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## **Qualified or not?**

**A case study about integration of people with intellectual disabilities on the labor market in Recife, PE – Brazil, using the “Quota Law” as a starting point.**

## **Abstract**

People with intellectual disability, as a category, are an especially disadvantage group, as they often are in need of interventions from the society throughout the whole life. In Brazil, work is considered a human right and important for the construction of the social and personal identity. There is a law, called the Quota Law, which demands all companies with 100 employees or more, to employ between 2 – 5 % people with disabilities. This law aims to ensure this social right for the target group. However, several studies are pointing at the timid result the law has provided concerning employment for people with intellectual disabilities. This study intends to detect barriers, important aspects and possible solutions in order to facilitate for people with intellectual disabilities to enter the labor market using the Quota Law as a starting point.

The study has an inductive and qualitative approach and the data is collected by semi-structured interviews. The respondents are all related to issues of people with intellectual disabilities and their integration on the labor market. Within the sample there are; persons with intellectual disabilities who have an employment on the labor market or have a desire to obtain a competitive employment; relatives to persons with intellectual disabilities; professionals working in two different non-government organizations (NGO's) in Recife that provides vocational courses for the target group and finally; respondents working at public ministries who act in the area of integration of people with disabilities on the labor market.

The result shows that the main barriers for people with intellectual disabilities in order to reach the labor market were considered; prejudices and discrimination of persons with intellectual disability; the lack of qualification of people with intellectual disability in combination of high qualification requirements by the employers; the lack of support in order to compensate for intellectual disabilities; that the work environments are not customized for the target group and; fear of loosing the Benefit of Continuous Support of Social Assistance (BPC).

Theories of perspectives on intellectual disabilities are used to understand current interventions in order to integrate people with intellectual disabilities on the labor market. One conclusion is that there is a need for further efforts towards the target group in order to really obtain an effective integration for people with intellectual disability on the labor market.

Key words: Intellectual Disability, Employment, Brazil, Barriers, Support, Social Work

## **Preface**

The idea of this study bases on my work experience of giving support to persons with intellectual disabilities. As my partner is from Brazil I have been there several times, but never with another object than vacations. Therefore I was curious of getting to know Brazil in another sense. I am very grateful that I have been given this opportunity!

The journey towards this final essay has been a real challenge but at the same time a truly enjoyable and valuable experience. I have learned incredible lot, both in terms of how social work concerning disability issues is structured in Brazil, but also in terms of taking my language skills of Portuguese to a new level.

Now, I finally arrived at the point of authoring a preface and I want to thank everyone who has made this essay possible. Especially all my respondents, without your stories this essay would never had been realized. Many thanks to my supervisor Johan Gärde who, since day one, has been struggling to make this journey possible and shown a great commitment and support. I also want to thank my family, both in Sweden and in Brazil, for all support. It is thanks to you that this journey has remained enjoyable until the end! I am also grateful for my prior understanding of issues related to intellectual disability, which mainly can be attributed to my father and my work experience within his organization. These prior understandings have been very helpful during the work with this thesis. I would also send thanks to Sérgio Sampaio and Magnus Tideman for valuable feedback. It gave me the affirmation that I was on the right track concerning previous research and the theoretical framework.

This essay has greatly exceeded the maximum number of pages specified as a framework by my institution. One explanation for this is that I considered it necessary to explain both the Brazilian context, and the area of disability issues, in order to facilitate for readers who are not familiar with these areas.

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# 1 Introduction

## Definition of Intellectual Disability

According to the American Association on Intellectual and Developmental Disabilities (AAIDD, retrieved 2013-07-24), intellectual disability characterizes, by “significant limitations both in intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills.” With *intellectual functioning*, they refer to “general mental capacity, such as learning, reasoning, problem solving, and so on.” This is usually measured by IQ tests and according to them an IQ score of less than 75 “indicates a limitation in intellectual functioning.” *An adaptive behavior* refers to “the collection of conceptual, social, and practical skills that are learned and performed by people in their everyday lives.” Kylvén (1981) divides intellectual disability into three stages; A, B and C, which refers to level of abstraction. The A-stage refers to severe, B-stage to moderate and C-stage to mild intellectual disability (pp. 31-33). Persons within this group are often excluded from activities within the society because of the characteristics of an intellectual disability. According to Tideman, people with intellectual disabilities “are a small and vulnerable group that is in need of support from the society, often throughout the whole life.” He says, “From the perspective of people with intellectual disability, it is essential that the need of support, service, and education are being met (2000, p. 38)”. According to him, people with intellectual disability, because of the kind of the disability, probably is in a greater and more prolonged need of the community efforts than any other group (p. 39). According to the World Report on Disability (WHO, 2011) “People who experience mental health conditions or intellectual impairments appear to be more disadvantaged in many settings than those who experience physical or sensory impairments (p. 8).”

## Disability and Work

According to Antonson (2003), “For a person with disabilities to participate, and feel involved, in the building of the society, and the social community, requires that he / she are fully incorporated in the society especially regarding the right to work in the regular labor market. (p. 14).”

In the United Nation Convention on the Rights of Persons with Disabilities, within Article 27, it is written that,

State Parties recognize the right of persons with disabilities to work, on an equal basis with others: this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities.

According to Araujo (2012), "Brazil was a signatory to the Convention for the Rights of Persons with Disabilities 2006." The National Congress approved the convention July 9, 2008 (p. 53).

## **The context of Brazil**

### **Welfare System**

The foundations of the system of social protection of Brazil began to evolve in the 1920s but according to Segura-Ubiergo (2007), it was only in the 1930s that the system began to expand to include an extended group (pp. 27 & 62). He writes that the Brazilian welfare system clearly can be distinguished from the Western European models of welfare state formation "which the progressive incorporation of an increasingly better organized labor force led to a series of social policies that responded to demands for more equality and protection from the risks of modern capitalist life (pp. 63)." The formation and expansion of the Brazilian welfare system is, according to Segura-Ubiergo, strongly related to the period when Getlio Vargas was president (1930-1945). The period of democracy continued even after Vargas's death 1954, until the military coup that overthrew President Goulart, 1964. "The social security system implanted by Vargas remained largely unchanged during this period (pp. 64)."

### **Disability History in Brazil**

According to the anthropologist Pamela Block (2007) the Brazilian "systems of support are historically unique from those offered in the USA and elsewhere, and at some historical moments, they were considerably more progressive and humane than what was available in other countries." While people with intellectual disabilities was institutionalized and sterilized in United States and other parts of the world this was, according to Block, not widely advocated in Brazil, although it also occurred. Instead, it was believed by professionals that the genetic heritage was influenced by environmental factors and could be affected through development of public health and social. Block writes, "Theories of innate 'pathological' inheritance were somewhat influential to the development theories and practices in Brazil, but such theories were tempered by the progressive and humanistic philosophies of key practitioners (...) (p. 179)". According to Block "The historical experiences of people with

intellectual disabilities in the USA is usually described in several stages: the growth of institutions; deinstitutionalization; and finally an, 'era of community membership' in which supports and services are person centered rather than institution-centered". In Brazil they do not share this evolution "as custodial facilities for people with intellectual disabilities were uncommon in Brazil (p. 184)." One important person for the distinctive difference between the practice in Brazil and other countries during the 20<sup>th</sup> century was the developmental psychologist Helena Antipoff who had a stance against large custodial facilities. Antipoff was "responsible for developing what became the Brazilian national model for special education and support services for people with disabilities (p. 187)." According to Block the work of Antipoff accelerated the process "by which biomedical treatment models were replaced with educational models in Brazil." She says that the two most prominent organizations existing in Brazil today, *the Pestalozzi Societies* and *Associations of Parents and Friends of the Exceptional* (APAEs), are a result of her efforts.

During the work with this study I have discovered two general aspects within the welfare system of Brazil considered important for persons with disabilities. Those are the Quota Law (Law no. 8.213/91, Art. 93°) from 1991 and the Benefit of Continuous Support of Social Assistance (BPC - Benefício de Prestação continuada da Assistência Social), established by the Federal Constitution 1988.

### The Quota Law

The quota law (Law no. 8.213/91, Art. 93°), obliges organizations with more than 100 employees to employ a percentage of 2 – 5 %, people with disabilities, based on the total number of employees within the organization. The law was regulated 1999 with Decree number 3.298/99 and within the Article 36° it says, "A company with a hundred or more employees are required to complete two to five percent of their positions with rehabilitated beneficiaries of Social Security or qualified disabled persons in the following proportion;

I – up to 200 employees, 2%

II – from 201 to 500 employees, 3%

III – from 501 to 1000 employees, 4%

IV – more than 1000 employees, 5%

In this decree three paragraphs are added,

§ 2 A person with disability is considered qualified, one who has completed professional education of basic, technical or technological level, or higher education, with certification or diploma issued by public or private institution, legally accredited by the Ministry of Education or equivalent body, or the one with the certificate of completion of the qualification process or vocational rehabilitation provided by the National Institute of Social Security - INSS.

§ 3 A person with disability is also considered qualified, one who has not undergone the process of habilitation or rehabilitation, but is able to exercise the function.

§ 4 The disabled person qualified under §§ 2 and 3 of this Article may apply to the intermediary agency forming part of the public employment system, labor for inclusion under this Article.

## **The Benefit of Continuous Support of Social Assistance**

The BPC is a benefit of social assistance policy, which includes the basic social protection under the Social Assistance System (SUAS - Sistema Único de Assistência Social) and to access it, it is not necessary to have contributed to Social Security. The BPC administration is conducted by the Ministry of Social Development and Combating Hunger (MDS), through the National Secretariat for Social Assistance (SNAS). SNAS is responsible for the implementation, coordination, regulation, financing, monitoring and evaluation of the benefit. The National Institute of Social Security (INSS) carries out the operation (MDS, retrieved 2013-06-17).

The BPC is an individual benefit which is not transferable after lifetime, and

ensures the monthly transfer of one minimum wage to the elderly, of 65 years or more, and persons with disabilities, of any age, with impairments of long term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. (MDS, retrieved 2013-06-17)

In order to get the BPC the person must prove that they do not have means to ensure their own sustenance, or have it provided by their family. The per capita monthly household income must be less than one fourth of the minimum wage.

## **Relation to Social Work**

As the area of social work is very broad, and the social work practice is applied differently in different social models, it is very hard to define “what Social Work is” (Meeuwisse, Sunesson and Swärd, 2000, s. 43). Social work could be considered to be the work made by professionals who have a social work degree on a social service office, but it could also be made within ecclesiastical charity work, philanthropy, poverty relief, voluntary organized work and so on (Meeuwisse, Sunesson, and Swärd). Payne writes that, all around the world,

within almost all societies there are a work made called *social work*. Payne suggests a perspective of social work understood as a social construction created by political, economical and social conditions. Meeuwisse, Sunesson and Swärd cite Payne, "it is through the interaction of these different groupings within the society that social work is constructed (Meeuwisse, Sunesson and Swärd, 2000, pp. 42)".

Within the European Association of Schools of Social Work (EUASSW, retrieved 2013-06-28) there is an ongoing discussion of how to define social work. In the most recent version the definition is formulated as follows;

The social work profession facilitates social change and development, social cohesion, and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work. Underpinned by theories of social work, social sciences, humanities and indigenous knowledges, social work engages people and structures to address life challenges and enhance wellbeing.

As described above, people with intellectual disabilities is a vulnerable group who very much depends on the support from the society through the whole life (Tideman, 2000, pp. 38 – 39.)

During this study I have had contact with professionals with various educational backgrounds such as Social Service, Special Education, Psychology and Legal Affairs. All of those are, within their professional role, important actors for the target group and creators of social work.

## **Problem Statement**

People with intellectual disabilities are, despite of the "Quota Law", in many ways still excluded from the labor market in Brazil. As employment is an important aspect of a person's integration in the society, and that exclusion from the labor market not only limits the person in a social, but also in an economic way, resulting in people with disabilities, and their families, to be a group specially disadvantaged and marginalized.

## **Purpose**

The purpose of the study is to detect barriers, important aspects and possible solutions, related to the objective of facilitating for people with intellectual disabilities to enter the labor market with the quota law as a starting point.

## Research Questions

In order to respond to the purpose I have tried to operationalize some research questions. I have chosen to divide those into three main questions, and some follow-up questions.

1. Which interventions are made in Recife to facilitate for persons with intellectual disabilities to enter the labor market, according to my respondents?
  - Which are the main actors in the field of intellectual disabilities according to my respondents?
  - Who is responsible for the questions of integration of persons with intellectual disabilities according to my respondents; major companies, non-profit organizations, the government, the municipality, the family, the individual it self, the society or some other actor?
  - What kind of support is there to get in order to enter the labor market according to my respondents?
2. Which are the main barriers, according to my respondents, for persons with intellectual disability to enter the labor market using the quota law?
3. What changes has to be done, according to my respondents, in order to facilitate for people with intellectual disabilities to obtain a competitive employment?

I consider that these questions have relevance to social work as the target group for the study is considered a vulnerable group in need of support from the society, usually throughout the whole life (See subheading above, *Relation to Social Work*).

## 2 Previous Research

According to *The Special Secretary of Human Rights* (Aranha, 2003), “the inclusion on the labor market is a right regardless of the type of disability that is present and their degree of commitment.” However, they write that they “still witnessed numerous cases of discrimination and exclusion, perhaps, caused by the lack of knowledge in the society that these citizens have the right to live not segregated and with access to available resources as well as other citizens (p. 5).” In this sense the Special Secretariat for Human Rights incorporated into the collection *Studies and Research in the Field of Disability* the studies *Work and Employment: Instrument for Construction of Social and Personal Identity* (Aranha, 2003) and *Building an Inclusive Labor Market: A Practical Guide for Professionals of Human Resources* (Nambu, 2003). Within the first study (Aranha, 2003) it is considered that the human nature is structured in relation to the environment, in the societies that the person

constitutes and with the work that they develop. The key issue highlighted within these sense is according to Aranha that it is in the social context of work that humans build their personal and social identity as well as their self-esteem and awareness of dignity (p. 8). “It was based on these considerations, among others, that work, in 1949, passed to be considered, a fundamental right human, ie, a fundamental right of all people, including those who have a disability (p. 9).”

The Quota Law is according to Leite (2011), “a major breakthrough in the Brazilian legal system”. However, several studies are pointing at the timid result the law has provided when it comes to employment for persons with intellectual disabilities (Veltrone & Almeida, 2010; Mourão, Sampaio & Duarte, 2012) and that there are to be changes in order to promote equality for this target group when it comes to inclusion on the labor market (Mourão, Sampaio & Duarte, 2012, Sampaio, 2012; Leite, 2011).

In the article *Selective Placement of Mentally Challenged People in Organizations: a qualitative analysis* (Mourão et al., 2012) it is shown that, despite of the Quota Law, people with intellectual disabilities are still in many ways excluded from the labor market in Brazil. In the article *People with intellectual Handicaps: The New “Working-Class Brats” of the labor organizations*, Sampaio (2012) it is shown that people with intellectual disabilities are treated with the same competitive demands as any other employed with the result that some of them was not able to maintain the employment. They do not get the support that they need in order to compensate for their disability. According to Sampaio (Personal conversation) the supports to persons with disabilities

are very few, almost nonexistent, in other words, in Brazil despite of the affirmative action of the Quota Law which requires companies with more than 100 employees to hire people with disabilities, especially in the case of workers with intellectual disabilities it requires that companies create other affirmative actions to enable and ensure employment for the worker (Personal conversation, Sérgio Sampaio, 15 march 2013).

Within his study (Sampaio, 2012) it was observed that there were only found elements of instrumental rationality within the organizations that he had studied, both non- and pro-profit. Instrumental rationality he defines as “action based on the calculation, oriented to the achievement of technical goals or purposes related to economic interests or social power by maximizing available resources (p. 234)”. Those are put in contrast to *Substantial Rationality* “action oriented in two dimensions: the individual dimension, which refers to self-realization, understood as realization of potentialities and satisfaction; and the group dimension, which refers to the understanding, in the direction of social responsibility and satisfaction (p. 244).”

The law forces large organizations to employ a certain percentage people with disabilities but statistics shown by Mourão et al. (2012) proves that the amount of employees with intellectual disabilities are very small. Mourão et al. refer to an article that tells, “the quota law may require hiring people with disabilities, but does not guarantee that there will be a healthy relationship between minorities, and the dominant group within the organizations (p. 211)”. By minorities I presume that they mean the employees employed through the quote (ie persons with disabilities) and the dominant group the rest of the employees. They also consider,

the fact that there is a law that requires hiring people with disabilities does not guarantee hiring people with intellectual disabilities, since the quota can be met from hiring professionals with any kind of disability” and further on “although the quota law is considered an improvement over the national legislation in the area, this system has responded timidly for their purposes (Mourão et al., 2012, p. 211)

### **3 Theoretical Framework**

According to Söder (2005) the disability research has expanded significantly over the past decades. An interest of what different groups of people with disability had in common lead to the establishment of disability as a category in the early 60's. It was mainly the need of different types of extra supportive measures that they had in common, “so that they would not fall behind in the general development of welfare (p. 13).”

Hjelmquist (2005) writes that disability research still mainly is carried on two legs; the individual-oriented and the social-oriented research. The social-oriented consists of research on attitudes and notions about disability, organization of society, citizenship and human rights (p. 31).

In my research I have chosen to interpret my data using theories of perspective on intellectual disabilities. I find theories of perspective on intellectual disabilities associated with theories of Anti-discriminatory and Anti-oppressive Practice. These theories aims to bring together areas of interest related to different groups that are vulnerable to discrimination for a comprehensive theory and practice, covering every conceivable area where people are discriminated or oppressed (Payne, 2008, p. 385). The main developments within this theoretical views, has, according to Payne, been concerning black people but other oppressed groups, such as people with disabilities, may to some extent according to him be located in those perspectives.

Björck-Åkesson, Granlund and J. Simeonsson write that discrimination could be divided into two kinds, *indirect* and *direct discrimination*. The direct discrimination is when a society,

or a group of people, actively works to exclude individuals that have certain characteristics. Indirect discrimination is such where people with certain characteristics are excluded, unintentionally, because the society is constructed in a way that causes those people difficulty in functioning. “Probably, both direct and indirect discrimination may occur in the case of persons with disabilities (p. 75).” They consider indirect discrimination as more prevalent.

One perspective that is related to the anti-discrimination work, and concerns people with intellectual disabilities, is the perspective of normalization (Payne, 2008). According to Payne, the principle of normalization “...aims to, as far as possible, include people with intellectual disabilities in an ‘ordinary life’ (p. 391).” I will describe the normalization principle and different interpretations of it further on.

According to Payne Anti-discrimination work should have empowerment as a goal (p. 400) why this work also could be considered related to theories of empowerment. Theories of Social Mobilization could also be considered relevant to my topic, as the Brazilian Quota Law has been one attempt to include persons with disabilities on the labor market. Payne writes,

Social movements, that promotes equality and social justice, and who work against oppression of all kinds, often relies on changes in the law. It has for example been attempts to change the law to prevent discrimination against people with disabilities, improving the availability of services for special groups and create protection for vulnerable people (Payne, 2008, p. 318)

He also writes, “The state could also account for some mobilization work. (...) It is only the government that can develop a long-term community planning and mobilize the necessary resources for this.” I consider that these three main theories of social work are linked together concerning disability issues and they all relates to the topic of my thesis.

## **Perspectives of Disabilities**

There could be considered three categories of perspectives on disability, which are a *Medical or Individual Model*, the *Social Model of Disability* and the *Environmental Relative Concept of Disability*. Historically there has been a development from an individual based perspective towards a more environment based one. Björck-Åkesson, Granlund and J. Simeonsson (2011) writes that a definition of disability whit a focus on the interaction of individual and environmental aspects clearly is colored by the debate on discrimination and equal rights that had begun in the middle of the 20<sup>th</sup> century, after the Second World War. According to them, this perspective was clarified 1993 by the *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* where the purpose of the term Handicap (i.e. disability) was considered “to emphasize the focus on the shortcomings in the environment

and in many organized activities in society, for example, information, communication and education, which prevent persons with disabilities from participating on equal terms (p. 74)". The first time UN defined disability as; "a function of the relationship between disabled persons and their environment" was 1983 (Björck-Åkesson, Granlund & J. Simeonsson, 2011, p. 74). According to the authors UN, within the *World Programme of Action Concerning Disabled Persons*, writes that disability "occurs when they encounter cultural, physical or social barriers which prevent their access to the various systems of society that are available to other citizens. Thus, handicap is the loss or limitation of opportunities to take part in the life of the community on an equal level with others (p. 74)."

Depending on which perspective is utilized the interventions in order to combat discrimination towards this group will differ. I will give a review of the mentioned perspectives as follow.

### Medical or Individual Model

Grönvik names this first approach *The Diagnostic- or Functional Capacity Based Delimitation*, which focus on the individuals and their impairment. Szönyi and Tideman (2011) say that the basis of the individual model is that there is one way of functioning that is considered normal (statistically). Some people deviate from this normality because of diseases, injuries or other causes, which can be measured through tests and examinations. Concerning intellectual disability, there is a perspective that Tideman (2000) calls the psychological where the disability is measured by IQ tests (p. 42).

As the disability, according to the medical or individual model, is related to the individual, interventions are directed on individual treatment and could include for example medication, psychotherapy, training programs or technical aids (p. 142). According to Danemark (2005) this definition, as it do only focus on the functioning of the person, could be considered not interesting for sociological perspectives (p. 20). But it is relevant to mention this model as the other two perspectives has been developed as critics of this model.

### Social Model of Disability

Grönvik (2005) names this approach *Ambient Based Delimitation* that he says developed in UK under the 1970's as a criticism of the Medical Model. Instead of focusing on the individual, this approach focuses on the weaknesses within the society concerning people with disabilities. These weaknesses are, according to this theory, considered the main

obstacles for persons with disabilities and disability is defined as *an unavailable or not adapted environment*. Instead of asking, “What kind of problem do your disability cause?” this model consider asking, “What kind of obstacle do the lack of adaption of the environment within the society cause?” Within this model they make a difference between *Impairment*, which they links to the individual functioning, and *disability*, which they consider is a definition of a *not adapted environment*. One of the key persons behind the creation and development of this theory is the sociologist Michael Oliver. According to him it is not the person’s individual characteristics, but the experience of being discriminated, that is interesting (Grönvik, 2005, pp. 44 - 45).

A social perspective concerning intellectual disabilities focus on the abilities of the person to cope with the demands of the society, which is what determines if the person has a disability or not (Tideman, 2000).

### An Environmental Relative Concept of Disability

The third perspective that Grönvik (2005) writes about is, what is usually called the Relative Concept of Disability, or Environmental/Relative Concept of Disability. This perspective is dominant in the Swedish policy on disability. According to him it is a perspective on disability with both social and individual dimensions. This perspective has, as in the social model of disability in England, its origin in a critique of the medical model and its focus on the individual. But unlike the social model, which only sees disability as a consequence of a lack of environmental adaption, the relative concept of disability defines disability as something that occurs in the interaction between a person with impairment and the environment. A disability is thus not only based on individual capacity, nor only on obstacles of the surrounding environment (Grönvik, 2005, p.46). A person can have a disability in one situation but not in another, therefore, the disability is considered context-bound (Calais von Stokkom & Kebbon, 2000, p. 34). According to this model, we should not talk about disabled people, but people with disabilities (Tideman, 2000, p.41).

A well-known application of the relative concept of disability is the WHO classification, *International Classification of Impairment, Disability and Health (ICIDH)*(Calais von Stokkom & Kebbon, 2000, p. 35). This classification, which had a linear causal relationship from Impairment (organ level) > Disability (personal level) > Handicap (surrounding level), was criticized and a new classification with a more circular causal relationship was created which had a more clear focus on the environmental factors. The new classification is called

the *International Classification of Functioning, Disability and Health* (ICF) and within the *World Report on Disability* (2011) it is written, “The ICF emphasizes environmental factors in creating disability, which is the main difference between this new classification and the previous International Classification of Impairments, Disabilities, and Handicaps (ICIDH)(p. 5)”. Within ICF there is, as in the social model, the delimitation between impairments and disability where impairments defines by “problems in body functioning or alterations in body structure” when, “Disability arises from the interaction of health conditions with contextual factors – environmental and personal factors”.

## **Perspectives on Normality and The Normalization Principle**

Despite different perspectives on what disability is and how it should be defined, there are also perspectives on how people with disabilities could be integrated in the society and not to suffer from discrimination. The normalization principle originates from the Scandinavian countries and the basic principles were formulated in the late 1950s by Niels Erik Bank-Mikkelsen from Denmark and Bengt Nirje from Sweden (Söder, 2003, p. 21; Tideman, 2000, p. 51). According Mallander, Meeuwisse and Sunesson (2009), the ideology of normalization started as a reaction against the gap between the living conditions, in institutions for people with intellectual disabilities and the ordinary society, during the development of the welfare state in the Scandinavian countries (p. 161). The Normalization principle then spread to North America and thereafter further on to other countries. The everyday definition is diverse and the interpretation of the concept is broad.

As the name Normalization Principle indicates, it is based on a quest for the *normal* (Tideman 2008, p. 53). Tideman says that what is normal could be defined in different ways and according to him there is three principal ways of defining it which. These I will review as follow.

### **Statistic Normality**

The first way of defining normality Tideman calls, *statistic normality*. According to this definition normality is the *average* or *ordinary*, and could for example be “based on standard deviation of a normal distribution curve (p. 53).” Normalization work linked to this perspective is, according to Tideman, directed on making it possible for people, despite being sick or having a disability, to live a normal life. Within this perspective, the focus is not of

changing the person in order to be normal, but to make the living conditions, the environment and the circumstances as normal as possible for the person.

### Normative Normality

The second perspective is based on the attitudes of what is considered normal within the society at the moment. This perspective Tideman calls a *normative normality*. This definition of normality is relative and context-bound and the normalization work based on this interpretation of normality bases on the quest to reach what is considered normal in the sense of admirable or desirable in the society at the time.

### Individual, or Medical Normality

The third way of viewing normality he calls the *individual, or medical normality*, and within this perspective the individual should be considered *normal* or *healthy*, i.e. not sick or deviant. “When someone is deviant from the normal, it is required treatment in order to achieve normality (Tideman, 2000, p. 53).” The normalization work based on this interpretation is directed on making the person more normal regarding attributes and behavior. In order to reach this goal it could be “required interventions such as treatment, education, rewards or punishments (p. 53).” According to Tideman, the goal within this interpretation is that “the deviant person should realize that it is different and should be trained to become normal.” The desire is that the person should be healthy, which according to Tideman, takes the forms of special training programs or habilitation or rehabilitation efforts (p. 54).”

### Two Interpretations of the Normalization Principle

There could be considered two main interpretations of the normalization principle; the Scandinavian and the American interpretation (Tideman, 2000, p. 54; Mallander, Meeuwisse and Sunesson, 2008, pp. 162-165). According to Tideman “the Scandinavian interpretation emphasizes the ordinary, statistically average, living conditions and aims to create conditions for normal life to people with intellectual disabilities.” According to this interpretation, the goal is not that the person should change, it is the surroundings that should be adapted and available to the individuals. Within this interpretation, the society makes wealth transfers, for example through special legislation, so that even persons with sever disabilities would get as equal terms as others and conditions as normal as possible, which they would not be able to

acquire on their own (p. 54). According to Mallander, Meeuwisse and Sunesson a clinical interpretation of the concept, one of *making the abnormal normal*, is not unusual even in Scandinavian countries, which they say was not the objective of the theoreticians (2008, p. 161). Instead they say that the goal is to “remove barriers to participation and to create conditions that benefit people with disabilities to live a normal life (p. 162).” The purpose, based on the Scandinavian interpretation, is based on the statistic perspective of normality and the purpose is not to make the person normal. The normalization efforts should focus on providing opportunities for a normal life even to those who are not "normal" (Tideman, 2000, p. 54).

The principal founder of the American normalization principle is Wolfensberger (Tideman, 2000), who has tried to make the Scandinavian wording more American, sociological and universal (Mallander, Meeuwisse and Sunesson, 2008, p. 165). The American interpretation has, according to Tideman (2000), the same fundamentals as the Scandinavian, but with a focus on the low status persons with intellectual disabilities has, which is cementing the exclusion of persons with intellectual disabilities. This downgrading process could, according to the American interpretation, be countered by letting persons who are deviating, conquer high status positions (p. 56).” In contrast to the Scandinavian normalization principle, where the goal is that the person access normal patterns of life, normal living conditions and a normal rhythm of life, Wolfensberger “speaks about normal (normative valued) measures to be used to achieve normal (normative valued) targets (Söder, 2003, p. 34.)” Tideman (2000) says, “at the same time as the normalization efforts, through a range of measures, should try to break and reverse the downgrading process by strengthening the individual, it should try to influence the values of the society in a more permissive direction (p. 55).” According to Mallander, Meeuwisse and Sunesson (2008), Wolfensberger argues that affirmative actions can be used to compensate for inferior preconditions but this kind of interventions should be used gently as it could point out persons with disabilities even more. This he considers could have a negative effect on their status (p. 165). Another measure of reaching normalization is *skills enhancement initiatives* such as education and training programs (p. 166). Even if Wolfensberger also consider that the society should change, Tideman perceives that he “puts more emphasis on that persons with intellectual disability, for example through model-based learning, should learn to behave as normally as possible (p. 56).” Antonson (2011) says it could be considered that Wolfensberger “went a step further when he requested that the community developed in a much more permissive direction (...) (p. 161).” For example he

suggested direct support to people with intellectual disabilities in order to reach the labor market instead of building special day centers in public services.

Tideman (2000) says that the differences between the Scandinavian and the American interpretation probably are related to the differences regarding the role of the government within the society. “In the Scandinavian countries, the emphasis on the role of the government as an instigator of normalization, for example by legislation, redistribution of resources and a strong public sector, is palpable (2000, p. 56)” which is not the case in America.

## Supported Employment

Supported Employment is a method that has developed from thoughts of normalization concerning intellectual disability and work. According to Antonson (2011) the method is in the line of the perspective that integration of people with intellectual disabilities on the labor market is to prefer instead of institutional solutions. Supported employment began in USA and Canada on the 1970's and had a focus on people who were “domed” to be considered not able to manage an employment on the labor market. One of the fundamental perspectives within Supported Employment is the idea that if a person succeed or not mainly depend on the social context and the available support (p. 162). Within Supported Employment there is a perspective that all people can be enclosed in the ordinary labor market if this is the desire of the person, assuming that they receive an individually adapted support and an appropriate job-match. The method is of a “place first, then train” (place-train) approach instead of an approach where the person should train first, *qualify*, before he or she eventually would get a competitive employment (train-place)(Patrick W. Corrigan and Stanley G. McCracken, 2005, pp. 31-37). In the article *Supported Employment: Evidence for an evidence-based practice* (Bond, 2004), there is shown a great empirical evidence that a place-train approach is more effective than a train-place one, if the goal is that the person should obtain a competitive employment. Supported Employment also advocates that it is better to train the individuals with real work tasks.

According to the *Institute of Social Technology* (ITS Brasil) it is, at the moment, developed studies in order to re-adapt the methodology of Supported Employment, “with the necessary adaptations of the reality of Brazil, and it is realized suitable actions of the establishment of partners from different institutions from Portugal, Spain and Italia (ITS Brasil, retrieved 2013-07-24).”

## Normalization in Brazil

In Brazil, as in other countries, it has been a process of normalization for people with disabilities (Aranha, 2003). In her study, *Work and Employment: Instrument for Construction of Social and Personal Identity*, it is referred to the statistical form of normality but also on a focus on offering forms of professional qualification. According to her the paradigm including normalization, which she calls *Paradigm of Services*, was a great advance compared to the totalitarian institutionalization. Nevertheless she says that it still showed limitations by almost exclusively focusing on the need to change the persons with disabilities. According to her, “denying the limitations imposed by a disability can be as discriminatory and exacerbate its role in a person's life (p. 14).” By denying them, society disclaims making the changes and adaptations that enable these people to participate in community life. She says that it has been shown to be wrong “to assume that all people with disabilities could be modified to the point of no longer present the limitations imposed by some of the deficiencies (p. 14).” Due to these and many other issues, she says that the idea of normalization began to lose strength. It was expanded a discussion of the fact that the persons with disabilities is a citizen alike any other, holds the same determination and rights of utilize opportunities available in society, regardless of the type of disability presented, and their degree of commitment (p. 14).

The methodology Supported Employment is mentioned in the study of Aranha (2003). There she refers to different options available within the society for the development of Supported Employment, but most of them are of institutional and collective approach. Only one approach, which she calls *Individual Placement*, was similar to the approach within the methodology Supported Employment (comp. Antonson, 2011; Bond, 2004).

In this option, persons with disabilities, already qualified for the exercise of their occupations, may require, in addition to the physical supports (re-organization of the environment, adaptation of objects and / or machinery), intensive and constant personal support initially in the process, which can be gradually removed, as this person achieve higher levels of autonomy (Aranha, 2003, p. 23).

## 4 Method

### Prior Understanding and Ontological View

During my childhood I often spent time at my fathers work, a day center for people with intellectual disabilities, and I guess that this has influenced my interest for disability issues. During 1994, this day center transformed into a private pro-profit organization and the organization started to provide daily activity and support to people with intellectual

disabilities on a more individual basis and with a focus on work. When I was 15 I had my first job within this organization and since then I have worked there during different periods. It is an organization driven by strong ideology of fighting for equal rights for persons with intellectual disabilities and this is something that greatly has influenced my values concerning disability issues. The work is mainly based on the method Supported Employment (Bond, 2004), adapted to the civil society in Sweden.

My prior understanding has primarily been beneficial for the work with this thesis. But it could also be considered disadvantage as it may distinguish from the current views on the issue in Brazil. As I described above, a work of introducing Supported Employment within a Brazilian context has been initiated, but from what I have found, Supported Employment has not been spread to the state of Pernambuco to any significant extent. With basis in this assumption, I have tried to be open to new ways of thinking.

I have my origin within a Scandinavian context and the prevailing perspective, which is the *environment relative concept*, has naturally affected my ontological conception of disability. This perspective has been described within the Theoretical Framework.

## **Research Approach**

This study has an explorative-descriptive approach based on an inductive and qualitative design. I think an inductive and qualitative approach is appropriate since I chose to do my study in a foreign country where my knowledge about the social systems is moderate. I also believe that an inductive and qualitative design, as Neuman (2003) mention, is a good approach for the purpose of coming up with new unpredictable thoughts and ideas (pp. 161-162). I also think that a qualitative method is better suited when it comes to interviewing people with an intellectual disability, as it allows that the questions are asked in a way that is customized to the individual level of understanding. Through a focus group Sampaio (2012) some general considerations was defined as important when implementing interviews with people that has an intellectual disability, “the questions should be short; complex questions should be avoided; if necessary, explain them and simplify them; speak slowly; give directions without inducing the answers (p. 238).”

I have been inspired by *participatory research*, described by Starrin and Söder (2005, pp. 103-114) which, the authors defines as “a way of conducting research where non-schooled scientists, in different ways, are involved in the process of producing knowledge (p. 106).” It could for example imply participation in decisions of what should be studied. I wanted to

involve those, whose circumstances would be object for the research, the persons whom actually are the objectives of the proposed interventions, in the process, to give their picture of the problem statement. Inspired by the study made by Sampaio (2012) my first thought was of doing some kind of focus group with persons within the target group, but then I considered it not doable because of the limitation of time. Even so, I wanted to get in touch with persons within the target group, and some professionals who act in the area of providing support. This, in order to get suggestions of important issues in need of getting highlighted, before I defined the purpose and the research questions. This procedure will be presented further on.

### **Initial preparations**

The first weeks of the work with this research, I tried to acquire knowledge of the context in which I chose to do my study and I begun by seeking information on the web. I searched for operators who act in the disability area through Google Search, webpages published by different public authorities and through databases of peer reviewed articles. I also visited the Federal University of Pernambuco in Recife in order to get a picture of in what way the field of Social Work acts in disability issues. Unfortunately, no one within the institution of Recife was doing research related to issues of disability, according to their coordinator of Social Service. I also contacted the author of an article that I found significant for my study, Sérgio Sampaio, and got a very fast respond and a great support that pushed me forward with my research. In the article *Institutional Utopias, Eugenics, and Intellectual Disability in Brazil* (Block, 2007) I first read about the association Pestalozzi. When I later saw the name on a public webpage I discovered the association Pestalozzi in Recife. I considered that the association could be a good start in order to find respondents for my study.

### **Formulation of Purpose, Research Questions and Interview Guide**

At the time of my first interview I had not defined the final definition of my purpose, or the research questions, as I wanted to have suggestions on what persons who has specific knowledge of disability issues within the Brazilian context thought was important to study. I was interested in doing the research about what barriers persons with intellectual disability face in order to enter the labor market as this issue is close to the knowledge that I have from my own work experience, even though within another context.

I searched on Internet and academic articles for entities in Recife where I could get in contact with participants for my study and I tried to get in contact with the local entities of the

two, according to Block (2007), “most prominent organizations currently providing services” in Brazil, *the Pestalozzi Societies and Associations of Parents and Friends of the Exceptional* (APAEs). I only succeeded to get in contact with the Association Pestalozzi and I was welcomed to make a visit. At my first visit I made an improvised interview with one of the functionaries, visited some of the workshops and talked to students and teachers. After this visit I defined the purpose and the research questions and started to work on the operationalization of the purpose into an interview guide (see annex).

As Neuman argues about how to define good measurable research questions, I am aware that the research questions of this study could be considered as too vague. The topic could also be considered too general. But, as Neuman (2003) describes it, developing a focused research question is a part of the data collection process in a qualitative approach. One typical qualitative research question is to discover new ideas, which is one of the aspects that I hope this study will result in (pp. 161-162). In view of what I wanted to accomplish with the study I chose to search for respondents that I considered have unique knowledge about the topic and I wanted to include actors within different levels of the society such as persons within the target group, providers of support and functionaries within public ministries.

Grönvik (2005) says that since different notions of disability differ in different contexts it means, in a research context, “that the choice of definition may affect the results of different analyzes, both from a theoretical and from an empirical standpoint (p. 52).” As I declared initially, I define disability according to the environmental relative definition, described within the *Theoretical Framework* chapter. According to Grönvik, it is important to distinguish *theoretical* and *operational* definitions. Theoretical definitions refer to that the researcher should, as exact as possible, describe what he or she defines with a concept. With the operational definition he refers to transform the theoretical definitions into measurable concepts (p. 53). My intention was to measure environmental barriers within the society but from the subjective perspective of the respondents.

The first research question and its follow-up questions aimed to give a general picture of the interventions made towards the target group. Through the responses on these I hoped to get indications on barriers, important aspects, and possible solutions for persons with intellectual disabilities in order to reach the labor market. The second and the third of the research questions aimed to directly ask about barriers and about requested changes, in order to facilitate for persons with intellectual disabilities to enter the labor market. Out of the responds on these questions, I hoped that some possible solutions would emerge. I operationalized the research questions into three different interview guides, adapted to each

group of respondents; “Persons with intellectual disability who has, or want to have, an employment on the labor market”, “relatives to a person with intellectual disability” and “professionals working within the area of disability issues”.

## **Reliability and Validity**

Reliability and validity are important issues of measurement in order to establish truthfulness (Neuman, 2003, p. 177). Validity refers to how well the questions provide answers to what we want to investigate. According to Neuman reliability means dependability or consistency (pp. 183) and refers to how we measure an issue and the techniques that are used (Djurfeldt, Larsson & Stjärnhagen, 2010, p.105). It can also refer to the replicability; Will we get the same result if we use the same questions in another study? If that’s so, the study has a high reliability (Djurfeldt, Larsson & Stjärnhagen, 2010, p.105). According to Djurfeldt, Larsson & Stjärnhagen the validity usually is higher in qualitative research but the reliability tends to be higher in quantitative research (p.105). Neuman writes that qualitative researchers see the “data collection as an interactive process” and that they fear that quantitative methods “may neglect key aspects of diversity that exist in the social world.” According to Neuman, qualitative researchers of social work are more interested in authenticity than truthfulness. What is valuable is what is true for the person who is the object of the study and most qualitative researchers concentrate on trying to capture how the studied person feel and understand events (p. 184).

As Portuguese is not my native language, when formulating the interview guides and the letter of consent, I asked for help from a friend who is native Brazilian and an English teacher in order to reach validity.

Grönvik (2005) says that validity always is important within research but it “becomes especially important when the concept to be measured has an abstract and not widely accepted content (p. 54).” I considered it very important to confirm the definition of intellectual disability used in Brazil and by the respondents as intellectual disability is a condition defined differently in different context. I used the concept *intellectual disability*, as it is the concept I have found used in most of the recent Brazilian literature related to intellectual disabilities (Mourão, Sampaio and Duarte, 2012). As I was not sure of what term the students at Pestalozzi were most familiar with, I started a dialogue about it within the two groups where I was supposed to collect respondents. Within this dialogues it was confirmed that the students were familiar with the concept. A more popular concept of persons with intellectual

disabilities in Brazil is “Special Persons” (Pessoa especial) and some of the respondents with intellectual disabilities used this term when they talked about themselves and other persons with disability. Another common concept used in public writings in Brazil is “carrier of deficiency”. According to one of the respondents from a public organization, this term is considerate negative as it is associated with contagious diseases. He says that after 2008, the year that Brazil ratified the United Nations Convention on the Rights of Persons with disabilities, the terms impairments and disabilities are considered as the correct terms, as it is the concepts that the convention advocates. Grönvik says that universal definitions has been criticized by post-modern theorists, which means that “experience of disability and impairment is limited and dependent on the specific contexts in which the experiences is made and the knowledge are developed.” Therefore I find that my procedure of consulting the respondents was relevant. Within the chapter of Theoretical Framework there is a review of different perspectives and definitions on disability.

According to Söder (2005), “research about social relationship does always occur based on a certain perspective. Fundamental assumptions, more or less conscious and explicit, decide what the researcher sees, how he / she see it and what questions he / she makes (p. 85).” I also consider it relevant to mention, as I discussed under the heading *Prior Understanding and Ontological View* about the values that I have obtained from my experience of work, that these could have affected the directions of the responds from the respondents, as I am the one conducting the interviews and formulating the follow-up questions. I have tried to be aware of this during the presentation of the result and not only display the responds, but also my follow-up questions.

### **Literature searches, databases and keywords**

In order to find scientific articles I used the databases Academic Search Premier, SciELO (The Scientific Electronic Library Online), Google Scholar and SOCINDEX. The keywords that I used, in several combinations, was intellectual disability, employment, Supported Employment, the Quota Law, Social Work, Recife, Pernambuco, Brazil.

To find literature about disability issues I searched on Libris, which is a national search service with information about titles at Swedish libraries. I have also searched for literature available at Legimus, which is a media website for people with dyslexia or visual impairment, where you can search and request custom books. Behind the website is the National Agency

for available media. The keywords used in this databases where; disability, impairment, supported employment, normalization, normalization principle.

Since I have Dyslexia, I primarily used editions available as custom books, which not always is the most recent edition. One technical aid that I have found useful in order to read PDF-files is the application Voice Dream, which read PDF-files with speech synthesizer. I found it especially useful to read articles in English or Portuguese.

## **Sample**

Neuman writes that qualitative researchers rarely use a representative sample, as the goal of the study usually is not to get a high generalizability, rather a deeper understanding of an issue. It is the relevance to the research topic that is important when selecting the sample. Neuman also writes that qualitative researchers rarely determine the sample size in advance. Instead they choose to select cases gradually (p. 209).

In this study sample where strategically selected with a *purposive sampling* and *snowball sampling*. Neuman describes that purposive sampling “uses the judgment of an expert in selecting cases, or it selects cases with a specific purpose in mind” and that it is an “acceptable kind of sampling for special situations (s. 211).” As my purpose was to *detect barriers, important aspects and possible solutions related to the objective to facilitate for people with intellectual disabilities to enter the labor market*, I thought the best manner to reach this information was to interview actors within different levels of action, related to the issue. My first priority was to ask the persons that really face the barriers themselves; persons with intellectual disabilities with a desire to enter the labor market. Then, in order to get a broader picture I chose to also include persons representing and providing support to these persons such as; their relatives; professionals within non-governmental organizations who works in direct contact with the target group in order to support them to reach the labor market, and finally; professionals working with this issue within public ministries.

## **The Respondents**

The first interview was with one functionary at Pestalozzi as I described under Formulation of Purpose, Research Questions and Interview Guides. After this first visit at the association I decided to return and interview some students and relatives at the association. I chose to interview students from two different courses, one for persons that already has some kind of vocational placement, either employment or internship. The other course was a vocational

course of administration with the goal that the persons would reach the labor market. Finally I made two more interviews with functionaries at the association. One of the functionaries indicated me to contact the State Superintendent of Support for People with Disabilities (SEAD - Superintendência Estadual de Apoio à Pessoa com Deficiência) where I later on got recommended the functionary at APABB and the respondent at the Ministry of Work and Employment (Ministerio do Trabalho e Emprego) in Recife.

Melicia Mesel is a regional coordinator of the Public Ministry of Work (Ministerio Publico do Trabalho) in the state of Pernambuco. I saw her cited in an article in *Folha PE*, already before I went to Brazil for this study, concerning the quota law and the inclusion of persons with intellectual disability. As I wanted to get in contact with someone working within a public organization I sent a message on the Facebook page of the Public Ministry of Work. There, I got an answer with information about the National Coordination Office for Promotion of Equality of Opportunity and Elimination of Discrimination in the Workplace (Coordigualdade) and they gave me the contact information to the Public Ministry of Work within the region of Pernambuco. There I got to know that Mesel was the person to contact concerning questions related to the quota law and inclusion of persons with intellectual disabilities within the ministry. After a few weeks of trying to contact her both by email and telephone calls I finally went to the ministry and waited for her to appear. After a long wait I managed to leave a message to her and after only one day I had an interview marked one week later.

As I said, both the functionary at APABB and the functionary at the Ministry of work and Employment were recommended to me by a functionary at SEAD. After the experience of trying to get in contact with Mesel, and also with short of time left on my stay, I just went to their offices with the hope that they were present. The functionary at APABB was there and spared a moment for the interview directly. At the ministry of work and employment I got to know that Fernando Cabral, who is a Labor Inspector of Legislation that, unfortunately had suffered an accident. But despite that he was on sick leave, he spared a time for an interview in connection with a seminar that he was going to hold the following week. I was also invited to attend that seminar as audience.

### **Data collection and research equipment**

During this study I made totally 17 interviews, ten short and six longer. The respondents of my study where as follow;

- Four functionaries from two different associations who provide vocational activities towards persons with intellectual disabilities.
- Nine students of one of the associations
- Two relatives to persons with disabilities.
- Two persons working at public ministries.

All the interviews were held single except for the one with the respondent from the ministry of work and employment, where a student from the Federal University of Pernambuco also were participating and asking questions. The interviews with the functionaries at the associations lasted about 30 minutes each, the interviews with students and relatives between 6 to 15 minutes and the interviews with the respondents from the public ministries lasted about one to one and a half hour each.

All of the interviews except two were recorded and the interviews that were not recorded were noted down during, and directly after the interview.

I had some problems with the recorder at some of the interviews therefore some parts were not recorded. Unfortunately one entire interview with one of the students was by mistake not recorded at all. The interview is accounted above but the data from this interview and from the other parts that got lost, I have chosen not to use, because of the risk that I did not correctly understand some essential part of what was said.

## **Processing of the Data**

I tried to transcribe the data as close to the time of the interview as possible. However, when I started with the interviews there was not much time left before I had to travel home. As a consequence my priority was to implement all the interviews that I had intended to do first. As the interviews were in Portuguese, which is not my native language, the transcription took very long time. According to Bryman (2008) you should expect at least six hours of transcription for one hour of interview (p. 95). Some of the interviews took me more than the double amount of time to transcribe because I had to check up words that I was not familiar with. During the transcriptions I color marked parts that I found responding to the purpose of the research and the research questions. I finished all the transcriptions before I started to translate the parts of the data that I had found significant. Afterwards I frequently returned to the transcriptions to consider other parts that also could be interesting to include. During the transcription, I have sometimes had problems with the translating because of my shortcomings in the Portuguese language. At those occasions, I have been helped by someone

who is native Brazilian, and in all of those cases, this person only listened to fragments of the recorded material, without any details of the respondent.

The work with the rubricating has been an ongoing process during the final work with the thesis.

## **Ethical Considerations**

In the implementation of my study, I have assumed the ethical principles described by Scientific Research Council of Humanistic- and Social Science. These principles are designed as four ethical considerations order to meet the requirements of; information; consent; confidentiality and utilization. Through an ethical form, that I have named *Statement of Ethical Considerations & Principles* (see annex), where I gathered information essential for the respondent.

The first part contains information about who I am, the purpose of the study and where the study aims to be published. In the second part I guaranteed that the respondent would be anonymous in the thesis, that all information would be treated confidentially and that when the thesis is completed, the interview material will be destroyed. I also informed that participation in the study is voluntary and can be canceled at anytime. There was also written that they have the right to take part of the final result.

Before I started each interview I let the person read the ethical form and in the case that the person wasn't able to read by themselves, I read the form loud. In the case of the students I initially informed about the purpose of the study in front of the class, that all participation is voluntary and that they could call off the interview at any time. I considered it important to ensure that all the respondents participated by their own free will, especially the respondents with intellectual disabilities and the relatives as they participate as private individuals. I also asked if they approved the use of the recording device during the interview and guaranteed them that it was only used in order to facilitate for me to ensure that the information that they gave would be cited correctly in the thesis.

In order to keep the data confidential I have chosen to call all the professional respondents from the associations as “functionaries” and not by their professional background. I have also chosen not to put any personal details within this thesis. Details such as ages and gender, which I have considered not significant for the result, cited from the interviews have in some cases been modified to avoid personal disclosure.

The two respondents from public ministries wanted to participate with their real names as they work within public organs. Therefore some parts of the data that could be considered as sensitive statements, on the demand of one of the respondents, are not included.

I have promised to send an electronic copy of the thesis to all the respondents when finished. In the case of Pestalozzi, the thesis will be sent to the office in Recife. As the majority of my respondents do not read or speak English I intent to translate the thesis to Portuguese in order to reach as many domestic readers as possible. But it depends on my future time and resources.

## **5 Results**

Within the result chapter I have focused on responding to the purpose which; *is to detect barriers, important aspects and possible solutions related to the objective to facilitate for people with intellectual disabilities to enter the labor market with the quota law as a starting point.*

The disposition follows the research questions and the headings within this chapter are based on the themes that I have seen emerge out of the collected data. These are divided into three parts; *Contextual Introduction*; *Barriers and Important Aspects* and; *Considered Solutions*. The first parts aims to give a picture of the context related to the subject. The second part contains themes based on the barriers that the respondent considered significant for people with intellectual disabilities. The last part contains some interventions that has developed as, or are considered, possible solutions in order to facilitate, or solve barriers, for persons with intellectual disabilities to enter the labor market. The data will be analyzed in the following chapter *Analysis* through theories of perspectives on disability, and previous research.

The information in this chapter is, unless otherwise indicated, based on data from the interviews.

### **Contextual Introduction**

Many of the professionals that I have interviewed told about an interactional work that is going on between different organs of the society such as public organs on federal, state and municipality level and representative organizations of people with disabilities. During the work with this study I have got in contact with many different operators who act within disability issues in Recife. A review on all of those is attached as an appendix in the end of

this thesis. The respondents within this study were selected from two different public ministries and two different NGO's.

Below are a description of these organizations and their work towards the target group.

## Public Ministries

*The Public Ministry of Work* is one of the branches of the Public Ministry of the Union and it is a federal ministry. Within the Public Ministry of Work, there is a coordinating body that acts in the area of *equality*, combating discrimination in labor relations, which is the *National Coordination Office for Promotion of Equality of Opportunity and Elimination of Discrimination at Work* (Coordigualdade). Mesel, one of my respondents, is prosecutor and the regional coordinator of this office. The work tasks of the prosecutor are, "if receiving complaints of noncompliance with labor laws, or if we become aware of a fact, open investigative procedures craft to determine whether that conduct really offends some principle or norm, and solve those, in order to regulate that conduct in the light of the law."

In the specific case of persons with intellectual disabilities, the action of the ministry is to get companies to effectively respect the Quota Law, to insure that they fulfill the quote.

*The Ministry of Work and Employment* is a supervisory ministry. One of its functions is to verify the companies' compliance of the worker protection legislation, in order to combat informality in the labor market and to ensure compliance with labor legislation. Cabral, one of my respondents, works within the Ministry of Work and Employment, specifically with the inspection of the accomplishment of the Quota Law.

## Non-Government Organizations

The Association Pestalozzi in Recife was created in 1976 and is a filial of the Federation of National Pestalozzi Associations (FENASP) who now includes over 100 entities (Pestalozzi Recife, retrieved 2013-06-27). In Recife they attend 160 youth and adults with intellectual disabilities from the age of 14 years.

The Association of Parents and People with Disabilities, of Employees of the Bank of Brazil and the Community (APABB) was created 1987 and is present in 14 states of Brazil. The office of Pernambuco was created 1995. APABB attends to about 200 persons with all kind of disabilities, the major part has an intellectual disability. The employability activities are provided to persons from the age of 16.

At both of the NGO's there is one functionary who handle the register of students, their curriculums and maintains the contact with companies. They also provide guidance to persons with intellectual disabilities in order to reach the labor market.

### The Associations – A link to the Labor Market

Both respondents from public ministries mentioned the important role of the non-government organizations as providers of support to people with intellectual disability. They also mention that associations representing this target group are important actors in order to include people with intellectual disabilities on the labor market. The majority of the students expressed that the main support was either given by the associations or by family members. Many of the students I interviewed show a lot of gratefulness for the support from the association and most of the persons, who had internship or employment on the labor market, mentioned that without the support of the association they would not have reached so far. So, in order to relate to my purpose, the work of the associations has been considered an important aspect for these persons.

Functionaries at both associations said that they do referral and guidance in order to support the persons to enter the labor market and told that they give some individual support to those who succeeds, in the case any problem appears on the workplace. The functionary on Pestalozzi said “we contact the companies to know how they are doing, they do also call us if they have any needs, and we go there to the company to talk. The persons do also always have contact with us, and we always talk to them if there are any difficulties. Then we go there and help...” The functionary on APABB said,

Besides promoting courses, we have this informal partnership. We are always in contact with the companies, with CIEE who works with the issue of employment and school, so that they can reach an employment. There are the organizations of apprentices, so then we are always doing referrals to them. And we are also always contacting the companies.

On both NGO's it was one person who was responsible of this contact and support. One of the functionaries on Pestalozzi said that there are, at the moment, about 30 students who have been supported to get a competitive job. The coordinator continuously has contact with the companies and the students. She says that if the companies have any need, or if the person tells about any difficulty, they go to the company and try to help. On APABB they have contact with about eight persons with intellectual disabilities who have an employment on the labor market.

When I asked the students at Pestalozzi if they have got any support from the municipality, the government or any social assistant, all of them answered “no”. Most of them say that the support they get is either from the family or from the Association. Both associations did as well have some activities of supporting and accompanying the families.

One of the persons who now have an employment says that one of the difficulties he had was the process, and the long wait, of getting employed. He says that he thinks that the institution of Pestalozzi should chase more support for them in order to get an employment.

### The Quota Law and the Social Function of the Market

According to both respondents from public ministries the companies has a social function to comply. Within both ministries there is an ongoing work with the objective to make the companies understand this assignment and to ensure that they comply with the quotes that are assigned for them. Mesel says that what the Public Ministry of Work charge, “is not only to make the company comply with the law, but to make them understand that they have a social function to fulfill within their business role.” One of these functions is to,

participate in this great action of including on the labor Market, those people who really suffer these obstacles, whom have a disability or some disease, or are in some sort of group that we call *group that suffers from discrimination*. So the role of the company goes beyond complying with the law, its role is to really understand, to understand that it has a social function to fulfill (...)

I asked Mesel about the right of persons with intellectual disabilities to obtain a work, as work is considered a human right, and if the Quota Law is able to fulfill this right. She answered,

Maybe I understood your question. I know, through this law, the candidate cannot go to the company and say, 'I have the subjective right to be employed', there is no direct subjective right, but it is a diffuse right as we call it. From the moment that there is the law of hiring persons with disabilities, automatically, in the society as one whole, potential candidates will emerge. Because those are persons who will candidate for the vacancies, the companies will make these vacancies available.

She continues, “I cannot call it a subjective right, because the company can independently choose another person with disability...”

She says that the Quota Law is not enough but when it came it was a great advance. “the law is a guaranty that, at least this minimum they have to comply, but this was only a first step. The law is from 1991, so it already exist in 22 years.” She says that it is incredible that they still are struggling with the accomplishment of a law that exists for so long. Today, she says, “it was supposed to have been evolved but there hasn’t been any significant progress, unfortunately.”

No one of the students that I interviewed, who not yet worked on the labor market, and only a few of the persons who had an employment or internship, knew about the Quota Law. Mesel says, “So, what I say is that this intervention is not enough, certainly not. We really have to search for other ways to increase this inclusion, to actually make the inclusion effective. But what I say is that even if this intervention is minimal, a first step, not even this is fulfilled by the companies.” She says, “So of course other alternatives, other suggestions, that come to help this process, of awareness of the companies, of shifting paradigms, you know, of effectively create options so that we can include more people into the labor market, those people with disabilities, of course those are welcomed.”

## **Barriers and Important Aspects**

### **Prejudices about People with Intellectual Disability**

The majority of the respondents mention prejudices about persons with disabilities as a barrier, prejudices within the families, within the Brazilian culture and the society in general. Cabral says that there also exist prejudices within the public institutions. The cause mentioned by most of the respondents was lack of knowledge about disabilities in general and particularly intellectual disabilities. Mesel thinks that the principal thing that has to change first of all is “this preconceived notion of companies in general. The culture, reaching people with disabilities in a restricted way.” She says,

the disability is not within the person with an impairment, the disability is in the eyes of those who sees... So what needs to be changed is that way of seeing people with disabilities, to see them in a complete way. Not with a blurred vision formed by prejudices. Because that culture exist, so it is that culture that needs to be changed, the culture of seeing people with disabilities.

Cabral says there is an obstacle especially concerning persons with intellectual disability, which he calls the *myth of everlasting babies*. “In general, you talk about persons with intellectual disabilities as ‘kids’ even if they may have reached an age of 30 years.” The concept “kids” was used in some of the interviews with functionaries at the NGO’s when referring to their students. Cabral says that there is a great risk for persons with disabilities to be treated as *everlasting babies*.

Two of the functionaries at Pestalozzi say that many employers think that intellectual disabilities always contain mental illness and that they could be aggressive and dangerous. Cabral says, “One aspect is fear of the unknown. They have a prejudice against how that person might react. (...) They think of all people with intellectual disabilities with an idea that

it is a dangerous person...” He says that there also is an aspect of the aesthetic appearance. “Many people with disabilities have a different look, it is the aspect of the vision of the person like if it was more uncomfortable than the aspect of a person with physical disabilities.” He continues,

And you have the aspect of the behavior. That people think that a person with intellectual disability always does have an inappropriate behavior. Considering, in the reality there are people with intellectual disabilities, people who are absolutely sweet, absolutely behaved, right. And without no danger, right. So this barrier has to be broken.

One of the students talks about the prejudices that he had suffered in contact with the agency of work,

I went there about ten times, the person looked at me like this, of my way of being, my specialties, they had no vacancy, so I went there again, no vacancy and again, no vacancy... So after a while I gave up. So here I am, I have already made my curriculum, now I am only waiting for a call, that a company calls me, right.

He says that it would be very difficult for him to go there again. Another person says, “people say like this ‘you will not make it, you will not manage to do that...’ But I don’t care... I lift my head and go away. I have already given up to many times.” He says that the prejudices are within their own families, within the whole society.

Another respondent express that the major barrier is that the companies do not give persons with intellectual disability a chance, “A chance to... I think they do not give a chance to someone who has special characteristics, because they think they’re not capable.” He says, “give them support, with support the person with disability could be there...” He thinks that the quote of the Quota Law should be higher.

Mesel tells about prejudices of the employers, “It’s not what they say (...) it’s what we verify in the practice. It is the prejudice of, perhaps; *imagining that these people are not able to adequately perform a function.*”

The functionary at APABB says that the companies get in contact with the association in order to fulfill the quotes because that the Ministry of Work is inspecting them. She calls the barrier *lack of information* and says,

...for many people, as we have contact with companies, they do not really believe in the ability of people with intellectual disabilities, and often when we send information of a person, they always search for persons with physical disabilities, right, usually people with physical disabilities, for example a deaf person who can read lips or use hearing aid, so well, they never seeks persons with intellectual disabilities. Then, when we tell about the public with intellectual disabilities, we always have to explain that they *can* work, they *are* capable too, but it is a great barrier, the lack of information.

## Discrimination of persons with intellectual disability

As a result of the prejudices people with disabilities are discriminated on the labor market. Mesel says that people with disabilities are “(...) eliminated from the process. When the companies include, they only include in order to comply with the Quotas.” She says, “(...) inevitably the practice demonstrates that they prefer those without disabilities, even if the person with a disability is more qualified, more prepared, more trained...” She says,

Nevertheless when there is a choice of the company, these people they are not chosen. (...) I can say this because the research and the data we have, show that there are people available to fulfill a function in several registers kept by public bodies. So there are registers where, we'll say, several candidates are available. So we do not justify, don't believe, when a company say that they cannot include a person because that they couldn't find any candidate.

Mesel says, “at the time of hiring a person with a disability, they only do this because of the law and not because he or she is a good candidate.” She says that the obstacles that the companies put up only are excuses. According to her the companies say that they do all they can to include persons with disabilities, but when the ministry initiate an investigation they ask which manners that were implemented by the company in order to fulfill this quota and they see that,

they did nothing! We look at what they've done and (...) there is no positive action. Sometimes they have not published any announcement in the newspaper, sometimes they don't have any referral to one of these public agencies that have these registers (...) there is no kind of referral to those institutions that represent people with disabilities, which also has a list of persons.

She says, “...perhaps, summarizing the main obstacle is the unwillingness of companies, entrepreneurs, to actually include the persons into the labor market. Because they exist, they are qualifying themselves, so they have the capacity to work.”

So there is discrimination of persons with disabilities in general in the society, but according to Cabral, within this group people with intellectual disabilities are the last ones to reach the labor market. “There is, as I told you, a scale where people with intellectual disabilities (...) they are the last ones on the scale. They are the last ones that the companies want to hire.” Cabral says that the great problem is that there is no specification of kind of disability in the Quota Law, the company can employ a person with any kind of impairments. Because of this reason the companies choose to hire the ones that have a mild impairment such as hearing or physical impairments. Mesel says that the companies want to,

choose between those people who are considered *person with a disability*, one that has a minimal disability that does not affect in any way, we say, *the production of the person*, or when this is not possible they put these people to do tasks that are not compatible with the capacity of the worker, or sometimes tasks with minor importance, like a form of segregation.

One of the students at Pestalozzi says that one big supermarket chain called students from the association to interviews but no one got employed. “They employed five deaf persons, so no one of us got employed because of this. (...) They only employed the deaf.” Concerning the employers, one of the functionaries at Pestalozzi says, “it is not everybody who wants (persons with intellectual disabilities), right. When I say that ‘I have a person who is like this, and this, and this’ and I tell about their characteristics they say, ‘ok that’s right, thank you...’ and the vacancy is lost to someone else...”

The functionary on APABB says that the majority of the persons that they attend to have skills of administration but the companies search mostly persons with intellectual disabilities for cleaning and the issue of general service. “Because they think that their capacity is to do this kind of work.” But she says that there are others who are included in other functions as well. Cabral says that they are struggling with the idea that the companies should not be able to discriminate, to “choose the ones with mild disabilities...”

### High qualification required

One of the students says that the company only calls those who know how to read and write. One of the functionaries at Pestalozzi says that they only seek for persons who have completed high school. One obstacle mentioned by functionaries on both of the associations is that persons with disabilities do not have the qualifications that are required by the employers. One of the functionaries on Pestalozzi thinks this is the major obstacle for the target group as she sees that there are a lot of companies looking for people with disabilities to employ. She, and many of the other professionals within my sample, tells about a common say that goes; *the companies wants a person with intellectual disability who reacts fast, with visual impairment who sees, with hearing impairment who hears and with physical impairment who can move easily...* She continues, “...they want to comply with the quote but they wants a person with disability who have all this characteristics and it is not possible, it doesn’t exists, right.”

Mesel says that there is another aspect of this issue, which is that the companies require high qualifications as a way of systematically exclude persons with intellectual disabilities. “...within the mapping of the company there is always, so to speak, there exists activities for all levels, right, we know that there are actually activities which need a major qualification, but there are also activities that would not necessary require high school graduation.” She says,

sometimes the companies put requirements that hinder the inclusion of these persons. The company itself puts requirements, which are really difficult to be fulfilled, but now as a way to say 'I tried but could not find anyone qualified.' But, what I say is that these are justifications that I don't sustain because it is always possible, within the mapping of these activities, to find activities that are, shall we say, suitable for all levels, including levels of persons with intellectual disabilities. Isn't it? Any company, within their organization chart, has there functions that can extinguish a bit more, but there are also those that extinguishes a little less, where the qualification could be built from training of the worker. It is always possible to included.

Both of the associations have some kind of register with curriculums or contact information of the persons that they support, which they pass to the companies when required. The functionary at APABB said that the companies usually send them profiles of what kind of person they want and then they try to match it with someone in their register. On Pestalozzi they have the same procedure and one of the functionaries says, "The companies' type the criteria's and I fill in, right." But most of the time the profile do not match any of the persons and both of the associations only send persons that they see have the correct profile. One of the functionaries at Pestalozzi said, "they want persons with intellectual disabilities to assume the function of checkout in a store, or of filling in protocols (...) this is to complicated for them. So, then, I enter in contact with the company and say that we do not have any students who have that profile." There was a similar example from the association APABB where the functionary said, "this week they called but it was to work with construction, and even to account for having done computer course, or of administration even, we did not want to send them there." She says that they always look at the profiles and the activities that the person has done.

### Lack of Qualification

Both of the associations that I visited offered vocational courses for persons with intellectual disabilities. Cabral says, "the great problem with vocational courses is that the persons are doing qualification, after qualification, after qualification. (...) The goal must be qualification, but qualification is worth nothing if you are not employed by anyone..." He says that, with vocational courses, the person gets the qualification but he or she is not linked to a company. This picture coheres with the information that I got from several of the students within my sample. Many of them say that they have gone through many courses already without no internship or practical experience of work in a real work environment. The association Pestalozzi provides courses, which includes an internship in the end. One of the functionaries said that the goal is to offer internships on the labor market, but that is not possible in all cases. Some of the students only get to do the internship within the association.

I asked the functionary at APABB, “If there is a person that want to work, for example as a mechanic, do you try to find that kind of job?” she answered,

If they are capable of that, but, as we have the curriculums of them all, if they don't have those experiences from here, if they haven't done any course, then... We always look like this, courses that the person has done, experience that they have, understands? (...) if it appears something, and the profile that the person has, what the person know... then we'll forward.

One of the functionaries at Pestalozzi says, “Today we no longer have students to send to the labor market because there are so many companies that need to comply the quotes.” But during my interviews with the students at the association Pestalozzi, the majority wanted to have a work on the labor market. Many of them were just waiting to be called. When I asked about those the functionary said,

they want to work but sometimes the agencies of the companies, it is like what I said to you, they want those who have finished high school, and we don't... it's difficult. When they have, there is one or another who have finished high school, and we know that it is maybe not a degree very well done, because of their difficulties right.

I asked, “but if there were conditions to give a continuative support for those persons, then you could send persons with less qualifications and they would learn to do something?” She responded,

But sometimes we see in the in daily life, that it is difficult to forward like this as well, when you know that the person do not have certain compromise, has no maturity. Right? It gets difficult, we cannot forward just to forward, it gets... The situation is complicated. Sometimes we see that a student in the classroom, the issue of feeling responsibility, the maturity, that they do not have the compromise, that kind of responsibility, like us, for example if he knows that the class starts at one and he gets here at two...

I asked, “but isn't that a part of the disability?”

Exactly, we understand that, right, but we are still working with these difficulties (...). There are students who have a lighter disability who matures, who will acquire these habits, you know, then in the future it will facilitate for that person to enter the labor market. And there are other students who, nevertheless the more we work, do not absorb this information.

There is, as I mentioned above, a focus on reading skills within the Association Pestalozzi. When I asked one of the relatives what was the disability of her daughter she said, “It is to read and write, right.” She says that she was in the normal school but did not learn anything. Now, at 20 years old, her daughter has started to learn. However, she still does not think that her daughter would ever be able to enter the real labor market. She says, “The barrier is the difficulty of the person itself, right. All of them are more delayed than normal persons. You have to have a lot of patient, have someone nearby to tell how the things work, right.”

Despite the lack of qualification, that maybe could be considered caused of the disability itself, there is an obstacle concerning the ability of fulfilling the ordinary school. The functionary at APABB says that what is needed is “capacity building”. Even if there are institutions like them who also promote some courses like computer literacy or other vocational courses she says that there is the issue of accomplish the formal education, “so that they get to finish the school.” She says that many persons with intellectual disability studies in integrated schools with people with, and without, disabilities “but they can not keep up and will continue to study permanently in that class, they pass the years but without actually learning, right. They say, ‘the government will leave an intern or an accompanying person’ but that does not happen, unfortunately.” She continues, “There are very few that we see, you know, that achieves high educational level...” She says that many persons with intellectual disabilities complete courses like computer literacy at these institutions without having completed the formal school.

We believe, right, we know that some could even complete superior education... (...) and we know that, to get a better job, to get better included (...) you have to be able to read and write well, but this do not happen which I think is because of the lack of accompaniment, lack of contribution by the government.

She thinks it is the same issue adults because there are persons who have reached the age of forty who are still studying. “I think it is the same, the issue of government encouragement of the public school, or of the institutions, this matter of investing in education.”

### Lack of Support

Many of the respondents mention the lack of support to people with intellectual disability in order to integrate those on the labor market. A support aimed to compensate for the specific difficulties characteristic for intellectual disability. One of the relatives said that she did not think that her daughter ever would be able to have an employment on the labor market. She thought that her future would be within the workshops of the association. When I asked if there were any support from anyone she said, “It would be good, if there were someone that could be there always, right. Because everything about her, her thinking, is more difficult.” I asked which the abilities of her daughter are, if she maybe helps with something at home, she says, “She does cut vegetables, sweep the house, she does domestic work... If I engage her like ‘sweep the house, set the table...’ she does it. If I demand, if she knows what has to be done.” I asked one of the functionaries at Pestalozzi if the persons don’t have the right to any support and she said,

but it is a constant support. It is a constant support, I call it a *supported work*, which is like 'do this, do that,' it has to be one thing at a time. Not every person out there has this patience, has this understanding, do you get the idea? So then we only forward those who have a profile that do not depend so much on this command, right? Many really need to enter the labor market but it's not possible.

I asked what is needed in order to integrate these persons, who do not have the requested level of qualification by the companies, and the functionary at Pestalozzi said, "Look this is what I said, a *supported work*, to have a more specific person, in order to be at the company constantly, to have someone from the company as well who has the knowledge to work with these special persons, something more linked, related to these persons."

One of the students that have an employment on a company explains that she had a very good start at her current job, and that they were very welcoming and happy to get her there. She said that she receives a great support both from her boss and from her closest colleague, a support that has been shown very important for her. She said, "once she (the colleague) was sick for 15 days, then I was so lost, I was walking around... My boss helped me, 'any doubt you can ask me', in order to not get so lost, right."

Cabral says that in the case of persons with more severe disabilities, especially in the area of intellectual disabilities, there could be good with a system of a supporting person within the company. "We call it a *godfather*... It is not anything more than someone whom will have an extra alert eye on the person." He says that this is not only for people with intellectual disabilities. It could be used for persons with mental illness as well,

for example for persons with schizophrenia, if the godfather realizes that the person is not taking its medicine. If the person starts to change, not taking bath, coming with clothes all... So the godfather will see this and will say 'Hey (...) I think John Doe is not taking his medication, call the psychologist' or another person, to talk to him.

I asked if it is the company that is responsible for having this *godfather* available and Cabral responded that there is no possibility for the Ministry of Work and Employment to demand the companies to have a person with this function. "We have not reached this stage yet, it is still very difficult for us to demand it. We cannot demand the companies, within our society, our reality..." Cabral tells that it is different in the school system. He says that, as the function of the school is to educate, the school has to hire a caregiver if a student has special needs. The school has to accept all students despite any kind of disability. "But yet the company, the company is not required to do that. The school is required to accept that student. (...) but the company is not obliged to accept." He says that the company has to hire people with disabilities but has the opportunity to choose who they want to hire. I said, "Because there are persons that, for them to be able to get included on the labor market, would need this kind

of support, right?” Cabral responded “Yeah, for those... Thus within our social culture... Yet this is very complicated because it involves the cost of one employee more. Right, it would be, maybe if the state had resources, they could put a person to do this work, right...” He continues,

... for those who have the capacity to work only with this kind of momentary support, like a blind person who needs someone to follow... This kind of support anyone who is trained could give, it is not required to hire a person to do this. But for those others, it is very difficult...

For those, the only solution that he could imagine at the moment were a “sheltered workshop or something like that.” But sheltered workshops are something that should be restricted, he says.

### Work environment not customized

All the interviewed functionaries at Pestalozzi say that one barrier is that the workplaces are not enough prepared to receive persons with intellectual disabilities. Mesel says, “...there are many of them (the companies) who do not care about their environment effectively, to insure that the environment is tailored to the needs of the person. Right? (...) They do not bother to look over the spaces, the furniture, the accessibility of these people...” She says that the environment sometimes is so detrimental that working in this environment becomes sufferable for the person who has a disability. “...really an environment that we call inhospitable. Right, an environment that is not welcoming.” Mesel continues, “it does not help that the companies say (...) ‘I will include a person with disability’ and sometimes only reserve these petty tasks, the tasks that we call of minor importance, as they would say ‘I’ll include, but then I’ll also do what I want with this person’ it’s not like that.”

The functionary at APABB told about a girl that had an auditory impairment who, after she got employed, did not receive any work tasks. She said that the person had said, “I’d rather be at home doing nothing than be there, seeing everybody working and I...” The functionary said that this kind of treatment makes the self-esteem go all down. Usually, she said, when the person gets employed,

the self-esteem goes up on top, right, at the work they produce, they get to feel capable, they can talk with their friends about what they do and say “I’m working”, or “I’m studying”, this is very good for them, right? But then lets say that someone ask ‘what do you do?’ and you have to answer ‘I’m just sitting...’ It’s complicated. It is not only about having a job, you have to really *do* something, not only be there as a figure.

She continues, “this makes them not believe in themselves, with no desire to participate in more selections... Because she had passed through a selection, practically one whole day here with us, and afterwards she got all... demotivated.”

One of the students said that she had suffered from many prejudices and bullying from the other employees on her previous employment. She says that there were persons saying that she wasn't to be treated well because she was different. “You shouldn't respect her, don't you see that she is *special*”. She says, “We don't have the ability to work in this way, right. (...) I like doing friendships, with respect, with love, within the company itself.” So it has been considered important that the workplaces, within the companies, are prepared in order to receive people with intellectual disabilities.

### Fear of loosing the Benefit of Continuous Support of Social Assistance

Many of the persons with intellectual disabilities receives the Benefit of Continuous Support of Social Assistance (BPC) and both respondents from the public ministries, functionaries at Pestalozzi and students, mentioned as a barrier, the fear of loosing this benefit if the person gets employed. According to Cabral, this benefit is only for families who live under really poor circumstances and, as I wrote in the introduction, the per capita monthly household income must be less than one fourth of the minimum wage. The person must prove that they do not have means to ensure their own sustenance, and do not have it provided by their family, in order to get the BPC. Many of the respondents say that the process of getting the benefit is long and bureaucratic and that the families have been fighting a lot in order to get the benefit. So they are afraid that if the person get employed, and then after a time will lose the job, they would have to go through that process again. And then, as they have shown that they where able to work, many are afraid that they would not get the BPC back. Cabral says that, according to the anterior legislation, the person lost the benefit permanently if they signed an employment contract.

Cabral says that there is another problem with the BPC, that it condemns you to receiving minimum wage forever. He knows persons that say, “I refuse the BPC, because I do not want to, internally, only receive minimum wage. I want to be promoted, I want to develop, I want to...” There is also the problem that the BPC “... isn't providential. It is not a benefit, it is a support. So if you die, your dependents will not receive... The BPC is what we call, *very personal*, it is tied to the person. (...) But if the person is working in the company, and he dies, the dependents will receive...”

## Considered Solutions

### Skills Enhancement Initiatives and Empowerment Work

At both associations there are activities in order to prepare the persons for the labor market. Both of the associations provide vocational courses to people with intellectual disabilities. At Pestalozzi there is a *professional training program* that includes five different courses with the “objective to include the learners into the labor market, formal or informal (Information from brochure).” Those are courses of administration, basic computer literacy, textile print, general service and basic cookery. Some of these courses include an internship on the labor market or within the association in the end. They do also provide *vocational workshops* “contributing to their social independence, which favors the inclusion on the informal labor market, with the support of the family (Information from brochure).”

Despite of these courses there is, according to one of the functionaries at Pestalozzi, a group of about 30 persons that comes to Pestalozzi three times a week at an evening course specialized for those who has an employment. The purpose of this course is to continue to develop and maintain the knowledge they received before they started working and there is a focus on improving reading and counting skills. Some of the persons have a formal contract of employment, others have a contract of internship between the company and the NGO. The last-mentioned group is obligated to come to this evening course.

As mentioned above, the functionary at APABB thought that one solution was “government encouragement of the public school, or of the institutions” and the matter of investing in education. At the unit of APABB in Recife there are courses of art, recycling and computer literacy.

There are also activities of leisure, which is held in the society and are accompanied by functionaries from the association. It could be activities such as visiting a shopping mall, go to the cinema or visit a park. The functionary says, “We do a lot of this issue of taking them to well known places, like the shopping mall, or if there are some circus.” She says, “We try to always bring them out to participate like other people, we try to work hard on the issue of integration.” APABB also provides sport, music and dance activities. They also have activities where parents participate and in the end of the year they do a trip together, sometimes to another state of Brazil, or to the interior of Pernambuco.

## Law Romario

There has been one attempt to solve the obstacle with the fear of loosing the BPC through a new law called the *Romario Law* (“Lei Romario” – Lei Federal nº 12.470 from 2011), which allows the person to sign an employment contract without loosing the BPC. Cabral says that, during the time that the person is employed, the benefit gets suspended and then, if for some reason or another, the person quits the job, the benefit gets re-activated automatically. One of the functionaries at Pestalozzi says that she has heard about a new law but that she still doesn’t know which law it is. Mesel says that the Romario Law is a very welcomed and significant law but she confirms that this new law is not enough spread. Mesel says “...with this law, it was created an alternative in order to encourage the persons to really go to the labor market. But I think that this law wasn’t enough spread, some people still do not even know the law exists.” So she considers that this is an obstacle too.

## Informal Labor Market

According to one of the functionaries at Pestalozzi, there is an informal labor market in Brazil that could serve for those persons who do not manage to enter the formal labor market, an informal labor market that develops activities that could be a way to autonomy. She says that there were some girls who participated in courses of textile print. Then, their families bought dish cloth and the girls painted them at home and sold them to neighbors and friends. She says, “this is another form of being useful, right, of being included in an informal labor market.” But, she says, “...this depends a lot on the support from their families, here at the school we are doing our part.” She says that they, at the meetings with the families, always tell about this option and give examples of students who have done this. “It doesn’t depend on us, it depends on the families if they want or not. We do also have a culinary workshop where we make popsicles, they could make this at home as well, right?”

Mesel says that there is another aspect of this.

People want to take the most advantage of it. Many of them receive welfare benefits, so they do not make the issue to go to the formal labor market, with formal I mean documented with a formal contract, and they work clandestinely. They turn itinerant, turn salesmen, prefer do informal work, why? Because they want to increase their incomes.

## Internship

In order to support those who are afraid of loosing their benefit, the association Pestalozzi works with a system of internship between the companies and the association according to the

Decree 87.497/82. One of the functionaries said that through their vocational courses “we contacted companies and they made room for curricular internships, suddenly, all those who are in the labor market now went from those internships. (...) The curricular internship turned into a paid internship.” Many of the employers are satisfied with the work of the students and want to employ them after the period of internship. Their prejudices changes when they get to know the worker, according to some of the functionaries at Pestalozzi. However some of the students do not want the internship to turn a real employment because of the fear of losing the BPC. For those they arrange so these internships can continue in the same form. She says, “We make contracts of six months, or of one year, it depends much on the employer, right. So it was from there it began. (...) But well, these contracts are only for those persons who want to work on the labor market and are afraid of losing their BPC.” She says that the majority of the persons that they forwarded to the labor market have a formal contract of employment. Both functionaries and students at Pestalozzi said that the person, in this way, continue to receive the benefit plus the income from the internship based on the amount of hours. One of the functionaries said that it is both good for the business owner as it is good for the student who receives two incomes. One of the students told that in his case the benefit goes to the mother as a contribution to the household and the salary from the internship he uses to buy things for himself and to travel with his girlfriend.

One of the functionaries at the Pestalozzi says that it is not the employment that is the most important for the person; it is all the other profits that come through the work in a real work environment, as opportunities to create relationships with coworkers and the senses of doing something meaningful. The internship also allows the person to work in an adapted way. Some of the persons work the whole day and others just work a few hours a day.

But there are also obstacles with this kind of internships, Cabral says.

We're not encouraging internship because that internship has no employment bond. At internship you do not get FGTS, internship doesn't gives... Doesn't counts for retirement account, internship do not give the health plan that these large companies give... (...) You do not have the benefit coverage...

## Legal Apprenticeship

Cabral tells about the network S that is the National Service of Apprenticeship. It is a system of institutions that has the objective to “Qualify and promote the welfare and provide a good vocational education (Brazilian government, retrieved 2013-06-05)”. Cabral mentions four of the institutions (completed with information from a governmental webpage):

- Senac: National Service of Commercial Apprenticeship - vocational education for workers in the sector of trade and services.
- Senai: the National Service for Industrial Apprenticeship - who is responsible for vocational education and industrial training, in addition to the provision of technical and technological assistance to industrial enterprises.
- Senar: National Service of Rural Apprenticeship - vocational education for rural workers.
- Senat: National Service of Apprenticeship in Transports - vocational education for workers in the transportation sector.

Those institutions were created to promote apprenticeship in their sectors. According to a governmental webpage, the entities of network S offer free courses in key areas of industry and commerce formed by organizations created by the productive sectors (industry, commerce, agriculture, transport and cooperatives). The network S has a network of schools, laboratories and technology centers scattered throughout the country. There are also offered paid courses generally more affordable than offered by private schools.

Cabral says that the big difference of apprenticeship in contrast to internship or vocational courses is that the person, during the time of the apprenticeship, is employed by someone. “You have your formal contract from the beginning, so you are really employed and have the right to FGTS, Health Insurance, basic food basket, everything... Retirement... (...) Every body has the right to retirement...” He says, “for persons with disabilities apprentice is better, professional apprenticeship.”

The programs of legal apprenticeships are, according to Cabral, during two years. The focus of the program is *learning* and it consists of two parts, a theoretical part, which is provided by the educational institution, and a practical part, which takes place within the company. The apprentice could for example be two days of the week at the company and three days at the institution or vice versa. Cabral says that with the new legislation you have the right to receive the BPC during the period of apprenticeship, but for a maximum of two years. The apprenticeship is meant for the person to qualify, to acquire professional knowledge. After that, the person could not do more apprenticeship without suspending the BPC. He says, “Why? Because there is no sense in seeking an *everlasting apprentice*... You seek a person to be included into the labor market.” This limitation is, according to Cabral, a way of ending up with the myth of the everlasting babies and the obstacle of persons with intellectual disabilities doing qualification after qualification.

No one of the functionaries or students at the association Pestalozzi mentioned Legal Apprenticeship and the functionary of APABB said that she had got information about it on a seminar the same day. She said that it was something that she was going to search more information about.

So, as with the Romario Law, this could be an obstacle caused by of lack of information. *But, is apprenticeship really an option for persons with intellectual disabilities?* Cabral said that according to the legislation, the institutes providing these courses could not require educational level within the admission process, concerning persons with disabilities. “...persons with disabilities should be evaluated according to their abilities, not by their educational level.” Cabral reads from the decree 3298, Article 28, which says,

The public and private institutions providing professional education will be required to provide vocational courses on a basic level to persons who are not active, persons with disabilities, conditioned on its registration of capacity of abilities to recovery and not on their level of education.

According to Cabral, he and the inspectors of the Ministry of Work and Employment, has been fighting hard with the S Network on the issue of accepting persons with disabilities. But I did not get any answer if there are courses of apprenticeship adapted for persons with intellectual disabilities in Recife. Cabral said that in Rio Grande do Sul they reached much further on this point. According to him, there is a company that is on the fourth or fifth group of apprenticeship of only persons with intellectual and mental disabilities. I asked if for example the Association Pestalozzi could provide a program of legal apprentice and he said “Apprentice program, very well, much better! That's more guarantee. And with apprentice program, the wage of the apprentice, the person will receive both (wage from the apprentice and the BPC).”

### Advocacy Work

Professionals from all the entities within my study witness about an ongoing advocacy work aimed to change perspectives and prejudices of persons with disabilities. Mesel says that the work of the Public Ministry of Work goes beyond the procedures of investigations and the public civil actions. They also do a lot of advocacy work such as public hearings with the companies and with other actors that are important for the target group. Mesel says that they for example work together with the Secretary of Work and Employment, the Secretary of Qualifications and the institutions of organizations representing people with disabilities such as the Associations.

We do public audiences to map out what the difficulties that people facing in order to enter the labor market are, and also to listen to the companies about what difficulties they have in order to include these people in their work environments. From there, we try to find solutions, making proposals, (...) also to effectively create an inclusive environment within the companies.

Mesel says that the Public Ministry of Work has a work that they call *educative*. A conduct, “in order to raise awareness of the city as one, the importance of people feeling active, to work, to be integrated into the labor market.” She says that the companies, in spite of being aware of their social function, need “to be able to create alternatives not only to include, but to really better benefit from that worker...”

Mesel also mentioned the work of the Ministry of Work and Employment, and specifically of Cabral, in order to changes perspectives. Cabral thinks that for disabilities in general it needs to be done a work of breaking barriers. Before my interview with him I was, as I mentioned above, invited to participate on a seminar for the companies that had been receiving a notification for not fulfilling the quotas. It was an event that started with some videos showing persons with different disabilities working as employees at different companies. After the films Cabral held a session talking about the Quota Law and the social function of the companies. Afterwards, all the present companies were called forward one by one, and were attended to, by functionaries of the ministry. Cabral thinks that an event like this is an effective way of combating prejudices. He does not have an evaluation of it but their “attempt is in that direction, to break barriers.” He uses a technique that he calls bite and blow. “In the same time as I speak heavy things to the companies I am telling them the light things, the good things, you know? And this play, in general, gives a good feedback. Thus, this job is not done all over Brazil, unfortunately...” He said that he was the one that started to really look deeply into the question of controlling the companies so that they comply with the quotas.

Cabral mentioned many times, both in the audience and during the interview, that he has an impairment; a mobility impairment. Mesel also mentioned this as something that also helps changing the perspective on people with disabilities.

Mesel says that the representative organizations of persons with disabilities are, “those that really brings to us, not only the wishes of the persons, but also all the problems that these persons live with in the practice, finally all the barriers...”

According to Mesel it is the entrepreneurial attitude of the companies that has to change. “Of thinking that the profit, you know the economic goals, are on top of everything else...” So she means that they have to face the expectation to preform the social function in a proactive form. “...to anticipate, offering alternatives, to find solutions.” She means that they has to show “that they really want to participate in this process in an effective way, not just

when they are charged, demanded, requested, investigated, tackled. (...)” She says, “Many of them do not really have awareness that they have a social function to fulfill.”

Mesel points at the importance of the companies,

treating workers with dignity, with respect, not only to comply with the law, but to create effective conditions. So, that people can realize themselves within that company, regardless of whether they have a disability, a limitation, or not. And to do this through positive actions (...) in there make a mapping, put that person in an activity that it can carry out without difficulty.

She says that the companies have to change their structure, “its services, its ergonomics, its furniture, its accessibility, so that people feel contemplated there, effectively integrated in that work environment.” It is important for them to “...understand that their role is not only economic exploitative, but to actually be enabler of improvements, increases, realization of the people...” She says, “All of this is within a major objective, which is not only aimed for the public ministry or the public bodies who deal with this theme, or of the institutions...” It is something that the whole society has to be responsible for.

The functionary says that they always communicate with other organizations on the field. The same day as our interview she had been at an information seminar where they had informed about a forum that the Ministry of Work and Employment is articulating. This forum, she says, is for various operators where they can report about discrimination. And when somebody do, the Ministry of Work and Employment, “start an action, they go there...” Cabral says that they use this forum as well for communicating findings and reports.

Mesel says that there really are series of obstacles “but these could be changed easily, right, with the engagement on the point of awareness.” She says,

there has to be a change of all aspects, of all the sides. The side of the person with disability, of the family, of the people around the person, of the institutions that represents them, of the public institutions, of the society as one, and specifically of the companies, of them opening up for this persons in an effective way...

## **6 Analysis**

In this chapter I will analyze the findings using the previous research and theories of perspectives on disability and normalization. The analysis is divided into following headings; *The instrumental rationality of the companies; The Importance of Support; Definition of “Qualified”; Responsibility of providing support; Possible Solutions and; Perspectives on intellectual Disabilities.*

## **The Instrumental Rationality of the Companies**

The majority of the respondents tell about obstacles caused by the fact that many companies only employ people with disabilities because the Quota Law demands them, and because the public ministries are investigating them. As mentioned in the result chapter, Mesel says, “From the moment that there is the law of hiring persons with disabilities, automatically, in the society as one whole, potential candidates will emerge.” However, one of the barriers according to the respondents has been considered discrimination of people with intellectual disabilities and that people with more severe disabilities are rejected in favor of persons with minor disabilities. Another barrier has been considered that companies do not care to adapt the environments in order to accommodate persons with disabilities. Two of the respondents say that when people with disability are employed, they many times only get to do work tasks with minor importance which is correlating with assumptions made by Sampaio (2012) who writes, “workers with intellectual disabilities occupy the lowest positions in the organizational hierarchy (p. 244).”

It is also shown that all the organizations studied by Sampaio, “based their management practices of people much more on instrumentality than in values in which the result did not interest them (p. 244).” One assumption is that if the goal of the companies is profitmaking, than the behavior of the employers, trying to find the most effective and qualified candidate to employ, could be considered natural.

Both of the functionaries at public ministries tell about their struggle of trying to change this perspective and try to make the companies understand, and comply with, their social function of including people with disabilities into their organizations. Mesel says that it is not only to make them comply with the law, but to make them really include people with disabilities in an effective way, not because they have to but because they understand that it is the right thing to do. Also within the study of Aranha (2003) it is written, “the entrance door for the person with disability to the company is, like for any other employee, the sector of Human Resources.” Both of the functionaries at public ministries talks about the importance of breaking barriers caused by prejudices as a way of opening the doors to the labor market for people with disabilities. This is also the focus of Aranha (2003).

*Is it realistic to believe that the goal of pro-profit organizations should change to a social direction instead of a profitmaking? Should it be dependent on the good will of the companies, or the support from non-profit organizations, if people with intellectual disabilities would be employed?* According to Mesel the Quota Law is not enough. The fact

that almost no one of the respondents from the target group within my sample knew about the Quota Law could maybe verify that the law, in its present form, is not adequately adapted to fit the needs of people with intellectual disabilities, in order to reach integration on the labor market.

### **The Importance of Support**

Many of the respondents pointed at the need of support that persons with intellectual disability has. One of the students that had an employment told about how dependent she was on the support of her colleague and how lost she had been when the colleague was absent for 15 days. As mentioned in the introduction, intellectual disability includes impairments concerning the ability to think in abstract terms, and do often also contains behavioral aspects. Tideman (2000) also considered this group as a “small and vulnerable group that is in need of support from the society, often throughout the whole life.” Sampaio (2012) writes that “People with intellectual disabilities, by its definition, needs support through guidance, supervision and technical assistance that help to compensate for one or more functional limitations; motoric, sensory or mental, in order to break barriers related to mobility, perception of time and communication.”

The support that the respondents talk about is of pedagogic character; a support of giving directions of what to do, how to do it and when it should be done. One of the functionaries mentioned difficulties of coming in time. But responds from functionaries at the associations, relatives and students, in correlation to the theories of Supported Employment, show that, with directions and support, the persons would be able to do a great work. This is also considered by Aranha (2003) who writes, “The experience, in Brazil, (...) has already shown that the great majority of people with disabilities, when given the proper support, are able to participate in the world of production and of achieving self-sufficiency (p. 23).”

Cabral talks about the solution of having a “godfather” connected to the person as an extra security and support which is similar to the ideas contained in the method Supported Employment (Bond, 2004). Within the method, both individualized support from specific supervisors, “job-coaches”, of Supported Employment and *natural support* from “co-workers” in the workplace are important aspects (Antonsson, 2003, pp. 21-24).

## Definition of “Qualified”

The requests of the employers, to fill the quote of the Quota Law with people with disabilities who have higher qualification than people with intellectual disability normally has, may be a reflection of how the intended target group for the quote of the Quota Law is described in the law. In the Decree number 3.298/99, within the Article 36°, it says, “A company with a hundred or more employees are required to complete two to five percent of their positions with *rehabilitated* beneficiaries of Social Security or *qualified* disabled persons... (my italics)”. Within the § 2 there is a definition of who is considered qualified;

A person with disability is considered qualified, one that has completed professional education of basic, technical or technological level, or higher education, with certification or diploma issued by public or private institution, legally accredited by the Ministry of Education or equivalent body, or the one with the certificate of completion of the qualification process or vocational rehabilitation provided by the National Institute of Social Security - INSS.

Within § 3 “A person with disability is also considered qualified, one who has not undergone the process of habilitation or rehabilitation, but is able to exercise the function.” According to the functionaries at both NGO’s most of the persons that they meet do not qualify themselves to the qualification requirements of § 2 as most of them has not completed high school, some has not completed the school at any level. And as one of the functionaries, and also one of the relatives said, without an ongoing support the persons would not be “able to exercise the function”, which within the § 3 is considered an opportunity for persons who has not “undergone the process of qualification or rehabilitation.”

Aranha (2003) describes *Individual Placement* as an available option for people with disabilities in order to reach an employment, there was described that persons with disabilities *already qualified for the exercise of their occupations*, may require intensive and constant personal support initially in the process (Aranha, 2003, p. 23). It seems that a support similar to the one advocated in the method Supported Employment should be an option but again, there is the concept *qualified* that has to be defined. If you use the same definition as in the *Decree No 3.298/99*, or if it is a person that is supposed to, after an *initial period of instant and constant support* should manage to *exercise occupational functions* without any further support, a great number of persons within the group *people with intellectual disabilities* are excluded (Comp. Aranha, 2003; Bond, 2004, Antonson, p. 162, 2011; Patrick W. Corrigan and Stanley G. McCracken, 2005, pp. 31-37).

## **Responsibility of Providing Support**

Aranha (2003) writes that, for people who have severe disabilities, who need ongoing support services for the execution of competitive work performed in the regular environment, it is referred to Supported Employment. But according to her, “The placement of people who have severe disabilities has represented the greatest challenge in order to respect the social rights to work for persons with disabilities.” She points at the importance of allowing “the inclusion of people with severe disabilities on the competitive labor market, without resulting in disadvantages for the employer (...) (p. 22).”

According to Cabral, they could not demand the company to offer this support, to employ another person in order to assume the function of a “godfather”. Neither are there, at the moment, any public funds in order to maintain this kind of support. He says that one option could be if the state had resources and could put a person to give this support. But he says that the Brazilian society has not come so far yet in the development of the welfare system. So one conclusion, in coherence with the one made by Sampaio (Personal conversation, 15 march 2013), is that the person depends on other affirmative actions of the companies than the law demand in order to enable and ensure employment for the worker. In other words it is required a *good will* of the company.

## **Possible Solutions**

At Pestalozzi they have developed a system of internship, for those students who receive the BPC and are afraid of losing it, as a way to be integrated on the labor market. This arrangement gives the person social profits such as opportunities to create relationships to co-workers in a real work environment and the sense of doing something meaningful. In addition to this, internship could be considered a link to the labor market as many of the internships that Pestalozzi arranges turns real employments according to one of the functionalities. But, as Cabral states, there are obstacles related to this form of internships including aspects of social security and that those persons are doomed to always receive a minimum wage. According to him, the system of legal apprenticeship was to prefer as it is limited to two years and has an employment bond. It do not seem to exist any adapted form of this approach for people with intellectual disabilities in the region. One possible solution, mentioned by Cabral, was that the associations could promote such a program.

Another option for the persons in order to feeling useful and to contribute to the income of the family was, by one of the functionalities considered, the “informal labor market”. But there

were different views on the justification of participating on an informal labor market. According to the functionary at Pestalozzi, this is an acceptable solution for those who do not meet the requirements of an employment on the formal labor market, but Mesel talks about this solution as something undesirable. The functionary at Pestalozzy also mentioned that it was dependent on the efforts and support of the families why this solution does not contribute to the independence of the person in relation to the family.

Concerning Law Romario, which was created 2011 in order to solve the obstacle with the fear of loosing the BPC, this law seems to not have been spread enough as the barrier *fear of loosing the benefit* still was mentioned as one of the major obstacles for people with intellectual disabilities.

### **Perspectives on Intellectual Disabilities**

The interventions BPC and the Quota Law could be considered in line of the Scandinavian interpretation of the normalization principle as these are wealth transfers with the goal to give equal terms and conditions as normal as possible to those who would not be able to acquire this on their own (Comp Tideman, 2000, p. 54). But affirmative actions could be used to compensate for inferior preconditions also within an American interpretation, even if these should be used gently as it is considered that these actions could have a negative effect on the status of people with intellectual disabilities. Many of the respondents describe that there still remains a culture of viewing people with intellectual disabilities as incapable of having a competitive work on the labor market in the society. Functionaries at the associations say that they meet a lack of knowledge and a lot of prejudices about people with intellectual disabilities, especially in the contact with employers. There is a view on persons as dangerous or incapable to perform a real work. Cabral also talks of the myth of people with intellectual disabilities as *everlasting babies*, especially within the families. One of the solutions has been considered advocacy work of changing perspectives in the society, of the families and of the employers. Therefore both the public ministries and the non-government organizations put a lot of efforts on advocacy work, of changing prejudicial thoughts within the society. This is in the line with the American interpretation of normalization where there is a focus on combating prejudices and the low status of persons with intellectual disabilities (Comp. Tideman, 2000, p. 56). According to this interpretation downgrading process could be countered by letting persons, who are deviating, conquer high status positions and Cabral

was, as both him and Mesel mentioned, a living example of a person with disability performing a work on a high status position.

Also the work of the NGO's could be considered in line with the American interpretation as they have a focus on strengthening the individual through skills enhancement initiatives such as education and training programs (Comp. Mallander, Meeuwisse & Sunesson, 2008, p. 166; Tideman, 2000, p. 55). But Wolfensberger suggested direct support to people with intellectual disabilities in order to reach the labor market instead of building special day centers in public services and in contrast, the Pestalozzi provides courses and workshops in segregated environments and the majority of the students were not considered ready for the labor market. Institutional solutions, such as Sheltered Workshops, is something that Cabral says has to be restricted and he advocates integrated solutions with employment bounds, which is in the line of the American interpretation of normalization and Supported Employment.

Mesel mentions that the persons could build their qualification out of training within the company, which is in the line of Supported Employment and its Place-Train approach. The approach of the NGO's seems to be of a Train-Place one, that the person should qualify before he or she could be placed on the labor market.

The view of the NGO's seems to me similar to the one within the medical or individual model, and to an individual or medical view on normality, where the focus is on treatment or education in order to make the person more normal regarding attributes and behavior (Comp. Szönyi and Tideman 2011, p. 142; Tideman, 2000, pp. 42, 53-54). This is something that I consider could be an obstacle for the target group if it results in people with intellectual disabilities, who have a desire to obtain a competitive employment, never reaches the labor market. The responds of functionaries from both NGO's shows that they only forward those who they consider meet the qualification requirements within the profile that the companies gives, which only represented a small part of the whole target group within the associations.

## **7 Discussion**

I am aware that the result of this study cannot be generalized in any significant extent as the result is based on subjective experiences and the sample is not representable for the whole society. However, I think the study has responded to my purpose as I have detected some obstacles that have to be overcome, many important aspects and also some possible solutions that could facilitate for the target group to obtain competitive employment. As the target

group of this study is considered a small and vulnerable group I consider that the result, indicating solutions for social change concerning this group, is highly relevant to social work.

However, with this study I have just scratch on the surface to an issue that involves many different aspects. For example, it would be interesting to dive deeper into the legislations concerning rights of persons with intellectual disabilities in Brazil and especially how current support is funded economically. As the support from the associations has been considered important for the inclusion on the labor market, it could be interesting to see if there are people with intellectual disabilities who do not receive any support at all. It has to be remembered that all of the respondents with intellectual disabilities within this study receive some form of intervention. It would also be interesting to see how the Social Services work with disability issues, and what role social assistants have to the target group. This could be an interesting topic for further research.

Concerning the analysis it would have been interesting to analyze the result with a focusing on Social Mobilization or Empowerment Work. Another option that I considered was analyze the data using theories on different types of welfare states.

## **8 Conclusion**

The result shows that the main barriers for people with intellectual disabilities in order to reach the labor market were considered;

- prejudices and discrimination of persons with intellectual disability;
- the lack of qualification of people with intellectual disability in combination of high qualification requirements by the employers;
- the lack of support in order to compensate for intellectual disabilities;
- that the work environments are not customized for the target group and;
- fear of losing the Benefit of Continuous Support of Social Assistance (BPC).

One barrier that I have found emerged out of the result is that the persons receiving support from the NGO's within this study have to qualify before they will be forwarded to the labor market. This leads to that many of the persons who have a desire to work on the labor market, and would benefit from obtaining a competitive employment, reach that.

The main interventions used to facilitate for people with intellectual disabilities was advocacy work of breaking prejudices and of individual skills enhancement to meet the requirements of the employers. Both of these interventions could be considered as in line with the American interpretation of the normalization principle.

One important aspect that I have found is how the concept *qualified* is defined and what perspective there is on people with intellectual disability in relation to this term. This finding has led me to question; *Is a person with intellectual disability considered “qualified” based on the person's own conditions or in comparison with others who does not have a disability? If the goal is that the person should perform as well as a person without an intellectual disability in order to be placed on the labor market, will this ever happen? Or are those persons doomed to work within a segregated even if they have a desire to be integrated on the labor market? How does this correlate with the idea that work is considered a social right and something essential for a person's personal and social identity?*

The support and adaption of the environment depends on the good will of the companies or on support from non-government organizations and there is no clear governmental funding for this. With this in mind it is not difficult to understand that the NGO's do not want to forward those that they consider do not meet the requirements of the employers, knowing that there is no guaranty of support for the person. With the same assumption, it is also understandable that one of the relatives thinks that her daughter never would have an employment on the formal labor market.

My conclusion is that, without an additional supplement concerning right to individual support, the affirmative action of the Quota Law is not of much assistance for people with intellectual disabilities. Both of the associations within this study provide some support to persons who have obtained a competitive employment. If there where invested more resources on this kind of support, more people would be able to obtain, and maintain, a competitive employment.

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## List of significant operators

### SEAD

“The State Superintendent of Support for People with Disabilities - SEAD is the agency of the Department of Social Development and Human Rights of the Government of Pernambuco responsible for coordinating, articulating, propose, advise and evaluate the implementation and execution of policies and government and non-governmental relating to people with disabilities within the State. Its main objective is to appreciate the uniqueness and plurality of the people, ensuring rights and creating opportunities for citizens with disabilities (<http://sead.sedsdh.pe.gov.br/apresentacao.php>, 2012-08-12).”

Their target audience is people with auditory, visual, physical or intellectual disabilities.

This is how they present what they do:

- Re-conceptualize existing ideas and attitudes about people with disabilities
- Engaging citizens with disabilities in productive processes, gathering activities, projects and events whose outcomes involve professional training and the generation of employment and income
- Ensure conditions for use with security and autonomy of spaces, urban furniture and equipment for the disabled person or person with reduced mobility
- Partnering and taking action around projects that aim to ensure to persons with disabilities access and use goods and social services.

### Network S

Network S is the National Service of Apprenticeship. It is a system of institutions that has the objective to “Qualify and promote the welfare and provide a good vocational education (<http://www.brasil.gov.br/empreendedor/capacitacao/sistema-s>, 2013-06-05)”. Cabral mentions four of them:

- Senac: National Service of Commercial Apprenticeship - vocational education for workers in the sector of trade and services.
- Senai: the National Service for Industrial Apprenticeship - who is responsible for vocational education and industrial training, in addition to the provision of technical and technological assistance to industrial enterprises.
- Senar: National Service of Rural Apprenticeship - vocational education for rural workers.

- Senat: National Service of Apprenticeship in Transports - vocational education for workers in the transportation sector.

Those institutions were created to promote apprenticeship in their prospective. According to a governmental webpage the entities of network S offer free courses in key areas of industry and commerce formed by organizations created by the productive sectors (industry, commerce, agriculture, transport and cooperatives). The network S has a network of schools, laboratories and technology centers scattered throughout the country. There are also offered paid courses generally more affordable than offered by private schools.

## **CIEE**

CIEE is the Center of Integration of Companies and Schools and are considered an important actor in the area of legal apprenticeship by two of my respondents. According to their webpage they are,

a philanthropic institution of social service maintained by the national business community. It is a non-profit organization, working with youth Brazilian student.

The main goal of the CIEE in these 48 years of existence is to find, for students at high school, technical- and superior level, opportunities of internship or apprenticeship, that will help them to put into practice everything they have learned in theory.  
(<http://www.ciee.org.br/portal/institucional/index.asp>, 2013-06-19)

## **STQE**

The Department of Employment, Vocational Skills and Entrepreneurship of Pernambuco (PE-STQE) aims to increase people's access to the labor market, preparing citizens to fill job vacancies or to improve themselves as entrepreneurs

([http://www.stqe.pe.gov.br/index.php?option=com\\_content&view=article&id=5871&Itemid=98](http://www.stqe.pe.gov.br/index.php?option=com_content&view=article&id=5871&Itemid=98), 2013-08-12).

## **INSS**

Cabral says that the INSS works with rehabilitation where many of the persons also have disabilities.

## **FGTS**

FGTS is a Guarantee fund for time of service (<http://www.caixa.gov.br/Voce/fgts/index.asp>).

## Interview guide in English

Person with ID:

- Background:
  - Age?
  - Disability?
  - Educational level?
  - Professional skills?
- What is your occupation right now?
- If employed:
  - How long time have you had your employment?
  - Did you have any difficulties related to receive an employment?
  - Did you get some support from anyone to receive the employment?
  - Do you get any support in order to maintain you employment?
- If unemployed:
  - How long have you been unemployed? / How long time have you been searching for a work?
  - In what area would you like to work?
  - Do you get some support from anyone in order to receive the employment?
- Which are the main barriers, according to you, in order to integrate persons with ID on the labor market?
- If something has to change in order to facilitate for persons with ID to enter the labor market, what would that be?
- About the Quota Law:
  - What knowledge do you have about the Quota Law of persons with disabilities?
  - Do you know anyone that has been employed through this law? / Is this law in help of people with ID?
  - Which barriers do you think there is for people with ID to get employed through this law?

Professionals:

- Background:
  - Profession?
  - Assignment/work tasks?
- Which interventions are made in order to facilitate for persons with ID to enter the labor market?
- Which are the main barriers, according to you, in order to integrate persons with ID on the labor market?
- If something has to change in order to facilitate for persons with ID to enter the labor market, what would that be?
- What knowledge do you have about the Quota Law of persons with disabilities?
- Quota Law:
  - Do you know any person with ID that has been employed through this law? / Is this law in help of people with ID?
  - Which barriers do you think there is for people with ID to get employed through this law?

Relatives:

- Background:
  - Age of your relative?
  - Disability?
  - Educational level?
  - Professional skills?
- What is her/his occupation right now?
- If employed:
  - How long time has he/she had his/her employment?
  - Did he/she have any difficulties related to receive an employment?
  - Did he/she get some support from anyone to receive the employment?
    - If so, what kind of support and from whom?
  - Do he/she get any support in order to maintain his/her employment?
    - If so, what kind of support and from whom?
- If unemployed:
  - How long time has he/she been unemployed? / How long time has he/she been searching for a work?
  - Do he/she get some support from anyone in order to receive the employment?
- Which are the main barriers, according to you, in order to integrate persons with ID on the labor market? / If something has to change in order to facilitate for persons with ID to enter the labor market, what would that be?
- About the Quota Law:
  - What knowledge do you have about the Quota Law of persons with disabilities?
  - Do you know any person with ID that has been employed through this law? / Is this law in help of people with ID?
  - Which barriers do you think there is for people with ID to get employed through this law?

## Interview guide in Portuguese

Perguntas para pessoas com Deficiências Intelectuais (DI):

- Fundo:
  - Qual é a sua idade?
  - Que deficiência você tem?
  - Qual é o seu nível educacional?
  - Quais são as suas habilidades de trabalho? Experiência de trabalho?
  - Qual é a sua ocupação agora?
- Se empregado:
  - Há quanto tempo você já trabalha?
  - Que dificuldade você teve para conseguir o seu emprego?
  - Você recebeu apoio para conseguir o emprego?
    - Se sim, quão tipo de apoio e de quem?
  - Você recebe algum apoio, a fim de manter o seu emprego?
    - Se sim, quão tipo de apoio, e de quem?
- Se desempregado:
  - Há quanto tempo você está desempregado? / Há quanto tempo você está procurando um trabalho?
  - Em que área você gostaria de trabalhar?
  - Você tem apoio de alguém para conseguir um emprego?
- Quais são as barreiras principais, de acordo com você, a fim de integrar as pessoas com DI no mercado de trabalho?
- Se algo tem que mudar, a fim de facilitar para as pessoas com DI para entrar no mercado de trabalho, o que seria?

Sobre a Lei de Cotas:

- Que conhecimento você tem sobre a Lei de Cotas em favor a as pessoas com deficiência?
- Você conhece alguma pessoa com DI que conseguiu um emprego através desse lei? / Esta lei facilita para pessoas com DI, a receber um emprego?
- Que barreiras você acha que existe para pessoas com DI para conseguir um emprego através desse lei?

Perguntas para os Profissionais:

Fundo:

- Profissão?
- Atribuição / tarefas de trabalho?
- Qual intervenções são feitas a fim de facilitar para as pessoas com DI para entrar no mercado de trabalho?
- Quais são as barreiras principais, de acordo com você, a fim de integrar as pessoas com DI no mercado de trabalho?
- Se algo tem que mudar, a fim de facilitar para as pessoas com DI para entrar no mercado de trabalho, o que seria?

Sobre a Lei de Cotas:

- Que conhecimento você tem sobre a Lei de Cotas em favor a as pessoas com deficiência?
- Você conhece alguma pessoa com DI que conseguiu um emprego através desse lei? / Esta lei facilita para pessoas com DI, a receber um emprego?
- Que barreiras você acha que existe para pessoas com DI conseguir um emprego através desse lei?

## Perguntas para parente de pessoa com Deficiência Intelectual(DI):

- Fundo:
  - Qual é o sexo da sua parente?
  - Qual é a idade da sua parente?
  - Qual deficiência ela/ele tem?
  - Qual é o nível educacional de ela/ele?
  - Qual são as habilidades profissionais de ela/ele?
  - Qual é a corrente ocupação de ela/ele?
- Se empregado:
  - Ha quanto tempo ela/ele já tem o seu emprego?
  - Ela/ele tinha algumas dificuldades relacionadas a receber o emprego?
  - Ela/ele recebeu algum apoio de alguém para receber o emprego?
    - Se sim, quão tipo de apoio, e de quem?
  - Ela/ele recebe algum apoio, a fim de manter o emprego?
    - Se sim, quão tipo de apoio, e de quem?
- Se desempregado:
  - Ha quanto tempo ela/ele esta desempregado? / Ha quanto tempo ela/ele esta procurando um trabalho?
  - Ela/ele obter algum apoio de alguém, a fim de receber um emprego?
- Quais são as barreiras principais, de acordo com você, a fim de integrar as pessoas com DI no mercado de trabalho?
- Se algo tem que mudar, a fim de facilitar para as pessoas com DI para entrar no mercado de trabalho, o que seria?

## Sobre a Lei de Cotas:

- Que conhecimento você tem sobre a Lei de Cotas em favor a as pessoas com deficiência?
- Você conhece alguma pessoa com DI que conseguiu um emprego através desse lei? / Esta lei facilita para pessoas com DI, a receber um emprego?
- Que barreiras você acha que existe para pessoas com DI para conseguir um emprego através desse lei?

## Statement of Ethical Considerations & Principles

Information about the research:

Me, that are making this research study Social Work an the Ersta Sköndal University Collage in Stockholm, Sweden. Now I am in Brazil in order to make my bachelor degree thesis and a scientific article and I intend to do a study on the inclusion of people with intellectual disabilities in the labor market in Recife. The purpose of my research is to detect barriers, important aspects and possible solutions related to the objective to facilitate for people with intellectual disabilities to enter the labor market with the quota law as a starting point. The study will be based on interviews with persons from the target group who have the desire to obtain a competitive employment, social workers on the Association Pestalozzi of, participants from the Public Ministry of Work, employers and other persons who acts in the area of inclusion on the labor market. The information provided will not be used for any purposes other than research.

I wish to inform you that:

- You will be anonymous in the thesis.
- All information will be treated confidentially and when the thesis is completed, the interview material will be destroyed.
- Participation in the study is voluntary and can be canceled at anytime.
- You do have the right to take part of the final result.

I have read this information:

.....

Signature

## **Declaração de Considerações Éticas e Princípios**

Informação sobre a pesquisa:

Eu que estou realizando esta pesquisa, estudo Serviço Social na faculdade Ersta Skönda University Collage em Estocolmo, Suécia. Agora estou no Brasil para fazer a minha tese de licenciatura bacharelado e um artigo científico, e tenho a intenção de fazer um estudo sobre a inclusão de pessoas com deficiência intelectual no mercado de trabalho em Recife. O objetivo da minha pesquisa é detectar os obstáculos, aspectos importantes e soluções possíveis relacionadas com o objetivo de facilitar a entrada de pessoas com deficiência intelectual no mercado de trabalho através da lei de cotas como um ponto de partida. O estudo será baseado em entrevistas com pessoas do grupo alvo que têm o desejo de obter um emprego competitivo, trabalhadores sociais sobre a Associação Pestalozzi do Recife, participantes do Ministério Público do Trabalho, empregadores e outras pessoas que atuam na área de inclusão no mercado de trabalho. As informações fornecidas não serão usadas para quaisquer outros fins se não para pesquisa.

Eu gostaria de informar que:

- Você na tese será anônimo.
- Todas as informações serão tratadas de forma confidencial e quando a tese for concluída, o material da entrevista será destruído.
- A participação no estudo é voluntária e pode ser cancelado a qualquer momento.
- Você também tem o direito de tomar parte do resultado final.

Eu tenho lido esta informação: .....

Assinatura