide awareness, support and acceptance of autism through education and training ([www.aactionautism.org](http://www.aactionautism.org)). The AACTION team is a volunteering team of American professionals educator specified in Structured Teaching who take vacation time of to travel to developing countries to provide training for family and educators in intervention approach of Structured Teaching (Ibid.). Through collaborating with local NGOs, the AACTION team runs workshops for educators, parents and others with the goal to increase their internal capacity to understand and manage the communicative and social impairments people with ASD have ([www.aactionautism.org](http://www.aactionautism.org)). By running workshops for educators, parents and others the AACTION team work to raise awareness of the social conditions and social problems people with ASD are facing in many of the developing countries and to qualify educators in different educational institutions, parents and others to socially support the need people with ASD by training them in the philosophy and principles of Structured Teaching (Ibid).

To sustain the social knowledge of the philosophy of Structured Teaching AFA has entered into a partnership with the AACTION team to keep the social workers updated in practicing the philosophy and principles of Structured Teaching. This trans-cultural factor is keeping the social workers social knowledge of structured teaching updated so they in according to the quotation can use the methodology in accordance to Foucault a truthful and disciplined way to help the children's the best possible way. The training of the AACTION team has significant impact on the social workers way of setting up a structured teaching environment in the classrooms:

*The next couples of days I will be observing the class of 6 teenage boys in the age of 15 – 17. All boys are tall and strong grown up boys. Irene (the social*

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<sup>28</sup> AACTION is abbreviated for Autism Awareness Campaign Through International Organization Networking

*worker) told me from the morning that all of these boys use to have huge amount of challenging behaviours – mostly hitting and pulling hair - and they were fighting each other as they would trig each other in one way or another. To deal with the amount of challenging behaviours the staff was constantly facing the AACTION Team came and helped to structure the classroom properly and develop individually schedules, work areas, work system etc. To deal with huge amount of aggressive behaviour one of the children's had the AAction Team made a special area for the boy to be screened from the rest of the class. After having set up the classroom in a structure setting all boys are, in the terms of Irene, kept 'busy' and do not get into fights or display the amount of challenging behaviour as they used to. Irene stated repeatedly that with the structured setting the AACTION team had set up, she was now more able to control the behaviours of the boys. (EN)*

The ethnographic observations describes the significant impact the training workshops held by ACCTION teams have on the social workers way of practicing the principles of Structured Teaching in the most accurate way to socially support the need children's with ASD have to be included in the educational activities. To practice Structured Teaching in an accurate way is not only important in terms of providing the most beneficial support for the individual children's it also have a significant affect in term of being a modeling school for teachers and social worker from other educational settings in India. This link will be unfolded further in the chapter of 'the Institutional organization.

Linked together the trans-local relation of the TEACCH Division and AACTION team are in terms of Foucault the cultural factors that together constructs and sustain the regime knowledge of the Open Door School (Foucault, 1997). In accordance with institutional ethnography it is the trans-local processes of the TEACCH Division that together carry and controls the social workers work processes and social knowledge of the discursive practice at the Open Door School.



### ***7.2.3 Structured Teacching***

In the first analytical part, the Discursive Practice of the Open Door School, we learned that social workers' understanding and management of challenging behaviours are being understood and managed in accordance to the philosophy and principles of Structured Teaching. Structured Teaching is the local cultural factor which directly constitutes social workers' work processes and social knowledge in regard to understanding and managing challenging behaviour. The trans-local processes of the TEACCH Division and the AACTION team are on the other hand the cultural factors that constituted and sustain social workers practicing of Structured Teaching and thus affect social workers' understanding and management of challenging behaviours. Affected by the social movement of AFA for facilitating a fully inclusive teaching environment for children's with ASD, Structured Teaching is the intervention approach AFA has committed to practice at the Open Door School. This because Structured Teaching is an intervention approach that with long terms goals offers skill development as well as fulfillment of fundamental human needs such as dignity, engagement in productive and personally meaningful activities, feelings of security, self-efficiency and self-confidence .

You may say that within the intervention approach of Structured Teaching AFA found an appropriate intervention method to evolve educational services that teaches the children's educational works skills and at the same time socially support the needs of the children's to be included in educational activities and peer-activities such as play and leisure activities. Whether this was a deliberate decision taken or it all happen by chance that Merry Barua got in touch with the TEACCH Division and later got contacted by the AACTION team will in this study remain unidentified. However fact is that the social workers at the Open Door School try to follow the principles of Structured Teaching to a maximum:

*The social workers are truly loyal in terms of practicing the principles of structured teaching like a manual. What I observe is that they are not just using elements of structured teaching they are following the principle of*

*Structured Teaching as strictly as possible. To practice an intervention approach as strictly as the social workers here at the Open Door School would not have happened in the integrated special schools and residential homes I have worked at home [institutions within the Danish Welfare system]. In none of the institutions we would follow one intervention approach manually. We would use elements from different interventions approaches. Elements we would found appropriated in terms of setting up an appropriated teaching environment for the abilities and functions of the students. We would to a certain extent set up a structure, as structure is needed for children's with ASD, but the structure would be discussed and reflected upon continuously and a lot of changes would happen in terms of the behaviours we would be facing. By following the structure strictly and not bending the rules can provokes in many situation challenging behaviours. Like today, a boy was refused to drink water as it was not time to drink water due to his schedule. The social worker took the bottle out of his hand and instructed him to move to his next lesson. The boy reacted consequently by biting his wrist and hitting his head. I would have given some water and then move on. There is no need to provoke challenging behaviours for the sake of practicing an intervention approach strictly' (EN).*

In the view of institutional ethnography, the social workers are acting institutional accountable towards the institutional ideology of the Open Door School and by being institutional accountable the social workers are activating the non-violent teaching policy by not using any forms for aversive methods but instead socially support the needs of the children's by setting up a physical structured environment in accordance to the principles of Structured Teaching. By being institutional accountable towards the practicing of Structured Teaching the social workers are likewise institutional accountable towards the goal of the social movement to fully include children's with ASD with educational settings. The social workers are found to be - in the words of Smith – integral with the production of the institution' (Smith, 2005:10).

As the ethnographic notes indicates I believe like the Indian social workers that structured is needed in regard to manage challenging behaviours. Structured is

needed to make the daily activities predictable for the children's as they are not able to communicate and express themselves due to their characteristic patterns of the disorder ASD. However, in comparison to the social workers at the Open Door School a structured setting in my understanding as a Danish social worker is a dynamic process which is always to be discussed and changed. I am clearly affected by my educational training as a professional social worker were we as Danish social workers are not taught specified to socially support the need of children's with ASD, but people within the general public in the need of care.

As a part of the educational training we are as social workers not trained in specific intervention methodologies. Institutional settings for children's with ASD within the Danish Welfare Systems have an eclectic approach in terms of practicing intervention methodologies (Høgsbro, 2007). As professional social workers with 3½ years training at the University Colleges of Social Education (Pædagog Seminariet) we are taught a reflective approach regarding use of intervention methodologies, our own actions and our judgment of the specific needs the children's and adults have. Consequently in our way of reflecting we become more ambivalence in being institutional accountable and ambivalent in regard to social demands than Indian social workers. As a Danish social worker states in the ETIBA report, an evaluation of the training and rehabilitation for children's with ASD within the Danish governmental institutions, '...for the sake of who do we do this for'<sup>29</sup> (Høgsbro, 2007:87). With the statement the social worker indicates that it is better for the child to have a stress free day by bending the rules of the daily structure. The social worker would, like myself have given the boy something to drink and move on. You may say that we as Danish social workers emphasize the need of the child rather than being loyal towards the Institutional ideology.

The social workers at the Open Door School are in comparison to Danish social workers more institutional accountable by practicing Structured Teaching manually and accordingly they are less ambivalent towards the social demands

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<sup>29</sup> My own translation

than Danish social workers. However, they do have other social conditions than Danish social workers. Being a part of a social movement, being a modeling school and being pioneers in terms of understanding and managing challenging behaviours without the use of aversive methods the social workers are working visionary and passionately to change the social conditions for children's with ASD in India. The question is what the vision for people with ASD in Denmark is? Indian and Danish social workers have in terms of Emerson different cultural premises for understanding and managing challenging behaviours.

Chiang (cf. chapter 3.1) found that challenging behaviours occurred more during structured activities than during free time. As mentioned in the ethnographic note, I did observe situations where I found that the loyalty of following Structured Teaching provoked challenging behaviours but even so, my findings cannot confirm the findings of Chiang's result. As Hastings stresses (Cf. chapter 3.0) social workers' beliefs have a significant impact in designing a successful intervention. With help from the AACTION team social workers at the Open Door School have successfully set up a non-violent teaching environment on the principles of Structured Teaching for socially supporting the needs of the children's to be included in the educational activities and peer-activities. Viewed with a critical eye, I observed a qualification lack in terms of the educational content i.e. the educational activities in terms of teaching the children's academics and other educational skills.

*'The social workers are working hard to follow the structures of the classrooms and the individual schedules of the students. But I do question if they ever change the structure and in particular the content of the activities. The structure is the same week after week, day after day and hour after hour. The content of the activities are almost the same and there are no direct educational long term goals set up for the children'. Many of the children's are not being challenged intellectually despite the fact they know some writings, numbers etc. There are educational goals set in terms of pre-vocational skills where there seem to be much focus on matching activities, imitation games like 'Do this' (the social worker do an action and the child has to repeat the action). But in terms*

*of academic skills there seems to be a lack. It is the same activities they teach. It particular became clear to me after nine months away and coming back. After my return I found children's are doing the same work system, the same matching games and only minor changes have happened in terms of the educational content. The children's are not being challenged intellectually even though the social workers are trying the best they can and with the few materials they have created by themselves.' (EN)*

To become a successful educational setting The Open Door School needs to qualify its educational content and educationally activities. There seems to be a need to set up long term educational goal for the Open Door School as well as the individual children's to make a meaningful content for the children's as well as the Open Door School as an educational school setting. As a social worker explicit explained to me about one of the higher functional boys:

*'...he is so intelligent and needs to be kept busy all the time otherwise he will come up with these funny behaviours. I try to make these academics, but it is not much, but it is all I manage'. (EN)*

In terms of qualifying the educational content of the Open Door School, the Open Door School could take up the idea of employing an educated teachers qualified in teaching academics. A qualified teacher with knowledge of how to teach academics would make the content of the activities more meaningful and challenging for the individually children's.

### **7.3 The Institutional Field**

This field, the institutional life, comprehends how the institutional organization of AFA magnifies the Open Door School as a modeling by being recognized as a National Centre for Autism. My starting point however is the Professional Discourse: Diploma in Special Education which is the cultural factor that trains the social workers the norms and standards of the discursive practice.

#### **7.3.1 The Professional Discourse: Diploma in Special Education (ASD).**

AFA was in 2003 recognized by the Rehabilitation Council of India (RCI) as a training center to train special educators in ASD and started the same year, the semi-professional Diploma Course in Special Education in ASD. Based on the non-violent teaching policy and the knowledge AFA has obtained through the TEACCH Division and ACTION team AFA started up the semi-professional education: Diploma in Special Education (ASD). The diploma course is a one-year training program where trainees

*‘... through extensive exposure in practical hands-on training and lectures learn to be comfortable with the principles and practices of working with persons with autism. Along with knowledge about autism and special education, the trainees gain knowledge of behaviour modification, social development, language development, and family counseling ([www.aactionautism.org](http://www.aactionautism.org)):*

Through daily practical training at the Open School and lectures by social workers at the Open Door School, trainees learn about the characteristic of the disorder ASD, learn how to set up a supportive non-violent teaching environment for children's with ASD in accordance to the philosophy and principles of Structured Teaching, they learn how to understand and manage challenging behaviours in accordance to the norms and standards of the discursive practice of the Open Door School. They become social workers specialized in the field of ASD.

Starting up the diploma course the amateurish approach at the Open Door School became professionalized. This means, all employed social workers at the Open Door School have a diploma in Special education and are not only the social workers working to socially support and teach the children's with ASD. They are also supervisors for the trainees during their daily practical training at the Open Door School. As supervisors for the trainees and other visiting educators who come to the Open Door School to observe, the social workers constitute a role model for how to socially support and teach people with ASD within an including teaching environment.

In terms of Foucault, the professional knowledge social workers obtain through their professional education, entails that social workers are learned to be disciplined towards the practice of the Open Door School. The social workers at the Open Door School are the pioneers of the trainees and other visiting educators in terms of how to understand and manage challenging behaviours in regard to the non-violent policy at the Open Door School. But also in accordance with social movement of AFA they are pioneers in terms of regulating the conduct and understanding of people with ASD among the visiting educators coming from all over India and Southeast Asia. As pioneers to promote a national welfare policy for people with ASD, social workers are entailed to be disciplined towards the discursive practice of the Open Door School to empower a professional non-violent teaching within educational settings for children's with ASD in India.

*'Today during the discussion time the social workers were discussion the behaviours of one of the students, the son of one of the social workers. The mother interfered in the discussion regarding her son. The mother was told not to interfere and was reminded by the director that they are not mothers or volunteers any longer, but professionals. I have repeatedly heard this reminder, 'that we are 'professionals'. Why is that so significant for the director? It is a parent organization, and most of them are mothers of children with ASD. They are first of all mothers who work passionately to change the lives of their children with ASD. Why is it important they become professionals? (EN)*

Being professionals is significant in the perspective of the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 (Act 44 of 1999) ([www.nationaltrust.in](http://www.nationaltrust.in)). With the act of 1999, ASD was recognized as a disorder and enrolled in the National Trust empowering work for facilitating a welfare society for people with disabilities, *'... to facilitate the realization of equal opportunities, protection of rights and full participation of persons with disability'* (Ibid.).

After reading the preliminary of Act No. 44 of 1999, I became aware why it is significant to be professionals. According to the preliminary:

*'Professional means a person who is having special expertise in a field, which would promote the welfare of persons with disability'.*

To promote a including welfare for people with ASD and other disabilities AFA needed to transcend the amateurish approach of the mothers into a professional discourse specialized in the field of ASD. AFA had to build up a professional discourse to be able to dominate and promote a social policy for people with ASD within the Indian society. This means, AFA had to adapt the non-violent policy and their social knowledge gathered for the already existing international professional episteme of the TEACCH program into professional norms and standards. Recognized as a training center AFA had in the view of Foucault gain the power within the field of ASD to produce the non-violent teaching policy and the Open Doors Schools intervention approach of Structured Teaching as the 'truth' intervention approach for teaching and socially supporting the needs of children's with ASD with educational settings (Foucault, 1977).

In terms of Honneth, social workers transformation from being mothers/volunteers/amateurs to be 'professionals' transcended the normative ideal of the non-violent teaching policy to a new national level (Honneth,1995). A transcending, where social workers as professional is given a significant importance in the social movement to promote rights for people with ASD i.e. promote human rights of protection and educational rights within the Indian Society, among others (Honneth 1995).

The contextual factor of the Diploma course and the professionalization of the social workers at the Open Door School is a significant cultural factor that affects the discursive practice of the Open Door School as it is within the training of the diploma course social workers are trained in the light of this study how to understand and manage challenging behaviours in regard to discursive practice of the Open Door School.



### **7.3.2 Status as the Indian National Centre for Autism**

This last identified social factor, Status as the Indian National Centre for Autism, is a trans-local relation that does affect the discursive practice of the Open Door School directly, but mutually magnifies the cultural factor of the social workers professional expertise in terms of promoting and dominating the social welfare policy for people with ASD within the Indian society.

Due to the intensive work of AFA and the expanding knowledge of the disorder ASD in India through the last decades, AFA was in 2006 dedicated as the Indian National Centre for Autism by Sonia Gandhi, President of the Indian National Congress<sup>30</sup> and became the primary organization specified in ASD in India. In the inauguration ceremony of the National Center for Autism, Gandhi pronounced in her speak that:

*‘The National Centre will enable Action for Autism [AFA] to expand and extend its activities to provide early and accurate diagnosis, make referrals to appropriate services, train and counsel persons with autism and their families, promote inclusion, train and inform practitioners and medical professionals as well as society at large, advocate for rights, undertake research activities, and help many more children with autism and their families’. (Inauguration ceremony by Smt. Sonia Gandhi, the 8<sup>th</sup> of September 2006 (Appendix 7))*

As a National Centre, AFA had become the official spokesperson of people with ASD in India to promote and dominate the social welfare for people with ASD and their families through advocacy, training, research and direct services ([www.autism-india.org](http://www.autism-india.org)).

With the recognition as a National Centre, the Open Door School was officially recognized as the modeling school for children’s with ASD in India ([www.autism-india.org](http://www.autism-india.org)). This implies an obligation to test, modify and adapt training techniques gathered from around the world to the Indian context before

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<sup>30</sup> The Indian National Congress is one out of two major political parties in India.

the techniques are being referred to as effective techniques to professional and parents in other parts of India (as well as Southeast Asia) (Ibid).

Overall, the status as a National Centre for Autism magnifies the social workers position as roles model. Not only in terms of teaching children' with ASD by socially supporting their social needs without the use of aversive methods, but also role models for the trainees and visiting educators who come to the Open Door School to learn to norms and standards of how social workers at the Open Door School understand and manage challenging behaviours.

### ***7.3.3 The Social Policy of India***

Being recognized as the National Centre for Autism AFA was given a dominating position in the process of developing a social welfare for people with ASD in India.

*I: What legally rights do people with autism have in India? I know that India have signed or ratified the UN convention of disabilities, but are they implemented?*

*S: Five years back or few years back not much was really being done. But now I think within the last year a lot have been done especially in regard to education. Nowadays a lot is being done so they can attend the mainstream and the teachers are being consciously trained. So in terms of the rights of education then something is really happening. But in regard to the law of India it doesn't include autism. There is no mention of autism in the laws. But they (the Indian Government) are, Merry is on the board, they are going to entrap them into the law ...so there will be coming new services (IA).*

People with ASD have still not gained recognition within the law of India and have no right as such. However with the influence AFA have gained as a National Centre AFA are on the board and has a significant impact on the new law which is, in this moment of writing, being formulated. Even though a lot have happen within the educational services does not mean people with ASD

are being given the right intervention approach and hence the socially support people with ASD need to be socially included in educational settings:

*S: Okay, what rights do they have? See, as such if we look at it upon institutions all citizens in the country have fundamental rights, but the reality is that very often, If, you have a disability you get deprive of this rights. After having ratified the UN convention there is now an effort to try and humanize disability laws with the UN convention to ensure that all the rights that are specifically mentioned in that. So, if, you go by the public institutions with the right to education and all that stuff, people with disabilities have the right to education, to employment, the right to be treated with dignity and respect, you know, all that is there. But the reality is that very often they are deprived of their rights of education, right. How? Because they are not ... well in many ways ... once they have no admission into schools because they have autism. If you have autism and you want to study mainstream school you may not be taken in because you have autism, because of the behaviours. Many schools will also not take them in because they have many challenging behaviours. Schools may take you in, but they may not give you the appropriated intervention and that is also a violation of human rights. Just getting to a school is not just getting your rights. Getting to a school and getting the appropriated intervention is getting your rights. So as for a person with autism the vast majority is getting into to school, but they are not getting the right education they need (IF).*

The quotation clearly indicates that children's with ASD despite the right of education are being deprived on their rights and there are children's within the governmental services who are still not receiving the – in terms of merry – the appropriated intervention i.e. the socially support children's with ASD need to be included with educational services. So despite of the social condition within the educational services there still is a need to promote awareness of the disorder ASD among professionals within ordinary Indian school services to understand and manage the challenging behaviours children's with ASD displays.

The mapping of the Open Door School confirms the findings that it is in many contexts the social movement of grassroots organizations which generates our

understandings of social problems and in their solutions of the social problems the grassroots organizations enters into a relationship with exiting professional episteme whom they rely on (Henriksen Bundesen, 2003). In fact, the social movement of AFA and the Open Door School is consistent with the social genesis of the Danish Social Welfare System.

The Danish social welfare system is generated by comprehensive movement of voluntary organization who generated the understanding of different social problems within the social areas as childcare, the disability sector, drug problems etc. (Henriksen Bundesen, 2003). In the post-war period, the amateurish approach of volunteering organizations running institutions had to take up professional expertise if they wanted to sustain their institutions and as well wanted to dominate social policy (ibid.). This meant that volunteering organizations became professionalized and professional groups within the public system took up the lead as pioneers in developing the Danish social welfare (Ibid.).

Viewed from the perspective of the history of the Danish Welfare, AFA needed to become professionalized to dominate social policy. This means they had to adapt their worldview as well as their social activities and institutions to professional norms and standards to get a dominating influence in making a social policy that includes people with ASD within the law of India. As a National Center for Autism AFA has gained political domination and is currently on the political board to entrap people with ASD within the new main law of India. But as Merry Barua states in the previous quotation - getting rights does not mean people with ASD will actually get their rights. People with ASD will still be deprived of their right and thus the social movement of AFA to facilitate a fully inclusive non-violent environment for people with ASD with educational services as well as the society of Indian moves on. And yet, with new services coming up in line with the new law the social workers role as role models for how to understand and manage challenging behaviours without the use of aversive methods have been strengthened further.

## 8.0 Conclusion

In the following I summarize my identification and mapping of the Open Door School and match the results with the research question that this study aims to answer:

**How do contextual and cultural factors affect the way in which social workers understand and manage challenging behaviour displayed by people with Autism Spectrum Disorders at the Open Door School in India?**

The identification of the discursive field of the Open Door School shows that the social workers understanding and management is understood and managed in consistent with the philosophy and principles of the intervention method of Structured Teacching, an American evidence based intervention approach administrated by the TEACCH Division in North Carolina. In terms of Spradley the identification of the discursive practice shows that the philosophy and principles of Structured Teacching is the acquired knowledge social workers at the Open Door School have learned, revised, maintained and define as the way to understand and manage challenging. Structured Teacching is the intervention approach that for Foucault objectifies social workers power / knowledge in how social workers at the Open Door School understand, define and manage challenging behaviours.

The analytical mapping of the contextual and cultural factors that organize the Open Door School shows that social workers understanding and managing of challenging behaviours is concerted and affected by the trans-local ruling relations with the three fields: The field of the Social Movement, the Discursive Field and the Institutional Field.

The mapping of the Field of the Social Movement shows that it is the experiences of three mothers of children with ASD that started the social movement of the Parent organization, Action for Autism (AFA). In opposition to the physical oppression and structural exclusion their children's were exposed to in a high-profile special school, AFA founded in 1994 the Open Door School

as a modeling school generated upon a non-violent teaching policy where any use of aversive methods was strictly forbidden. The mapping of the field of the social movement, shows that social workers at the Open Door School are affected by the non-violent teaching policy and in terms of being a modeling school social workers at the Door School are the pioneers, the role models for supporting the need of children's with ASD to be included in Educational activities and peer-activities without the use of aversive methods.

The mapping the Discursive Field, shows that Merry Barua (founder of the Open Door School) went to the TEACCH Division in North Carolina and took up training in the philosophy and principles of Structured Teacching and found an appropriate intervention that matches the non-violent teaching policy of the Open Door School. Accordingly, Structured Teacching was introduced and implemented at the Open Door School and founded thus generated the social workers understanding and management of challenging behaviours. To sustain the understanding and management of the social workers practicing of the philosophy and principles of Structured Teacching, AFA entered later into cooperation with the American organization, the ACCTION team. The ACCTION team, a team of professional educators, travels to The Open Door School to provide training for the social workers and thus sustain the social workers understanding and management in consistence with the philosophy and principles of Structured Teacching.

The mapping of the Discursive Field also shows that social workers at the Open Door School are practicing the philosophy and principles of Structured Teacching manually and are accordingly found to be institutional accountable in practicing the long term goal of Structured Teaching namely the social support the needs children's with ASD have to be fully included within educational settings. In terms of the long term goal of teaching educational skills such as academics, the mapping found a lack of quality of the educational content. Accordingly a suggestion of employing a professional teacher qualified to teach academic is made.

The mapping of the Institutional Field shows that the non-violent teaching policy and the implementation of Structured Teaching concertedly generated the recognition of AFA as a training center by the Rehabilitation Centre of India. AFA started in 2003 the semi-professional education: Diploma course in special education in the field ASD and hence, transformed the amateurish approach of the Open Door School to a professionalized discourse. The mapping shows that this transformation has a magnified impact on the social workers understanding and management of challenging behaviour as it is during the diploma discourse the social workers are taught and trained to understand and manage challenging behaviour in consistent with the norms and standards of the Non-violent teaching strategy and the philosophy and principles of Structured Teaching.

The mapping of the Institutional Field also shows that AFA was in 2006 recognized as the Indian National Centre for Autism by President of the Indian National Congress, Sonia Gandhi. As a National Centre for Autism the Open Door School was official recognized as a modeling school for other professional educators, parents and others in India to come and learn how to set up a supportive teaching environment in accordance with the norms and standards of the Open Door School. The recognition as a modeling school is shown to have magnified social workers role as pioneers and role models in understanding and managing challenging behaviours. in consistence with the non-violent teaching policy and the philosophy and principles of the Open Door School.

Throughout the mapping of the ruling relations I have reflected upon my own cultural premises for understanding and managing challenging behaviours as Danish social workers. I have reflected upon how I as a Danish social worker is governed and controlled through a comprehensive documentation system if I in any incident have to use force in managing challenging behaviours.

I have reflected upon the eclectic intervention approach and reflective approach I have been train to conduct as a social worker, a reflective approach that make me more ambiguous towards social demands by bending the rules in the sake

of the individual with ASD and thus not practicing the principles of the intervention approaches.

Despite the rights of protection of People with ASD in Denmark, I have reflected upon the fact that people with ASD with Danish institutional settings still experience neglect in terms of aversive use. In addition to this, I have reflected upon the importance of social workers to be good role models in managing challenging behaviours without the use of aversive methods. Also I have reflected upon the importance of social workers to defy their fear to speak up and question, if, they observe colleagues or others using aversive methods in the process of managing challenging behaviours displayed by people with ASD – this no matter if you are a Danish social worker or social worker at the Open Door School.

Reflecting upon the social genesis of the history of the Danish welfare system, the mapping of the Open Door School confirms the findings that it is in many contexts grassroots organizations which generates our understandings of social problems and in their solutions of the social problems, the grassroots organizations enters into relationship with exiting professional episteme whom they rely on (Henriksen & Bundesen, 2003).

### **8.1 Further Perspectives**

The mapping of the Open Door School confirms the findings that volunteering grassroots organizations in many contexts must adapt professional knowledge and expertise to gain recognition as well as domination on social policy (Henriksen & Bundesen, 2003). In a further perspective it would be of interest to study what general conditions makes it necessary for volunteering organization to adapt the norms and standards from a – mostly American - existing professional episteme to build up a sustainable organization. Also to study how existing professional episteme such as the TEACCH program is being spread out international. In the lights of this study it would be interesting to explore how Merry Barua got connected with the TEACCH Division and whether it was a contingency that Structured Teaching matches the non-violent teaching policy?



Whether other educational settings in India have adapted the professional episteme of the Open Door School? Also it would be of interest to study the purpose of the American organization of the AACTION team. Is their goal to spread out the professional episteme of Structured Teaching? Overall it would be of interest to study whether an adaption of professional norms and standards is a general premise to gain recognition within the cultural premises of any organization in a western country as well as in the developing countries such as India? This because, the cultural premises of Danish volunteering organizations that was running institutions in the post war period could choose to either adapt to an existing professional episteme or close down (Henriksen & Bundesen, 2003).

## **8.2 Methodological reflections**

Being a beginner in doing ethnography my personally journey to the Open Door School has not just been a learning process in conducting ethnographic fieldwork and learning how to navigate within the cultural context of India and particular the Open Door School. It has been a challenging process in learning how to do ethnographic work in all its aspects. Throughout the study I have been reflecting on my methodologically choice and use of institutional ethnography. During the study as I became more and more known with the theories and analytical tools of Institutional ethnography, I became aware that it was not possible to use the analytical tools of text in accordance with institutional ethnography.

Analyzing text in institutional ethnography is analyzing how organizational documents such as Acts, action plans etc. are affecting and shaping social workers work and beliefs (Smith, 2005). While doing fieldwork, I became aware that finding and getting access to documents that shapes social workers work at the Open Door School were hard to get as there hardly exist any. I was therefore forced to use my own transformed text (ethnographic notes and interviews) of the social workers statements and my own observations in my process of analyzing how contextual and cultural factors constitutes the social

workers understanding and management of challenging behaviours. Conducting research in a developing country with different forms of regulations than western countries has in other words affected my analysis.

Making use of western sociologies in a developing country has not just been a challenge in regard to institutional ethnography. It has also affected my theoretically choice. Theoretically, my starting point of this study was to study whether and how people with ASD was recognized in India in the perspective of Honneth' Recognition theory. But due to the cultural premises of oppression of people with ASD in India still are exposed to the use of Recognition model of Honneth appear to be too trite. Hence, I deselected the use of Honneth' model of Recognition, but does however refer to Honneth in the analytical description.

In the process of this study I have reflected upon my methodological choice of institutional ethnography. I have more specific considered to merge institutional ethnography with discourse analysis in terms of Fairclough, but I soon realized that merging Fairclough and Smith limited my mapping due to Fairclough focus on reproducing existing discourses. My focus was not on whether the Open Door School was reproducing an existing discourse. My focus was how contextual and cultural factors actually concerted and constituted the discursive practice of the Open Door school and accordingly affected social workers understanding and management of challenging behaviours at the Open Door School.

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## **10. Appendix**

**Appendix 1:** Ethical reflections

**Appendix 2:** Selecting informants – the progression and reflections

**Appendix 3:** Guide for interviewing

**Appendix 4:** Guide for observing

**Appendix 5:** Reflections regarding my role as an observant

**Appendix 6:** The process of writing field notes – reflections.

**Appendix 7:** Message by Sonia Gandhi, Inauguration Ceremony, Sep. 2006

### **Appendix attached on disc**

**Appendix 8:** Guide for observation, Work & Safety project

**Appendix 9:** Application for conducting research at the Open Door School, January 2010

**Appendix 9A:** Project Description, January 2010

**Appendix 10:** Application for conducting research at the Open Door School, Marts 2011

**Appendix 10A:** Project Description, Marts 2011

**Appendix 11:** Transcriptions of interviews

**Appendix 12:** Honneth' - Theory of Recognition

## Appendix 1

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### Ethical reflections

My ethical reflections and approach for conducting research at the Open Door School was among others that the informants were to be asked to participate voluntarily as informants and the informants were to be informed about my ethical rules for participating in my study. This included that their names would not be mentioned anywhere (anonymity), that confidential information would not be written in the final report, that the report would be recognizable for the informants. Overall, I wanted to make sure that the informants felt safe by participating in the project and had the right to say no to participate.

To make sure that all of my informants understood my ethical approach, I asked my gatekeeper to inform the informants in Hindi. My intention to involve the gatekeeper was to make a linguistic security that my informants understood and agree with the ethical terms. However involving my gatekeeper in this process turned out different in terms of my intentions as the selected informants were told to participate and not given any choice. They were told that I would observe them for one week and I would have to interview them after my observational time. Consequently the informants did not participate voluntarily but was in my terms 'ordered' to participate and hence, the procedure for contacting and making relations with my informants at the Open Door School did not turn out the way I had planned. This caused a lot of reflections of it would affect my relations with the informants and my study in general. Fortunately this was not the case as all of my informants were most informative, open and positive in regard to my participation, casually conversations, and informal interviews. Over time I realized that as a part of being a modeling school the social workers at the Open Door School are used to being observed by externals and hence, the gatekeepers way of 'just' telling the informants that they will be observed and interviewed is a part of the culture and being a social worker at the Open Door School.

## Appendix 2

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### **Selecting informants – the progression and reflections**

In the process of selecting informants, I selected my informants in consultation with my supervisor. The final selection of informants was made after having observed the organization of the Open Door School for a few days. Through these days I had an opportunity to relate with all of the social worker and hence get an insight of which social worker who could be potential informants in accordance to Spradley criteria for selecting informants: enculturation, current involvement, an unfamiliar scene, adequate time and non-analysis (Spradley, 1979). As mentioned I selected in consultation with my supervisor for experienced social workers who were in terms of Spradley seen as acculturated and currently involved. However most essential the all spoke English fluently or brokenly.

According to Spradley it is essential for an ethnographer doing field work to create, maintain and sustain a fruitful relationship with your informants (Spradley, 1979). Throughout my time of observation I have in the best positive way respected the informants in terms of interrupting them more than necessary in their daily work and have negotiated my role as observant with each individual informant. All informants have shown reciprocated respect and even invited me openly back for further observations during my second visit.

## Appendix 3

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### Interview guide

As mentioned my interview guide are developed on inspiration of the theoretically basics of Emerson' four fundamental factors for understanding the social processes that makes an understanding. The four factors are outline in the left column in the following interview guide. The middle column consists of my thematically questions which I need to ask for answering my research questions. The thematically questions are made as a guideline for myself whereas the questions for interviewing in the right column are questions made as research questions for my informants to answer.

<b>Emerson's four factors for identifying social processes that makes an institutional setting</b>	<b>Thematically questions</b>	<b>Questions for interviewing</b>
<b>- Social rules regarding what constitutes appropriated behaviour in the Open Door School</b>	What social rules exist for appropriated behaviours? What is seen as in appropriated behaviours?	Could you describe what appropriated behaviors for the students are? The way student behave appropriated here at the Open Door School? Could you describe in appropriated behaviors? (Hands to you self, sit straight, sit quietly etc.?) How would you describe the influence structural teaching has in terms of how appropriated behaviour is deemed? Is
<b>- The ability of the social worker to give a plausible account of their behaviour</b>	How do social workers justify their behavior in terms of managing challenging behaviour? Which arguments do they	Could you describe what happen in situation where the child X displays challenging behaviours? Could you describe the

	use for their way of managing challenging behaviours?	way you acted in terms of managing the challenging behaviour displayed and can you describe why you acted as you did?
- <b>The beliefs held by other social workers in the setting about the nature of ASD and the causes of the persons 'challenging' behaviour.</b>	What do the social workers belief causes ASD? & What do the social workers belief causes challenging behaviours?	Could you describe what you believe are the reason why students display challenging behaviours? Describe what you believe causes challenging behaviours? Describe why the students are displaying these kinds of behaviours?
- <b>The capacity of the setting to manage any disruption caused by the person's behaviour.</b>	How are challenging behaviours ought to be managed by social workers at the Open Door School?	How would you describe to me as a social worker how to manage any type of challenging behaviours? What kind of rules, procedures or approaches do you have to manage challenging behaviours? Could you describe those strategies / behavioural modification techniques the Open Door School is using to manage challenging behaviours?

## Interview guide for interviewing Directors

In extension of my observations and interviews with the four social workers and the behavioural management consultant, I sat up the following thematically questions before interviewing the director of the Open Door School and the director and founder of the National Centre of Autism. The purpose for interviewing the directors was to cover the social relations and trans-local processes for how contextual and cultural factors actually made the intervention approach at the Open Door School to cover which trans-local processes actually implemented the intervention approach of structural teaching at the Open Door School. The following thematically questions were developed in

according to my already collected ethnographic knowledge after observing and interviewing the four social workers and the consultant. In other words the interviews with the directors were extended with following thematically questions:

<b>Smith's social theory of institutional ethnography</b>	<b>Thematically questions</b>	<b>Questions for interviewing</b>
<p><b>Social relations</b> - <b>Contextual and cultural factors</b></p>	<p>The Indian government – how is the link economically, politically etc. with the Open Door School?</p> <p>Being an NGO – how does this affect the choice of structural teaching and the way for understanding and managing challenging behaviours?</p> <p>What does it imply to be a modeling school? – How does it affect the way social workers manage and understand challenging behaviours?</p> <p>The AAction Team in America – how is the cooperation? Is the Open Door School obliged to use structural teaching in terms of any kind of relationship / sponsorship etc.?</p>	<p>How is the Open Door School linked with the Indian Government? Are there any economically supported?</p> <p>How does it affect the Open Door School that it is recognized as a modeling school for implementing intervention approaches to an Indian context?</p> <p>What is the link between the use of Structural teaching, ABA and VBA as the interventions approaches at the Open Door School and the Open Door School being a modeling school implementing western intervention programmes into the culture of India? How is the link between the facts that the Open Door School is a modeling school and that structural teaching is the primary intervention at the Open Door School? Does the connection with the AAction team have</p>

		<p>an influence in terms of using structural teaching as one of the primary intervention approaches – if so – how?</p> <p>How do you cooperate with the American NGO AAction team in terms of implementing Structural teaching at the Open Door School? Are there any economically support between the Open Door School and the AAction Team</p> <p>What influence does it have that the Open Door School is a modeling school in terms of electing intervention approaches?</p>
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<b>Honneth's theory of Recognition - Human Rights</b>	<b>Thematically questions</b>	<b>Questions for interviewing</b>
<b>Spheres of Rights - Human Rights</b>	<p>Have people with ASD gained politically right in India? How has the UN Convention on the Rights of People with Disabilities been ratified in India? How are people protected against violence at AFA? Through politically or moral laws? How are the morally law in regard to protect people with ASD towards physically restraints in relation to challenging behaviours?</p>	<p>Could you describe to me the politically Rights of people with ASD in India?</p> <p>Could you describe to me the morally Rights for People with ASD at the Open Door School in relation to challenging behaviours?</p> <p>Could you describe to me how social workers at the Open Door School is ought to manage challenging behaviours in avoiding any violations of the students?</p> <p>Is it written down how</p>



		the teachers are ought to do when students are displaying challenging behaviours?
<b>Sphere of Solidarity - Structural teaching</b>	When students displays challenging behaviours of a negative characteristics - How does structural teaching technically enable the students to sense oneself as a unique valued person? How does structural teaching make it possible to develop an individual' self-esteem when a student display repetitively negative behaviours in terms of challenging behaviours?	

<b>Foucault' theory of power / knowledge</b>	<b>Thematically questions</b>	<b>Questions for interviewing</b>
<b>Regime of knowledge</b>	Which regime of knowledge exists within the Open Door School in terms of understanding and managing challenging behaviours?	

## Appendix 4

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### Guide for observation

The observation guide is developed on elements of the Work & Safety project and, like the guide of interviewing, the four factors of Emerson to identify the social processes of how institutions manage and understand challenging behaviours. The left column in the below figure illustrates the four factors of Emerson and the middle column the elements of from the Work & Safety guide I find relevant. On the basis of the four factors of Emerson and the elements of the Work & Safety guide the right column illustrates the focus of my own developed observation guide.

<b>Emerson's four factors for identifying social processes that makes an institutional setting</b>	<b>Work &amp; Safety</b>	<b>Guide for observing</b>
<ul style="list-style-type: none"><li>- <b>Social rules regarding what constitutes appropriated behaviour in the Open Door School</b></li></ul>	<b>Cultural themes:</b> Are there any cultural themes that define legitimated & illegitimated behaviours of the students? Culturally themes that forces certain actions by the social workers.	Identifying the social rules: What social rules exist for appropriated behaviours? What is seen as inappropriate behaviours? What are appropriated behaviours?
<ul style="list-style-type: none"><li>- <b>The ability of the social worker to give a plausible account of their behaviour</b></li></ul>	<b>Pedagogically episteme:</b> How does the staff justify their acts and precautions? Is there a link between what staffs says and actually do in terms of managing challenging behaviours? What is the attitude of the staff in respect of the individual's human rights verses the intervention	How do social workers justify their behavior in terms of managing challenging behaviour? Which arguments do they use for their way of managing challenging behaviours?

	approach?	
<ul style="list-style-type: none"> <li>- The beliefs held by other social workers in the setting about the nature of ASD and the causes of the persons 'challenging' behaviour.</li> </ul>		<p>What do the social workers belief causes ASD? &amp; What do the social workers belief causes challenging behaviours?</p>
<ul style="list-style-type: none"> <li>- The capacity of the setting to manage any disruption caused by the person's behaviour.</li> </ul>	<p><b>Pedagogically episteme:</b> Intervention approach</p> <p><b>Socio-technics:</b> What different kind of techniques do the social workers use to manage challenging behaviours?</p>	<p>Intervention approach:</p> <p>What different kind of techniques do the social workers use to manage challenging behaviours?</p> <p>How do intervention approaches / techniques organize the everyday work at the Open Door School? How do the approaches prevent, provoke and manage challenging behaviours in the everyday work?</p>
	<p><b>Organizational narratives –</b></p> <p>Recurrent narratives that maintains identities, norms and particular issues for discussion.</p> <p>Narratives such as:</p> <ul style="list-style-type: none"> <li>- 'We are good at....'</li> <li>- 'Our problems are...'</li> <li>- Exemplary cases regarding particular occurrences and particular point.</li> </ul> <p>Narratives can define the organizational community that</p>	<p>Are there any recurrent narratives that maintain the identity of the Open Door School?</p> <p>Are there recurrent narratives regarding norms in relation to managing and understanding challenging behaviours?</p> <p>Are there recurrent issues for discussion in terms of managing and understanding challenging behaviours?</p>

	gives it a certain identity. An identity that may take them to the outside world as an innovative organization or likewise.	
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The following figures are built on the same concepts as the interview guide. They take set in the theories of institutional ethnography, Honneth' theory of Recognition and Foucault' theory of power/knowledge.

<b>Smith's social theory of institutional ethnography</b>	<b>Thematically questions</b>	<b>Guide for observing</b>
<b>Social relations</b> - <b>Contextual and cultural factors</b>	<p>What does it imply to be a modeling school? – How does it affect the way social workers manage and understand challenging behaviours?</p> <p>The AAction Team in America – how is the cooperation? Is the Open Door School obliged to use structural teaching in terms of any kind of relationship / sponsorship etc.?</p>	<p>Being a modeling school - how do the social workers speak of this fact? Does it affect the everyday work?</p> <p>What is the link between the use of Structural teaching, ABA and VBA as the interventions approaches at the Open Door School and the Open Door School being a modeling school implementing western intervention programmes into the culture of India? What are the narratives of this linkage and what affect does it have in the everyday work?</p> <p>Does the American NGO AAction team affect the everyday work at the Open Door School?</p>

Honneth's theory of Recognition	Thematically questions	Guide for observing
<b>Spheres of Rights</b> - <b>Human Rights</b>	Have people with ASD gained politically right in India? How has the UN Convention on the Rights of People with Disabilities been ratified in India? How are people protected against violence at AFA? Through politically or moral laws? How are the morally law in regard to protect people with ASD towards physically restraints in relation to challenging behaviours?	Do the social workers use physically restraints in terms of managing challenging behaviours?  Which non-written rules exist in terms of using physically restraints?  Which forms of restraints are legitimated and which is not?  How does the staff speak of the rights of the students?  In which way does the staff speak of recognizing the students? Do they speak of their rights?  What is the morality in regard to using physically restraint in any forms?
<b>Sphere of Solidarity</b> - <b>Structural teaching</b>	When students displays challenging behaviours of a negative characteristics - How does structural teaching technically enable the students to sense oneself as a unique valued person? How does structural teaching make it possible to develop an individual' self-esteem when a student display repetitively negative	

	behaviours in terms of challenging behaviours?	
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Foucault' theory of power / knowledge	Thematically questions	Guide for observing
Regime of knowledge	Which regime of knowledge exists within the Open Door School in terms of understanding and managing challenging behaviours?	Which methods / techniques does the staff refer to?

## Appendix 5

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### Reflections regarding my role as an observant

When doing participant observation you do not, chose your own field role as ethnographer Hammersley, et al, 2007). Most often you are ascribed a role by the actors in the field (Ibid.). To make sure I was given a role as an observant and not as an experienced social worker, I made it clear it from the beginning in process of applying for permission to conduct research at the Open Door School that my purpose was to observe the Open Door School as a master student and not to operate as a social worker or consultant. My intention was to observe the social workers at the Open Door School by 'shadowing' them i.e. follow the social workers in their everyday work and let them teach me how they manage and are ought to manage challenging behaviours doing their everyday work. Hence, my intention was not to be fully participating neither taking on a passive role by just being observant (Spradley, 1979). In terms of my informal and formally interviewing my intention was to interact with the informants to get an insight and to learn how I should manage challenging behaviours if I worked as a social worker at the Open Door School. Hence, the purpose of during participant observation was to acquire a moderate role where I would be active participating and attentive, but at the same time keep a research distance in my relation with the informants (Spradley, 1999). Before my arrival to the Open Door School my gatekeeper agreed and gave me permission for taking on a moderate role for observing and gave me accordingly a written approval.

Despite the written approval of my role as participant observant a discrepancy between me and my gatekeeper arose. According to my gatekeeper observing meant fully participation on an equal footing with the staff. My gatekeeper expected me to work as a staff member due to my education as a Socialpædagog and experience. This understanding was in contradiction of my intention for observing. According to Burgess, I was as a newcomer to the Open Door School ascribed to taken on the role as a social worker and not a student doing participant observation as a master student as agreed in advanced. The

discrepancy caused a lot of frustrations and reflections in the beginning. Reflections such as whether my gatekeepers understanding of 'observing' would have been different, if, I had withheld my educational background as a Socialpædagog. It also caused reflection regarding how to cope with this assigned role I was given due to my educational background and the accordingly expectations from my informants to give them feedback on their work including counseling in relation to their structure and intervention programmes. Thus, I experienced the dilemma of being an educated social worker and being a master student.

Being an ethnographer in a field study is according to Burgess an ongoing process of exchanges and negotiations between the ethnographer and those being explored (Burgess, 1984). This means the role of the ethnographer negotiates and renegotiates continuously between the ethnographer and the informants and other actors who are involved in the research project. Accordingly to my gatekeeper' expectations I renegotiated my role as an observant. Through discussions and getting to know more of each other the gatekeeper let it be up to my own judgment which role to take up, but most importantly she consented that I should not act as a consultant for the informants. The informants were informed hereby. However it turned out to be a beneficial agreement for the informant as I due to lack of staff were involuntary forced to be fully participant. Overall, my role as a participant during my first visit to the Open Door School as an intern was an alternation between fully participant and partial participant. However my role as an observant during my second visit in spring 2011 was as a passive observant. The staff situation had changed in comparison to my first visit. A new big team of trainees meant that nomination between staff and children's were one to one.

However throughout my observational time I have in according to the observational guide of the Work & Safety been reflecting on how to control my observations. Controlling your own observations is according to the guidelines essential to create an insight of the organizational structure and the culture of the Open Door School. It is essential to be aware how an observation may



change subject whether you choose to shadow a certain informant, get an overview of a conflict, break, daily routines or you choose to sit in in a specific room to observe what is going on between changing staff and children's. Hence there are different ways for observing how the everyday work is concerted in an institution.

My way for observing has mainly taking place by shadowing the informant / the class teachers. I have been following my informants and continually been interviewing them informally through casually conversations or as Smith calls it through 'talking' with my informants (Campbell & Gregor, 2004).

## Appendix 6

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### **The process of writing field notes – reflections.**

Because of my alternating observational role between participating fully and partial it became clear to me from the beginning that I had to work out my own guidelines for how to control my observations as a basis for writing up my field notes. Also from the beginning it was clear to me that due to my observational role it was not possible to bring paper and pen and write down observations accordingly.

Hence by reading about Spradley' (1979) different types of field notes I started to write condensed description. This means to write down sentences, words or phrases as a memory for a later expansive explanation of situations I had observed. Thus I carried always a small notebook and pen in my pocket to write down key words or terms of situations I had observed and whenever I had time, I wrote it all in an expanded explanation. My guideline to write down the expanded explanation included firstly a description of the situation observed and secondly to describe my own reflections regarding the situation observed. My own reflections are in other words my interpretations of my observations, which means I make use of my myself as a 'thermometer' to measure what the observed situations emotionally do to me. The described procedure turned out to be ideal in terms of my frames and conditions for observing.

Due to my challenges of having to fully participate and not having time to write field notes, I started taking photo' of the physical environments, objects, events, or performances which I experienced and observed at the Open Door School. I started carrying my still digital camera on me all the time for the simple purpose to take photo' of any event or object to memorize my experiences and observations.



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Sonia Gandhi  
President



#### MESSAGE

I am glad to learn that the work on the National Centre for Autism is complete. This is a very important step in the provision of services for persons with autism in India. Action For Autism has been pioneering the autism movement in India and this is a noteworthy step in that direction.

The National Centre will enable Action For Autism to expand and extend its activities to provide early and accurate diagnosis, make referrals to appropriate services, train and counsel persons with autism and their families, promote inclusion, train and inform practitioners and medical professionals as well as society at large, advocate for rights, undertake research activities, and help many more children with autism and their families. Its plans include efforts towards further ensuring their future through the setting up of group homes and creating employment opportunities.

The National Centre for Autism will empower individuals with autism and I hope will in time enable them to become spokespersons for their own rights. In turn, the empowerment of people of different abilities will enable our country to progress and prosper.

The National Centre is the result of the dedication and determined efforts of a group of parents at Action For Autism, who have changed the way we in India view Autism. I wish their efforts and this particular endeavour every success and hope they continue to receive all the support and encouragement that they richly deserve.

New Delhi  
September 5, 2006