

SOCIAL EXCLUSION OF THE ADULTS WITH ASPERGER
SYNDROME IN SOUTHERN FINLAND

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ABSTRACT

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The main aim of this study was to examine 'how and why' the adults with Asperger syndrome in Southern Finland get socially excluded. The research investigates what forms of social exclusion towards adults with Asperger syndrome exist in Southern Finland. It also examines how the special needs of the adults with Asperger syndrome are met. The research gives proposals from the findings on how to avoid and alleviate the social exclusion of adults with Asperger syndrome in Southern Finland.

The study followed a qualitative research method of open semi-structured interviews. Two different groups of people were interviewed for this research; four adults with Asperger syndrome and three union leaders. The union leaders belong to the Autism and Asperger Foundation which advocates for the rights of people with autism and Asperger in Finland. The union leaders are also parents to children with autism and Asperger syndrome and possess expertise from parenting experience. During the study special attention was paid on the life experiences of the adults with Asperger syndrome. Some of the interviewees volunteered to take part in the study following an advertisement in the Asperger empowerment group online social network. Others were selected using the snowballing method.

The study revealed that despite the existence of some policies to prevent and eradicate social exclusion, the implementation of the latter is poor. The formulation of some policies does not take in to account the special needs of people with Asperger syndrome according to the study. Finally there is need for a transparent and simplified welfare system which is accessible and well understood by people with Asperger syndrome. The study revealed that adults with Asperger syndrome are not happy with the child welfare department. This calls for the development of new professional approach in tackling cases involving parents with Aspergers syndrome. The study found that there is need for more family support for these parents. The main areas of social exclusion for adults with Asperger syndrome are; labour, family life, social capital and cultural exclusion. The study found out that exclusion from the labour market led to other forms of exclusion. It was clear that education is not the reason people with Asperger syndrome are excluded from labour but lack of supported employment. The government approach on the labour exclusion so far, has been provision of more vocational training. The study found out that there is a need for a change in this approach. There is need for more research in the field of social exclusion of adults with Asperger syndrome to combat this predicament in the society

Key words: social exclusion, Asperger syndrome, adulthood, processes of social exclusion, social exclusion paradigms, integration, and inclusion, qualitative research

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1. INTRODUCTION

My thesis seeks to look deeper in to the social exclusion of adults with Asperger syndrome in southern Finland. I was driven in to this topic after doing a work placement in a group home for people with learning disabilities in Vantaa. There I met adults with Asperger syndrome and build interest in their social inclusion. I also chose to look at the social exclusion of the adults with Asperger syndrome because they are highly susceptible to social exclusion due the nature of their disability.

Asperger syndrome is one of the unseen disabilities which recently got recognition by World Health Organisation in 1993 (Schopler, Mesibov & Kuncze 1992 ,23). Asperger syndrome is an inborn disability and cannot be treated. Those with Asperger syndrome encounter challenges in communication and social relations (Lawson 2003, 9-10). The adults with Asperger syndrome are highly vulnerable to social exclusion, due to the nature of the disability. Social exclusion not only addresses poverty issues but also social relations and communications limitations (Silver 1994, 531) This thesis seeks to identify the relationship between Asperger syndrome as a disability and social exclusion amongst adults living in Southern Finland. Approximately 40,000 of the population of Finland have Asperger syndrome, (The Finnish Autism and Asperger Foundation). This shows Asperger syndrome does not affect a minority group and their social exclusion should be addressed with heightened seriousness.

Social work aims in inclusion of marginalized groups and so addressing issues of social exclusion lies in the backbone of social work. Asperger syndrome is a learning disability which gained recognition by the World Health Organization in 1993 even though it was discovered in 1940 (Schopler et al. 1992, 23). The most pre-dominant characteristic is the limitation of social skills in the people having Asperger syndrome. The nature of this disability hence makes the people with Asperger syndrome easily socially excluded.

1.1 Research aims motivation and relevance

‘People with disabilities are undoubtedly among the most vulnerable at risk of social exclusion. Furthermore, less than a third of disabled people in working age are in employment, often low paid jobs’ (Yfantopoulos 2008, 4).

The aim of my research is to answer the research questions below;

1. What forms of social exclusion do adults with Asperger syndrome in Southern Finland face?
2. How are the special needs of the adults with Asperger syndrome in Southern Finland met?
3. What changes need to be done to combat social exclusion of adults with Asperger syndrome in Southern Finland?

The findings of this research will help professionals adjust the approach used in preventing and tackling the social exclusion of the adults with Asperger syndrome in Southern Finland. This study also seeks to show why, the approach used in preventing social exclusion of adults with Asperger syndrome, needs more attention than the other disabilities. The results of this research will also help policy makers in the approach used in formulating policies to prevent social exclusion of adults with Asperger syndrome.

2 INTRODUCTION TO ASPERGER SYNDROME AND SOCIAL EXCLUSION

It is important to provide clear definitions of the terminology being used in my thesis. Some of the definitions are highly contested but I will choose the definitions which best reflect my research topic.

2.1 Definition of Asperger syndrome

Asperger syndrome is a neurological disorder which is also classified under the pervasive development disorder. It refers to a group of disorders characterised by delays in the development of socialization and communication skills. The people with Asperger syndrome exhibit difficulty in social interaction, unusual play with toys and other objects for children, difficulty with changes to environment and routines, repetitive body movement or behaviour patterns, delay in the development of motor skills like walking or biking, one way conversations meaning they only focus on their topic of interest, inability to read facial expressions and literal understanding of words. People with Asperger syndrome also are 'monotropic' referring to inability to multi-task. They are unable to divide attention and attend to different things at once. (Lawson 2003, 31.)

Asperger syndrome was first discovered in 1944 by an Austrian paediatrician Hans Asperger who was specialized in remedial pedagogy. He worked with children in his clinic where he took note of similar behavioural traits which he studied and classified. He wrote his findings in German and only got an official translation in English in 1991 by Frith. His work got official recognition by the international classification of diseases, 10th edition (ICD-10) by world health organization in 1993 and 1994 it was included in the diagnostic and statistical manual of mental disorders 4th edition. The syndrome was named Asperger after the paediatrician who discovered it. (Schopler et al. 1992.)

According to Gillberg (2002), Asperger syndrome is often referred to as high functioning autism but it always carries a negative connotation. Therefore, I have decided to use Asperger syndrome which will be evident throughout my text.

2.2 Definition of adult

According to Barnes & Mercer (2003, 137), personhood signifies a refinement of the notion of humanity that differentiates between specific roles or statuses. It focuses on expectations of what it means to be a child, adult, man or woman and therefore may change over the life course.

Adulthood definition can be classified based on biological factors, legal, psychological, or socio-cultural perspective. The definition of an adult changes from place to place in different societies. Using the social cultural perspective an adult gets this title after acquiring certain practices in his culture such as being married for a man in the Semaqberi native community in Malaysia and having a child for the women in this community is the indication of adulthood as opposed to the men (Ing 2010). Subsequently, the definition of an adult varies from one cultural setting to another.

The legal age is 18 years old in the case of Finland for a person to be considered an adult. Early adulthood would be 18-40 years old. Late adulthood would include 41-65 years old. At the age of 18 years, the person is expected to be responsible for his life and property. It is not only viewed from the angle of the age, but also from his physical, cognitive and emotional state. An adult is also expected to be competent enough to make proper decisions regarding his life. (Aiken 1998, 22.) People with learning disabilities are involved in decision making about their lives through supported decision making by their social workers or guardians. Responsibility of a person's life also demands that one is able to finance his cost of living among others.

Below are some of the general expectations from an adult in the society (Aiken 1998, 35);

1. Get a formal professional training and engage in a professional job
2. Establish a permanent sexual or love relationship with a partner
3. Having and rearing children
4. Keeping a good relationship with family members
5. Engaging in satisfying leisure activities
6. Acquiring a stable financial position and having the ability to plan his finances

The above listing may not necessarily be applicable in all societies and certainly not in these post-modern times. It however reflects better majority expectations from the majority adult person.

In Finland, getting married in the early years of a relationship is not considered important but being in a love relationship and bearing and rearing children is important. Some of the core values and beliefs amongst the Finns include self-reliance and independency, hatred of debts and perseverance (*sisu*), (Lewis 2005, 54). The women in Finland are expected to be mothers and carrier women due to the communal day-cares services offered by the municipalities (Lewis 2005). On the subject of adulthood and disability, Priestly (2006), argues that disqualifying an adult from labour market on the basis of his disability is labelling him non-adult and a marginalized citizen. On the issue of competitive labour he cautiously notes that persons with disability not only take/should part in production but more importantly is that they consume the products. This places them on the same platform as non-disabled persons and the debate of employment and wages should take this in to account.

According to findings from the Inclusion and Autism Research report in 2000, many parents worry that their adult children do not have any friends other than family members and only 11% have some form of employment. According to Barnes and Mercer (2003), there are different perceptions and expectations from people with disabilities in different societies. In Kenya the Maasai people treat a person with disabilities equal as the one who is 'abled'. He accompanies other people in the daily activities depending with his age. An adult male with disabilities goes hunting with other adults without disabilities. On the contrary in the western societies, production is capitalist driven and people with disabilities may not possess the ability to match the desired pre-requisite. (Barnes & Mercer 2003.)

2.3 Definition of social exclusion

The term social exclusion originated from a French word 'exclus' which denoted one being outside the social contract and served as a threat to social inclusion (Social exclusion as concept and policy template in the European union 2011). In the 1960's France was faced by a great economic crisis which left many unemployed and led high

poverty amongst the immigrants workers and high social class stratification. Poor neighbourhoods also known as 'ghettos' emerged. These were mainly occupied by the immigrant population. The poor were referred to as 'les exclus' by the politicians and media.

The term social exclusion gained a new meaning in 1974 and is attributed to Rene' Lenoir a senior government official in the Chirac government. The term 'Exclus' referred to the people living in poverty, unemployed, people with disabilities, substance abusers and those people who had anti-social behaviour (Rogers, Jalal & Boyd 2008, 245) . Social exclusion was defined as a rupture from the national solidarity and the government put in place policies that work to bring solidarity. The solidarity also takes into account the fragmentation of marriages and family ties amongst the excluded. The goal of achieving societal solidarity is holistic and differs from the British social exclusion unit in the government, which is aimed at increasing productivity.

Social exclusion can be defined as economic and social deprivation which is multidimensional in nature. The multi-dimensional aspect of social exclusion means that it may result from a number of factors which build on to the latter.

'Social exclusion is a multi-dimensional process in which various forms of exclusion are combined: participation in decision making and political process, access to employment and material resources, and integration in to common cultural processes (Madinipour, Cars & Allen 1990, 22).

3 ASPERGER SYNDROME IN DIFFERENT PERSPECTIVES

In order to understand Asperger syndrome, it is important to view it in its different perspectives. This includes Asperger syndrome as a disability, the human rights and laws that protect those with Asperger syndrome as well as the special needs of adults with Asperger syndrome.

3.1 Asperger syndrome as a learning disability

Asperger is classified under cognitive or learning disability. People with cognitive disorder may have challenges in various types of mental tasks and the degree varies a lot. People with Asperger syndrome have difficulties in three main areas which include rigid thinking, communication and social interaction (Lawson 2003, 10). Asperger syndrome is also classified under pervasive disorder which is characterized by a delay in the development of socialization and communication skills. They may also have a delay in motor skills such as walking. The definitions of the terms ‘disability’ and ‘learning disability’ are highly contested. I will explore the two disability models to define the latter and look at the implications of these definitions. There two disability models include; the medical model and the social model.

3.1.1 The medical model

The medical model lays emphasis on the impairments on the body defining the disability. The limitations of the body functions are coined on the impairments. The approach to dealing with the impairment is therapeutic rehabilitation. The limitations in participation of the person with disabilities are ‘blamed on him’ (Taket et al. 2009). The medical model has also been referred to as ‘the personal tragedy model’ (Drake 1999, 10; cited in Thomas & Woods 2003, 15). A term such as ‘handicapped’ has been used in the medical model to refer to persons with disabilities and suggests their limitation in functionality is based on their impairment. This has gained strong opposition; subsequently, in 2002 the term ‘handicapped’ was replaced by ‘with disability’. The inclusion approach in the medical model has been focused on the impairment rather than building an enabling environment as well (Payne 1997, 21-22; cited in Thomas &

Woods 2003, 15.)

3.1.2 The social model

The social model defines disability from the functionality of the person and holds the society responsible for enabling participation of the person with disability by environmental modification. This approach of defining disability has also been coined by the World Health Organization in 2002. The social model also refers to the social, cultural, political and economic factors as elements of oppression and exclusion regardless of a person's impairment (Oliver 1996) and (Taket et al. 2009).

The social and cultural factors are highlighted in the theme of intent. Intent may be used to refer to the attitudes and purposes of others which are reflected in their behaviour. It is influenced by structural policies and laws put in place by different states. In this theme two main issues are important. The first one is the negative attitudes which are reflected in behaviours such as ignoring people with disabilities, talking to them in demeaning ways, and lack of willingness to mend communication breakdown. The second one is knowledge and awareness of disability which will influence our behaviour. Lack of the life experiences of people with disabilities by the care providers or those who offer services to them in general leads to poor services and creation of unnecessary barriers (Taket et al. 2009, 83).

3.2 Human rights and Finnish legislation

The United Nations declared April 2nd as the world autism awareness day. The UN secretary Ban Ki-moon recognized in his message the stigmatization, discrimination and lack of enough support for these people to lead a meaningful life. He further pointed out the high isolation and violation of human rights faced by people with autism disorder, (The UN Secretary General's message 2011).

The UN disability convention recommends that all forms of discrimination against people with disability be removed. It demands that the national states to put laws and policies to protect the people with disability. This includes enabling them to get good

education, housing and competitive jobs. The convention also demands that the people with disabilities be enabled to live independently and be included in the community. Aspects of participation, inclusion and equality are highly emphasized in the convention (The UN Disability Convention Articles 22 and 15 2011).

Finland has not yet ratified the disability convention but has a law that forbids discrimination of other people based on age, gender, sexual orientation, religion or race. The non-discrimination act 21/2004 in Finland protects discrimination of all kinds including disability (The Non-discrimination Act 21/2004).

According to the Finnish law, under the social welfare act 710/ 1982; the municipalities are responsible for providing social welfare.

The definition of social welfare here forth refers to social services, social assistance, social allowance, social loans and related measures intended to promote and maintain the social security and functional capacity of the individual, the family and the community (The Social Welfare Act 710/1982)

Under section 7(The Social Welfare Act), the municipalities are entitled to provide their residents with the following services; social work, child guidance and family counselling, home-help services, housing services, institutional care, family care and activities supporting the access to employment and specific work for people with disabilities .Discrimination affects the people in all spheres of life but mostly in the micro-level which is the personal level. It constricts their life choices and offers unfair life chances (Taket 2009, 28). According to Zastrow (2009, 52), social justice refers to a situation where all members of society enjoy same basic rights, opportunities, social benefits and entitlements. He also urges that, the economic justice is also embedded in social justice. Economic justice hereby refers to ability to participate in the labour market and possess material wealth. The non-discrimination act works towards attaining social justice. Therefore, my thesis will address social justice in relation to adults with Asperger syndrome.

3.3 Special needs of adults with Asperger syndrome

Everyday life skills are experienced in the micro-level (the personal level) sphere of life. They include a number of issues as discussed below.

Time awareness is one of the biggest challenges experienced by people with Asperger syndrome (Aston & Attwood 2009). Some people follow the clock very rigidly while others find it impossible to keep track of time. Those who rigidly follow the clock take offence when others are slightly late or in case of any time alterations at work or at home. Thus need for training in time awareness and coping with changes in schedules.

Special interests and communication is another issue which often causes problems between people with Asperger syndrome and others. People with Asperger syndrome tend to build an interest in a particular subject and talk about it for long. This makes those around them to feel neglected and particularly among friends and family. Some tend to drool or stare at people or items and cause awkwardness. There is hence need for awareness training for people with Asperger syndrome when this is happening and learns to pay attention to topic of interest to those around them. This will help to strengthen the relation of person with Asperger syndrome with those around him (Aston & Attwood 2009, 99).

Environment control is a way of people with Asperger syndrome to build a safe environment of routines. They may impose this on their family members without Asperger syndrome and this may be considered abusive and cause conflicts (Aston & Attwood 2009, 100).

People with Asperger syndrome may also lack skills in self-grooming as well as other skills such as budget keeping and paying bills on time, cleaning the house (Aston & Attwood 2009, 98). These do not apply to all adults with Asperger syndrome as every individual is very different. There is need for training and support in these areas especially for families with children.

3.3.1 Work life

Capitalism as a means of social production has caused fragmentation of the society in to

two; the proletarians (those selling their labour) and the bourgeoisies (owners of capital). According to maxims theory, the bourgeois dictate the terms and conditions of their production. Therefore, the people who cannot match the criteria are left out. This often is the case for people with disability. Theories of post-modern world which disintegrate the social model of disability have fuelled the capitalist trends globally. The result is more marginalization of people with disabilities in the labour market. (Barnes, Oliver & Barton 2002 89-95.)

According to Bicknell (1999), adults with Asperger syndrome need supported employment services in order to get and stay employed in the open employment. The most important thing in securing employment according to him is right career choice. The persons with Asperger need to identify their strengths and interests and get a matching carrier. The challenges likely to be experienced by adults with Asperger syndrome in employment should be put in to consideration while designing a supported employment plan (Bicknell 1999, 19). Bicknell (1999) addresses the issue of opening up to the employer about one's diagnosis of Asperger syndrome during a job interview. He urges that if the employer discriminates against the interviewee on his diagnosis basis, he would have later discriminated against him at work. He points out that it is important that the employer is told about the diagnosis before signing a job contract so needed arrangements and adjustments can be put in place right away to maximize the employee's output.

According to Harkarpaa (2010) employers fail to keep their clients in employment because they do not offer the needed support during employment. They only focus in offering help in getting employment. She also criticizes how the supported employment centres seem to focus on the needs and interests of the jobseekers and fail to do the same for the employers. These two issues, she attributes as the cause for failure in their services. The same views were expressed by the president of European Supported Employment (EUSE), in the 2011 conference in Copenhagen (EU study of supported employment in Europe 2011). He emphasizes on the need to address oppressive work practices and formulate a person centred approach.

3.3.2 Family life

Communication with partners and family members is a challenge with Asperger syndrome due to the nature of the syndrome. Just as in many couples without Asperger syndrome, communication breakdown is the leading reason for marriage breakdowns. As a result many adults with Asperger syndrome are not married or in any long term relationship. Having a child in the family of two adults with Asperger syndrome often brings a problem of the other partner fighting for attention like a sibling (Aston & Attwood 2009, 95). This issue may cause a lot of commotion as well as sharing child rearing responsibilities and there is need for a therapist intervention.

The children of parents with Asperger syndrome feel like they are not emotionally valued by their parents. They appreciate that parents have been able to provide them with material things. Subsequently parents with Asperger syndrome need family support services to enable them build healthy relations. (Aston & Attwood 2009, 112.) According to Attwood and Aston (2009), in the case only one spouse has Asperger syndrome, a dilemma arises on the issue of telling the other partner's family members about his Asperger diagnosis. Disclosure to the in-laws of the other partner without Asperger syndrome may mean a negative response and render him being treated as an outcast by his family members.

According to a research carried out by Aston (2003), parenting by an Asperger adult can prove quite challenging due to lack of empathy and single focus distractedness. She reported that the parents tend to easily get distracted and shift focus from looking at the child to other interests easily. Also partners who have no Asperger syndrome reported that 'it felt as though they were taking care of another child' (Aston 2003, 101). Empathizing is particularly a challenge in the case of how to treat and understand children as people with Asperger syndrome have a challenging in inferring to the other person's state of mind. According to Aston (2003), most parents with Asperger syndrome reported problems in playing with their children according to the children needs and wishes. She also found out that they had a challenge recognizing different needs for different ages and often treated their children like adults.

Intimacy can prove challenging for adults with Asperger syndrome as it is not easy to read facial expressions and tell what exactly their partner wanted. This may result to frustration in the relationship as emotional needs are not met (Aston 2003, 108).

4 THEORETICAL FRAME WORK, KEY CONCEPTS AND PREVIOUS RESEARCH

Most of the previous research studies related to my thesis have focused on rehabilitation and support for adults with Asperger syndrome. Among these is Luotyo Projekti which aimed at finding ways of labour inclusion for adults with Asperger syndrome. It focused on the processes of labour exclusion on the micro-level (personal world, see chapter 4.2.1). Findings revealed that adults with Asperger need support during the turning points and transitions in their lives. These according to the report are the times they are most vulnerable and may end up socially excluded. Another thesis by Anu Rausadoja (2006), evaluates how the vocational training at Keskuspuisto helps adults with Asperger in developing their life skills. His findings revealed that the adults need support even after leaving the vocational training institute. Learning life skills for adults with Asperger syndrome is a lifelong entity. Worth mention is a research study that evaluated the how students with Asperger can be supported in school by Immonen Minni (2010). Results from this research revealed that communication methods and the learning environment have to be adjusted to suit the student.

My research is related to the above mentioned studies. However, it differs from the above studies because of the studies' core focus. They have focused on one form of social exclusion or focused on the processes of social exclusion only. My research covers all forms of social exclusion and not only addresses the social exclusion processes on the micro level but also the meso and macro-level. I decided to use this approach in my work because social exclusion is a multidimensional process (Madinipour et al. 1990, 22) and so is disability (Taket et al. 2009). The study also identifies the three social exclusion paradigms (Silver 1994) and the redistributive discourses (Levitas 1998) as vehicles for social inclusion/exclusion. In my thesis in discussing social exclusion I will reflect mainly on the works of Hilary Silver 1994. I will discuss the different concepts of social exclusion, the dimensions, the processes and measurements of social exclusion. I was unable to find many studies on my thesis topic.

4.1 Concepts of social exclusion: solidarity, specialization and monopoly paradigms

The three paradigms of social exclusion are solidarity paradigm which came from the French ideology on social solidarity. Specialization paradigm comes from the US and British where exclusion is based on ideas of discrimination. Monopoly paradigm is evident in Western Europe where exclusion is associated with group monopoly formation. (Silver 1994, 531.) The three paradigms have different causes and meanings in each. Solidarity paradigm refers to break from social ties and focuses mainly on social relations and social bond that binds individuals to the larger society.

There are shared values and rights within the moral society, around which the social order is build. The solidarity paradigm is based on Durkheim's theory of social order. The French republican government ideas of social exclusion were based on this paradigm. Specialization paradigm is dormant in the US and UK is rooted on the liberal individualism and neo-liberal philosophies. The economic productivity is vital and every individual is expected to specialize in different areas of economic productivity. The markets demand the least government involvement in controlling exchange of goods and services. Individuals become excluded when they do not play a part in the economic productivity. Individuals also are seen to have different potential in the contribution to the markets. The solution of exclusion in this paradigm is creation of jobs. (Silver 1994.)

The Monopoly paradigm is based on Marxist theory which blames exclusion on the group monopoly. The post-industrial capitalists markets which have a wide income gap and weak policies favouring business interests are responsible for creation of social stratification. The way of combating exclusion in this paradigm is citizenship rights. According to Max the solution for unemployment is not more training but adjustment of the policies regulating the markets. The strong social welfare is designed to rid the social exclusion in this paradigm. (Silver 1994, 531.)

The social exclusion discourses serve as key definition of social exclusion and suggest ways to bring inclusion. A redistributive discourse focuses on poverty; the moral underclass discourse main focus is the morals and behaviour which may be anti-social and social integrationist discourse which focuses on paid work (Levitas 1998, 7). They

also give meaning to the political decisions put to tackle social exclusion. In the case of redistributive discourse it's driven by the social democratic politics to eradicate poverty and reduce the income gap in the society.

The redistributive discourse model is based on Townsend's work. In his definition of social exclusion he pays attention to the material possession.

‘Individuals, families and groups can be said to be in poverty when they lack the resources to obtain the types of diet, participate in the activities and have the living conditions and amenities which are customary, or at least are widely encouraged and approved, in the societies to which they belong’ (Townsend 1979,32) and (Ronaldo 2004,12).

The European report (1994 & 2010) on social exclusion, also focused on integration in to the labour market as the remedy to address poverty and eradicate social exclusion. In the case of moral underclass discourse, it is neo-conservatism driven. It blames the strong state welfare on causing the people become socially excluded and create a culture of dependency. It proposes that individuals should be pushed to be self-reliant and only short term welfare support is made available to the neediest (Levitas 1998, 18). The social integrationist discourse is reflected in the European inclusion policies although its implementation in Britain is different from the ideal solidarity paradigm as it follows neo-liberalism. The social integrationist discourse focus is on the family instability as a vital institution in the society make-up. The breakdown of the moral and cultural ties leads to disintegration of the society. It is highly influenced by the Durkheim sociology and catholicism.

4.2 Processes of social exclusion

The processes of social exclusion can be analysed in three main areas reflecting on how the individual interacts with his environment. The micro level analyses the experiences of social exclusion of adults with Asperger syndrome with their immediate environment. This could include their social ties such as his family, and friends, their work place, housing and households among others. The meso- level of social exclusion is the implementation of policies and administration in the institutional level. This

analyses how the evaluation and implementation of policies contribute to the social exclusion of the adults with Asperger syndrome as a group. The institutions could include the education system, the healthcare institutions and many others. Finally the macro-level is the highest as it is the formation of the policies for the state. This analyses the participation of the adults with Asperger syndrome in policy making and how they affect their lives. It also reflects on the power relations between the decision makers on the division of resources and the recipient groups.

4.2.1 Micro-level of social exclusion

The micro-level of social exclusion is also referred to as the individual level of social exclusion. At individual level the focus is in the life course and its multidimensional aspects. The life course has three main ideas; trajectories, transitions and turning points. The life course is an accumulation of different experiences. A transition is a change in state that may be the entry or exit point to a role in one's life. A turning point is a major change in one's behaviour path (Elder & Shanahan 2006, 665). At the individual level the social rights play a great role in shaping the life course. A transitional point like getting in and out of paid work can be mitigated by unemployment state insurance. In the absence of such an institution then the adult with Asperger syndrome is likely to be socially excluded. The same views have been shared in a report 'Luotyö projekti' (Aarniokoski & Hetemäki 2010, 15), which see the transitional points as the biggest cause for labour market exclusion. A turning point is a big change in the individual's behaviour trajectory. A turning point could involve bad health or formation of a disability which equally needs to be handled carefully. In such a turning point case, it is important that proper rehabilitation in the case of a disability is offered to enhance quick adaptability. Unexpected life events like loss of loved ones to death or breaking up of marriages may lead to social detachments and have great impact in the individual's social life.

4.2.2 Meso-level

In meso-level of social exclusion there is a social divide in groups. These sub-groups may include the unemployed living in poverty or those with a certain disability or lacking education and in our case adults with Asperger syndrome. In these groups, there are shared cultural values which draw the boundary and anyone outside it is viewed as

having different attributes opposite to the groups. (Silver 2007, 15.) The outsiders are hence locked out of opportunities and stigmatized. The excluded groups need to realize the power they have to fight for change. They are usually left out in participating in making policies that affect them. They should push for their voice to be heard and their wishes taken in to account in formulating the policies that address their social challenges. Failure to doing this results in policies that only add more oppression to their existing conditions. The government policies are sometimes to blame for these groups' formation of insiders and outsider; as they define these groups in the laws. (Silver 2007, 16.) These may include housing programs, education, laws on gender, religious and ethnic groups. The state has a role to play in capacity building of these groups.

4.2.3 Macro-level

The macro-level represents the policy making at the highest level. How the states formulate policies regarding state welfare so as to reinforce solidarity is an example. In formulation of policies matters put as of importance dictate to what extent the problem will be solved or increased. Some welfare regimes are accused of causing more exclusion than inclusion (Silver 2007, 18). The European states have put down indicators of social exclusion but each state has implemented different policies to address these issues. In UK emphasis is on paid work and other social democratic states have put state-welfare which offers insurance in case of unemployment and advocates for minimum wage employment as a strategy to get back to labour market.

The legal policies and laws are not enough to counter discrimination as has been observed previously by the EU states until the EU court threatened sanctions. The only solution is to allow member group to have an institution to fight for their rights. A second way is associative redistribution which is to include members of excluded groups (Silver 2009, 21). The meso-level links the macro-level and micro-level and plays a very important role. There is obvious interconnectedness of these processes and any changes in one level affects all the others. A good example is the power relationships and representation of certain groups' interests in these different levels, in resource allocation.

4.3 Social rights and citizenship and state welfare

Social rights can be defined as those entitlements expressed in terms of law and other forms which take care of the individual's social needs and are necessary for his social cohesion and societal solidarity (Daly 2007, 15). Social rights only emerged in the twentieth century as the last in the three development stages of the citizenship rights in the Western development according to Marshall (1950). The first development was the development of the civil rights in the 18th century, then the political rights in 19th century and finally the social rights. (Cited in Mau & Verwiebe 2010, 42-47.)

In Finland the state welfare follows the universal model which cares for all its citizens. This follows the monopoly paradigm approach of addressing issues of social exclusion by creation of a strong state-welfare (discussed in chapter 4.1). The adults with Asperger syndrome are entitled to equally enjoy their social rights like all the other citizens. The state welfare has been criticized to reduce and increase social exclusion at the same time. First we will analyse how it has worked to reduce social exclusion. In the Scandinavian countries the state welfare provides communal day-cares which enable mothers to leave their children in day-cares and go to paid work. This has seen a remarkable increase of women participation in labour market. It has also enabled women to resume to their paid work shortly after having babies. (Brown & Crowmpton 1994, 95.)

The state social welfare serves to ensure social rights mainly categorized as protection in case of job loss or unemployment, healthcare, housing and education provision, cultural activities participation, family assistance which includes both financial and social among others prevent social exclusion. The progressive income taxing system reduces the income gap in an effort to build an egalitarian society in most Scandinavian countries (Gough, Eisenschitz & Andrew 2006, 87). The progressive taxing is an element of re-distributive discusser aimed at reducing the income gap. The European committee for social cohesion has laid down the above factors as vital for inclusion in the state welfare programs. The social welfare is intended to reduce social exclusion but as some critics have put it, sometimes the social welfare creates poverty traps (Gough et al. 2006, 95).

Social welfare causes poverty in a number of ways. One is the fact that its universality

leads to giving social assistance to people who do not need it like the child benefits given to all families. Second it focuses on the household creates dependence of women to men. Third the state has to carry out investigations to assess the income, expenditures and household needs of the claimants. This goes against the capitalist fundamental ideology of privacy to households. Fourth many people do not apply for the benefits as they do not want their privacy impinged during the investigation, as well as the complicated slow bureaucratic processes.

Finally there may be behaviour changes of claimants to qualify for benefits tailored to a particular household. The minimal tax imposed on low wages may encourage some to go to employment but on the other hand such jobs are usually manual and heavy and not attractive to many. (Gough et al. 2006, 95.) Study findings regarding this issue are discussed under labour social exclusion.

The state welfare policies in supporting motherhood make women of bearing age less attractive employees as the employer is expected to pay a handsome sum to cover maternity allowances. The father of the child's employer does not face this burden, hence making employers prefer male employees to women of bearing age. This certainly builds more chances of exclusion from the labour market on women more than men.

One of the biggest obstacles in delivering public services under the state welfare is the resistance of increased taxation on businesses even during great economic growth. This is attributed to the autonomy demanded by capitalists' elites in the globalized world. In the case of high taxation imposed on businesses, most businesses opt to invest their capital in other less taxed countries. This reduces the state revenue and as a result there is strain on amount of finances available for expenditure on state welfare. (Gough et al. 2006, 88.) The rise of cost of living, and the cutting down on expenditure by the states, increases poverty.

The delivery of public services has been embedded on business priorities and as a result poor funding for the elderly homes and hard drug addicts, as well as rehabilitation for the people with disabilities is evident. This follows an argument that these groups of people are not useful to the labour market.

The public spending is also more in the middle class areas because the middle class pay

more income tax as well as having the ability and connections to lobby for better services. Poverty hence becomes a vicious circle as children from poor families perform poorly in school due to low attention span from hunger or poor diets and lack of quiet space and guidance to do homework at home. (Gough et al. 2006, 89 & Miller 2004.) Outsourcing of services in the private sector has resulted to very low quality of service in a measure to cut spending by the state. This has also resulted to poor wages and working conditions for the employees in the service sectors of these privatized institutions.

‘Neo-liberal reforms of public services have thus tended to worsen outcomes for the poor and socially oppressed and widen the gaps between them and the rest of the population’ (Gough et al. 2006, 93).

According to Ivanov & Muras (2006, 99), the main areas of exclusion include: exclusion from labour, exclusion from the goods and services market. The subjective social exclusion which includes mainly the social networks and mental health are also measured. Social consequences such as suicide rates, crime rate, turn out at parliamentary elections, are measured.

5. METHODOLOGY

My research report mainly focuses on analysing the processes of social exclusion, which make people with Asperger syndrome susceptible to social exclusion. In that light, it also seeks to explain why people with Asperger syndrome are highly vulnerable to social exclusion. In addition to these, my research seeks to identify the role that the government plays in the social exclusion of adults with Asperger. My main research goal is to identify possible solutions to combat social exclusion faced by adults with Asperger syndrome in Southern Finland. In this chapter I will explain which research methods I chose and give a detailed account of the research process.

5.1 Classification of research

My thesis is a qualitative research. The research gives more emphasis, on the experiences of people as source of data. According to LeCompte & Schensul (1999), it is important that the people tell their stories and the meaning attached, and then the interpretation is made from it after. I chose a qualitative research because it defines the empowerment teachings of working bottoms-up. In this context empowerment refers to doing community work to bring change by paying emphasis on the service user's strengths. The service user can best define the problem and should be heard in planning the change. A qualitative research is a research in which people make sense of the life they live by sharing their experiences. Holloway (1997) emphasizes that; it pays attention to people's everyday life which is the right methodology to mirror social exclusion. Social exclusion is an everyday experience that needs a longitudinal research approach. In case of time limitation only people's narratives can be useful. An empirical approach of data collection relies on information gathering through observation or experience.

5.2 Methods of data collection

I chose to use interview method in my data collection. My interviews were divided in to two categories;

- a) Five adults with Asperger syndrome
- b) One focus group made up of three leaders of The Finnish Autism and Asperger Foundation. The leaders of the autism and Asperger syndrome are all parents of children with autism disorder. They have experienced autism disorder through parenting and from it they draw their expertise.

The language used in conducting and analysing the interviews was English. I interviewed five adults with Asperger syndrome with the age range of early twenties to mid-forties. I did one focus group interview which included three members. I conducted personal open interviews guided by semi-structured interview questions. Open interviews mean that there is flexibility for the respondents to express themselves. However, in order to keep the conversation in the right direction of my research questions, I used semi-structured interview questions. Semi structured interview questions give the interviewer ability to build on a theme and get detailed information on it. A personal interview as opposed to other interview methods (internet and telephone interviews), enables an interpersonal interaction and a relationship can be build more easily. The interviewer can encourage the respondent to open up to answering sensitive questions by instilling confidence in him (Connaway & Powell 2010, 170).

My group of respondents have a challenge in getting the non-literal meaning of words hence having an open interview enables the interviewer to explain the questions further. It is also easier to authenticate the respondent as opposed to the internet and phone interviews. One of the suggested disadvantages of open interviews however the cost of travelling is and time consumption. In my case it was not a big barrier as my respondents live close by and the travel costs were not hefty. My decision not to use questionnaires was the fact I wanted to collect information about peoples' daily life experiences which is best expressed in narratives and questionnaires have a limitation on this. My group of respondents also understand the literal meanings of statements and formulating a questionnaire that answers my research questions would not be easy. I

also used audio tapes in my interviews for precision of information as it is impossible to write down everything respondents say. It also gives possibility for the interviewer to go through the information and capture meaning of expressions using respondents' own words (Connaway & Powell 2010, 171).

5.3 Data collection process

I started off by preparing interview questions and contacted autism and Asperger organization in Helsinki. I used them to introduce me to people with Asperger syndrome and interviewed them as well. I got three adults to interview by posting an advertisement in the empowerment social network for people with Asperger syndrome in Finland. The members who were interested called me or emailed me and we arranged and made interviews. I got two more participants through snow balling from other participants. In one case I did not complete the interview from one of the personal interviewees as the respondent withdrew mid-way. I was therefore forced to discard the latter's interview information. I used audio tapes for recording the interviews and transcribed them myself due to confidentiality issues. I spent six hours to transcribe one interviews a result having done long interviews of one and a half hour each. This could be attributed to detailed accounts on the questions asked since it involved their life experiences.

During the research process, I developed my listening skills and patience. I also learnt to be an effective communicator and learnt so much from my respondents. It also expanded my knowledge about Asperger syndrome.

5.4 Interpretative phenomenological analysis

I used the interpretative phenomenological analysis. Interpretative phenomenological analysis pays attention on the meaning the interviewees as main source of data give to their experiences. (Howitt & Cramer 2008, 380) The personal interviews I carried out revealed that all individuals had very different life experiences. In my analysis, I took this in to consideration which follows the idiographic approach. In an idiographic approach, all individuals' experiences are treated as different from others which is the

opposite of homothetic. However no matter how different the experiences were, they all converged and formed similarities. The analysis process followed first familiarizing me with each interview by reading and re-reading. Then I made notes followed by making themes of data and further connecting different themes. My result reporting therefore takes in to account of both homothetic and idiographic approaches. It is important to mention that I did not systematically analyse the focus group data. This was based on the idea of user participation. I wanted to pay more emphasis on the experiences of the people with Asperger syndrome as they see it. The focus group was very informative on the available services and issues involving the policies. However, since they do not have Asperger it would be wrong to use them as a primary data source for the experiences of adults with Asperger. Community work emphasizes the need to work directly with the people experiencing the challenges. This includes going to them and see the experiences through their lives. This also is referred to the grass root approach which is aimed at empowering the people. Empowerment here denotes, enabling the people to be able to make decisions to change and make their lives better. (Combat Poverty Agency 2007, 15.)

5.5 Research ethics

I did not need any permits to conduct my research. I, however, had to watch some ethical issues which are standard while conducting a research in the social sciences.

Respect for persons is one of the main ethical issues. According to the Belmont research and Nuremberg code (Israel & Hay 2006, 36), human beings as subject of research need to be granted autonomy and those with mental disability need protection. The wishes of the interviewees needed protection. Subsequently, while conducting my interviews one interviewer dropped off mid-way, so I had to respect her decision. Another ethical issue is beneficence which refers to avoidance of any material that may not be contributing to the wellbeing of the subjects of study and focusing on the benefits instead (Israel & Hay 2006, 36). Justice is another element to put pay attention to giving credit to all that contributed to the research and that one's credit in the research not is taken by another. All participants need to have consent of their contribution to the research. Assessment of risks involved in the research was done to ensure that all unnecessary risks were avoided. Participants need to be well informed about the process and I did this before I

commenced with each interview. I explained the aims and goals of the interview as well as what I intended to do with the information collected.

According to Gregory (2003, 49), confidentiality is a core professional and ethical value in social work that has to be observed at all times. It mainly points to the importance of respecting the respondents' privacy. In my reporting of the findings the respondents' identity has to be covered entirely and any information that might jeopardize it is avoided. However, if the respondent is happy to have his identity used publicly then this issue can be overlooked although a written consent is advisable. Due to the issue of confidentiality I transcribed the interviews saved in the audio tapes myself and discarded the tapes afterwards as I made a verbal promise to my respondents that the audio tapes would be discarded afterwards. I also decided to use the term 'interviewee' in reporting my findings as part of the confidentiality. This was due to the small number of my interviewees with Asperger syndrome who could otherwise be easily identified using a letter coding.

According to Lincoln & Guba (1985), cited in (Thornicraft et al. 2011, 308), there are four key elements which define reliability and credibility. These are trustworthiness, transferability, dependability and conformity. Trustworthiness refers to the ability to maintain honesty in data collection and reporting. This is also a professional ethic in social work which I followed. According to Thornicraft et al. (2011, 308), dependability refers to the ability of obtaining similar findings if the same context was maintained and research was conducted by someone else. This questions the suitability of the method of data collection. In my case I used semi-structured open interviews which are the best way to learn about peoples' past experience. (Connaway & Powell 2010, 170).

Conformability refers to the findings being a pure product of the systemic research without biasness (Thornicraft et al. 2011, 308). I maintained a neutral perspective of the whole subject because I do not share the experience of having or living with someone with Asperger syndrome. My position as a researcher was purely as a student in social studies aiming at the professional development. This can be learnt by accessing how social workers contribute to the exclusion process of adults with Asperger syndrome. It also helps us develop preventive work in areas that are needed as well as our own skills.

I derived my motivation from the goals of social work; which is to fight for social justice. Despite my research using a mix of theory and empirical approach, I gave strong emphasis in the empirical part as a way of defining my results. The personal interviews which entailed adults with Asperger syndrome included two whom had acquired a doctor's diagnosis and other two who know they have Asperger but have not had it confirmed by a doctor. The credibility of those without a doctor's diagnosis cannot be refuted on such grounds as the rationale behind it is also discussed in my findings. Transferability which refers to the application of the findings to other groups of people is a concept that can be applied on this research (Thornicraft et al. 2007, 308). Despite everyone experiencing the world in his own way there is a vast similarity in the subject of social exclusion.

6. FORMS OF SOCIAL EXCLUSION

Most forms of social exclusion are experienced in the micro-level (see chapter 4.2.1) as a result of national policies. My respondents explained how they experience their daily life-world as a result of having Asperger syndrome and facing social exclusion. I will also try to highlight the different forms of social exclusion faced and most importantly the processes. I will also look at the policies affecting them and which paradigm of social exclusion Finland is following. The following are the forms of exclusion experienced by adults with Asperger syndrome that I was able to establish in my research.

6.1 Exclusion from access to health services

Getting a diagnosis for Asperger syndrome in Finland can be done by a general practitioner or other specialists certified to do so. However some people with Asperger syndrome do not want to get a doctors' diagnosis. They cited having a problem with the therapeutic rehabilitation doctors recommend after confirming the diagnosis. One respondent answered to the question; how old were you when you were diagnosed with Asperger?

'Well it hasn't been really diagnosed by doctor. But then I recognized I had as I was then about in my mid-thirties. I don't need this paper, it has no meaning. But if I have to go to doctor, and explain my life history and cry and they put me on psychiatry and medication and later give me a paper. What does it help? I know I have Asperger syndrome and I now understand myself. 10 years ago I looked like a typical Asperger but now when I tell people I have Asperger they say I am kidding. I used to walk with a slouching posture like most people with Asperger do. I also used to stammer a lot'

Doctors are perceived to change their approach on the people with Asperger syndrome. One interviewee said she does not want her diagnosis in her records because doctors will prescribe antipsychotic medication for her if she complained of headaches. These negative attitudes stop them from obtaining the diagnosis .They search about the syndrome by them and find other ways to cope with their daily challenges. The

findings suggests that the doctors are still following the medical approach of defining disability ; whose approach of rehabilitation is therapeutic as opposed to the social model which builds an enabling environment.(Discussed in chapter 3.1)

Speech and motor therapy is provided by the municipalities for people in need. According to Frith (2001, 180), speech therapy works best if the diagnosis is done when the person is young. Speech and motor development are delayed and can be observed during the first three years. At an early age the individual can learn to overcome the speech challenges and train to keep a straight posture. Due to the novelty of the syndrome, the older generation did not get a diagnosis and failed to receive the needed speech and motor rehabilitation. ´speech development is delayed in some people with Asperger syndrome. Some respondents noted that many people with Asperger syndrome are very bright but fail in interviews due to their speech impairment. They are not able to pronounce words clearly and hold a slurred speech as well. The interviewers regard them as intellectually incapable and fail to offer them job opportunities. As a result of not getting motor rehabilitation, the adults walk with a sloppy posture and appear to lack balance. (Frith 2001, 12.) Some of the young adults received the speech and motor therapy at an early age. One respondent from the personal interviews reported being mistakably diagnosed with dyslexia when he was three years old. He got both speech and motor therapy as opposed to the older respondents.

According to the personal interviewees, a feeling of being lost and confused is experienced throughout one's life if Asperger diagnosis is not made at an early age. Therefore, they recommended for people to get a diagnosis at an early age in order to get the necessary rehabilitation and understand themselves. Frith (2001, 24) argues that social rehabilitation is the hardest in the rehabilitation areas needed by people with Asperger syndrome. Research on rehabilitation of adults with Asperger syndrome at Keskuspuisto vocational college, has also shown that only few people are able to completely overcome their challenges (Rasoja 2006).

6.2 Exclusion from social capital

According to Halpern (2005, 2-5), social capital refers to the social networks which are necessary in building contacts to get or progress in labour market as well as personal relationships. Social cohesion needs high social capital to happen and bring solidarity. He argues that social capital is necessary in a person's life development and wellbeing as well. Strong social ties with friends and family are necessary for social support in times of crisis. Leisure activities expose people to opportunities to build social capital. Inability to take part in leisure activities and employment in the open labour market results to low social capital. According to the response from my respondents, social capital is a key ingredient lacking in their lives looking at it on a micro-level.

Regarding establishing intimate relationships, the personal interviewees felt that it was challenging to establish; especially with people without Asperger syndrome. One respondent said;

‘if I went to a night club and I saw a nice looking girl I came to your table I will talk about other things but after two minutes I will only talk about a band called ‘Kiss’. So when I meet people I don’t know what to ask. I just like to watch people talking and it’s like ballet but if I am there suddenly it’s not ballet anymore but gymnastics. I think these people are so clever how they can quickly find topics to talk about.’

According to the personal interviewees, starting a conversation with a stranger is very challenging for them as cited above. They said that, they often switch to discussing topics of their own interest such as collection of stamps or particular rock artists. This makes the other people lose interest in them. They also revealed dreading being in crowds of unfamiliar groups as they feel ignored. One interviewee said;

‘Well I have experienced in social groups I get excluded very quickly. Some experiences are scary. I stare at people without even noticing it myself and they get uncomfortable they think it a little creepy. I had this problem, like my friends after party my friends come and say that ah! This person thinks that you were staring. Somehow when there are lots of interesting people around me I pick a specific object or person and then start staring. I am learning to try and avoid it.’

According to Dubin (2007, 25), ignoring someone’s presence by refusing to include

them in a group conversation is a form of bullying. People with Asperger syndrome find it hard to join in a conversation and need some encouragement to do so. Failure to include them in conversations is 'social exclusion'. Another issue besides the challenges they face in trying to make new friends is the 'insincere friends'. According to the personal interviewees, such friends were many while growing up, especially in junior high and often resulted to bullying. Some however, revealed experiencing the same friends in adulthood. One interviewee said;

‘Well I had not really friends. They came and took cards and Finnish old stamps that my father had left me. One stamp was worth 100 Euros. They were hitting and beating me and I was scared to say anything. When I was a teenager, they asked why I did not have a girlfriend-‘are you fag or not?’ As an adult they did steal my girlfriends and talked bad things about me, but later on I threatened to beat them.’

The personal interviewees shared that, they found it hard to trust new friends. As a result they befriend family members and other people with Asperger syndrome. According to Patric (2008, 98), many people with Asperger syndrome lack social reasoning and astuteness. This inhibits their ability to recognize the truth in people's word. They also have difficulties reading facial expressions and are unable to interpreted non-verbal communication. This renders them victims of abusive strangers who take advantage of them. The personal interviewees also shared that, it was easy for them to be around other adults with Asperger syndrome. They were also happy to befriend family and fellow people with Asperger as they did not have to explain what Asperger syndrome were. They often found themselves in small network of friends whom they could spend time with. They paradoxically expressed their interest in expanding their friends' network outside family members and fellow adults with Asperger syndrome.

According to Fukuyama (1995), at the meso -level, social capital helps in building trust in strangers in the economic market (cited in Hapern 2005, 8). The trust opens job opportunities as well as increased voluntary work. The results reflect high economic growth at the macro-level. This shows how important it is for the government to put structures and policy to build social capital for adults with Asperger syndrome. The low social capital may also be blamed on the low public awareness.

According to the respondents from focus group, enough is not being done to raise public

awareness on Asperger syndrome. Although there are no proven results testing the public knowledge on Asperger syndrome; the respondents from the personal interviews reported daily experiences of people without knowledge of Asperger, even in public offices.

6.3 Exclusion from family life

On the issue of families it was evident from the study findings that divorce and broken families was a common issue. They often loose custody of their children and are often left wondering why it had happened.

‘My baby’s’ mother had a problem with’Child protection’ yes those devils. What they do and what they protect is something else. And suing them is a long process. So they took our child away and made us sign papers and did not explain to us. They allow us to see our child 3hours every third week in the presence of social worker. This child protection is like East Germany. They are totalitarians. I was very sad every time I saw her so I decided to forget the situation.’

The anger and bitterness of losing their children’s custody was expressed by a number of parents. They felt that instead of supporting families to stay together, the social office was quick to take their children away.

‘I lost custody of her when she started abusing drugs. Since I worked late to support the family and I was a single dad after I got divorced. So she started hanging around with the bad groups and got in to trouble. I had asked the social office before that for someone to visit the home and help with keeping it clean but they refused and also help my daughter because a father cannot understand. They said they did not have money but when they had to pay 100,000 for foster care they suddenly had money! I felt very frustrated. It’s difficult for a dad to work and be a parent and help with homework. So I wonder if it was good for our family.’

These turning points of the interviewees’ lives posed stress and immense sadness as reflected from the citations above. According the personal interviewees, the main problem in the family support is the financial diuresis experienced by the municipalities. The municipalities are quick to give custody of the children to the social office and relieve themselves off the financial burden. One personal interviewee said;

‘I have only problem in child protection office. People who have no morality at all! People who make decisions based on rumour. In that office

you are guilty until proven innocent. I have not told them I have Asperger but I hear that they treat everyone so bad. The municipalities do not have money so when they take child away so the money comes straight from government. This is a very stupid situation in Finland.

I think if both adults in a family have Asperger have a child they need help from social office with care and cleaning. But when we ask for help the social protection office takes child away. There is no middle way- its either you take care of the child or not. They are not different from terrorists from Chechnya terrorists who kidnap your children and give you back at a price. I tell all my friends not to ask for help from social office.'

According to the citations above, there is lack of regular child and family counseling services to aid in preventive work. According to Aston (2003, 97-101) as discussed in details in chapter 3.2, parents with Asperger need plenty of support. This should be done all the time to keep the family together since the parents face more challenges in communicating with their children. The municipalities in Finland have however; have failed to recognize these needs. There is need for use of a different approach in this area.

6.4 Exclusion from access to public services

This topic seeks to look at processes which lead to exclusion of adults with Asperger syndrome from services. A number of factors contribute to this form of exclusion. Poor attitude from service from service providers was registered by some of the respondents. One respondent said;

'I have been in Kela at one time and this is one reason I try to work all the time. It's easier to be in work environment than KELA. So filling the paper work is hard and has many similar answers and if you fill the wrong one you don't get the money. They say to me but you were in university how you cannot fill this simple paper? So they don't understand how you can be so clever in one field and so stupid in one field. They think you should be all round clever or stupid.'

KELA is the Finnish national security fund which gives financial support to the citizens entitled social security (Kela). Some of the respondents cited to experience a hard time filling in the paper work without help as cited above. The poor attitude of the workers' in these offices discourages some adults with Asperger syndrome from visiting these offices. This occasionally results to the latter going without their financial support entitlements.

The other issue in applying for social support is the many different agencies in the public sector who handle different issues. This involves a lot of paper work which is very stressful and confusing the respondents from my personal interviews experienced a hard time doing all the paper work and visiting different offices. One of the respondents from my personal interviews mentioned having being homeless for three months and selling empty bottles to raise money for food.

The process of allocating different support funds is not open to the applicants. They do not know what they are entitled to and who is supposed to give it. One personal interviewee said;

‘Then in allowances you can get huge help in money or nothing. If you have little difficulty you get nothing. Then if you have a lot of difficulties then you get a huge amount. If you get too much rehabilitation is as bad as having no rehabilitation. Its same situation! What should happen is they should see you as an individual and judge from this. Everyone has different needs. The people mostly in need don’t get the energy to pursue the services like those with depression. Even some students I know in university one gets 40hours a week personal assistant and another needs some help get nothing’.

On the issue of public awareness, people with Asperger syndrome felt like enough was not being done. They said that the general public did not know what Asperger syndrome was. This results to a negative attitude and poor treatment like avoidance or being treated like someone with a low intellectual capacity. One respondent said;

Most people with Asperger are very clever but may speak in a funny way so in public people talk to them like they were a child and like they don’t understand anything. This is very annoying.’

6.5 Exclusion from labour market

The Employment Services Act (1005/ 1993) in Finland covers the duties of the labour office among which is provision of vocational rehabilitation to promote access to employment. Exclusion from labour market is economic injustice, which is a segment of social injustice, according to Zastrow (2009). This form of exclusion denies the

excluded group the right to participate in meaningful production and possess material wealth.

According to Harvey (2008), many adults with Asperger syndrome have been employed previously in low paying jobs which only lasted a few months. They also have big gaps of unemployment years in their records. The response from the personal interviews revealed that all of them have been unemployed for a long period of time. Only one of them had worked in the open employment for more than three years. All the other three have done a couple of job trainings which did not offer employment afterwards. The interviewees expressed a sense of frustration and despair on job situation. One personal interviewee said,

‘Nowadays they say you have been unemployed for too long may be you won’t stay with us for long. Or maybe you are too old for this job and there is someone younger for this post. May be I will never get a job. Maybe I should start my own businesses’

The sense of hopelessness and despair in finding a job was expressed by two other respondents on the personal interviews. The latter are also above the age of 40 years. According to the personal interviewees, those below 30 years are optimistic of acquiring a job on completion of their education. The older generation argue that it’s only easy to get casual jobs that are physically demanding. According to the personal interviewees, there is a big concern with the approach used by the unemployment office in handling unemployment. The issue of constantly sending them to school and poorly organized on job trainings is not fruitful. They argue that they have undertaken numerous trainings and they have not been able to get in to open employment. They expressed frustration on this approach and as one interviewee below describes it, they no longer want to take part in those programs.

Two years back and it was work practice and after 6months it was over and after I did not get a job. Boss said I was an excellent worker but! That is why I hate these work placements. they may be could keep me as unemployed worker but the labour office say no. if they want to keep me longer then no longer than 6months then it’s not legal. I don’t want to be asked to give free labour and the companies are making money from my labour.

There is need for more emphasis in the work adaptability approach such as supported employment as opposed to on job training only. The reason for the departure of people with Asperger syndrome from paid work is often job termination which is not related to inefficient education. (Edmonds & Beardon 2008, 20.) This is contrary to the argument by Barnes & Marcer (2003, 49), who state that employment pre-requisite have moved from need for physical ability to mental ability. People with Asperger syndrome have very high academic qualifications but face difficulty in finding and keeping employment. In my opinion it is also a paradox for Finland which follows a monopoly paradigm to use provision of more education to address labour exclusion. The monopoly regime's approach to labour exclusion is work adaptability as opposed to the specialization regime that offers more education for labour integration.

Harvey (2008) and Bicknell (1999), attribute the biggest challenge to inability to keep a job for people with Asperger syndrome on wrong carrier choice and lack of supported employment. Contrary to this is the amount of stress and burnout that people with Asperger syndrome face on choosing a career of their interest. One of the interviewees from the personal interviews narrated how he used to overwork himself due to working in his field of interest. He mentioned that he worked 14hours a day despite being paid for only seven and a half hours a day. He said that during that period his relationship with family and friends deteriorated. In a different paradox the problem lies with the bosses as far as change of career position is concerned. According to one interviewee;

‘When the bosses offer promotion in the office to supervisor, then they (people with Asperger) have to discuss their diagnosis. However, before they never have to discuss this. They ask the boss to drop the offers they are incapable of handling the job. They have to explain to the boss what Asperger is and suddenly in the eyes of this boss it's not the good computer IT Mr. X anymore, but some neurologically damaged strange person. When they have to retrench, so they think there is this mentally retarded Mr. X that is stressed and can crash any tine. He will crash anytime let's fire him! Yes then again are people who have Asperger but do not know they have it. They then take the leadership positions and then get huge burn outs and take long sick leaves and then unemployed themselves before they get fired. This has happened too many of my friends’.

The issue of sharing the Asperger diagnosis with the employer is a turning point for adults with Asperger syndrome. There is lack of trust on the employers and so the people with Asperger syndrome are afraid to disclose their diagnosis. This shows two main problems, stigmatization from society as a result of lack of public awareness of Asperger syndrome. Secondly, the tough economic times that has made jobs very competitive.

On the issue of supported employment, the focus group interviewees, revealed the challenges faced by people with Asperger in getting an evaluation appointment.

‘The people with Asperger syndrome need to make application from the social office for evaluation after obtaining a certificate of Asperger syndrome diagnosis from the doctor. The evaluation qualifies them for the service but due to limited number of evaluators and many applicants, the applicants have to wait for long. They can also apply for this service from the private sector but they have to pay for it. As a result many deserving applicants do not receive the service’.

According to Steinert & Pilgram (2007, 136), unemployment is the biggest driving force to social exclusion and equates unemployment to social isolation and ‘personal decay’. Their work follow the ideas of Townsend definition of social exclusion and the report European Union report (document number ‘com (94)333’).

In Finland there are no employment quotas for people with disabilities but the government pays for any extra costs of adjustments made at the work place for the purpose of building an enabling environment. This follows the redistributive discourses which aims to strengthen the social welfare and income gap reduction through progressive taxation. As mentioned earlier in my discussion on social rights and citizenship, the progressive tax is not always attractive. In the case of low tax for the low earners, the jobs are usually manual and heavy. (Gough et al. 2006, 95.) Most of my respondents said that due to their age (mid-forties), they feel they cannot take such physically demanding jobs. One personal interviewee said,

‘Those days when I was younger I could pick any jobs. May be you are too old for this job and there is someone younger for this post. May be I will never get a job!’

The vast majority of my interviewees have had jobs in the past so the question is how they found themselves unemployed? This question can be analysed in the different levels of social exclusion processes. One interviewee said he got unemployed after his company was sold out. This is was a transition point in his work life. According to findings from a research 'Luotyö projekti' (Aarniokoski & Hetemaki 2010, 15), adults with Asperger syndrome get excluded during transitional moments (micro-level) in their lives.

Unemployment effects are vast and play a great role in social exclusion as revealed by the study findings. It is very expensive for the government which has to pay unemployment benefits and social support to the unemployed. Early pensioning as a result of disability is very costly as well to the state. According to reports from OECD (2008), the cost for depressive illness has increased by 150% in the private sector in Finland. According to statistics by Organization for Economic Cooperation and Development (2010), there is higher poverty experienced by people with disabilities approximately 22% as compared to people with non-disabilities 12%, (sickness, disability and work: breaking the barriers, accesses 20.09.11). According to findings from the research 'inclusion and autism' (2000, 1983), about 14% of adults have no employment, no voluntary work and do not receive any benefits and they worry about their future as their life has no structure and lacks purpose for living. Poverty, poor mental health and substance abuse are the main social effects of unemployment as discussed below.

6.5.1 Poverty

According to a report from OECD (2010), the relative poverty of people with disabilities has increased compared to the adults of working age in Finland, Ireland and Germany .This also translates to the low household disposable income for those living with disability as compared to those with non-disabilities (OECD 2010, 55). There is 80% of population living with disabilities in Finland and not receiving a disability benefit although only 30% of the population are not receiving any public benefits (OECD 2010, 57). The statistics also suggest in most countries in Eastern Europe (Greece in particular); there is a high tendency for one to receive a disability benefit

after long-term unemployment. This according to research has revealed a high tendency of individuals receiving the disability benefits not going back to employment (OECD 2010, 64-67).

The interviewees expressed concern on the issue of long-term unemployment hindering them from getting jobs. They mentioned that employers are reluctant to hire them after they had been unemployed for long. Long-term unemployment and poor mental health could be analysed under the person's life trajectory. This is because they limit any chances of future employment of the person. The other issue was the availability of only physically demanding casual jobs, which is challenging as a person ages. Subsequently it results to a static state of long-term unemployment (poverty) and the state welfare dependency. According to Townsends (1979, 32) & Ronaldo (2004, 12), exclusion is measured in terms of inability to afford basic material resources for households. This was expressed by the vast majority of my interviewees.

6.5.2 Poor mental health and substance abuse

Finland recorded the highest disability claims of 68.5 % overall disability claims from mental health in 2008 among adults of age 20-34 in the OECD countries (OECD 2010, 62). According to the personal interviewees, they experience depression and anxiety often. They also revealed how they suffer regularly from depression and the take it had on their lives. One personal interviewee said;

'..Because I slept a lot, I missed classes and had a lot of assignments pending. I thought I could still do it but because of depression I did not have much power.'

This was a transitional point of the interviewee's life. Depression lowers the quality and structure of a person's life and is evident from the citation above. The respondent was a student in college at the time he suffered serious depression. This came as a result of going to school and moving away from home. As a result of not meeting his assignment deadlines and missing school, he was dropped from the course. Looking at this situation it is a combination of two elements; a turning point (moving away from home) which was not addressed, which led to a transitional point (depression from school work burn out) followed by another turning point (dropping out of school). Others also mentioned how sad they were during the time they suffered depression even though it came from

different sources. Despair on the hope of finding a job in the open labour market; was recounted by most of my respondents as a source of depression. They said they hate living on the social welfare and long to have jobs and live normal lives. The other issue was the broken families and loneliness which made them sad and depressed. According to the personal interviewees, high anxiety and use of drugs and alcohol as medication provides periodic calmness and peace. This can be addressed as a turning point in a person's life. One personal interviewee said;

, 'before I used to drink a lot when but now I don't use alcohol. I was also smoking marijuana. If you drink beer it makes you calm for the two hours. If you drink shots and you are shy, it makes you brave. At least they think that but I don't think it's the truth. Most of them are heavy drinkers and so this spoils their health. Most of my friends with Asperger syndrome have died from alcoholism but still people keep drinking.

According to Gaus (2007, 209), many people with Asperger syndrome, abuse drugs and alcohol to cope with the anxiety they experience as a result of Asperger syndrome. He argues that it can be very addictive because it gives a short term calming effect. According to some of the personal interviewees, it is easy to make friends in the pubs while drinking than outside. This is also another pulling factor for the substance abuse for them. However despite many adults with Asperger syndrome living on welfare support, they still spend a lot of money on alcohol and drugs. One personal interviewee mentioned how, he suffered big debts and begged for food after spending all his money on drugs and alcohol. Other than debts, those caught in the web of substance abuse also suffer poor health which may result to death. This is a good example of effects of social exclusion (labour exclusion) which is as a product of both macro and meso levels is in the life world/micro-level, (see chapter 4.2).

6.6 Cultural exclusion

According to Byrne (2005, 143), cultural exclusion denoted the cultural characteristics of those excluded. These include lack of capital which can enable them get jobs in the open labour market. It also includes lack of knowledge and ability to access the cultural products in the post-industrial society we live in. Cultural exclusion speaks against liberalism ideologies which are in favour of possessive individualism and question abuse of societal values in doing so. Byrne also urges the definition of culture to go

beyond arts which is the main approach used in defining measures needed to avoid cultural exclusion provided by United Nations in Standard rules in the equalization for persons with disabilities recommendations report (2007).

According to Byrne, our cultural life in the post-industrial is driven by paid employment and consumption which defines our identities. The inability to participate in the production and consumption means you are culturally excluded. He also points out that paid employment resulting to minimal wages is also an excluding factor. According to the focus group respondents, many adults in Finland with Asperger syndrome live on welfare support. The financial support is very little and barely enough to meet all their basic needs. This makes them automatically culturally excluded following Byrne's definition. The national, personal and religious holiday's celebrations are a luxury not known to people with Asperger syndrome. Those who celebrate these days rely on their family members' financial support. Another issue is the inability to take holidays away from home which is a Finnish culture. Most families travel to other cities and even abroad twice a year for holidays. The adults with Asperger syndrome cannot afford such expenses as my respondents reported.

According to Barnes and Geof (2003, 52), leisure has become a very important part of our lives in these capitalist times. Leisure touches not only on consumption of highly priced goods and services but also defines our identities. This however is a luxury that most people with disabilities miss out as a result of poverty. Through leisure activities people build a social network, as well as use it to express their freedom, power, status and ambitions. On this issue respondents from my personal interviews expressed their frustration on lack of funds to spend on leisure activities. According to Martin & White (1988), here forth referred in Barnes & Geof (2003, 52-53), the governments fund equipment necessary for mobility and does not fund leisure activities for people with disabilities. This has resulted to adults with minimal salaries which fall below the average with fewer choices for leisure activities. On the macro-level, it is hence clear how the states contribute to the cultural social exclusion. On the meso-level, there seems a clear class division of the working class elite who meet in certain places and belong to distinguished members only clubs.

The respondents from the personal interviews blamed the inability to get invitations to parties on the lack of wide networks of friends. Therefore, lack of participation in social functions resulted to limited chances of making new social contacts. To summarize, the cultural exclusion is a direct effect of macro-level of social exclusion (lack of leisure resources allocation for adults with Asperger syndrome) and it is experienced at the micro-level; the inability to participate in leisure activities due to lack of funds.

6.7 Exclusion from supported living

All of my respondents said that they have not been able to get supported living services in their accommodation. The reason to this they claim is that, the municipality only offers such service to those with very high needs for supported living. One respondent said,

‘Because of depression I did not have much power.
My room was a junk yard. I could not even cook food in my kitchen,
because it was full of trash’

He explained that this happened after he moved from home to live alone while attending university. This transition as explained in chapter four follows the micro-level transition process of social exclusion. The stress of leaving home to live alone was too much and university studies cemented the problem. He was unable to clean his apartment, resulting to intense dirt and clutter. This is an example of how the poor policies (lack of policies that entitle students with Asperger syndrome supported-living at the macro-level) lead the poor mental health and exclusion from education for adults with Asperger syndrome. It clearly shows the multidimensionality of social exclusion and disability (Taket et al. 2009, 28) and (Madinipour et al. 1990, 22).

6.8 Exclusion from education

The exclusion from education seeks to look in to the processes of exclusion from education for adults with Asperger syndrome. People with Asperger syndrome possess from average to above average IQ. According to Asperger (1938), many people with Asperger syndrome excels in the case of learning by heart but fail where reasoning is put in to practice (cited in Attwood 2007, 228). Despite the challenges faced by people

with Asperger syndrome in learning, some do excel highly in their subjects of interests due to the ability to focus keenly on their interest subjects; Examples of these include Marc Fleisher a post graduate in mathematics. (Attwood 2007, 228-242.) According to Howley (2007), students with Asperger syndrome should undergo an integrated education system and have their needs put into perspective.

In Finland, there is an integrated education system where students with Asperger syndrome share the same class as the students without Asperger. The students with Asperger syndrome however have a tutor who gives part-time tutoring and counselling. This concept was introduced in the early 1990's as a move to inclusive education. Initially there were separate schools for students with special needs. The integrated education system is tailored towards ensuring a quality education for all, and taking in to consideration the individual needs of all students. According to the respondents from the personal interviews, those who attended school in the 70's and 80's did not receive an integrated education. This is coined to the novelty of Asperger syndrome diagnosis. One of my respondents who went through an integrated system felt that it helps only when assigned a tutor. He mentioned that he was only assigned a personal tutor after he had suffered a serious depression leading to hospitalization at the age of ten. He said that it is challenging to prove the need for a tutor at school while your class performance was average. In high school he was not offered a tutor and he struggled through and graduated with average scores. According to him, the school only organizes for a personal or group tutor in case of behavioural or health problems.

As students with Asperger syndrome, the interviewees felt that they were easy targets for abuse and needed support to excel in their studies. Their biggest disappointment was the inability of the teachers to understand them and their 'strange' behaviour (social exclusion at the meso-level). Some personal interviewees however, encountered teachers who noticed their attention disturbance by noise in the class and arranged extra coaching for them. They expressed gratitude for 'these teachers' and revealed that this helped them get good scores in their class work. Attwood (2007) suggests that, despite a student with Asperger syndrome having a high intelligent quotient scores, the class teacher should demand for a tutor to accompany the student in class. This follows the need of students with Asperger syndrome for guidance during lectures.

All interviewees from the personal interviews experienced bullying in all their school life. They were also not popular and felt neglected by other students. In one instance one interviewee narrated how she ate ice and raw dirty vegetables every week, so she could become sick and avoid school. She said her parents were strict and would otherwise not allow her to stay at home unless it was a contagious infection such as flu or diarrhoea. She remembered how painful the bullying experiences were and how sad she felt. Another interviewee narrated how his fellow students made him steal from the supermarket in order to become their friend. They teased him and often questioned his sexual orientation since he did not have a girlfriend in his teens. In another sad event, the mother of one interviewee who has Asperger was accused spreading lies and malice after reporting bullying of her son to the teachers. According to Dublin (2007), bullying in schools should be avoided and dealt with very seriously. Bullying is the biggest cause for depression of adolescent students. The effects of bullying which includes mental trauma remain in one's life for years. This affects and shapes one's life in some instances and touches on the life trajectory ideology in the micro-level process of social exclusion. Some adults have low self-esteem due to bullying that happened while they were teenagers in school. Bullying of students with Asperger syndrome is very common in schools according to the response from the personal interviews.

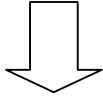
Supported accommodation for students with Asperger syndrome is highly recommended according to my findings from the interviews. In one instance, the young adult with Asperger had moved to independent living after college admission. He narrated how hard the transition was and how he ended up with a 'junkyard' (his words), in his kitchen. He said he had resulted to ordering pizza every day and ended up in huge debts because of using his credit card. The clutter also provided a stressful environment adding to the high pressure from school. He was unable to submit assignments on time and was asked by his teacher to join vocational colleges for people with Asperger syndrome. According to this interviewee, if he had received supported living services, he would have coped with the independent living transition. The supported living service for independent living is only provided to people with learning disabilities or physical disability in Finland. In some cases some people with Asperger syndrome may be offered the service.

According to the focus group interviewees, the selection criteria for the service are not clear. It is also hard for the people with Asperger to prove that they need the service from the municipalities. According to Howley (2006), flexibility in schools and institutes of higher learning is necessary for supporting the students with Asperger in schools. In one case, the interviewee expressed how frustrated he felt when he too dropped out of school in his final year of university in order to work. This followed after his spouse gave birth and he wanted to support his family financially. He argued that, it is very stressful for someone with Asperger to go to university and work during his free time. This also points on the transitional points discussed at the micro-level as being highly stressful for people with Asperger syndrome. He also added that he was unable to go back and complete his education due to the stress of work and parenting. Dropping out of university has affected his ability to get professional jobs since. He can only find casual jobs which he argues are demanding physically.

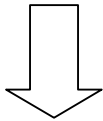
Other respondents who have attended vocational schools and acquired several certificates expressed their frustration and despair in the education approach. They complained about the labour office sending them for more education and training and failed to ensure they got employment afterwards. It is surprising that Finnish unemployment follows this approach despite following the monopoly paradigm defined by Max which is against offering more training to address labour exclusion (Silver 1994, 531). According to a research thesis by Raudasoja (2006), adults with Asperger syndrome may excel in studies but need supported employment to integrate in to the labour market. The research thesis was carried out in the Keskuspuisto Vocational College using the latest training program TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children). TEACCH was introduced in 1972 in Northern Carolina as the first state in America, which accepted community based program for people with learning disabilities. It is regarded as one of the best teaching programs. (The National Autistic Society 2011). The results revealed that even though the interactive skills of people with Asperger syndrome improved, they still needed support to cope at work and other areas of their lives.

6.8.1 TABLE 1: A summary of the social exclusion processes

Macro-level (formation of policies by the state guided by the three paradigms: monopoly paradigm in Finland following a re-distributive discusser. Others are laws and legislation, EU directives and human rights implementation, social rights definition)



Meso-level- groups exclusion (implementation of excluding policies by institutions; education system, healthcare, social security- Kela, child protection office, unemployment services)



Micro-level (the life world)

- life-trajectories- growing up without Asperger syndrome diagnosis, bullying in school, dropping out of school/ higher education
- transition points- divorce, loosing custody of children, poor mental health , moving from home to start independent living, loosing a job,
- turning points- alcohol and drug addiction, Asperger rehabilitation(speech therapy and learning life skills)

7 SERVICES AVAILABLE FOR ADULTS WITH ASPERGER SYNDROME

In this chapter I will unravel the services available for adults with Asperger syndrome. I will also discuss the policies behind these service allocations. It is important to look in to the services available for adults with Asperger so we can identify what is missing or why the services are falling short in meeting their intended goals. It is also important to bear in mind that Finland follows the Monopoly regime and a re-distributive discusser discussed in chapter 4.

7.1 Employment

According to the Health care Act (738/2002) in Finland; support for people with disabilities and guidance in obtaining treatment as well as rehabilitation is a social right. This also covers the necessary environmental modification at work place to suite persons with disabilities. The main actors in dealing with social exclusion of adults with Asperger syndrome in southern Finland include the following;

- 1) The state of Finland and the municipalities; provides some services and out sources others. All the ministries work together in this area mainly the ministry of social affairs and health, the ministry of education and the ministry of labour.
- 2) Non-governmental non-profit organizations such as Autismisaatio which offers rehabilitation for people with Asperger syndrome in Helsinki
- 3) Private organisations such as Helsinki Asperger centre which offers Asperger diagnosis
- 4) Autism and Asperger foundation which disseminates information regarding Asperger syndrome and conducts advocacy work for people with autism and Asperger syndrome

7.2 Supported employment

Services are organized by each municipality after getting a diagnosis and evaluation. This however is offered to people who need help in getting started at work and are able to keep employment. Long term support is offered to people who are severely disabled by the state. This according to my findings however, is the policy but the realization is a big challenge. According to the group interviewees, it is very hard to get an evaluation appointment. One can wait for up to six months and even after getting the appointment, it is not easy for people with Asperger syndrome to prove their needs during assessment.

7.3 Crisis management

This involves social workers assigned to some people with Asperger syndrome for the purpose of ensuring all financial assistance and counselling is done. The social worker acts like a case manager and is the mediator between the service user and the available services. This service is organized by the municipality of the service user, upon receipt of a referral in case of a crisis in the service user's life. According to the personal interviewees, the social workers are only active in the picture when a crisis emerges in their lives. They complained that they do not get support for preventive work when they need it. This was felt especially by the interviewees with families.

7.4 Vocational training

There are vocational training colleges whose goal is to train working skills in different fields of professions for people with Asperger syndrome. One of them is Keskuspuisto vocational college which offers special vocational training for adults with disability. The curriculum is flexible and allows for the students to plan their studies together with a study counsellor. Some students get on campus accommodation where they get training on daily basic skills as well. The main aim is to empower the students to integrate in to the society fully. The training pays attention on the individual students' strengths and works to improve the weakness. This service is provided by the municipalities according to the law in the Occupational Health Act 738/2002.

7.5 Assisted living

There are group homes in residential areas, arranged home visits and subsidized rental flats. People with Asperger syndrome have very different needs as in the case of living where some may need support full time, some do not need any support in accommodation. These services are provided by the municipality according to the law (under the Act 738/ 2002 Section 20 & 21), as part of their civil rights. However they need to show their need for this service according to section 20 of the act. According to the focus group interviewees, it is challenging for adults with Asperger to prove their need for the service due to 'the invisible nature of Asperger as a disability'. Some private non-profit organizations like Autismisaatio provide such services as well as everyday skills coaching.

7.6 Speech and rehabilitative motor therapy

According to Howlin (2007), some people with Asperger syndrome may have speech problems as those diagnosed with dyslexia and may need a speech therapy. This means that they are unable to pronounce words in a way that can be understood by others. Some may experience difficulty in finding the right words to express their thoughts. People with Asperger syndrome may also have poor motor co-ordination resulting to clumsy movement and slouching posture. The municipalities offer speech therapy as well as motor rehabilitation as required by the law under the Occupational Health Act (738/ 2002).

7.7 Counselling services

Specialized counselling tailored for changing challenges posed by Asperger syndrome is offered by Asperger coaches. Such services are provided by the state from private sector and non-profit organizations like the Helsinki Autismisaatio. According to the Occupational Health Act (738/ 2002), the municipalities have the responsibility to provide family support and counselling. According to the personal interviewees, the

counselling services are not sufficient. They also complained of the cost sharing system employed by the state on this service. This means that the state pays part of the bill and the service user pays the remaining part. They expressed their frustration as the amount they need to pay is a lot since they were unemployed. As a result, they don't seek for counselling services.

7.8 Diagnosis services

The public hospitals as well as private organizations such as Helsinki Asperger Centre and Autismisaatio offer diagnosis services. This is easily accessible according to the personal interviewees even though some feel like having a doctor's diagnosis is useless. They feel that it was enough that they knew it themselves and learnt how to cope with the challenges. According to the study findings, there is also stigmatization by the medical doctors who are quick to prescribe anti-psychotic drugs to the people with Asperger syndrome. According to the personal interviewees who discovered their diagnosis in their 30's it was not necessary to get the drugs at all. Apparently, they claimed to have developed skills over time on how to overcome some of their challenges; such as anxiety as a result of Asperger syndrome without rehabilitation.

7.9 Self-help groups and unions

According to Barnes & Mercer (2003, 101), the people with disabilities have formed social groups being driven by quest for social justice, equality and participation. This is a disability culture which believes in a radical democratic approach for empowering themselves. Their culture unifying element is the shared interest in social and political issues need for change not their impairments. This echoes the views of Silver (2007), who emphasizes of oppressed groups regarded as 'outsiders' to come together and fight for social justice. This is reflected in the meso-level of social exclusion as discussed in the following chapter on processes of social exclusion. There are many self-help groups for people with Asperger syndrome where different services are offered beside moral support (emotional and psychological encouragement). They organize seminars and get speakers who educate them on different aspects touching their lives. They also have a

social network on internet where they exchange ideas and make friends.

The Autism and Asperger Foundation is an organization for people with Asperger syndrome in Finland and plays the advocacy role to policy makers. They also educate teachers and employers about Asperger syndrome. These seminars enable teachers in schools to identify and address the needs of students with Asperger syndrome. They advise employers on how to work best with people who have Asperger syndrome. The work of the union is limited by inadequate funding. The interviewees from the focus group were distressed by the little funding they receive from the Finnish Slot Machine Organization. They blamed the limited funding on their inability to carry out enough empowerment activities and creating public awareness on Asperger syndrome. Unlike some of their counterpart disability unions that are involved in the government's politics, they do not participate in politics. This can be used to explain how the interests of the physically disabled are highly represented in the policy making as opposed to people with Asperger syndrome.

7.10 Social support

The social welfare in Finland takes care of the basic needs of the general population such as food housing, clothing, transport and health. According to the Social Welfare Act 710/ 1982, the state and municipalities shall provide social welfare to all its citizens. Social welfare in this context has the following definition;

‘For the purposes of this ‘Act’ the social welfare means social services, social assistance, social allowance, social loans and related measures intended to promote and maintain the social security and functional capacity of the individual, the family and the community’ (The Social Welfare Act 710/ 1982) .

All citizens of Finland are entitled to the social welfare according to the law. This is important as it ensures that all citizens get their basic needs (food, shelter and clothing).

7.11 Integrated education

According to Meijer (2001), Finland provides an integrated education system. The students with Asperger syndrome with average and above average IQ attend the same classrooms as the typical students. They get personal or group tutors to help them in school. They however need to apply for the service from the municipalities. The Asperger students with a low IQ go to special schools just like other students with low IQ.

8. RECOMMENDATIONS AND DISCUSSION

In this chapter I will show the missing pieces needed to complete the puzzle as well as critically analyse the effectiveness of national policies in Finland. Finland follows the solidarity paradigm of social exclusion. As a result Finland puts emphasis on a strong social welfare. The findings have revealed that even with a strong social welfare policy, social exclusion is still high amongst adults with Asperger syndrome. My recommendations are derived from my study findings as well as supported by theories. My main findings on this study are on labour exclusion, social capital exclusion, family life exclusion and education exclusion. According to my study, these four areas of social exclusion are very dominant and significant in the lives of adults with Asperger syndrome. I will also look at the meso-level; the contribution of institutions in social exclusion of adults with Asperger syndrome.

Their needs discuss at this point, some basic underlying ideologies in my approach of social exclusion of adults with Asperger syndrome. Some of the two most contested words are integration and inclusion. According to Wolfensberger (1972), integration from his principle of normalization denotes the process and measures put in place to maximize the potential of a person in community life participation (Wolfensberger 1972, cited in Flynn & Lemay 1999, 272). Wolfensberger (1972) categorizes integration in to two; physical integration and social integration. Physical integration involves accessibility of buildings and physical settings. Social integration involves the personal interactions and a relation of the two groups namely the excluded and included. According to Wolfensberger and Thomas (1983), social integration is only considered to happen when the 'included' voluntarily interact with the 'excluded' and accept them. This takes place while participating in 'culturally normative' activities in 'normative settings'. They also points out physical integration as a pre-requisite for social integration to occur. Social inclusion can be used to refer to physical integration which also denotes 'mainstreaming' or used to refer to social integration. They argue that social inclusion is based on human rights which lead to forceful or coerced interaction which does not always lead to acceptance. They emphasize that acceptance is based on voluntary participation of the 'included' and the 'excluded'. (Cited in Flynn & Lemay 1999, 274.)

In my recommendations, the term social inclusion is used to mean social integration as I have mentioned that the word carries a contested meaning.

8.1 Labour inclusion

There are employment quotas put in place in countries like France, Portugal, Italy and Greece which have seen an increase in employment for people with disabilities. This could be employed in Finland as well in a move to keep more people in employment as opposed to disability benefits (OECD 2010, 79). An employment quota for people with disabilities is a form of positive discrimination. According to Steinmeyer (2003, 133), positive discrimination refers to bias treatment to a specific people. When the bias treatment is not in their favour, it is referred to as negative discrimination. Steinmeyer argues that lack of enforcing mechanisms to enable people with disabilities to participate fully in the society is negative discrimination. Employment quotas will ensure the inclusion of people with Asperger syndrome in the labour market.

The idea of supported employment came from USA in 1994. It involves training of individuals at the job site after giving a trial work placement, and giving continued support twice monthly. Although there are similar programs in Finland, research has shown that follow up support at the job site is not offered. This is the most important part of the program however it is not provided. In addition to supported employment a policy that provides wages subsidies should be formulated. A wages subsidies program (macro-level inclusion) involves compensation by the state to the employers; to ensure that people with disabilities receive same wages as those without. This helps to compensate the employers in the case of low input from the employees with disabilities. The aim is keeping people with disabilities in full time employment. Such policies have been enforced in Belgium and Slovenia and proved successful. (Steinmeyer 2003, 90.)

Vocational training helps people with disabilities to learn how to take part in the productive market. This training would help people with Asperger syndrome to learn work ethics and train on such skills from early age and learn how to cope with the stress of working environment. There are vocational training institutions in Finland but results from my research showed all those who have been unemployed for long are offered

such training. My study findings also revealed that vocational training only helps with a small part of the problem. This implies that of the challenges experienced by people with Asperger last for life, despite the training. Subsequently, support plans should be arranged bearing this fact in mind.

According to OECD (2010), the main problem in vocational training is the involvement of many actors for the same service. This makes it hard in defining the service users and the responsible service provider (OECD 2010, 149). There is need for the service providers to work in unison to reduce unnecessary duplication of services and build a clear structure. In my opinion, this would also help to assign specific responsibilities to different service providers and be held accountable.

8.2 Social capital inclusion

According to Tacket (2009, 30), social capital are those personal relationships that build social networks which are productive. Social capital is very vital in permeating the open employment. According to my research findings, people with Asperger syndrome possess very low social capital. The social capital can be built through different Medias as discussed below

According to findings from the autism and inclusion research (2000), early diagnosis of Asperger syndrome is essential for a healthy life. It argues that this diagnosis would enable to develop an enabled environment to meet the needs of people with Asperger syndrome. The same views were echoed by my interviewees.

According to my study findings, not all students with Asperger syndrome receive services to enable independent living. Such services would include a support worker who visits once a week to ensure that things in the house are in order. Such areas would include the cleanliness of the apartment, ensure bills are paid on time, and check on the general health of the service user. According to the personal interviewees, such support would reduce the stress level which is high for students and parents with Asperger syndrome. The allocation of the funds by the municipality (macro-level) for this service should be increased as this would allow students to stay and perform better in school. It would also help families in building better relationships

8.3 Family life social inclusion

There is need for Asperger syndrome awareness to healthcare providers. This will enable the professionals such as social workers, teachers, school counsellors, health workers, unemployment office workers and caregivers to identify and attend to the needs of people with Asperger syndrome. Providing a handbook with different learning disabilities and the needs of these groups, would be helpful in achieving this goal. In cases commanding such knowledge, then a quick reference can be made.

A one stop shop ideology for people with disabilities can also be implemented. The aim of this is to co-ordinate the service providers for people with disabilities in order to avoid the stress and confusion which results from multi agencies involvement in one issue. Another step to social inclusion would be availing easy accessibility of Asperger syndrome needs evaluation. The study findings have revealed how cumbersome the process is in Finland. (Discussed in chapter 6.4.)

Another step would be giving higher benefits to individuals undertaking rehabilitation training programmes. This would encourage people with Asperger syndrome to participate in the programmes. The challenge of this approach is the need for long-term rehabilitation programmes. The issue of insufficient family therapy support could be addressed in many ways. One of them would be declaring families made up of parents with Asperger syndrome as risk groups. This is not to stigmatize them but to qualify them the right to the family support service; which is only offered during crisis according to the law. According to the revised Finnish Child Welfare Act 417/2007 in January 2008, early intervention in child protection and family support (open care) is the responsibility of the state (Child Welfare Act 417/2007). Hopefully with the full enforcement of this law, parents with Asperger syndrome will benefit from the open-care services. Unfortunately the act does not have a provision for specialised child welfare social workers in the fields of disability. In the Finnish Child Welfare Act (417/2007) section 14, the social workers in child welfare are required to understand the needs of the children. It should lacks to address the knowledge of 'special parent groups'; such as parents with Asperger syndrome. This part of the law in my opinion should be revised to cover knowledge of the needs and challenges of such 'special parent groups (with learning disabilities)'.

8.4 Education inclusion

Integrated education system in the mainstream should be used for students with Asperger syndrome. Special attention needs to be given to address needs of each student. Bullying is very common in junior high and high school as found out in my research. Effects of bullying on people with Asperger syndrome are evident in adulthood and destroy ones self-esteem (Dubin 2007) .According to recommendations from the Autism and inclusion (2000), there should be evaluation of the quality of service provided to the people with Asperger syndrome including education. The Ofsted evaluation system has been recommended to measure if the service is meeting the needs of individual service user.

There is need for research on the best rehabilitative measures for people with Asperger syndrome. According to the personal interviewees, the medical approach is highly resisted. They expressed the need for a non-medical approach of rehabilitation on the challenges posed by Asperger syndrome. Asperger syndrome got recognition recently and has not had enough research input. More research is needed and the government should fund projects researching ways to reduce the social exclusion of people with Asperger syndrome.

The resource allocation process should be fair, open and based on person-centred planning approach. The integration approach needs to move from physical to social integration in schools. One interviewee said;

There is need to integrate Asperger students in normal classrooms so they can learn to adapt to the society. Because usually they are put in their own focus groups or put in a class of students with learning difficulties

According to Wolfensberger (1972) however, placing students with Asperger with students without Asperger in same learning environment is not enough. Measures should be put in place to ensure social integration takes place and eradicate exclusive practices such as bullying. Creation of awareness on Asperger syndrome would enable other students understand better what Asperger syndrome is and subsequently build better relationships.

9. CONCLUSION

There is need for strong representation of the people with Asperger syndrome. There is need to carry out strong self-advocacy programs. The union for people with Asperger syndrome needs to get vigilant on its advocacy roles to the policy makers. In my opinion the policies that are in place to address social exclusion do not address the needs of adults with Asperger syndrome. It is clear one size does not fit all in this case. The government should also partner with the unions doing advocacy work for people with Asperger. This could be through funding and involvement during formulation of policies affecting people with Asperger syndrome. If change is to come, there is need for the policy makers to take a bottom-up approach. This involves having the people with Asperger syndrome define their challenges and possible solutions. If the epidemiology numbers are precise, (10% of Finnish population has Asperger syndrome and autism; then this is not an issue that should be ignored as it does not affect a minority group.

9.1 Professional development

According to the study findings, there is need for specialized family and child welfare social workers in Asperger and other learning disabilities. The study findings suggest that child welfare officers play a great role in meso-level social exclusion of adults with Asperger syndrome. There is need for different specialised child welfare officers who understand the challenges and needs of parents with Asperger syndrome. It is clear that a social worker cannot carry out her roles effectively, without being competent about the underlying background issues of the service user. The social work seeks to fight social injustice such as social exclusion of certain groups not contributing to it. During the formulation of policies, it is vital for social workers to involve the service users.

There is also need for social workers and healthcare providers to understand the manifestation of different disabilities. They may not learn by heart but may be have a handbook in the office. This would help them understand the service users and offer better service especially in public offices.

This would reduce the stigmatization experienced by adults with Asperger syndrome as indicated in my study findings.

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Appendix 1

Questions asked/ discussed during personal interviews

a) background information

1. Which age group do you fall to?
 - i. 20- 30 years
 - ii. 31-40 years
 - iii. 41 years and above

b) Employment

1. Are you currently working? If yes what kind of job do you have? Is it a professional job (you have received training for)?
2. If you are not employed how long have you been employed?
3. What professional qualification do you have?
4. What is the attitude and treatment from your working mates and management? have you experienced any form of discrimination at work?(teasing, lack of promotion, overworked)
5. Is your work environment modified in any way to accommodate someone with Asperger syndrome (task based- focus on results not process and high time limits)?
6. How easy is it for you to get employment in the mainstream market? Explain why?
7. Does taking a job in the main stream market put you at the risk of losing your social benefits (social support)?
8. What role does work play in your life?

c) Education

1. What level of education do you have? Did you need special education in school? Did you get it?
2. We're /are the teachers in your school sensitive to the needs of someone with Asperger syndrome?
3. Did you experience bullying in school? Did you miss school due to bullying and was it from teachers or fellow students?
4. Did you have friends at school and how well did you fit in their social circles? How did this make you feel?
5. Do you think fellow students and teachers understood/ understand what Asperger is and how to treat with Asperger with love and respect?

d) Access to good and services

1. Do you face difficulties while accessing services from the public sector due to your communication style? What attitude do you experience from these offices?
2. Do you have any difficulties shopping for your groceries and do you need any help?

e) Family and friends relationships

1. Do you have a big social network of friends and family? are you close to the people in your social network?
2. Do you experience attitude problem from your family and friends- are they ashamed of you because you have Asperger syndrome?
3. Have you ever experienced harassment or unfair treatment from your family and friends? For example, name calling and teasing?
4. How knowledgeable are your family and friends about Asperger and how to treat people with Asperger?
5. Have you ever experienced discrimination from your family and friends based on the fact you have Asperger such as not being invited for family functions and parties?