STATE OF EXISTENCE

A Minor Field Study on Liminality and Enforcement of Existence in Jordan

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Abstract

This study comprises a three month fieldwork and 25 interviews conducted in Jordan on community based rehabilitation of persons with intellectual disability. The analytic procedure was conducted in an explicit and systematic manner much inspired by Grounded Theory. Interviewing social workers engaged in introducing community based rehabilitation in Jordan the study came to unveil their struggle with acquiring social positions for their previously liminal clients. This process took place closely interconnected with, and in opposition to, the social workers perceptions of resistance. Reception from the community initially consisted of resistance and consists of a denial of social existence of persons with intellectual disability. Denial of social existence was tightly bound to denial of existence in public space and the denial of visibility and exposure in the community. The study follows the work of creating and enforcing social existence for persons who were recurrently denied such. Hidden, avoided and feared the social worker places the child with intellectual disabilities in the midst of the community, most often within public schools.

Keywords: Intellectual Disability, Social Work, Strategies, Jordan, Community Based Rehabilitation

Prologue

On Mars 15 by night, we arrived at Queen Alia Airport just outside Amman, Jordan. Being tired, hungry and thirsty but most of all insecure of the situation, we took off with a local bus, hoping to reach our destination. This insecurity of the situation had a grab on us for several days and could partly be perceived as giving rise to our curiosity of the new country. As Swedes we were not used to the nonexistent sidewalks and the city being absolutely crowded with cars. Coming from a country with a great extent of political organisation and fiscal services on a national level, it was hard adjusting to the poor city planning. We were amazed to see people having picnics just by the road, actually any road, even a highway. The sand coloured houses were built with great stone bricks and, for us as foreigners, they all looked the same. Many houses were luxurious, proudly rising five or six floors from the ground. We were soon taught that the kind of building us as Swedes would think of as an apartment building hosting living for numerous families, here generally belonged to one agnatic kin. A friend told us a story of a family conflict of another friend of him; a son and his wife were moving from abroad to Jordan to live with his mother and father and some of his brothers. As every son and his family had one floor each, he as the newest to arrive built a new floor on top of his brother's, promising his wife the house terrace on the roof. However, when finishing his floor, another son, also living abroad, decided to move back home together with his wife and family. This situation had caused great grief and conflict among the brothers, their wives not settling for less (i.e. the terrace) than had been promised them. For us, this story also somewhat explained why there could be a very luxurious and meticulously kept house; still just outside of the property was a waste ground. Coming from the permeable but also legitimizing powers of the nation state Sweden, it was a culture shock to navigate in a nation building agnatic kin as the central organizing principle.

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1 Introduction

1.1 Background and Context

Jordan is a tribal community in which the traditional family is organised as patrinlineal, patrilocal and patriarchal. In Jordan, marriages may be both endogamous and exogamous and when women from several cities of Jordan made a public list of the most challenging problems they meet as women of Jordan, polygamous marriages was listed first (Sonbol 2003). Jordan is controlled by the highest standing of the country's different Bedouin Tribes; King Abdullah II whose House claims to be and is acknowledged as ascendants of the Holy Prophet Muhammad. The King has several agreements with the Bedouin clans to protect the land and story tells it that men of the Bedouin Tribes address the King by first name as to show that he is the highest standing of their people but he is still a part of their people (Al Oudat & Alshboul 2010). By referring to the advent of several security forces, among them the Arab Army and the Desert Patrol mainly performed by Bedouin tribes and reaffirming the values of the Bedouin tribes, Anthropologists Al Oudat and Alshboul (2010) claim that the tribal structure is incorporated into the state structure of Jordan. An argument associate professor of Islamic history, law and society Sonbol (2003) agrees on, arguing that "… Jordanian political and commercial elite and their tribal allies who constitute an important bloc of the security forces to espouse a discourse that supports mobilizing their power over Jordanian politics and wealth" (p. 251), although neatly veiled in an, according to Sonbol (2003), non-existing legitimacy referring to Islamic thoughts and shari'a law. Rather, argues Sonbol (2003), Jordan law can be traced to a number of sources from European traditions to patriarchal tribal values of family honour, having a direct effect on what it implies being a woman or a man in the Jordanian society. Anthropologists Al Oudat & Alshboul (2010) hold that the Bedouin values intertwined with the security forces were *"a collective security and responsibility in the tribe, clan and family"* (p. 70, Batikiotes, 1967, p.20)

Although Abdullah I, the great grandfather of the present King, had dreamt of creating a Syrian Empire (Al Oudat & Alshboul 2010), as is one of the traditional categories of organizing land and people in the Middle East (Lewis 1998), claiming that the Hashemites are Kings of the Arabs, the Hashemite house soon gave up this aspiration and has of today no announced intentions of other ruling than the internationally recognized land of Jordan (Al Oudat & Alshboul 2012). What had previously been despised, i.e. clefts among the Arab

people based on a division of land, is now the state of existence for Jordanians as well as Arabs from other countries and today Jordan nationalism may symbolically be summed up in the words of the King "Jordan First", implying that if the state of Jordan and its citizens do well, it will serve the whole Arab region.

1.2 This Thesis

The Swedish Organisation of Individual Relief (SOIR) Jordan works with children and adults with moderate and severe intellectual disability in Amman and surrounding areas. SOIR works with children with intellectual disability (ages 4-16) by initiating and maintaining school classes in collaboration with public schools and local Zakat Committees in Jordan administered areas as well as in Palestinian Refugee Camps and under UNRWA (United Nations Relief for Palestinians in the Near East) administration. The organisation also works with adolescents and adults (ages 14-35) by initiating and maintaining Vocational Training Centres in collaboration with local Zakat Committees and local Charity Societies. Apart from initiating collaborations with the local partners and financially supporting such projects, SOIR contributes with a Community Support Team. This team consists of two professional social workers, a nurse, two physiotherapists, an occupational therapist and two special education teachers. Professionals in this team visit the projects regularly and provide individual and need-based services for the users of the schools and the vocational training centres.

This thesis is based on a three-month field study in Amman and surrounding villages. During the period of mid March to the beginning of June 2012 the authors of this Bachelor's thesis lived at the Head Quarters of SOIR in Amman, Jordan. It is the result of 25 interviews with personnel at SOIR and local partners. Furthermore the authors have participated at different projects, such as vocational training centres, special schools and special classes within public schools, in a more open manner. The material collected throughout this work has been simultaneously analyzed in a systematic manner much influenced by Grounded Theory and using Open Code 3.6 (Umeå University 2009) when analysing the material. The collection and use of the material in this project has been in accordance with the ethical recommendations by The Swedish Research Council.

The process of starting community based school classes and community based vocational training centres is still a very active one. SOIR Jordan initiates projects and agrees with public schools and the Ministry of Education to initiate school classes for children with

intellectual disability in public schools. The agreements SOIR makes with their local partners span over three years and include a gradual withdrawal of social and economic responsibility on behalf of SOIR and an increasing social and economic responsibility on behalf of the local partner. Throughout this thesis we have understood this as a strategy aiming at initiating institutions throughout which persons with moderate and severe intellectual disability are provided with existence in public space, visibility in the local community, and an accepted social role. Thus, it is of utter importance that such institutions are gradually handed over to the community –"the community need to feel that this (auth. rem.: these children) is a part of them" (B 433), as one of our informants working more structurally declared to us. In fact, SOIR is in a process of withdrawing from Jordan and until 2015 the field staff is working on the sustainability of mainstreaming intellectual disability in the Jordan society. The goal of the organization is to mainstream children and adults with moderate and severe intellectual disability into existing institutions of the society and to create long withstanding institutions for these adults and children in the society.

1.3 Outline of the Problem

Disability, impairment or handicap may seem to be notions with substance and meanings that everyone knows of and therefore it may seem that they need no explication. However, the equivalence of concepts as disability, impairment and handicap does not exist in all languages. For example the Punan Bah of Borneo does not know of such inclusive conception including different types of... types of what? Types of deviance? Of non-functional characteristics? Of difference? What exactly does the notion disability imply?

In the Punan Bah society in Central Borneo, social roles are not ascribed with reference to any kind of performative ability (Nicolaisen 1995) and having a 'dis-ability' is thus not with reference to individual performance whether regarding physical, psychological or productive ability, as long as one is not perceived as a witch or spirit. An equivalence of terms as disability or handicap is traditionally non-existent in most African languages, as Anthropologist Devlieger (2010) puts it on the Songye language of the Songye people in former Zaire: "... the concept of ''disability'' (or handicap or an equivalent) that takes various impairments together in one convenient concept did not exist... "(p. 70).

Sociologist Turmusani (2003) describes how persons with disability in Jordan historically constitute an ambiguous position; some, as the blind (still reciting verses from

the Qu'ran) have been perceived as holy, while people with other disabilities, as persons with intellectual disability have been viewed on as the parents suffering a punishment or fate, as the result of sin. Jordan, as several other countries, has a history of excluding persons with disabilities, and Sociologist Turmusani reported from Jordan in 2003 that intellectually disabled persons, in general, generated the least positive attitudes among the public. Turmusani's (2003) dissertation included practices as hiding family members with disability at home, thus totally isolating persons with disability from public space and social contexts outside of the family.

SOIR Jordan has been working community based since the early 90's; however, it is still a work in process. Community Based Rehabilitation initially emerged from a lack of economic means in order to provide for persons with disability in lower and middle income countries during the 80's. However, a major review by the World Health Organization in the early twenty first century showed significant results in regards to social inclusion and poverty reduction, still, evaluating Community Based Rehabilitation with persons with intellectual disability has been a low priority (Robertson et al 2012). Special education researcher Qaryouti (1984) reported a positive change of attitudes towards blind and deaf persons as a consequence of familiarity in Jordan, however, at the same time reporting that such positive change of attitudes was not expressed towards intellectually disabled persons in Jordan, at the time.

Anthropologist Devlieger (2010) stresses how notions in our language and inherent substance of such notions always are constructed in accordance to certain contexts and identifies a structurally passive component and a structurally dynamic component in any system of classification. The structurally passive component emphasizes our dependence on and the unavoidable existence of classifications for "without them the world is not intelligible" (p. 73). The more dynamic component of classifications is that they are in fact constructed and as constructions are subject to change (Devlieger 2010). Perceiving disability in the sense of Anthropologist Douglas (1966) as anomalous polluter and taking account for Anthropologist and Ethnologist Strauss' (1963) dichotomous view on systems of classification, Anthropologist Devlieger (2010) poses disability as a notion with great potential to challenge oppositions structurally, i.e. to challenge the mere perception and categorization of existence into dichotomous entities.

Viewing the notion of disability, and thus the persons inhabiting and living such notion or social position, as carrying potential for structural difference in existing dichotomous schemes of categorization is highly relevant in this paper as we study processes of change in the social positions of persons with intellectual disability, as reflected upon by the social workers at SOIR Jordan. Is there an inherent potential of breaking schemes of categorization by enforcing existence of persons in liminal positions? And if so, have we in any way found the strategies of the social workers, nurses and principals etcetera to use such strategies in their social work?

1.4 Purpose of This Study

Our interest is in how the staff interprets and describes the social positions of persons with intellectual disability and processes of change in such social positions. The purpose of this study is to asses how social workers and other professional staff performing social work regarding persons with intellectual disability, reflect on community responses when introducing and maintaining Community Based Rehabilitation, including reports of their understanding of the views, attitudes and actions taken by the community, individually or organized, towards children with intellectual disability. The purpose has also been to analyze how these professionals relate to community responses when they reflect upon their social work strategies.

1.5 Research Questions

- In which ways do the professionals relate their experiences from meeting the community in their work, initiating, maintaining and extending Community Based Rehabilitation, to their views on and choice of social work strategies?
- How do the professionals interpret and describe the social positions of persons with intellectual disability and processes of change in these social positions?
- Is there a shared, possibly implicit but deductible, 'main concern' among the staff with regards to their work of initiating, maintaining and extending Community Based Rehabilitation and in which ways is such 'main concern' constructed?
- In what ways may such 'main concern' have an effect on how the performed social work is described?

2 Previous Research

Since this study was highly influenced by grounded theory the following research has not been read nor reviewed before our own understanding of our field, with all its generated concepts had been created and fully interconnected. Turner (1969) and Douglas (1966) had been reviewed years ago, thus their analyses' was part of our preconceptive framework. We want to emphasise the emergence of concepts from the field and not from literature.

It is shameful to have a family member with disability in the Arab context, it is "an ordeal to be endured by the family" (Turmusani 2003, p. 49; Nagata 2008, p. 69). It affects family identity (Al Krenawi et al. 2011) and in fear of disgrace and losing standing, families are reluctant to admitting having a disabled child (Turmusani 2003). The notion that everything comes from Allah and therefore the disabled child comes from Allah is quite prominent in previous research from the context (See for example Turmusani 2003; Bryant et al. 2011; Crabtree 2007). However the reason Allah may have for giving a family a child with disability differs according to beliefs; interpretations of the birth of a disabled child in Arab context have, in studies, shown to be positive forces towards acceptance of the child (Crabtree 2007). The child can be seen as a divine mysterious plan and the acceptance of the child may be perceived as integral to the acceptance of Islam (Crabtree 2007). The disabled child can be viewed as a blessing, a source of learning and as a means of gaining acceptance of the will of Allah – implications of being chosen by Allah (Bryant et al. 2011). It is common, however, with reports on stigmatizing implications of having a child with disability and the perceived reasons of Allah. The view that the disabled child is a test to determine the faith of individuals by not showing any "distress or bad feelings towards it" (Turmusani 2003 p. 52) is the way the Jordan society tends to perceive disability. Thus, a disabled child is nothing to be happy or even neutral towards. Rather it is a fate to be tolerated (Turmusani 2003). When families in the United Arab Emirates have a child with intellectual disability, family members generally describe "feelings of denial, guilt, shame and stigma" (Khamis 2007, p. 851). These feelings tend to prevent families from seeking services (Khamis 2007). Sometimes the birth of a child with disability is considered a curse or a punishment from Allah, bringing depression and feelings of hopelessness and in some cases covered or open rejection of the child (Crabtree 2007). Another belief is that Allah sends children with disability as a trial of difficulty and sorrow for the parents. In this trial the parents would learn forbearance and

acceptance of the will of Allah (Bryant et al. 2011). In Jordan parents might hide their children with congenital disorders (e.g. Down syndrome) or turn down medical treatment and resort to "waiting for the children to die" (Young 1997, p. 161).

Anthropologist Ingstad (1995b) is, however, sceptical of what she calls the myth of the hidden disabled as well as the concept of 'attitudes towards persons with disabilities'. Ingstad (1995b) discusses this myth of the hidden disabled claiming that it is derived from a need to convey sympathy towards persons with disability without having to do any real societal change. Concrete societal change would threaten those in power. By blaming the care giving family and the community of bad attitudes and by reducing discussions on poverty and limitations of health care those in power can avoid true societal change (ibid 1995b). Research often addresses family members and their attitudes. Ingstad (2001) fear this will put even more blame on the family with a disabled child and may serve as an excuse for governments not to tackle poverty and poor health conditions when premature deaths or other tragedies strikes families with disabled members, blaming the families of a lack of will to care.

In Jordan there is a particular discrimination against people with intellectual disability and women with disability (Nagata 2008). There is also severe discrimination and prejudice being faced by children with intellectual disabilities whom are described as "voiceless and vulnerable people" (Nagata 2008, p.74). Bearing a disabled child is associated with stigma and sufficient reason for husbands to take a second wife (Crabtree 2007; Al Krenawi et al. 2011). Rejection of the mother and the disabled child is in cases tacitly assumed (Crabtree 2007) and women tend to hide the child's condition from fathers (Al Krenawi et al. 2011). The mother is blamed and ashamed for the birth of a child with disability (Al Krenawi et al. 2011; Turmusani 2001a) and the burden to care for the disabled child in Jordan falls on the mother with scarce or no help from the extended family (Young 1997). Women receive an inferior position within the family and society of Jordan (Turmusani 2001a). As women they are already appreciated as less, and worth less when allocating family resources (e.g.: who goes to school, or who receives assistance in marriage broking) a tendency that increases when adding the position of disability (Turmusani 2001a; Abu-Habib 1997). The presence of a disabled child within the family in Jordan, as in Pakistan (Bryant et al. 2011, p. 1398), affects the "marriageability" of their siblings (Young 1997, p. 166). In fear of hereditary effects other families will not marry their children with those who

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are siblings of disabled. This has an effect on the female siblings to a larger extent then the male siblings because when married, the cost and care of possible disabled children will fall on the father and his kin (Young 1997). The husband's family, afraid of future costs, can even call off the marriage when a disabled child is born of a close relative to the bride to be (Young 1997). Women with disability in Jordan are commonly kept at home without education while their male counterparts have the family's approval to access services (Turmusani 2003). Because women with disability in Jordan are considered to be unable to marry they are regarded endless moral and financial burdens on their families (Turmusani 2003) and the unmarried female life is considered one "not worth living" (Turmusani 2001, p. 75).

In Jordan special education for children with disability takes the form of either education in separate schools or education in public schools but in separate classrooms, two thirds of the children receiving special education have intellectual disability (Turmusani 2003). Teachers in the Palestinian territories, with experience of students with disability, were largely (60%) supportive towards children with disabilities attending public schools (Opdal et al. 2001). However, all (n=90) of the participants were negative to the idea when it involved children with intellectual disabilities, they did not consider them "includable" (Opdal et al. 2001p. 150). In Lebanon head teachers believed some children to be easier "included" than others, most difficult to include was students with "mental difficulties". These students were sometimes considered "impossibilities" (Khochen &. Radford 2011, p. 147). There is a fear among some parents of non-disabled children towards educating "non-disabled children together with students with disabilities" (Khochen &. Radford 2011, p. 147) in Crabtree (2007, p. 58) described as a fear of the non-disabled children copying wrong behaviours. These children were to be avoided should one prevent once own child from picking up on their bad behaviours (Crabtree 2007). The reluctance of having inclusive education comes both from parents of children with and without disability (Khochen &. Radford 2011). Some parents of children with disability prefer special schools and many parents of non-disabled children would withdraw their child from the class – should a child with disability join (Khochen &. Radford 2011).

It is the spread of attributes within the individual that is referred to as stigma – for those who possess a stigma attribute, e.g. a sensory impairment, are not just blind or deaf as we "tend to impute a wide range of imperfections" (Goffman 1963 p. 15-16) on

those labelled with deficiencies. When the labelled deficiency has spread the whole person embodies a stigma and anything she does in the social realm, e.g. reading and eating, is met with surprise and wonder (ibid 1963). Possessing a stigma attribute or not is determined by the expectations of others and expectations are in turn determined by the roles culture expects us to shoulder (ibid 1963). Failing to acquire such a role is failing to be human (ibid 1963). The disabled is given a negative identity by society and as such stigmatization is "less a by-product of disability than its substance" (Murphy 1995, p. 140). For the Punan Bah people of Borneo no equivalent concept to disability exist (Nicolaisen 1995). Instead those failing to secure marriage and children – fail to achieved personhood and are subsequently seen as disabled (p. 50). Similarly the inability to produce children was in Islam law historically viewed as a disability in itself (Vardit 2007). Failing to achieve cultural ideals is failing to gain full personhood (Nicolaisen 1995). Anyone that is associated with the stigmatised individual in their social structure becomes obliged to share some of the stigma (Goffman 1963). The stigma spreads from the stigmatised individual through the socially structured definitions of relations – in a diminishing intensity, delivering courtesy stigma (Goffman 1963).

Similarly to Goffman (1963) view on stigma, anthropologists Ingstad and Whyte (1995) express that whoever is considered to be disabled is determined by the expectations derived from the specific culture or context. Who is considered disabled is related to fundamental and culture specific assumptions on personhood and what it means to be a human being (ibid.). Ingstad and Whyte (1995) argue that disability emerge in relation to the ideals of a good and functional life. It is towards these cultural-specific ideals that people measure themselves and others. As subverters of ideals persons with disability are resented (Murphy 1995, p. 143). They represent the fearsome possibility that I too can distort from such ideals – I too am vulnerable (Murphy 1995). American Anthropologist Murphy (1995) uses van Genneps rites de passage to understand situations of persons with disability in the US. These processes may rewardingly be viewed using theoretical tools of anthropologist Van Gennep as regards rites de passage, i.e. passage rites consisting of three phases: separation, margin and aggregation (Turner 1969). Rites de passage relate closely to social roles and positions, cultural norms and expectations. Each identified phase consists of a set characteristics; the separation phase is distinguished by communicating a "detachment (of someone, auth. rem.) of an earlier fixed point in the social structure or from a set of cultural

norms … or both" (ibid, p. 94). The following phase, the margin or limen, is characterized by being in an ambiguous place where one can hardly be categorized, there is no pre-existing position for the subject, still, she or he seem to exist. It is in this phase that Devligier (2010) find great potential for challenging our/a locally existing, although in many localities, dichotomous categorization process. This phase is often associated with death and invisibility and sometimes danger - an unorganized, polluting content in the social system, if one wishes to use the parlance of anthropologist Douglas (1966). The last phase, the aggregation phase, includes the reaggregation. According to American Anthropologist Murphy (1988) persons with disability in the US are in a constant state of liminality. Persons in a state of liminality elude cultural specific classifications because they are "neither here nor there" – they are "between and betwixt" positions assigned by law, custom, and convention (Turner 1969, p. 95). According to Murphy (1995) people in the public do not know how to interact with persons with disability, because toward persons in a liminal state there are no cultural guidelines on how to behave (p. 146). Like Turners (1969) liminals they are invisible, un-sexed and asexual. Persons with disability experience no transition to a definitive state, but remain permanently undefined (Murphy 1988). Attempts of moving persons out of liminality are oftentimes performed, for the Songye people of former Zaire this is done by regarding disability as a symptom and giving much attention to find a solution for the problem that underlines the condition (Devlieger 1995).

3 Methodology & Analytic Procedure

3.1 How Data Became Data

25 interviews were conducted, 17 of them recorded through field notes and 8 tape recorded and transcribed. Simultaneous fieldwork was conducted as the researchers lived at the organization around which the study revolved. The interviewees for the 8 tape recorded interviews were selected through theoretical sampling, i.e. directed by the problem of interest derived from the former 17 interviews and the estimations on who would shed further light on the issue this thesis came to discuss (Glaser 1978). Of the 8 latter interviews 4 consists of a first and a second interview with two different participants. An interpreter was used in the 17 initial interviews as well as in one of the latter. The interpreter was an employee at SOIR, in which many of the informants were employed. Thus, the interpreter

knew the informants whom were interviewed, even those working in local projects, e.g. the government employed principals. The relatively slow translation process made it possible to take word-for-word notes in the initial 17 interviews. Apart from interviews the material comprises field notes. These were written during participation on staff meetings at the organisation, visits to local schools and vocational training centres, participation in festivities with the children with intellectual disabilities at public schools as well as days spent with and without English speaking personnel in schools and vocational training centres. Interviewees were government employed principals being responsible for classes for children with intellectual disability, personnel at vocational training centres for adolescences and adults with intellectual disabilities, special education teachers, social workers, occupational therapists, and physiotherapists – all involved in the introducing and maintaining special classes in public schools and equivalent work with vocational training centres as well as policy assignments in governmental legislation on the issue of disability and their rights – have likewise been conducted. The length of the interviews varied and span from 30 minutes to 2h and 15 minutes. This is a consequence of a very qualitative and exploratory (as in exploring what informants express and trying not to force direction in the interview) interview line-up. We often made field notes on recurring themes and subjects which could be gateways to a broader understanding of the field. We had a mutual agreement from the start not to ask too specific questions, but to merely be aware of our assumed codes and sometimes unclear categories in our minds, and only if an interviewee mentioned something that could be linked to our codes and or unclear categories we could ask for more information. After the initial 17 interviews the emerging codes and categories and their relations directed the sample. Sociologist Charmaz (1990) argues that delaying focused theoretical sampling, fosters gaining an in-depth understanding, and should only be used after the researcher has identified key concepts and developed some hypotheses about their relations. On the other hand, Glaser (1978) emphasises staying open once theoretical sampling, which per definition involves focus, is done.

During interviews we tried to question and re-question as to show that we did not doubt our informant's honesty but our own understanding. This often times meant following up on specifics in answers received – asking informants what they meant with specific descriptions or words. As we do not understand Arabic and were helped by an interpreter it was easier to ask our informants what they actually meant – adding multitude

and differentially to our material. Of course, translating from Arabic to English has an impact on linguistic nuances. In addition, using an interpreter implies involving yet another person in the complexity of the interview.

Conducting the interviews we were never interested in arriving at a 'real meaning' or the 'truth', but rather to find out what the views of our informants were and how they reflected upon their choices of social work strategies. We asked our informants to describe concrete situations when explaining their social work strategies. Asking for concrete situations we could further the interview and at the same time resisting from leading our interviewees – keeping the point of departure for their answer open but yet specific, as recommended by Kvale (1996), Director of the Centre of Qualitative Research at Århus University.

When asking principals what they thought when they were given the instruction from government officials to initiate special classes for children with intellectual disabilities in their schools, some of our interviewees mimicked what their own actual facial expression had looked like when they had received such order. Our aim was to "support the interviewees in developing their meanings throughout the course of the interview" (Kvale 1996, p. 226). Finding recurring themes in our material we tried to ask in a manner where the questions did not imply too much but where we still managed to go deeper into some of the codes/notions whilst others came up. To use an example, the notion of disability being contagious,: one interviewee told us that the parents of the non-disabled at her school were afraid to let their children go to school together with children with disabilities, when we asked her how the parents expressed their fear she said that 'they think it is like a sickness' (B 536). Another interviewee referred to a man who refused to drink from the cups at her school as a sort of resistance and because he was afraid. When we asked her what the man was afraid of she said 'because they are mentally…' (B 932). Later on in the interview when we asked her how she talked to the man about this she said 'I told him, you are sick yourself, you have a kidney problem…' (B 930). Thus, our interviewee from the first example talks of disability as being contagious with a certain distance, she knows and can explicitly talk about the notion of disability being contagious. The second interviewee at another school gives us a description with less distance and more from the inside of this notion; although asking her repeatedly on the subject she is not able to explicitly express this underlying notion. She is,

however, able to explain her own actions and through such express the notion of disability as contagious.

Interviewing is a delicate process; there are always risks of projections and expectations from the interviewers to the interviewee, resulting in less valid data. Of course somehow our presence during the interviews has had an effect on how the interviewees have responded. Anthropologist Briggs (2007) claim that the complexity of the interview situation is likely to be underestimated, interviewees and thus their reflections in the interviews may be highly affected by the framings of the situation; is there trust towards the interviewers? Do the interviewees know how the information from the interviews will be dealt with? What could it mean that two Swedish students from Lund University, enters the Jordan field of a Swedish organisation about to close down and with their head office in Lund? What did we represent for the interviewees and how may this have affected the interviewees? And how may our views of their views of us have had an effect on our behaviour and, further down the road, the analysis of the data? Only sincere reflection and trying to explicitly express our own views (of their views of us and other) and work with such views as consciously as possible have helped us in this very complex process.

3.2 Analytic Procedure

The analytic procedure was conducted in an explicit and systematic manner much inspired by Grounded Theory as explicated by Glaser (1965; 1978; 1992; 1998) and Glaser & Strauss (1965; 1967) including influences from the hypothetic deductive method. It was a process conducted simultaneous with interviewing and field work. Using Open Code 3.6 we had our material on the computer screen organized in a line by line manner. Reading and, after further collection of data, re-reading our material in this way we coded sentences and happenings in this line by line manner thereby fragmenting its narrative structure. Every code was an attempt to conceptualise what the sentence, happening, or incident[1], indicated (Glaser 1978). No preconceived codes were assigned to the material; instead the codes used

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[1] Alvesson & Sköldberg (2009 p. 60-61) have rendered it unfortunate that Glaser & Strauss does not provide us with an explicit definition of the term 'incident'. Drawing from grounded theory's symbolic interactionisitic roots (Strauss was a student of Blumer) they find it reasonable to equate an incident with a social interaction. This is in our view not valid. It seems more reasonable to believe that an incident can be anything in the form of empirical data that points towards the researcher's perception of her conceptualisations. I.e. the incident is what it is only in relation to that which it is an incident of. The researcher makes it an incident when she makes conceptualisations out of her data.

on the data were conceptualized from the data (Glaser & Strauss, 1967). In this way the analysis and the coding became an inseparable part of the same process towards generation of theory. Already during initial coding we were looking for main themes or main processes in the data that accounted for or related to emerging conceptualisations (Glaser 1978). We asked specific data fragments: "what category or property of a category does this incident indicate?" (Glaser 1992 p. 39). Reading and re-reading the raw material and the codes next to each other, as presented in the software, we deduced working hypotheses and more abstract categories. Analysing each instance in our material with the same code, looking at similarities and differences in the raw material and making a judgement of what similarities these instances carry and in which way they differ, constantly asking the question of whether they differ more than they are similar, we decided to keep, withdraw or change codes in each individual instance. We asked our growing understanding of the data: what is the underlying pattern?, the "main theme", the essence of what is going on or our informants "main concern or problem?" (Glaser 1992 p. 94). An incident and following codes oftentimes bore an inherent deductive potential, leading to a working hypothesis, (i.e. temporary hypothesis with a potential of being less temporary), which could possibly lead to more explanatory categories. We always analysed the collected material as a whole and did never consider a working hypothesis throughout which grew more firm categories without having several instances with such concrete substance as it was considered bearing an inherent deductive potential. The fragmenting nature of explicit coding may make interpretations and theory-build from it more difficult (e.g. Alvesson & Sköldberg 2009). However, at the same time the joint process of explicit coding, self-reflection and analysis poses a more systematic procedure than explicitly going straight from data to theory (Glaser 1965, Glaser & Strauss, 1967, Glaser 1978). Over-bridging data and analysis throughout explicit coding, conscious reflection and memo-writing has facilitated a joint-analysis in this thesis.

Examples of concrete substance with inherent deductive potential is when a social worker explains how a mother has told her that her daughter with intellectual disability 'has no mind' (B 1172), or, and a less concrete one, when another social worker explains how she takes the children with disability to the grocery store and makes a point of letting the children with intellectual disability choosing something they want from the store, making a point of the public experiencing that these children can make a choice, and

explaining to us how many people who see it for their first time are surprised. Another instance, deducted to the same set of categories (albeit opposite), is when one of our interviewees explains how parents tell her that they have been advised not to provide their children with physiotherapy for the children 'will die' (A 249), actually treating the children as dead long before they are. From these and many more instances we deducted the set of categories 'human – non human'; the social workers talking to us about instances where persons with intellectual disability is expressed as without mind or being treated as dead before being 'physically dead', or the social work strategy of showing that the children can choose in the grocery store, i.e. that they have preferences and intentionality.

Depending on how one defines what is human some of our deductions from these instances may seem slightly arbitrary, this is why we have provided the reader with the grocery store example. We consider this example to be the most ambiguous instance in this set of categories, as 'intentionality' may not be included in the local assumption of what it means to be human. When referring to persons with disability as 'being human', some incidents could be included in the conceptualisation 'intentionality' as its conceptualisation and another segment could be included in the conceptualisation 'similarity to non-disabled' being its conceptual label, temporarily defining the category 'being human' as an intentional subject being similar to non-disabled persons. Having found inherent substance in the code 'being human' as dominantly being 'intentionality' and 'similarity to non-disabled', we questioned how field close the original code 'being human' actually was, had we perhaps coded what we defined as 'human', i.e. intentionality and similarity to non-disabled and had thus not been considerate of how 'being human' was actually defined in the field? Going back to the parts of the field notes and transcript which were ascribed the code 'being human' we realized that clusters of incident referred explicitly to 'being human', other referred to 'similarity to non-disabled'. Although, the code 'being human' might have been a broad code arisen from a few clusters of incidents and the contexts in which such arose, analysing critically in a constant comparison of codes, substances of codes and potential categories[2], as well as comparing such with field notes/transcripts and the context in which the material is expressed we could understand this code in relation to resistance which the staff has met through parents expressing that their children 'have no mind', or from reports

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[2] Glaser (2011) however, uses the words code, concept, property and category as synonymous since they all refer to conceptualisation of latent patterns.

on mothers being exclusively neglecting towards the needs of their child with disability and or letting their child with disability do all the household work and their non-disabled siblings nothing. Viewing data as "raw" have received critic from Alvesson & Sköldberg (2009) who claim that data is always theory-laden, and "merged with theory at the very moment of their genesis" (p. 58). Rather than treating "raw" data the authors illuminates such data as constructions of "empirical conditions, imbued with consistent interpretive work" (pp. 283-284). By suggesting a delay in literature review, there are such considerations in grounded theory. However, we agree on Alvesson & Sköldberg (2009) critic on grounded theory, as we too find assumptions of how data is made rather naively constructed within the grounded theory paradigm – clearly there is interplay of actors, expectations, other unaccounted variables and context in which the data is made.

3.3 Theoretical coding

Working with categories deducted from the raw but coded material we focused on understanding how each category actually relate to the other categories, at this time we realized the social workers concern of persons with disability being identified and or treated as 'dead' and codes concerning social work strategies carrying a concrete reference to showing the public that persons with intellectual disability has intentionality, a mind and the same feelings as non-disabled. Our category 'distance' could be subdivided into five codes that differed from each other in the way distance was 'done' towards persons with intellectual disability: distance by difference, spatial distance, distance by isolation and conceptual distance. The uni-formative concept of these however is that they all in their contexts sum up to resistance against intellectually disabled participation/ existence in public spaces. When analysing our code 'proximity' we often, but not exclusively, found the opposite characteristics: spatial proximity, proximity by participation, proximity by ascribing human properties to persons with disability, proximity by similarity and proximity by love. In the process of trying to understand this cluster of codes and its theoretical relationships we ended up with all, except one, stating that spatial proximity makes change in attitudes among the public possible by exposure of persons with disability to the public (and sometimes in this exposure explicitly ascribing human properties to the persons with intellectual disability) and by participation of persons with intellectual disability and non-disabled in activities and positions (as citizen/students etcetera) with an included position.

Analysing this cluster of codes we ended up with an anomaly not knowing how to understand (proximity by love); after additional time of analysing and collecting more material we realized that the code 'proximity by love' was exclusively expressed in social pedagogical contexts where personnel were interacting directly with persons with disability rather than sociological (as battling more spread views and "knowledges" on disability held by, parts of, the public), which had been our focus when analysing the codes and their relations. Such theoretical coding, i.e. conceptualizations of the relationships between conceptualised data (Glaser 1978), were for us a main part of our analytic process and it proceeded alongside substantive coding and data collection. Another example is the realization of an intimate connection between family organization and the absolute refuse of persons with disability, which arose only after extensive time of collecting, coding and analysing the material. Although disability as contagious had struck us before, collecting, coding and analysing but maybe most of all, just being in this context, made us realize some of the ways in which the existence of disability tends to question the tribal system and what one of our informants calls 'the close connection between people in Jordan /…/ where everybody is relatives' (C 1710-1730). When conducting theoretical coding the individual interviewees and their differences also tend to become more anonymous in advantage of finding more general tendencies in the material; finding general patterns and tendencies in such anonymized manner cannot and does not go beyond the views of the social workers.

3.4 Possible Preconceptions

The possible pattern of intellectual disability being experienced as contagious struck us very early in the process and was most likely influenced by the theoretical reasoning of Mary Douglas (1966) in Purity and Danger. This theoretical reasoning was part of our pre-existing conceptual framework. Social Science researcher Henwood & Environmental Psychologist Pidgeon (2003, p. 134) describes this as a philosophical dilemma when discussing how theory does not simply emerge from data but are interpreted through an analyst. By analysing our theoretical thinking and thus to some extent our strategies when collecting data against (at least some of) our pre-existing knowledge, we could more easily control our strategies when collecting data and gain a deeper understanding of our theorizing, i.e. consciously position ourselves. We agreed on the major importance of literature influence being less the importance of not involving pre-existing knowledge and more the importance

of an awareness of different influences of knowledge. Sociologist Charmaz for instance (1990) describe how she sensitized herself with theoretical concepts before her research began in order to "look for themes and issues within the data". We have chosen to dive into the literature on our substantive field in the late process of analysis when we felt that our analysis was "strong enough" (Glaser 1998, p. 76) to stand in reference to existing literature. Collecting and analysing the material for this thesis, we have tried to use our pre-existing knowledge in a sensitizing way. As an example, when meeting our participants for interviews we had the code of disability being contagious, derived from earlier interviews, in mind when our interviewees sometimes began talking about eating, drinking and going to the same (or a different) toilet. We also had this notion in mind when observing where the children eat and where the bathrooms are, although not "confirming" our working hypothesis on disability and disease but rather to proceed with an as open mind as possible still being aware of this notion. Without accepting some simple explanation of disability being contagious as an explanation to the bathrooms being separate for non-disabled children and children with disability, we still kept notes that this was the general way. We were also open to the possibility that separate bathrooms may mainly or partly be of other reasons but that the notion of disability being contagious still may exist. We have tried to be open to different notions in relation to disability while in field and have tried to avoid a premature focus and thus the field in the process but rather to work with broad sets of possible codes and categories in order to know when to ask our interviewees to elaborate further.

3.5 Ethics

The Swedish Research Council (2009) provides four ethical principles which students and researchers should be aware of. In accordance with the principle of information and of consent we approached SOIR with the exact information on what we wanted to do, we later presented ourselves and our interest to all our informants and made clear that it was voluntary for them to talk to us. We gave them our contact information and told them that if they later changed their mind and they could contact us and we would remove the data they had provided us with. When we used tape recorders we asked consent to this explicitly. We explained to all our informants what our interest was and what our research was going to be about, we also made sure to tell them that it would be anonymous to participate. One may

question how voluntary it de facto was for our informants to talk to us since their boss had already given her consent for us to carry out or research within the organization. There was no doubt a pressure to accept being interviewed. None of our informants declined to be interviewed; however they had a large power over what they chose to tell us. Some told us almost nothing and answered questions on how their work proceeded with that it went well. Thus some did decline to being interviewed albeit in a more subtle manner. After conducting our interviews we sent out an e-mail to all our informants, written in English and Arabic, reminding them of what our research was going to be about and that their participation was voluntary and that they could only contact us to withdraw the information they shared. In accordance with the principle of confidentiality and the principle of use we kept our data stored with passwords and did not share it with anyone. Neither did we talk to anyone outside the research team of what individuals had told us in a way as where they could be identified. Our interest was never in specific individuals but in how our data was connected as a whole. We informed our informants on how we planned to use the data and will not use it for any other purpose than those which we initially agreed on with our informants. Citations from our interviewees are presented within apostrophes. When the transcripts have been edited lightly for readability this alteration is presented within brackets.

4 Empirical Data & Analysis

4.1 Introduction – Grounded Theory, Empirical Data and Analysis

Grounded Theory is a technique which aims at coding existing material, at the same time viewing the material and the codes for any patterns and, by constantly comparing incidents and codes in the material, abstracting categories (broader notions in which codes but also recurring contexts can be perceived as properties of these notions) and ultimately, using constant comparison and hypothetical reasoning followed by theoretical (and general) sampling, finding how abstracted categories relate to each other. Thus, results from grounded theory are quite anonymous and the end result does not generally declare descriptive parts such as who said or did what, nor does it provide the student or researcher with analyses as actor analysis or gender analysis. In this work we have chosen not to fully

follow the recommendations of skipping the descriptive level and moving directly into some explanatory level. In order to obtain as much transparency as possible in our work, we have chosen to describe the process throughout which the more explanatory categories and the relation between categories grew. (B 203) and similar symbols refer to incident in our material and are present in the text in the same quest for transparency.

Using such an inductive approach, we will initially present our data as codes and categories, comparing contrasts and similarities with notions used by researchers who also have entered their work with a very inductive approach, mainly researchers within the field of medical anthropology. In doing this, we hope to situate the concepts, categories and occurrences of this work in a broader and more theoretical context. Perceiving such notions as constantly in the making, hoping that this work will broaden or strengthen a limit of meaning inherent in such notions, we do find the explanatory emphasis of grounded theory rather complicated. The notions risk no longer being in process when introducing an explanation, a recipe for how they should be used. There is a risk of grounded theory providing an ultimate reference in the process (of filling the notions); a 'this is how it is'. Being aware of this problematic situation, we have chosen to situate the concepts and categories, i.e. including the properties of the categories, in a more theoretically open context. However, when it comes to the relations between the categories, rising out of our theoretical coding, especially such relations which may provide an answer to the question 'why?' we want to emphasize that such explanatory theory should only be taken as one (of many) possible explanations of the main concerns of the people of this specific field and that such explanatory theorizing should be perceived as a theorizing of the life worlds of the social workers rather than 'how it is'.

4.2 Overview of Analysis

As social work strategies in the process of introducing Community Based Rehabilitation in this specific field, i.e. introducing persons with moderate and severe intellectual disability to local institutions, was commonly reflected upon when social workers were asked more general questions about their work, the interviews increasingly circumflexed the social workers view and experiences of community reception of Community Based Rehabilitation and social work strategies upon such community reception. This subject clearly and persistently throughout the interviews reflected a construction of a social worker ideal and

of 'the other' in relation to such ideal; while the community often times did act, at times previously had acted in manners expressing distance and difference between the non-disabled population of the local communities and the persons with intellectual disability, the social workers always reflected upon their own work and choice of social work strategies as working with proximity towards persons with intellectual disability. At least in the shared constructions of the social workers, this was their job; to show love towards persons with intellectual disability, to show the community that persons with intellectual disability 'have the same feelings' (B 1188) and to remind the community that they too are vulnerable. The distance code, in different manners ascribed to the community as an act of the community, may be perceived as a baseline from which the social workers could construe their own working ideal and choice of strategies. Social workers talk about 'the other' as a community which denies persons with intellectual disability inherent human properties and given social positions. Sometimes this ideal of proximity even seemed to have an effect on the actual social work strategy. As when one social worker reflected upon a meeting she had with a man who did not want to drink out of the same (clean) cups as the children with intellectual disability, the social worker told him 'but you are sick yourself, you have a kidney problem' (B 930). This statement is gateway to several interconnected notions; the social worker believes that the man believes that the children carry a contagious disease; however the statement also shows the social workers own ideal of proximity towards persons with intellectual disability. While the social worker could have explained to the man that the children does not in fact carry a contagious disease, he instead choose to refer to 'similarity in solidarity' with specific reference to mutual vulnerability between him and the children whose cups he seemingly had rejected. In this instance, the social workers' beliefs about the man and the social workers' own ideal of proximity actually seem to have determined the situation, for why did she not inform him that their condition are not contagious? However, and as we shall see below, this strategy is also a part of social work strategies making persons with intellectual disability human from a perceived and expected non-human position among 'the others', providing persons with intellectual disability a way out of liminality.

In our material there is a clear 'denial of social existence' of persons with intellectual disability, intimately bound to denial of existence in public space and the denial of visibility and exposure in the community, ultimately inhabiting a socially accepted role.

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Community resistance is performed by denying persons with intellectual disability social existence. The social workers report that persons with intellectual disability are hidden and isolated avoided and feared by the community in general. Our interviewees explain such actions of the community with reference to beliefs that these children are without central human properties and or beliefs that their conditions are contagious, and feelings related to such views on disability and persons with intellectual disability, as fear of persons with intellectual disability and of having a family member with intellectual disability. The social strategies used when introducing community based classes often depart from these perceived beliefs and can be summed up by the claim that spatial proximity may open up for changes in community reception.

The core category that emerged from the data analysis much inspired by grounded theory was 'Enforcing Existence'– a central category relating directly to the perceived 'other'; the community denying persons with intellectual disability existence in public spaces. This category also relates to the framing of the social work, i.e. introducing Community Based Rehabilitation and initiating school classes for children with intellectual disability in public schools, a framing which in itself may be perceived as a form of enforcement of existence for persons with intellectual disability in public spaces. 'Enforcing Existence' also relate directly to individual strategies enhancing such enforcement, such as giving persons with intellectual disability the opportunity to make a choice of preference in front of non-disabled people. 'Existence' in this analysis is tightly bound to sociality and essentially refers to social existence, i.e. the state of being human by being ascribed human properties and inhabiting an acknowledged social position. In this thesis we define social position as positions of identity which people collectively acknowledge and throughout which people understand each other and themselves. In this analysis we focus on how social workers reflect upon the social position of persons with disability, with concrete references made to their work with these persons, and the possibility of changes within such position or within the field of ascribing positions. A core social position is, of course, being human. Other social positions are being someone's son or daughter, being a student, being an employee etcetera. Positions of identity are, of course, closely related to personhood although we have distinguished between social positions and personhood by defining personhood as the embodied experience of inhabiting a social position. We have chosen to solely use social positions as an abstract understanding of the sociality of existence and not

personhood since personhood may relate more closely to personal experiences of inhabiting a social position.

When looking at the material as a whole the spectrum 'denied existence – enforcing existence' emerged as a baseline throughout which we could compare categories as proximity and distance and their respective properties (proximity by love, proximity by participation, proximity by similarity, spatial proximity and distance by difference, spatial distance, etcetera). This baseline in not explicitly referred to and is apparent when looking at the material as a whole, in a more anonymous manner and should not be mixed with social workers way of reflecting – but a part of our analysis of the material. An interrelated notion of social existence is visibility; enforcing existence implies making persons with intellectual disability visible in public spaces, a fact which the social workers were aware of and took advantage of in their social work. Persons with intellectual disability are exposed to the public eye throughout Community Based Rehabilitation, in and of itself a strategy aiming at ascribing persons with intellectual disability social positions in their local community. However, the staff also conducts more specific strategies in accordance with this principle. Strategies on enforcing existence of persons with intellectual disability could include information on possible medical reasons for its existence, as well as showing love towards the children with intellectual disability in public (i.e. social) spaces or giving the children with intellectual disability possibility to make a choice in public spaces, thus showing the community that these children inhabit central human properties. The strategies build on the framing (Community Based Rehabilitation) in which the social workers have to find themselves. Within this framing of bringing children with intellectual disability to the community, the social workers conduct strategies in accordance with such framing conditions.

4.3 The Distance Category

The distance category includes approaches played out, or previously played out, by 'the other'. The category includes three properties: Spatial distance, Distance by Difference with the sub-property distance by the making of persons with intellectual disability non-human and conceptual distance. There were also instances in the raw material which fit in this category but could not be organized in any other way than under the main concern in this category; resistance towards participation/existence of persons with intellectual disability in

public spaces. Examples of such instances have been when social worker express how parents leave their children at school and 'want to forget about them for a few hours' (B 918), when the community around a new project does not want to greet people working or in any way participating in the project, when grandparents tell their children not to bring their grandchildren with intellectual disabilities when they visit (A 1599), when parents choose not to bring their children with intellectual disabilities on visits to their grandparents because these do not accept them (C 1660) or when mothers and their children with intellectual disabilities are driven away from the family by their agnatic kin (C 1639). Distance by difference includes events where the social workers explain how the public have expressed opinions emphasizing the difference between persons with intellectual disability and non-disabled. The sub-property of Distance by Difference, the making of persons with intellectual disability as non-human merely refers to events where persons with intellectual disability are expressed as different by being non-human, i.e. having no mind, no feelings, no productivity or no intentionality. Spatial distance clearly overlap fully with the central property of this category; Resistance towards participation or existence in public spaces and isolation by the own family.

4.4 The Proximity Category

The Proximity category mainly exists in the field of strategies and approaches battling denial of existence of persons with intellectual disability in public spaces and consists of six properties, i.e. six patterns of approaching resistance towards the existence of persons with intellectual disability in public spaces, and a construct of the social worker ideal. These patterns, consists of strategies as: Spatial proximity, Proximity by Love, Proximity by Participation, Proximity by Similarity, Proximity by Ascribing Human Properties to persons with intellectual disability and Proximity by Solidarity. Spatial Proximity is closely connected to Proximity by Participation since Proximity by Participation generally includes direct participation between persons with intellectual disability and actor/actors from the community. Proximity by Participation includes events such as playing with other, non-disabled children 'they come to the play centre, the centre schools can come to the centres here so that the children can play and have fun' (C 2118), having a regular job and being included in a pension system (C 267). This code also refers more directly to social workers aspirations to mainstream these children, as one social worker told us 'they should as I told

you, first that we want them to live together and be raised together so that they can know each other better' (C 706), or as reflected upon by another social worker: 'sometimes we meet other schools at this playground, they play together and the children asks questions about the children with intellectual disability. But also that they see that children with intellectual disability have the right to go to the playground' (B 1618). In the weakest sense, proximity by participation is demarcated as participating by inhabiting the role as a student at a public school. However, even in this weakest, more abstract sense, although Proximity by Participation does not necessarily imply direct contact between persons with intellectual disability and actors from the community, it does imply Spatial Proximity.

The other properties of this category does oftentimes overlap with Spatial Proximity but does not necessarily imply Spatial Proximity, although, perceived as strategies for enforcement of existence, Spatial Proximity can be perceived as a goal of the strategies. Proximity by love has only come up in examples referring to social pedagogical settings and is performed in the relation between the teachers and the child or adolescent with disability, at times this relation is consciously exposed to worried parents (of the child or adolescent with disability) as when the social workers 'meet with parents to show that teachers will accept their children' (B 568). The social workers may also convince the parents by stating that 'we are here like a family, we are here to take care of your son, your' son is our son' (C 1940). Proximity by love is also performed in order to convince the children that they are accepted 'the children in the way we, you know like, take care of them, in the way we love them and show them how we love them' (C1252). 'We have to work with love, the child must trust the teachers' (B977). Such conscious exposure is most often used when performing other strategies, such as of Proximity by ascribing human properties to persons with intellectual disability in public spaces, however, Proximity by ascribing human properties can also be performed as a direct enforcement, giving families homework as to let their persons with intellectual disability choose whatever he or she wants in the grocery store (B 1190). Proximity by ascribing human properties is a conscious strategy which includes ascribing intentionality and emphasizing the similarity of persons with intellectual disability to non-disabled, as such Proximity by ascribing human properties can be perceived as a sub-property to Proximity by Similarity. Proximity by Similarity is characterized by events as 'just going to the school with their back packs as their brothers and sisters, the children feel well from such things' (B 895), or more closely connected to the social worker ideal of

proximity 'they (are, auth. rem.) human being like me and like you' (C98) or the suggestion of the social workers to the parents that they 'have to deal with these girls as the other sisters' (B 1187). Another sub-property to Proximity by Similarity is Proximity by Solidarity characterized by situation 'anyone can have a child with disability, it is a right to go to school' (B845), 'this could happen to any family and it can come when you get old, plus God have ordered us to take care of people with disability' (B859). It also includes events as when a social workers questions a man not wanting to drink from the same cups as the children upon which the social worker reminds him that he is, in fact, sick himself (B930). The difference between Proximity by ascribing human properties and Proximity by Similarity is that Proximity by ascribing human properties exclusively refers to strategies of making persons with intellectual disability human, as defined by the direct statement or by the context (i.e. when a persons with intellectual disability is referred to as a non-human; the property distance by difference and the sub-property distance by the making of persons with intellectual disability as non-human). Proximity by Solidarity, on the other hand, is a strategy referring to similarity in vulnerability, a social worker consciously referring to the mutual vulnerability of us all or of the person in front of her and persons with intellectual disability when meeting resistance of existence of persons with intellectual disability in public spaces. Altogether the Proximity category consists of social workers framing and strategies of enforcing existence of persons with intellectual disability.

4.5 Spread

Our interviewees relate to spread and the avoidance of such spread in many ways. When a school class for children with intellectual disability is initiated parents and teachers are worried that this will have an effect on the other (non-disabled) children. The adults have believed that the non-disabled children may do the same things as the disabled, may also incorporate 'bad behaviours' or may catch the contagious disease 'disability'. In different ways a fear of 'spread' relate to proximity and distance, similarity and difference. A resistant approach towards non-disabled children doing the same things as disabled children, a fear of spatial proximity and an avoidance of touching 'disability' with the tip of the tongue by actually mentioning the word, a perception that the family has disability when one family member has it, all relate to spread in different ways. Perceiving intellectual disability as a contagious disease almost metaphorically but yet literally explain how different actions and

assumptions are related to 'spread'. Whether it is escaping them at playgrounds (B 1891) or moving 4-5 tables away, at restaurants (B 963) and conceptual distance, emphasising difference to oneself, towards persons with intellectual disability are preferred as well as why similarity in behaviour are feared by the 'others'. Disability is spread through spatial proximity as well as proximity in behaviour, a fear inducing belief targeted by social workers adopting spatial-, participating- and conceptual proximity strategies not only placing the children with intellectual disability in the midst of public schools, spatial proximity, but from that proximity encouraging joint activities, parties, playing at the playground and any interaction they can between the children with intellectual disability and those without.

4.6 Disability as Contagious

During several interviews with principals at the local public schools the notion of 'disability as contagious' was expressed, indirectly or directly. One principal at a local school expressed how teachers in the school worried about their students being affected by the children with intellectual disability from the school class to be opened 'they thought that disability would spread to the other children as a form of sickness' (B 536). Parents of the non-disabled students had expressed the same concern; 'they think it is contagious, like a disease' (B 536), she said. Her strategy in meeting such resistance mainly concerned listening and talking empathically about disability, reassuring that intellectual disability was not contagious. Meanwhile, the class was enforced on the school and after some time came to be more accepted. Another principal at a local school in a rural area had met tough resistance, angry parents running into her office asking 'what is this?!', 'these children here?!'. She expressed how parents of non-disabled students had been worried that their children will do the same thing as the children with intellectual disability and accumulate bad habits throughout such proximity. This principal, being under quite extended pressure, explained to 'others' from the community how the children with disability will have their own classrooms, their own classes and will not do the same things as the non-disabled students. In this situation she referred to spatial distance and actually seems to have expressed the exact opposites of the more general strategy of the social workers; 'proximity by participation'.

The social workers talk about intellectual disability oftentimes being perceived as a disease spread through spatial proximity and similarity in behaviour. They also refer to intellectual disability as a hereditary condition 'some of the families they have this feeling

that this is hereditary. (C 947), 'it is their thinking that it is hereditary and it can happen if I give my daughter to this man or if I can take from their daughters also it will be the same. And I will have this in my family' (C 968), 'the first thing that comes to their mind: that it is hereditary' (C 950).

Anthropologist Douglas (1966) expressed her view that certain apprehensions on defiled phenomena may serve as a mirror of the view on present social order and that a status of liminality may be perceived as polluting. Presumed in such reasoning is that social order implies restriction. In this perspective, intellectual disability being perceived as contagious, may be an analogy of the view on the social order, what does intellectual disability actually put to question in this context?! Our material shows that having a family member with intellectual disability equals to the family having disability, in this sense disability is spread; it is a somewhat borderless property and one could question whether this is an analogy of the somewhat borderless female body used to tie with other families but also to demarcate ones' own family integrity. The borderless properties of the female body need to gain the family, perhaps impossible if others suspect that the female body may bear disability stricken genes – what comes out of her may be polluted.

4.7 The 'Fear and Fear' Code

Fear of persons with intellectual disability is a recurring theme in our material and relates to resistance of spatial proximity but especially to resistance of proximity by participation, which most often implies spatial proximity and direct contact between persons with intellectual disability and non-disabled from the community, such as non-disabled students from public schools. School personnel have met parents whom were angry and in despair over how classes of children with intellectual disability could be opened at their schools. When reflecting upon such meetings the personnel recurrently express how parents are afraid of the persons with intellectual disability. The social workers explain to us how parents of non-disabled children are afraid that their children will acquire the same bad habits as they believe that the children with disability have, they are afraid of this if their children and the children with intellectual disabilities 'do the same things' (B 759 raw material, in code: proximity by similarity/participation). Parents of non-disabled have also expressed the belief that the children with disability are sick and that their disease is contagious, that they 'make crazy movements' (A 1252) 'are strange', 'are not like us' (A 1269), 'are not worth education

because they will not give anything back' (B. 395) and 'will afflict their sickness on the other children' (B. 535).

On the other hand, the social workers report how some parents of children with intellectual disabilities have expressed fear of letting their child go to a public school with reference to an expected non-acceptance from teachers and other children, instances of such fear is demonstrated when the social workers tell us that parents express that they cannot believe that anyone can love or accept their child with disability, 'parents of students (with intellectual disability) here were afraid to bring the children out of their home. They couldn't understand how the teacher will accept their children' (B 565). Sometimes parents refused to send their children with intellectual disabilities to public schools, 'no I fear that they are going to laugh at my son or I feel that maybe the teachers hurt them' (C 1318). Our interviewees also tell us how families of persons with intellectual disability may experience fear of the family being isolated if showing that they have disability.

4.8 Life and Death - Humans and Nonhumans

'Parents of the non-disabled children did not want to admit that these children (the children with intellectual disability) existed in society' (B 731). Some of the explanations of taking distance towards persons with intellectual disability that the social workers report expressed to them, relate to a non-human state. When social workers describe how mothers express that their daughters with intellectual disability 'has no mind' (B 1181-1182), or that they 'refuse to breastfeed them out of fear' (C 1900), or when mothers and fathers of children with intellectual disability have explained to the social workers that they have been advised by physicians, in cases 'renowned doctors for psychiatrics or neurologists' (A276), not to provide physiotherapy for the child 'will not benefit from physiotherapy' (A 273), 'will die' (A 240) 'will not still be alive' (A 249), 'will not live' (A 251), 'will not be alive for a long time, maybe one year maybe some months and then he will die' (A 265), 'just leave him' (A 273), 'don't do anything, he will not benefit' (A 925), they express an underlying problematic of persons with intellectual disability being less human or treated as if dead. The strategy of exposing the children with intellectual disability in public spaces and once in a public space, e.g. showing the public that these children have a intentionality, is a strategy showing the public that these children have intentionality, wills and wants which they can express. Once again, a strategy intimately related to an understanding of the public, or 'the other' as

perceiving people with intellectual disability as non-intentional subjects and a remedy to such faulted understanding using exposure and thus visibility in public space, letting these children choose what they want from the supermarket and thus convincing the public that these children can choose, inviting the mothers to school for mothers' day where the children with intellectual disabilities give gifts to their mothers (B 302) or taking them to playgrounds and shopping malls. Views of 'the other' and constructions and choices of ones' own social work strategies are in this way intimately related. On this spectrum, spreading from 'distance to proximity' and 'from non-human to human', the social workers have, throughout concrete examples, expressed their views on the different communities and oftentimes their views on themselves and choice of social work strategies have been created in opposition to their views on the communities. There has been a parallel dimension in the stories of the social workers, namely time. Some interviewees express how 'the other' had been before and how 'the other' was now, referring to a journey regarding approaches from distance to proximity, from expressing views of persons with intellectual disability being non-human to now being perceived as human; namely that there has been a change within the community. At newly initiated projects, perceptions of 'the other' were similar to how it had previously been in projects where SOIR had been engaged for a long time.

A central line of thought in this paper is how the approaches of the community towards introducing persons with intellectual disability into public spaces and socially accepted positions, is constructed towards a baseline where the social workers perceive intellectually disabled persons in the communities towards which they work, as being denied existence in public spaces by 'the other', an 'other' who also express a will to spatial (and other types of) distance and invisibility. Our interviewees express how people in the grocery store exposed to situations in which persons with intellectual disability are given the opportunity to make a choice of preference and does so, look as if they were shocked, people looking from a distance 'can't believe that the children with intellectual disabilities managed to take the school bus on their own' (B 986), and parents are 'quite surprised' that their children with intellectual disabilities create things in vocational training centres (B 1347) and 'shocked when hearing that their child wash dishes and help in cleaning' (A 940) – these 'others' do not expect persons with intellectual disability to perform as if human. To convince parents, social workers have put them in rooms within the vocational training centres with windows towards the rest of the centre. There they have been able to see for

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themselves what 'their child can do'. Social workers mimic the parents surprised facial expressions when seeing that their child was able to eat with a spoon and was helping in clearing the table, stunned by surprise the parents 'didn't know what to say or do' (A 948). Throughout our material denial of social and visible existence of persons with intellectual disability seem to parallel a denial of persons with intellectual disability as having human properties and or at all being human.

Medical Anthropologist Nicolaisen (1995) studied disability among the Punan Bah of Central Borneo and describe how persons with disability are not seen as a differing category and are a given part of their community, however, if perceived as a spirit, being born as a twin or perceived as a witch, the person becomes a feared and polluting person. The fear of twins, spirits and witches in the Punan Bah community may be explained by Douglas (1996) that they are feared because they are viewed as problematic to categorize with regards to their characteristics towards which the formation of social identity is constructed. These people 'wither away' among the Punan Bah. They too are feared and avoided, denied social positions and ultimately physical existence.

Among the Songye of former Zaire, deformed children may be thrown into the river to 'be returned to God' (Devligier 2010, p. 75). Such actions are conducted by ritually appealing to God; however, the effects are ultimately death - a denial of physical existence conducted throughout infanticide. Among the Songye of former Zaire, children with deformities are perceived as the result of a wronged relationship between the people and God. Thus, in line with Anthropologist Douglas (1996) reasoning, one could expect the relation to God to be a strong characteristic towards which social identity is constructed, thus when this relation is wrongful, shown by a polluted baby, it need to be corrected.

In line with the thinking of anthropologist Douglas (1996) it is possible to pose the question towards which characteristics the social identity in Amman and surrounding areas is constructed? And characteristic in specific is the taboo 'disability' a reflection of? Medical Anthropologist Nicolaisen (1995) describes the Punan Bah of Central Borneo as a society where 'individual ability is not crucial for the formation of social identity' (p. 53) and juxtaposes the importance of individual ability in the West for the formation of social identity and this non-importance of individual ability for the formation of social identity among the Punan Bah. Clearly, the notion 'disability', a non-existing notion among the Punan

Bah, closely relate to 'ability' and may be viewed in the light of the strong emphasis on individual ability for the formation of social identity in the West.

However, in Amman and surrounding areas, although there interestingly seems to be an active change in the social positions of persons with intellectual disability, this change is initially practically enforced and persons with intellectual disability are traditionally reported to be polluting (see section on the views on disability as contagious), are said to be feared and avoided, many times denied human properties and categorized as non-human. This society too, like the Punan Bah, traditionally provides social positions by characteristics as status of kin. In Jordan economic power is also seen as a great asset. However, the field of this study almost exclusively consist of personnel working with persons with severe and moderate intellectual disability in poor families. This implies that the field for this paper is persons with severe or moderate intellectual disability born into economically marginalized families.

Historian of Medicine Buckingham (2011) provides an account of Brahmanic texts in which persons with impairments are expressed as low status with reference to them having low ritual status. In Brahmanic textual tradition, persons with intellectual disability, expressed as 'idiots', were disinherited since they were judged to lack the ability of important rituals for the family, most importantly to lack the ability to bury their father, a ritual characteristic of social identity of high caste people in parts of India. An alternative example of how family and cultural traditions may relate to the construction of social identity, assessed by studying approaches towards persons with disability.

Being in field we found two kernel points for the formation of social identity which relates to ability; the ability to work, to be productive and provide for oneself and possibly others and the ability to bring forward the family, in our material an ability relating intimately to social positioning in accordance with norms and notions of sex (and) gender, to tie socially (and bodily) with other families. Whether the relationship between these two characteristics and the individual were a forcing one or a more freely one, i.e. the extent to which it was accepted not to fulfil these characteristics seemed to rely on the resources of the family and the surrounding area, especially with regards to 'ability to work'.

We are of the understanding that before a child is conceived, a more or less certain social position is prepared for the child in terms of expectation. Depending on the resources of the locality (as the family but also the welfare state), the balance of rights and

obligations are accounted for differently. A child born into a system of limited resources is a child who needs to fulfil more social obligations in order to be granted the right to social existence. In such calculation, children with disability actually bring a minus value; they are not expected to be productive or have the possibilities to provide for their family when they grow older, they require time, money and effort from the family and they make it difficult to marry away your daughters. Using more theoretically grounded thinking as referring to social positions can be, and is in our work, grounded, using a more general explanatory model, as referring to social expectations and earning the right to existence depending on the extent to which ones possibility to action is estimated, may be more complicated. Anthropologist Devlieger (2010) holds that when something is rigidly classified as anomalous, as is the case of persons with intellectual disability in Amman and surrounding areas, the boundaries of what it is not, as well as of what it is are more easily accessible. Conducting such analysis on the field of this paper it becomes clear that being a human implies intentionality and similarity in behaviour and looks to other humans. Being human also seems to preclude visible and recognized existence in public spaces, making enforcement of existence in public spaces most important. Being a human requires to tie to socially to other humans, on the playground as well as throughout agnatic kin identity. However, it also poses the question of whether it is easier to achieve a human status coming from a good kin or being born into a family of greater economic status? When trying to mainstream children, adolescents and adults with intellectual disability, do the social workers adapt to strategies broadening of the concept 'being human' or do they focus more on changing inherent material in the notion 'disability' - perhaps both at the same time?

4.9 Distance and Difference

Occurring repeatedly in our material is a constant search for distance and difference, the constant search for a clear and visible border between the self and the deviant, the human and the non-human; ultimately a denial of (social) existence for persons with intellectual disability, possibly a strategy to avoid spread of pollution to one self. There have been no social and acknowledged positions for these children and adults. Traditionally persons with intellectual disability are hidden in their homes, they have filled no other function than to put to question the genetic material of their closest family and put the social connections of the family at risk. It is still occurring that the mothers of persons with intellectual disability

fail to acknowledge the human properties of their child with intellectual disability and isolating persons with intellectual disability is a less common but still occurring practice, especially in the rural areas. Sociologist Turmusani (2003) has expressed how intellectual disability sometimes is perceived as something from the devil. One of our interviewees, working with negotiations when initiating community based rehabilitation projects, expresses how people react if they are visiting their neighbour and suddenly there is a child with intellectual disability in the same room. Our interviewee expressed dramatically pointing at the child saying (loudly) "Haram!" "Haram!" (Not lawful according to Islam).

Apart from the taboo and possible analogy to the social system that disability being contagious may imply, effects of disability, as shame, is also instantly spread to the closest family; if a close family member has disability, the family has disability 'there is a thought that there is disability in their genes and others who get to know about another family member with disability will not accept marriages to these families. The whole family has disability in their genes' (B 384) a view supporting of properties of the content of disability as something that can, in fact, be spread.

Perceiving intellectual disability as a disease implies to some people that carriers of the condition disability can be cured 'some people think that it is like a disease and that the girls can be healthy again' (B 1209) 'they believe it is like a disease and hope that these girls will get rid of this disease, they want to relive them from the disease' (B 1213). In our material, such thoughts on persons with intellectual disability being cured, relate closely to expressing pity for persons with intellectual disability, a property of the Proximity-Distance Category, since exclusively expressed in situations where people express concern and positive feelings but still clearly marks a distance between themselves and whoever is subject to feelings of pity; persons being construed with lower status than the construer.

4.10 Time and 'the other'

The social workers also explain that their strategies have resulted in a change in behaviour of 'the other' related to a time dimension. After some time of exposure and proximity towards persons with intellectual disability 'the other', i.e. the attitudes and approaches towards persons with intellectual disability of most people of the specific but any local community (so far) have changed: 'in the beginning, parents wanted to hide their children, but now no'

(B 1882), 'they (have) change(d) a lot especially the girls are not always able to go out of their homes' (B 1120), 'the situation is better now: they are showing them out but in the past they were hiding them at home. Not every family but some families don't care about their child with intellectual disabilities as their non-disabled siblings, they don't clean them, don't dress them properly' (B 1283). Another social worker explain to us how 'it has changed, we made this possible. We took the children to the community. We let them deal with the people outside' (B1703). The social workers also use concrete situations to measure such change, referring to a change of behaviour of the generalized 'other', as when the local McDonalds had invited a school class of children with intellectual disability to come and eat there (B 781) or when another school class of children with intellectual disability was invited to a festival at another school (B1205). Another measure of change was when civil persons in public space have acted as if they were ascribing human properties to persons with intellectual disability: 'first the man in the supermarket gave the children crisps as a pity and asked them to leave. Now it is not like that, they know that they (persons with intellectual disability auth. rem.) can make a choice and ask them' (B 1705).

4.11 Strategies of Making Persons with Intellectual Disability Human

Exposing persons with intellectual disability in public spaces is one strategy of enforcing existence which implies making persons with intellectual disability visible to the community. At the same time, as a staff member, being aware that the interplay between the staff and the persons with intellectual disability is exposed and throughout such awareness show love and proximity to persons with intellectual disability may be categorized as a social work strategy. Having and exposing a mutual relation based on showing adequate and expected feelings – as when encouraging mothers to treat their children with intellectual disabilities as their other sisters because, the social worker emphasises, she has the same feelings (B 1188) or to talk to their children with intellectual disabilities and listen to them because 'the parents were not listening a lot to their children with intellectual disabilities' (B 1361) or encouraging parents to give their child with intellectual disabilities some responsibilities, since they gave them none (B 1175) and to give them opportunities to choose, since parents did not like to give their children choices (B 1190) are strategies and techniques of enforcing

existence and making persons with intellectual disability human. The mere existence of persons with intellectual disability in public spaces is an exposure implying visibility, a physical existence hard to neglect. Treating persons with intellectual disability with respect and as human beings and because of an existing and (mostly) true relation between the staff members and persons with intellectual disability, existing in public spaces becomes the exposure of a person with intellectual disability who is socially connected and who thus inhibits an enforced position with the inherent possibility to act in a socially accepted manner. Most, if not all, of the strategies of opening up the position of intellectual disability throughout showing the 'other' that these persons have inherent human properties, thereby enforcing existence and not only visible exposure, are consciously conducted by the SOIR personnel and staff members at the local projects.

This is a process of acquiring the social position 'human' in which the theoretical tools of anthropologist Turner (1969), the positions of persons with intellectual disabilities and the inherent potential in such, as well as the strategies of the staff, may be more thoroughly viewed. Persons with intellectual disabilities in Jordan are in a highly liminal position, being denied (social) existence, being perceived as polluting and being feared. As liminals, persons with intellectual disabilities do not inhabit such a 'human' position. Rather, such a position has to be created for her. On the social workers' initiative, persons with intellectual disabilities are exposed while interacting with staff members when non-disabled audiences are present. In this the staff member creates a position for persons with intellectual disabilities which open for other treatment than traditional practice of persons with intellectual disabilities. The community, i.e. audience is exposed to a situation in which persons with intellectual disabilities are human. Persons with intellectual disabilities are already in a liminal, i.e. uncategorizable and feared position, they have, most often, since birth been detached from their social connections, having no or minimal social or economic expectations nor are they expected to uphold (other) family relations throughout fulfilled social obligations. Making persons with intellectual disabilities human involves convincing their relatives and the community that they have central human properties, as intentionality, and making visible to relatives and the community that persons with intellectual disabilities can be loved and respected and can love and respect - that persons with intellectual disabilities can be part of a relation. However, it also involves convincing parents that their children 'can improve' and be 'productive'.

When initiating a new project, and as part of mainstreaming persons with intellectual disability work of every project, there seems to lie an intention of guiding the 'abled' public towards ascribing persons with intellectual disabilities the socially acknowledged position human. As a new project is initiated the staff at SOIR, together with key personnel from local projects, provides lectures and meetings with the community. The community is invited to listen to the work of SOIR as well as the nature of intellectual disability and the rights of children and adults with intellectual disability. Some projects have also persuaded a religious woman from the mosque to talk about persons with intellectual disability from a religious perspective and exercising religious authority. Apart from these campaigns to affect the views, feelings and approaches towards persons with intellectual disability, people from the close community are invited to visit the school classes or vocational training centres, to actually see or meet persons with intellectual disability. The social work is in the process of acquiring the being 'human' on behalf of the persons with intellectual disability. One strategy of 'easing in to' the making of the 'human' position with the old liminal position is to start of by abstractly representing persons with intellectual disability' throughout merely talking about the nature and existence of persons with intellectual disability. SOIR may hold lectures for all the children of a school, as well as all its personnel and parents of non-disabled students, when initiating a school class for children with intellectual disability. The 'public' receives information. The public is also invited to their local project to see for themselves what is going on. When invited to a local project, a person from the community may act as participant or as a spectator, upon his or her own preference. If a cluster of people, as a school class from another school is invited, the children are invited to come and play together with the children with intellectual disability, i.e. as participants.

A supposedly comfortable way to approach someone in a liminal position is of course with as much distance as possible, making sure that one is not affected by such contagious and polluting condition. On mothers day or other celebrations, the social worker invite as many as possible from the community to be part of the celebrations. Mothers of non-disabled and disabled children sit in the audience as social interaction with the previous liminal position is being acted out on stage, a strategy of visibility to create comprehensible and categorizable associations to persons with intellectual disability. In such process, the principal of the school may be coached by SOIR personnel how to act, in such cases that she

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needs to show the school that she can love persons with intellectual disability, she needs to hug them, respect them and laugh together with them. She is an authoritative symbol in front of an invited audience and she needs to affirm the right to (social) existence of children with intellectual disability in this public space. Children with intellectual disabilities receive gifts and respond with happiness. The children dance together with non-disabled pupils, meet in a social space as humans.

When social workers and other staff at SOIR and the local centres initiate happenings in order to make persons with intellectual disability 'human' they generally adopt one of two strategies.

The first approach can be expressed as possibilities of persons with intellectual disability to improve and be productive; therefore they are granted existence in public space. This strategy is in line with approving existing boundaries for humanness and non-humanness and aims at proving that persons with intellectual disability, with rehabilitation, have the potential to perform in accordance with social obligations required in order to be ascribed the social position 'human'. Such a social obligation may be to embody the characteristic of 'being productive', i.e. being able to produce and have an income. Parents may be told that their adolescents or adults with intellectual disability will have the possibility at the vocational training centre to be productive and more self-sufficient if the parents believe in them. People from the public are invited to vocational training centres to see products created by persons with intellectual disability. The social workers explain to us how parents are surprised in such situations and when having a hard time believing that their children have created such products are shown further evidence. The mother who doubts her son's ability to eat with a spoon is placed in a room with a window towards the dining hall and the father, who doubts the origins of the wooden table are invited to see his son at work, see humanness happen. This strategy is most often performed by social workers with regards to convincing the public of persons with intellectual disability's potential to humanness. Worried parents who are seeking counselling from the social workers are shown examples of other persons with intellectual disability who have 'improved', i.e. qualified for humanness on existing conditions, learned the right behaviours, learned how to eat, learned how to walk, learned to be productive. This, especially in relation to the direct or indirect denial of persons with intellectual disability being human, is an indication of the necessity to earn the right to social existence, earning a socially accepted

position; being accepted as a human being, being accepted as similar to non-disabled and or as someone's son or daughter.

Most of the families that SOIR work with are not only families with a member with intellectual disability; they are most often also poor. In such context one can understand the need of the persons with intellectual disability to be self-sufficient and productive, in order to provide for their family, but also, if their parents eventually pass away before them, to provide for themselves. There is however, a difference between the need of training persons with intellectual disability to be self-sufficient as well as the need to integrate persons with intellectual disability into the working market and between talking interchangeably of rights of persons with intellectual disability and self-sufficiency and productivity.

The other strategy we managed to identify consists of *not* accepting existing conditions to qualify as a human being, instead of working under such conditions, working against them. One might claim that this approach expresses the humanness of persons with intellectual disability, therefore right to social existence in public space, training to improve and be productive in the Jordan context. This is the strategy of the social worker who explains that these children (already) *are* human and as human have human rights. Characteristic for this strategy is a lack of emphasis on rehabilitation[3]. Being human is rather a precondition that the social workers express to the community rather than rehabilitation as a means to a goal of recreating the deviant into the normal, i.e. the nonhuman into the human. The child does not need to improve but rather be allowed her inherent right. In this part of the material, informants talk interchangeably about resistance from the community towards the existence of persons with intellectual disability in public spaces as denial of human properties, fear of persons with intellectual disability and a will of spatial and conceptual distance. These informants most often talk interchangeably about such resistance and the inherent rights of persons with intellectual disability and of their inherent human properties, their similarity to non-disabled and their possibility to improve regarding their capacity to learn how to eat or walk by themselves. This strategy revolves around taking societal institutions and services that are available for human citizens and expanding

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[3] Clearly we do not oppose rehabilitation for a child or adult in need - rehabilitation is a very good thing! Rather we want to understand the premises upon which staff members build their thoughts and arguments when talking about productivity - possibility to improve, rights and (implicitly) being human, interchangeable or in such way as some states (in which many persons with intellectual disability are not) are preconditions to 'being human'.

these to persons with intellectual disability. It involves policy agitation; make them inhabit the socially accepted position 'student' for persons with intellectual disability in public schools.

After an enforcing stage of visibility and proximity the social worker continues with securing the acquired position, student within a public school, on behalf of the persons with intellectual disabilities. The social worker turns her gaze towards public opinion, parental protests and teacher attitude. She supports interaction with the position, since a position cannot exist in social vacuum. In the case of student she provides fellow-students in encouraging joint-parties, leisure activity. Indeed, the social worker needs to create social relations towards the newly acquired position since she cannot with her single relation towards it - secure it. She tells the non-disabled student that she cannot work alone, she needs their help. They are thus asked to visit the students with intellectual disability, asked to play with them. She herself works as social model and as such tries to inspire others to establish social relations towards the new position. She shows them love, talks to them as students and as humans. She also encourages authority to take up the task of social modelling. The principals are persuaded to attend festivities, to visit the classrooms and to hug the children. When audience, e.g. parents and community members, are present, e.g. on school festivities, authorities may be used to put on a more persuasive social modelling show. The social worker supplies material attribute to the position, since this might not have been included in the government agreement when the position of student was first acquired. Classroom furniture, school-books and educational toys. All is provided in order to convince the public of the genuineness of the position the persons with intellectual disability now inhabit.

As previously mentioned, the one-to-one social work strategies oftentimes depart from the kind of resistance which is expected or expressed from members of the community. When the strategies are on a one-to-one basis they most often depart from expressed resistance on behalf of the other person, such as an expression of perceiving persons with intellectual disability as bad and wanting distance by difference but also spatial distance – a common pattern in our material - is met by talking about proximity by similarity and informing about the rights of these children to enjoy school services in their local community.

Another strategy is the exposure of persons with intellectual disability in situations where they can be ascribed human properties as intentionality shown by the possibility to make a decision. Intentionality can also be argued with reference to `possibility to improve´, most often occurring when parents do not believe in their children having human properties such as a mind. Showing love was prematurely categorized as an anomaly but as we got more grab on the material we realised that showing love, especially in public spaces in the eye of the community, is a way of showing proximity by acceptance. However, showing love as a strategy most often occurs when in a more or less special space; the class room for children with intellectual disability. Having material of some parents being afraid to let their children leave home and go to schools since they cannot understand who could possibly accept their child, and the teachers referring to love as a matter of trust, we are of the apprehension that it is possible that parents as well as students need to be shown that they are loved, the starting point being that they can not possibly be.

When some of our informants, over and over again, gladly informed us that the mothers use 'if you don't do this and that, you cannot go to the centre tomorrow' we felt we could not fully understand what they actually meant. Only throughout comparative analysis did we realise that this statement, apart from the obvious that the children appreciates the centre, showed that the mothers actually ascribed their children intentionality.

4.12 Family Organisation, Gender and Persons with Intellectual Disability

'Here in Jordan the families are very tightly connected... the family is the basis of existence here... '. Organization of the family in Jordan stretches from a nuclear family living in an apartment, a quite new phenomenon in Jordan, to patrilocality and arranged endogamous marriages, i.e. living with the family of the husband and marrying a kin, often times according to arrangements of the family. Associate professor of Islamic history, law and society Sonbol (2003) report how, although consanguineous marriages are on the decline, 42.5 % of married couples in Jordan are married to their kin, oftentimes a first or second degree cousin. Thus, the majority of marriages in Jordan are estimated to be exogamous, i.e. marrying outside of ones' own kin, such marriages may however be partly or fully arranged.

The husband is traditionally perceived as sole breadwinner and although women according to Jordan law have the right to work, at the same time it is established that a married woman does not have that right unless her husband allows her to (Sonbol 2003). In 1998 the average working years of women were estimated at 3.7 years and about 12-16% of all women were involved in any type of salaried employment (ibid 2003). As persons with intellectual disability in the field of this thesis generally were enforced existence solely in the female sphere, (children with intellectual disability went to special classes in public school for girls, no matter the sex of the child, working with families of children with disability most often implied working with mothers, persons with intellectual disability on the streets (male space) were often perceived as doing wrong, it is of great importance to somewhat investigate the position of women in public space. In fact, women with intellectual disability may be in such uncategorized position that they may inhabit a position with greater potentials of existence in public space than do non-intellectually disabled women.

Women in Jordan are highly controlled as regards their mobility and tolerance of their existence in public space is limited. Jordanian Islamic scholar sums up the experience stating that "a Muslim woman should not go out too much, leaving her home must be for an important reason" (Sonbol 2003 p. 93). Women in general are referred to the private space of home but quite a few do take a job, at least for some years. Women working in Jordan are in an ambiguous position, they do have an important reason to go out but where is the line, when do they go out too much? Anthropologist Droeber (2003) who conducted a two year field study on religiosity of young women in Jordan explicates how dressing in a more traditional way, such as veiling, wearing a hijaab, biljaab or niqab may be perceived as a social compromise; the woman, not being protected by the borders of her home, but being so by the borders of her clothing. The necessity of such compromise may be perceived as an outcome of their highly ambiguous position. Women owe their family to obey their male guardians and limit themselves from other social settings than home; practices throughout which patriarchal power and family honour coalesce.

A woman in Jordan is under the guardianship of her father, and should her father pass away, another close relative, as an agnatic uncle will be her guardian. When a woman marries, her husband becomes her guardian, he now has the right of her obedience and should she be disobedient he has the right to withdraw from economically supporting

her. A wife is bound to obey her husband according to shari'a and any wife who does not, actually draw a burden upon her sisters, as Islamic scholar Sonbol (2003) puts it; "Who would want to marry into the family of a woman who has brought discord and conflict into her home and her husbands' life?" (p. 95). This encapsulation refers to women who do not obey their husbands, thus being outside of the husbands obligation to support them economically and a sound base from which women can apply for divorce, although most often denied one (ibid 2003). This reasoning may rewardingly be juxtaposed to the findings of Sociologist Turmusani (2003), as well as the data of this paper, that it is hard to marry away your daughters if the family has disability, i.e. if any family member has disability, which poses one answer to the question 'why distance and difference?' as regards the isolation of persons with intellectual disability; they are simply hidden.

The implications of having a child with intellectual disability are many and different. 'For some 'it's like a trauma happened to the family. They are shocked, their child is retarded, they never dealt with retarded children most of them.' (C 1579). It has implications for the family as a whole 'there is a thought that there is disability in their genes and others who get to know about another family's member with disability will not accept marriages to these families. The 'whole family has disability in their genes.' (B 384). In some cases the family has an acceptance of the child and a will to work with the child from his or her capacity. This is reflected by some of the staff at SOIR as a goal to strive for when working with families and a goal not a few families have reached. In other cases persons with intellectual disability may be isolated, the mother may be held responsible for bringing disability to the family (in an exogamous marriage in a patrilocal society, the kernel family traditionally live with the family of the father) and at times the child with disability is denied any rights; to schooling, denied the love from the mother or even to eat together with his or her siblings. Having a child with disability may equal to not having met the obligations of the relatives and as a woman and mother of such a child one may be held responsible for bringing disability to the family and thus be refused by the fathers family, the family that a newly wedded man and wife traditionally lives in, in a patrilocal society. Our material shows that some families, after a child with intellectual disability is conceived, does not want to 'deal with the wife' (C 1639) and the mother of the child with intellectual disability may experience that her kin 'always laugh' (C 1643) and that the children of her husband's kin would 'hurt her child, laugh at him and hit him' (C 1648), 'say that we don't have that we

don't know you and we don't want to deal with you' (C 1650). Mothers may 'move away from the area they were living in' (C 1651) because of such. Some mothers feel 'devastated' (C 1652) and 'suffer for years with their husband's family' (C 1653). The consequences of having a child with disability is, at times, rejection from the closest family of the child, and putting the mother as responsible for bringing the disability to the family. If the mother is a first cousin blames might fall on her closest relatives who are not part of the agnatic kin: 'maybe if her mother is from the outside, they will blame her', 'they feel mostly shame in the same time the mother feels sometimes the guilt and that she is the one to blame.' (C 1581). Such is the case when social workers explain that: 'the mother she goes like: my child he is retarded, oh my God, the family of my husband they are going to blame me, they are going to say that I am the sick one, that's why the child is retarded'(C 1629). The mother in this case has reason to fear since 'the husband's family doesn't accept the idea of having a retarded child so they can maybe cut her out of the family' (C 1629). Although religion is hereditary through the father, the social workers in this way talk of the 'other' perceiving disability as hereditary through the mother, in some sense a strategy for agnatic kin to deny disability in their own family. Most often in arranged marriages the bride and groom are relatives, first cousins or further away. Denying your far off family in order to keep your closer family "disability-free" seems a great crime in a society where family, even far off family, is an obligation. In filling the carrier of disability with notions like: 'bad/have bad behaviours', 'sick', 'contagious condition' (possibility of spread of a bad condition), 'dangerous' (may spread to you or your children) 'without mind', 'without intentionality' (without basic human properties), the crime of the relatives denying the existence of persons with intellectual disability may seem less severe.

The social worker's refer to the 'others' view of the children and adults with intellectual disability as embodying a stigma immediately spread to their family and making arranged marriages of their daughters without disability very difficult. 'It has been common to hide children with intellectual disability in these areas. If other people knew, they would not come and marry their relatives. They are shy to show them' (B 766). The social workers explains how hiding children with intellectual disability, i.e. not acknowledging them to 'others' as part of the family, is a direct strategy of acquiring marriage: '(It is, auth. rem.) something in the mind of the people, from this shame knowledge. If you have a family member with disability people would not want to marry your daughter.' (B 1479), 'some

relatives does not want to take children with intellectual disability outside, they feel shy, you cannot marry away your daughters if you have disability within the family' (B 868).

Marriage seems ultimately to be perceived as the bond between two persons and them embodying the bond between their families, as such, marriage becomes a family issue, arranged or otherwise. Not being perceived merely as a commitment between two people (the bride and groom) but rather as a family issue, the bride and groom and the relation of the bride and groom become an arena on which the identity of their kin is played out, and as such identity is played out and expected to be confirmed in any marriage. Everyone is equally responsible for upholding the identity and status of everyone else within the kin group. Every married or marriageable person, especially tied by blood and if close kin, less so if tied by marriage to ones' own blood, poses as an arena in which the family's pride and honour, ones' own pride and honour and the pride and honour of ones most beloved, is played out and relations, alliances or otherwise, between families are perceived as kernel points in the family status and identity. This is traditionally a patrilocal society, which puts greater control on girls for they are the ones being 'married away', i.e. the actual link throughout which bonding with other families may take place and as such their bodies may be viewed as symbolic fields on which family integrity is demarcated, they need protection from the spread of a disabled family member. Having a family member which put to question the obedience of a wife, as expected, or the quality of the genetic material of the family, is highly stigmatizing and may in this way pose a threat of isolation of the family from social existence.

Using the theoretical framework of Anthropologist Douglas (1966), persons with intellectual disability in the Amman area may be perceived as in an ambiguous state since they are clearly a part of their own family but at the same time, they put to question a central ability of the family. The existence of a family member with intellectual disability may have the social effect of a disability of the family to tie socially with other families and inhabit a socially accepted position. This social disability of the family seem to be mainly with references to polluted genetic material, but there are other tendencies as the perception that parents of a child with (intellectual) disability being punished for some sin. Ultimately these children and adults may be denied existence as to deny and prevent stigma and social disability of the family to connect to other families.

Denial of existence of persons with intellectual disability in Jordan, is about social existence and social workers strategies often actualize the current social order: 'in the beginning mother did not want to meet them some of the parents did not want to show out the children, they do not like their child with intellectual disability to be outside, to show that they have disability' (B 766). 'Others didn't want to show their child out of home' (B 1406). 'Some people didn't want to show their children.' (B 1426), 'one child is new and when he came here he was 10 years old and it was the first time he left his home' (B 577), 'when they started the girls came from home, they knew nothing, had never been out of home' (B 1034), 'when it came to the community, inside the community, they thought it is something they should hide.' (B 1888), 'some people will hide their children at home. They are refused in the community' (B 855). The isolation is quite effective, a social worker explains to us: 'I was visiting a family and one door was open, then we saw the child, before we didn't know that this family had a child with intellectual disability' (B 1484). The social workers question a social discourse placing persons with intellectual disability in a liminal position, sometimes by explicitly addressing the issues by talking to the parents: 'here in our culture there is a lot of people feel that its shame to have a retarded child. So when I talk to those people, I started to ask them: Why you are shy or ashamed? (C 1360), or in a strategy indirectly focused on the 'other' by working with the children: 'we train how to cross the street or go shopping but the families' don't take them or some just leave them out. (B 1280), 'take these children to the markets. Teach them how to buy because the family didn't take them to any place so we make this our responsibility' (B 779) and are met by resistance towards their strategies of changing this social discourse, positioning these children and adults in situations where they have rights and where their abilities are recognized, positioning them in situations throughout which the children and adults with intellectual disability are made to be 'human'.

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