

## INTERNSHIP REPORT

# Breaking the glass ceiling for people with intellectual disabilities

Drawing lessons from a qualitative case study on inclusiveness in an organizational board

L.K. Franssen



STUDENT NUMBER  
2652661

COMMISSIONING PARTY  
Amsterdam UMC, chair of  
Disability Studies

ECTS + COURSE CODE SPECIALIZATION  
27\_ECTS-AM\_1120

DATE  
12-07-2019

VU SUPERVISOR  
E.E. de Wit

ATHENA SCIENCE SHOP



## Colophon

Title: Breaking the Glass ceiling for people with intellectual disabilities

Key words: inclusion, intellectual disabilities, board functions

Author: L.K. Franssen

Commissioning organization: Amsterdam UMC, chair of Disability Studies

On-site supervisor: Dr. M. Bakker

VU supervisor: E.E. de Wit

07 – 2019

Course code: AM\_1120

This internship report was established in cooperation with the Athena Science Shop.

## Athena Institute

Faculty of Science

VU University Amsterdam

De Boelaan 1085

1081 HV Amsterdam

The Netherlands



## Preface

This report is part of the master Management, Policy Analysis and Entrepreneurship in Health and Life Sciences. During the last five months I did research on how boards can become more inclusive, in order to increase the participation of people with an intellectual disability.

You are about to read the result of my first individual qualitative research. I really enjoyed the past five months, but it also has been a challenge. Both qualitative research as disability studies were new for me which made the process challenging. I experienced setbacks by doing research in a whole new field and finding a suitable framework was not easy. Furthermore, I went out of my comfort zone doing interviews by myself. After a lot of rewriting I can finally say I am satisfied with the result. But, this would not have been possible without help. Hence; there are a few persons I would like to express my gratitude for.

I would like to thank my supervisor, dr. E. de Wit, who oversaw my progress and made the time to formulate extensive feedback.

I also want to thank the (former) board members, coach and management assistant of SPZ. Thank you all for the interesting conversations and all your enthusiasm to participate in this research. I think it is rare to find a research population this enthusiastic.

A special thanks goes towards my on-side supervisor, dr. M. Bakker. Without her this report would never be finished. I would like to thank her for all her knowledge, input, brainstorm sessions, feedback and the guidance she gave me during my very first individual qualitative research. Furthermore, I would also like to thank her colleagues from Disability Studies in Nederland for their advice.

Lieke Franssen

July 2019

## Executive Summary

### Introduction

Although various movements and approaches have been suggested throughout history to understand and support Persons with a Disability (PwDs) as well as legal frameworks such as the Participation Act of 2005, to protect PwDs, full inclusion in all facets of society remains a big challenge. Despite the efforts to mainstream disability-, particularly people with intellectual disabilities (ID), continue to face stigma, negative attitudes towards disability and other barriers at the workplace. Especially people with a mild intellectual disability (MID) have to deal with the invisibility of their disability resulting in patronizing or overestimation of their capabilities and stereotyping. PwDs are less likely to have administrative and professional positions than employees without disabilities. Moreover, employers are more willing to hire persons with physical disabilities for professional and managerial positions than applicants with an ID. Therefore, this research aims to answer the research question: *“What lessons can be learned from a board with a board member with a mild intellectual disability regarding feelings of inclusion?”*

### Contextual framework

The framework used for this research is based on the 4 phases of inclusive climate as proposed by Pless & Maak (2004), on the interrelated categories of inclusion by Farrell (2004), disability mainstreaming by UNWRA (2013) and the framework of inclusion as proposed by Shore et al., (2011).

The concepts that were thought to be most significant for this research are included in the conceptual framework and were used to identify the lessons learned from a board with a board member with a MID, in order to create suitable workplaces for people with a MID in board functions on a larger scale.

### Methods

No earlier research has been conducted about how to make boards more inclusive and what contributes to a successful placement of someone with an ID in an administrative function. To gain insight into the functioning of the board and their behaviors and systems a case study with a qualitative approach was carried out. An in-depth case study was executed, where 9 board members of a board with a board member with a MID were interviewed. Analyzing and coding the data was done with the coding program MAXQDA.

### Results

Several lessons can be derived from the interviews. First, a coach is of great importance when trying to reach equal participation within board functions. Furthermore, it is relevant to stick to the agenda and to offer specific support when necessary. Hereby, attention for needs is required. The role of the

chairman is a key role and requires certain leadership skills. The fourth lesson is the relevance of a trial period including an extensive evaluation. The board member with a MID needs affinity with the subject and in order to represent the target group, practical experience and expert knowledge is needed.

The board member with a MID is always present but cannot contribute to all agenda items during the meetings. Especially topics that could not be prepared are hard.

Not a lot of changes were made before the board member with a MID started her term in the board. The board member with a MID also requested the board to not change specific for her. Within the board a feeling of belonging exists.

## **Discussion**

In this case study, the role of the coach was mentioned multiple times. Nevertheless, it remains unclear if participation is about acting independently or being able to participate as result of needed support. On one hand, participation mainly seems to mean that PwDs should be able to integrate into regular settings. But, on the other hand, is coaching seen as one of the most important activities in order to become more inclusive. Remarkable is the fact that all board member state that no organizational changes were made before the arrival of the board member with a MID. The board member with a MID did not want the board to change anything especially for her. In the literature, this is explained by the principle of self-stigma. To ensure that full participation is possible, the idea of integrating into existing structures must be abandoned; it makes more sense to look at what is needed to realize optimal participation, for inclusion. An ongoing discussion about equity vs equality exists. Equity and removing obstacles both correspond to disability mainstreaming. Mainstreaming could profit from the concept of universal design.

## **Conclusion**

Despite that the board member with a MID cannot fully participate on all subjects during the board meetings, the results show that the board of SPZ is an inclusive board. All board members experience this board as inclusive, and that is the goal. The aim of inclusion is to contribute to quality of life. Working results in the feeling of belonging. In order to establish inclusion, attention for needs with consideration of the equity principle is necessary. However, this might not be needed if disability was mainstreamed and more workplaces were created according to a universal design.

## Table of content

<b>Preface .....</b>	<b>4</b>
<b>Executive Summary .....</b>	<b>5</b>
<b>List of abbreviations: .....</b>	<b>9</b>
<b>1. Introduction .....</b>	<b>10</b>
<b>2. Contextual background .....</b>	<b>12</b>
2.1 <i>Disabilities</i> .....	12
2.1.1 Intellectual disability .....	12
2.1.2 Barriers for inclusion at the workplace .....	14
2.3 <i>Right to inclusion</i> .....	14
2.3.1 Participation Act .....	14
2.3.2 Quotum Act .....	15
2.3.3 UNCRPD .....	15
2.3.4 Personal and economical relevance .....	15
2.4 <i>History of Inclusion</i> .....	16
2.4.1 Social Inclusion .....	16
2.4.2 Disability studies .....	17
2.5 <i>Stakeholders</i> .....	18
2.5.1. SPZ .....	18
2.5.2 People with an ID .....	18
2.5.3 Dutch Government .....	19
<b>3. Theoretical Background .....</b>	<b>20</b>
3.1 <i>Inclusion</i> .....	20
3.2 <i>Inclusive Climate</i> .....	21
3.3 <i>Disability mainstreaming</i> .....	22
3.4 <i>Inclusion in work</i> .....	22
3.5 <i>Conceptual Framework</i> .....	23
3.5.1 Inclusive leadership .....	24
3.5.2 Inclusive Climate .....	24
3.5.3 Disability mainstreaming .....	25
3.5.4 Outcomes: inclusion .....	25
3.6 <i>Sub questions</i> .....	25
<b>4. Methods .....</b>	<b>26</b>
4.1 <i>Research design</i> .....	26
4.2 <i>Research respondents</i> .....	26
4.3 <i>Data collection</i> .....	27
4.3.1 Interview design .....	27
4.4 <i>Data Analysis</i> .....	28
4.5 <i>Credibility and dependability</i> .....	28
4.6 <i>Ethical considerations</i> .....	29

<b>5 Results .....</b>	<b>30</b>
5.1 <i>Case description</i> .....	30
5.1.1 Organization .....	30
5.1.2 Board member with a disability .....	31
5.1.3 Coach .....	32
5.1.4. Recruitment process .....	33
5.1.5 Board meetings .....	34
5.2 <i>Lessons learned</i> .....	35
5.2.1. Procedural Lessons .....	35
5.2.2 Practical lessons .....	36
5.3 <i>Inclusion</i> .....	37
5.3.1 Inclusive leadership .....	37
5.3.2 Inclusive Climate .....	37
5.3.3 Disability mainstreaming .....	38
5.4.4 Outcomes: experience of inclusion .....	39
<b>6. Discussion .....</b>	<b>41</b>
6.1 <i>Key Findings</i> .....	41
6.2. <i>Comparison with literature</i> .....	42
6.3 <i>Limitations</i> .....	43
<b>7. Conclusion and Recommendations .....</b>	<b>45</b>
7.1 <i>Conclusion</i> .....	45
7.2 <i>Recommendations</i> .....	45
<b>References .....</b>	<b>46</b>
<b>Annex 1.....</b>	<b>58</b>
<b>Annex 2.....</b>	<b>60</b>
<b>Annex 3.....</b>	<b>62</b>
<b>Annex 4.....</b>	<b>63</b>



## List of abbreviations:

DSM-5: The Diagnostic and Statistical Manual of Mental Disorders

ID: Intellectual disability

LFB: The Landelijk Federatie Belangenvereniging Onderling

MID: Mild intellectual disability

PwDs: Persons with a Disability

PDD-NOS: Pervasive Developmental Disorder Not Otherwise Specified

SPZ: Sociaal-Pedagogische Zorg

SRV: Social Role Valorization

UNCRPD: The United Nations Convention on the Rights of Persons with Disabilities

Wajong: Wet werk en arbeidsondersteuning jonggehandicapten

WIJ: Wet investeren in jongen

WSW: Wet sociale werkvoorziening

WWB: Wet Werk en Bijstand

## 1. Introduction

Ever since the Universal Declaration of Human Rights of the United Nation was introduced in 1948 (Brems et al., 2009) there has been increasing attention for the welfare, participation and full emancipation of various minority groups, including persons with a disability (PwDs) (Sorée, 2010). Although various movements and approaches have been suggested throughout history to understand and support people with disabilities, as well as legal frameworks such as the Participation Act of 2005, to protect PwDs, full inclusion in all facets of society remains a big challenge (van Eerten, 2007; van Ogtrop, 2009). In particular, with regards to supporting the participation of PwDs in various forms of employment, has proven to be difficult in the Netherlands (Roulstone & Williams, 2014).

The lack of inclusion is shown in many ways. In 2013, approximately 1.6 million people, 14% of the Dutch workforce, had an occupational disability. The percentage of unemployment for people with an occupational disability is 15.8%, which is more than twice as much as the unemployment percentage for people without disabilities (7.6%) (CBS, 2015). Research has shown that people with an occupational disability are less fortunate on the labor market and are rejected more on job applications compared to people without an occupational disability, despite their capabilities (Jones, 2008). Numbers of CBS (2017) show that PwDs, with work capacity have less often a permanent contract or paid work at all, compared to people without disabilities. PwDs disability are more often unemployed and discriminated on the labor market (Ravaud et al., 1992).

The reasons for this lower work participation are multitude. Studies show that there is lack of social equity for people with a disability as result of negative attitudes towards disability (Hernandez, 2000; Zheng et al., 2016). Stereotypes and myths regarding a person's inability to perform a job still exist, precluding PwDs from receiving offers of employment (Feldblum, 1991).

Arguably, there is a multitude of reasons to plead for improving the level of inclusion of PwDs. From a social perspective it is important to avoid the negative consequences of unemployment. People that are unemployed have a greater risk on symptoms of depression and anxiety (Griep et al., 2016; McKee-Ryan et al., 2005; Mohr et al., 2011) while their self-esteem and life satisfaction is often lower compared to people that are employed (Griep et al., 2016; Lucas et al., 2004; Mohr & Otto, 2011). Participation in the labor markets leads to independence and the acquisition of social contacts and building more support systems. Work also contributes to the social cohesion of citizen (Vornholt, Uitdewilligen & Nijhuis, 2013) and people with positive social relationships live longer (Holt-Lunstad, Smith, & Layton, 2010). Furthermore, work offers possibilities for the development of the personality, self-realization and self-respect (Veenhoven, 2018; Vornholt et al., 2013). From an economical perspective an improved level of inclusion is also validated. The use of the capacities of people with ODs is important to encounter the consequences of the aging population and to keep the social security system in the Netherlands affordable. As such, it is deemed vital that the labor market becomes more inclusive and people with the ability to work are guided into regular jobs as much as possible (Ministerie van Sociale Zaken en Werkgelegenheid, 2013).

Moreover, there is too little follow up or translation of The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) of 2006, which states among others that PwDs should have the same rights as every other citizen (Blankman & Vermariën, 2015). However, if participation occurs, glass ceilings are still considered a problem. The glass ceiling is a phenomenon that is witnessed in gender mainstreaming as well. Somehow, PwDs do not rise above certain positions in organizations and remain stuck in bottom position in an organization (Greenwood & Johnson, 1985; Roulstone & Williams, 2014). As such, inclusion often remains a matter of presence and fails to be something that actually fulfils the rights of persons with a disability as formulated in the constitutions.

Because of the increased awareness on disability mainstreaming in the Netherlands, particularly after the country's ratification of the UNCRPD in 2016, there has been more attention and effort to include PwDs in various positions (Baart & Maier, 2016). However, jobs for PwDs have been primarily available in the secondary labor markets, the labor markets with among others low level skill requirements and few opportunities for advancement. PwDs are less likely to have administrative and professional positions than employees without disabilities. Moreover, employers are more willing to hire persons with physical disabilities for professional and managerial positions than applicants with an intellectual disability (ID), because the expected productivity of people with an ID is lower (Adelmeijer et al., 2015; Greenwood et al., 1991; Scheid, 1999). Despite the efforts to mainstream disability throughout all facets of society, particularly people with ID, continue to experience stigma, negative attitudes towards disability and other barriers at the workplace (Adelmeijer et al., 2015; Hernandez, 2000; Scheid, 1999; Zheng et al., 2016). Especially people with a mild intellectual disability (MID) have to deal with the invisibility of their disability resulting in patronizing or overestimation of their capabilities and stereotyping (Goldin, 2012). The various initiatives which have been presented by employers to include more PwDs and to create a more inclusive labor market rarely involves the use of people with an ID.

One of the initiatives who included someone with an ID comes from SPZ. One of the essential principles of SPZ is creating a more inclusive society. According to the principle 'practice what you preach' SPZ searched 2 years ago for a board member with a MID. As a result, all parties have experienced in practice what it means to become an inclusive board, where people with and without disabilities work together on an equal level. So far, little research has been done into how to successfully include people with an ID in administrative functions. Therefore, this research aims to answer the question: *"What lessons can be learned from a board with a board member with a mild intellectual disability regarding feelings of inclusion?"* by exploring in depth the case of a board member with a MID in the board of SPZ. This research will focus on the different experiences of relevant stakeholders, create insight into how this process has proceeded to explore how boards can become more inclusive in order to create more suitable workplaces for people with a MID on a larger scale.

## 2. Contextual background

To bring inclusion to a higher level several contextual factors and the development of approaches to persons with disability in society will need to be considered. Government policies drafted around this issue will be explained, the way intellectual disabilities can be understood will be defined and various recent barriers to inclusion in organizations will be addressed. Furthermore, relevant initiatives for inclusion will be discussed and relevant stakeholders will be explained.

### 2.1 Disabilities

There are several types of disabilities, 6 types of disabilities will be explained more elaborately. The first type includes physical disabilities including physiological, functional and/or mobility impairments. Another type of disability concerns visual disabilities. Visual disabilities include people who are totally blind or people with visual impairment. The third type is hearing disabilities. Mental health disabilities which can take several forms is the fourth type of disability. The fifth disability type concerns learning disabilities, which are specific and persistent disorders of a person's central nervous system affecting the learning process. The last type of disability aims to cluster intellectual disabilities which are characterized by intellectual development and capacity that is significantly below average. ID involves a permanent limitation in a person's ability to learn (Bar & Gates, 2018; Hallahan et al., 1997). This research will focus on persons with an ID.

#### 2.1.1 Intellectual disability

An ID is a limitation in intellectual and/or social functioning. An ID may occur during pregnancy, at birth or in an early phase of childhood (Den Besten & van Vulpen, 2006). Several forms of ID do exist, which can range from e.g. PDD-NOS, as part of the Autism spectrum, or Down's syndrome. Every form has its own specific characteristics but can be classified under corresponding characteristics in the international classification system of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V). The DSM-V defines ID as "a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains" (American Psychiatric Association, 2013; p. 33). The DSM-V states the following three criteria must be met:

- A. Deficits in intellectual functions e.g. reasoning, problem solving, planning, abstract thinking, judgement, academic learning, learning from experience. This must be confirmed by clinical assessment and individualized standardized intelligence testing;
- B. Deficits in adaptive functioning, resulting in failing to meet developmental and socio-cultural standards for personal independence and social responsibility. Without ongoing support, the adaptive deficits limit functioning in one or more activities in the daily life e.g. living independently, social participation, communication. This limitation occurs in multiple environments e.g. school, home, work or the community.

### C. Onset of intellectual and adaptive deficits during the developmental period

According to the DSM-V, IDs can be expressed at four different levels of severity, including mild, moderate, severe or profound, which are not determined by the level of IQ but are defined on the basis of adaptive functioning (DSM5, 5<sup>th</sup> edition 2014). Adaptive functioning determines the level of support required. Characteristics of a moderate ID are among others, individuals conceptual skills lag markedly behind those of peers all through development. Pre-academic skills and language develop slowly. Academic skill development is mostly at elementary and support is required. Social and communicative behavior is different than peers. Communication is less complex. Social cues may not be interpreted accurately as result of limited ability of social judgement and decision making. An extended period of support is needed to become independent in individual café for personal needs as eating and dressing. Independent employment can be achieved in jobs with limited conceptual and communicational skills with support from co-workers and supervisors (Browder et al., 2018; (DSM5, 5<sup>th</sup> edition 2014). A severe ID is characterized by a limited attainment of conceptual skills. A person with an ID has little understanding of among others written language, number, quantity and time. Grammar and vocabulary are limited in spoken language. Support is required for all activities of daily living and supervision is required at all times (Beadle-Brown et al., 2016; DSM5, 5<sup>th</sup> edition 2014). With a profound ID, the conceptual skills involve the physical world rather than symbolic processes because there is limited understanding of symbolic communication in speech and gesture. Understanding of simple instructions is possible. Desires and emotions are mostly expressed through nonverbal communication. The individual is dependent on others for all aspects of daily physical care, health and safety. Simple actions with objects may be the basis of participation in some activities with high levels of ongoing support (DSM5, 5<sup>th</sup> edition 2014).

This research will focus on the mild severity level of IDs. Characteristics of a MID are among others no obvious conceptual differences for preschool children but for school-age children and adults there are difficulties in learning academic skills involving time and money. Support is needed to meet age-related expectations. Furthermore, people with a MID are immature in social interaction compared to their age mates. Also, language, communicating and conversations are less mature. They have a limited understanding of social situations and a higher risk of being manipulated by others. During adulthood, support is needed for organizing, transportation, shopping, home and child-care organizing money management. Employment is often in jobs which do not require conceptual skills (DSM5, 5<sup>th</sup> edition 2014; Woittiez et al., 2014).

In 2014, 0,85% of the Dutch population (142.000 people) had an IQ below 70 and were categorized as someone with an ID (RIVM, 2014). In 2008, approximately 55,000 people had an IQ between 50 and 70 (moderate intellectual disability) and about 2.2 million people had an IQ between 70 and 85 (mild intellectual disability) (RIVM, 2014; Woittiez et al., 2014).

### 2.1.2 Barriers for inclusion at the workplace

A disability can generally hinder people from finding and performing work (Bonnacio et al., 2019; CBS, 2017; Jones, 2008; Lindsay et al., 2015). The percentage of unemployment for people with an occupational disability is 15.8%, which is more than twice as much as 7.6%, the unemployment percentage for people without disabilities. (CBS, 2015). Research has shown that people with an occupational disability have less chances on the labor market and receive more rejections on job applications compared to people without an occupational disability even though they share the same qualities (Jones, 2008). Figures from CBS (2017) show that disabled people with work capacity have less often a permanent contract or paid work at all, compared to people without work restrictions. A disease, disorder or disability makes it harder to find a job. A higher risk of poverty for people with an occupational disability is a result of less participation in the labor market (Schur, Colella & Adya, 2016). A potential barrier for achieving social equality for people with a disability are the negative attitudes towards disability (Zheng et al., 2016). The attitudes of employers seem to depend on the type of disability employees have. From a meta-analysis researching the attitudes that employers have with regard to people with an occupational disability appears that employers are often more positive towards persons with a physical disability than towards persons with a mental disability. People with a mental disability are expected to perform less well (Hernandez, 2000). Other research supports this finding by concluding that the willingness of employers is much higher when it comes to adaption of a physical occupational limitation than a mental disability (Adelmeijer et al., 2015; Scheid, 1999). Choices for specific disabilities can therefore be based on the expected productivity of this person in the organization. The expected productivity is higher for people with a physical disability than a mental disability. However, different attitudes towards different types of disabilities also exist among PwDs which is called disability hierarchy (Stewart, 2004). A study of Hayward (2005) emphasizes the existence of a stable disability hierarchy among people with disabilities. Within this hierarchy, the position of people with physical disabilities is at the top of the hierarchy in contrast with those with a mental retardation or physiological disability which position is at the bottom of the hierarchy (Bone, 2017).

## 2.3 Right to inclusion

### 2.3.1 Participation Act

To become more inclusive, the Participation Act was introduced on the 1<sup>st</sup> of January 2015 (Borghouts, 2014). The aim of the Participation Act is first of all, harmonization of different regulations (Wet Werk en Bijstand (WWB), de voormalige Wet investeren in jongeren (WIJ), de Wet sociale werkvoorziening (Wsw), Wet werk en arbeidsondersteuning jonggehandicapten (Wajong)). An important principle of the Participation Act is that it is based on a participation society in which every citizen can contribute to

society as a full-fledged citizen. The personal strength per citizen is an important part of this principle (Ministerie van Sociale Zaken en Werkgelegenheid, 2013).

The Dutch Government has made various instruments available, in order to encourage employers to hire people with an occupational disability. These instruments aim to reduce the potential hurdles that could be faced when hiring someone with an occupational disability. First, the government can provide candidates for vacancies at a company (Adelmeijer et al., 2015). Furthermore, the Participation Act includes subsidies for wage costs, wage dispensation and external guidance and support (Adelmeijer et al., 2015; Ministerie van Sociale Zaken en Werkgelegenheid, 2013).

### 2.3.2 Quotum Act

When the Participation Act was implemented in the Netherlands, the Quotum Act was also introduced. The Quotum Act is a mean which stimulates employees to hire more people with an occupational disability. If organizations do not hire enough disabled employees, a fine can be put into effect of 5.000 euro per unfilled workplace. The Law applies to organizations with more than 25 employees, which states that at least 5% of the employees should have an occupational disability (UWV, 2017). The number of jobs that needs to be created has been set for each year. To make sure people with an occupational disability have a higher chance on a regular job the goal of creating 125.000 jobs for them was set in 2015. Public organizations have to realize 25.000 jobs for disabled people in ten years' time. The private sector must provide 100.000 of this type of workplaces (Putter, Cozijnsen & Rijken, 2015). At the end of 2016, the creation of 20.5000 jobs was realized.

### 2.3.3 UNCRPD

In 2016, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was implemented in the Netherlands. The aim of the UNCRPD is to improve the position of disabled people, including people with an ID. The UNCRPD states among other things that PwDs should have the same rights as every other citizen in the Netherlands. Stating that they have the same right to use education and public transport, live independently or have a job. The central government is responsible for the implementation of the UNCRPD. To implement this convention correctly, knowledge about the situation, the care and support they receive and need of people with an ID is necessary (Wiottiez et al., 2018).

### 2.3.4 Personal and economical relevance

Increasing the labor market participation is not just solely about the intrinsic human right to work, but as mentioned in the introduction, being productive/ having a job can also have important consequences for the wellbeing of PwDs (Blankman & Vermariën, 2015; Holt-Lunstad et al., 2010; Vornholt et al., 2013). Work is also related to social role valorization (SRV) (Wolfensberger, 1998). The goal of SRV

is to create or support socially valued roles for people in society. SRV contributes to the experience of meaningful social roles which have a positive effect on aspects as among others respect, dignity and authenticity. (Wolfensberger et al., 1996). Furthermore, the use of the capacities of people with occupational disabilities is important to encounter the consequences of the aging population and to keep the social security system in the Netherlands affordable (Zijlstra et al., 2012). Zijlstra et al. (2012) emphasize the demographic developments, like ageing, which lead to shortages in the labor market, while on the other hand the 'lower end' of the labor market seems to become more extensive as a result of increasing demands and expectations of working people. This results in organizations having problems finding enough suitable personnel, and at the same time there are people who cannot get work. This situation has undesirable consequences for both society as for PwDs. It is important to ensure a labor market participation as high as possible because it results in a utilization of human capital and economic growth. This will strengthen the Dutch economy and support for the social security system will continue to exist as a result of more active people in the labor market (Zijlstra et al., 2012).

## 2.4 History of Inclusion

Throughout history, the most dominant way of understanding disability was based on the medical model (Smith & Bundon, 2018). The medical model of disability focusses on disability as an individual deficit with the need to be cured (Shakespeare, 2006). The medical model perceives disability as caused by factors within the individual (Llewellyn & Hogan, 2000). However, the medical model of disability has been heavily criticized (Smith & Bundo, 2018). The first problem of the medical model is that for defining disability, it relies purely on bio-physical assumptions of normal resulting in defining PwDs as defective or not normal while others, without a disability are defined as normal and definitive (Meekosha & Shuttleworth, 2009; Smith & Bundo, 2018). Another point of critique is the localization of the disability 'problem' solely within the body of the individuals rather than explaining disability as an artefact of society (Goodley et al., 2012; Thomas, 2007). As result of the growing criticisms on the medical model of disability, the social model of disability has been developed as an alternative understanding of disability (Smith & Bundo, 2018). The social model of disability; which identifies disability as a culturally and historically phenomenon (Shakespeare, 2006), and states disability is caused by the environment which not meets the needs of PwDs (Llewellyn & Hogan, 2006). Furthermore, the social model of disability focusses on social change and revolution (Goodley, 2017; Oliver, 1996).

### 2.4.1 Social Inclusion

Cobigo et al. (2016) proposed a framework for social inclusion. The framework illustrates that social inclusion is centered on experiencing meaningful and expected social roles. A social role can be seen as meaningful from the perspective of the individual when the role meets personal expectations, choices



and needs and is meaningful from the group's perspective when it fulfills the community's expectations, choices and needs. The mutual satisfaction from both parties, in this case from the board and the person with an occupational disability builds trust and reciprocity (Cobigo et al. 2016) Reciprocity relies on trust that the person has the competency to perform the expected social roles (Lemay, 2006). Performing these valued social roles in combination with enjoying reciprocal relationships lead to a sense of belonging to a group (Western, McCrea & Stimson, 2007).

#### 2.4.2 Disability studies

Disability studies is also related to this social approach. In the 1970's, Disability Studies emerged as a research field that studies disabilities and approaches disabilities as a social, cultural, politic, historic and relational phenomena (Rioux, 1997). A disability is defined as "the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers" (Goodley, 2016). Gabel (2005) defines disability studies as: "an emerging interdisciplinary field of scholarship that critically examines issues related to the dynamic interplays between disability and various aspects of culture and society. Disability Studies unites critical inquiry and political advocacy by utilizing scholarly approaches from the humanities, humanistic/post humanistic social science and the arts" (Gabel, 2005). Several goals are related to disability studies by Goodley and van Hove (2005), the first goal is collaborating with and increasing the politicization and expertise of PwDs. The second goal is to theorize and understand the different conditions of disablement, exclusion, oppression and marginalization of PwDs. The third goal according to Goodley and Van Hove (2005) is developing social theories that expose the relational, material, cultural, political and social conditions of disablement. Furthermore, it is a goal to promote professional practices that create opportunities rather than limit them and to criticize and inform anti-discriminatory disability legislation and policy. The fifth goal is developing practices through which PwDs fully participate in the research process. It is also important to encourage the individual and collective responsibility of people 'without restriction' to change the conditions of disablement. The last goal is to build and develop a model on disability as a social affair; promote a participating community. Participation is essential, also for people with a disability. Participation includes more than presence: belonging and active listening are crucial (Biklen, 1992). Perenboom & Chorus (2003) state that performance in itself is not necessarily related to participation. Participation is about being in control measured by "the possibility to do or gave somebody doing things the way I (the respondent) want". A person is participating by fulfilling personal goals and his or her societal role (Perenboom & Chorus, 2003). Disability Studies is about talents, dreams and desires of people with a label (Claes, 2014).

## 2.5 Stakeholders

An overview of the stakeholders in this research is given in order to take all the different organizations and individuals into account.

### 2.5.1. SPZ

SPZ is a foundation which supports people with an ID by offering financial support to associations and foundations to carry out projects. The capital of SPZ is derived from a merger between various foundations in 2009. SPZ wants to support projects which focus on helping people with an ID and which give them the opportunity to develop themselves. With subsidy money, for example, they develop a new method for guidance, a new technology or a new working method. New solutions that make life easier for as many people with an ID as possible. According to the principle ‘practice what you preach’ SPZ searched 3 years ago for a board member with a MID. As a result, all parties have experienced in practice what it means to become an inclusive board, where people with and without a disability work together on an equal level (Stichting SPZ, n.d.) SPZ will be studied during this research. Within SPZ various stakeholders exist.

#### 2.5.1.1 The board of SPZ

The board consists of six board members, one management assistant and a coach. The board members do not receive any salary from the foundation but do receive a yearly compensation for their expenses. SPZ has no employees. The meetings are free of any paper; hence every board member receives a tablet at the beginning of their term, which they can use for the meetings.

The board of SPZ believes it is important that an experiential person with a mild intellectual disability is included in the board as well, however, with coaching for this person as important condition (Stichting SPZ, n.d.).

#### 2.5.1.2 Coach

To support the board member with a MID, a coach is hired by SPZ. The coach is an employee for the national interest organization by and for people with an intellectual disability in the Netherlands. The vision of this organization consists of the believe in a society where people with a disability can simply participate, with the same rights and obligations as all other citizens. This participations requires guidance and coaching from a coach.

### 2.5.2 People with an ID

In 2014, 142.000 people in the Netherlands had an ID (RIVM, 2014). All people with an ID are potential stakeholders within this research because of their interests in the potential outcomes. This research will focus on inclusion in all levels of an organization which may lead to increased employment possibilities for people with an (intellectual) disability.

### 2.5.3 Dutch Government

As mentioned before, the Dutch government introduced the Participation Act in 2015 (Borghouts, 2014) with the aim to become more inclusive by increasing labor market participation for PwDs (Rijksoverheid, 2016). The outcomes of this research may stimulate labor market participation in all levels of organizations which can contribute to a successful implementation of the Participation Act. Furthermore, a labor market participation as high as possible will help strengthen the Dutch economy and support for the social security system will continue to exist as a result of more active people in the labor market (Zijlstra et al., 2012).

### 3. Theoretical Background

To explore what is needed to become an inclusive board, it is important to understand what is meant by inclusion. In the following chapter inclusion and its different categories will be explained. Additionally, there are more requirements to become an inclusive board than solely hire a PwDs. A conceptual framework of the concepts of ‘inclusive climate’, ‘disability mainstreaming’, and ‘the-inclusion-at-work-framework’ of Shore et al., (2011) will further delineated the criteria and needed adjustments for inclusion and emancipation within the labour market.

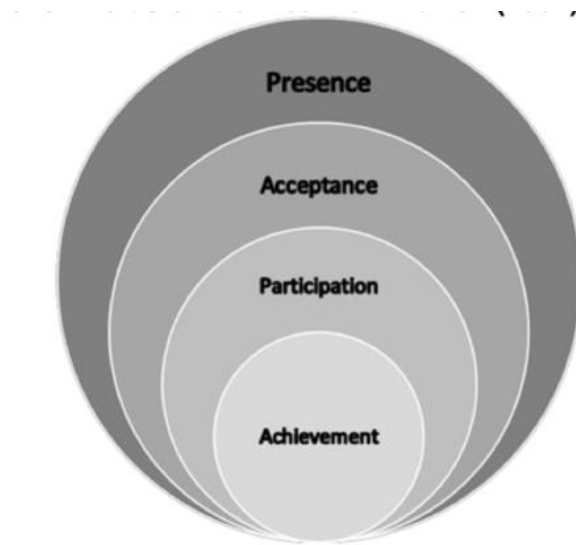
#### 3.1 Inclusion

Inclusion is related to quality of life and means that every citizen can participate in all facets of society in his or her own way, without the existence of dominance or marginalization (Houten 2009; Kröber, 2008; Ruigrok, 2002; Schalock & Verdugo, 2002; Young et al., 2005). According to Schalock and Verdugo (2002) there are 3 ecosystems levels in which inclusion occurs. The *micro-level* defines people with a disability having accepted social roles in the form of for example, neighbor, volunteer or employee. People have a social network and are not only supported by professionals in the workplace but also by informal networks like colleagues or classmates. At the *meso-level*, people with a disability experience social acceptance and appreciation for the roles they play. The *macro* level is the level of the government. This level is about coherent legislation and regulation aimed at inclusion and increasing the chances and opportunities for people with a disability in this area. An example of inclusion at the macro-level is the introduction of the Participation Act.

Physical presence within a community does not guarantee inclusion, because taking part in activities and using communal facilities does not necessarily result in meaningful social contacts or reciprocal connections with others (Ager et al., 2001). Hence, inclusion is not only about physical presence but is also about the subjective feeling of belonging to a group (Cummins & Lau, 2003; Hall, 2009).

In 2004, Farrell proposed that inclusion not only comprehends *presence* but also *acceptance*, *participation* and *achievement*. Even though Farrell’s categories are focused based on children and inclusion within school, it gives a clear definition on what inclusion should entail. *Presence* refers to the extent to which PwDs attend for e.g. lessons in local schools or attend work or committee meetings. The extent to which e.g. fellow students, colleagues, teachers, neighbors or supervisors welcome all PwDs as full and active members of their community or company refers to *acceptance*. *Participation* addresses the extent to which PwDs contribute actively in activities. Lastly, *achievement* refers to the extent to which PwDs learn and develop e.g. positive views of themselves. The PwDs need to achieve good levels of achievement in both their work as behavior. The same study of Farrell suggests that these categories

are interrelated components which can be modelled as shown in figure I. This figure reflects how the first three categories influence the fourth (Farrell, 2004; Riviere, 2016)



*Figure I - Interrelated categories of inclusion*

### 3.2 Inclusive Climate

An inclusive climate is required to ensure a successful labor market participation of PwDs (Bonaccio et al., 2019; Pless & Maak, 2004). An inclusive climate means that PwDs perform well and that hidden talent emerges (Pless & Maak, 2004). The aim of creating an inclusive climate is that every employee feels respected. An inclusive climate includes values as acceptance, tolerance, mutual respect and cooperation (Downey et al., 2015; Khan et al., 2019; Klimoski & Doanhue, 1997; Nishii, 2013). According to Pless & Maak (2004) the creation of an inclusive climate happens in four phases (Figure II). First, it is important to create awareness and the understanding about the different background of all employees in the organization. In the second phase a vision of inclusiveness is developed (Nishii & Rich, 2014). This vision will emerge in the business principles in the third phase when reflection on the principles of the organization is important. The last phase is about adjusting HR processes such as adapting the recruitment process to diversity and conducting performance evaluations to develop confidential relationships and receive feedback for personal development (Pless & Maak, 2004). Developing an inclusive climate is necessary in the organizational strategy for achieving higher long-term performance (Lirio et al., 2008).

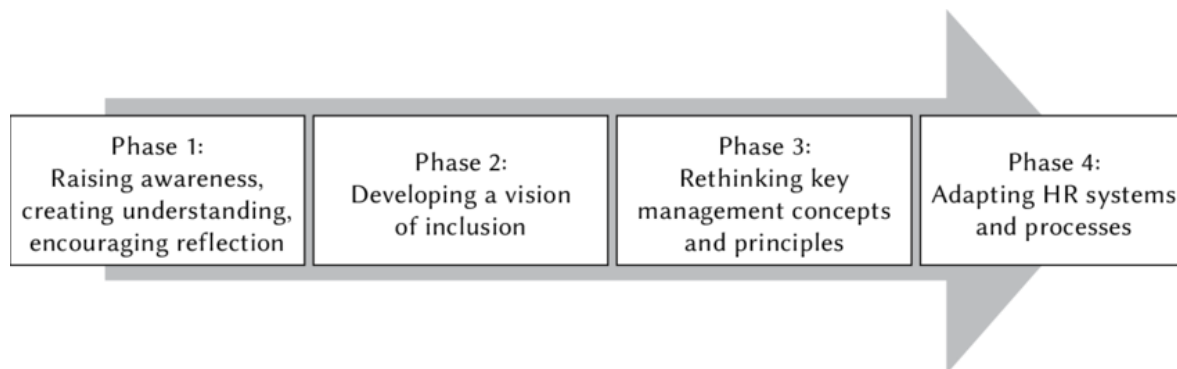


Figure II – The creation of an inclusive Climate

### 3.3 Disability mainstreaming

Disability mainstreaming is a strategy to reinforce inclusion, which is a process of assessing and addressing the possible impact of any planned action on PwDs. Besides, it helps to address the barriers that exclude persons with disabilities from the equal enjoyment of their human rights. Mainstreaming is about challenging discrimination and involves the ability to ensure inclusion for PwDs by supporting basic services. Resulting in the opportunity to enjoy the equality of access to those basic services as for example education and health (UNRWA, 2013). The aim of disability mainstreaming is to embed disability considerations while programming, within project design, policies, protocols and during staff training. In order to find structured ways of responding to the needs and circumstances of PwDs, disability mainstreaming involves a process of supporting programmes (UNRWA, 2013).

### 3.4 Inclusion in work

Shore et al., (2011) proposed a framework for inclusion (figure III), with potential contextual factors and outcomes associated with inclusion.

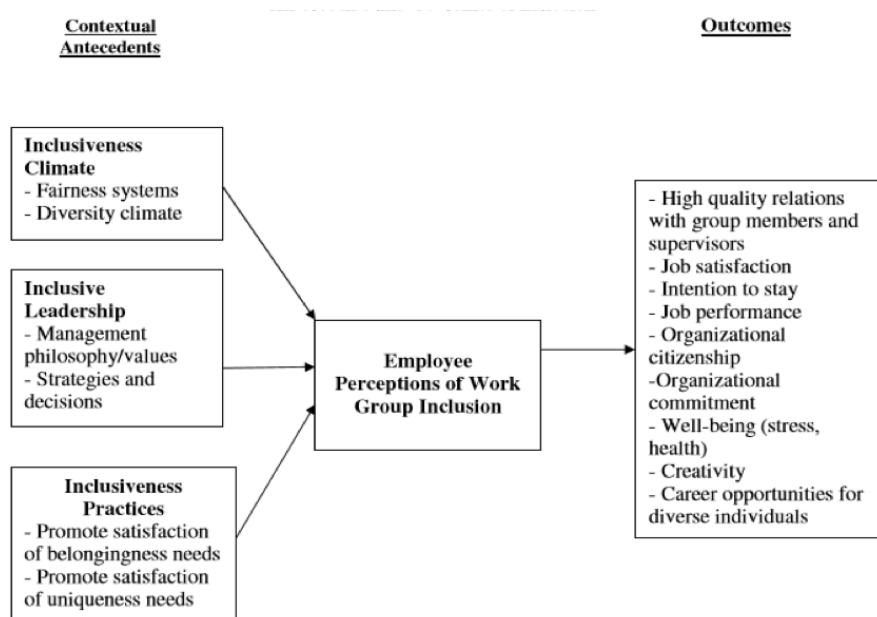


Figure III – Framework for inclusion – Shore et al., (2011)

Within their framework, they propose contextual factors which may contribute to perceptions of inclusion. Contextual factors are seen as part of the environment, which provides stimuli to all individuals. Furthermore, contextual factors are used for the interpretation of information (Mowday & Sutton, 1993; Weick, 1979). Contextual antecedents include leadership and climate which both contribute to group processes building a work environment for the individuals' perceptions on inclusion (Bilimoria et al., 2008). One of these antecedents is inclusive climate, in which policies, procedures and actions of organizational leaders are in line with an equal treatment of all existing social groups. In an inclusive climate there is particular attention to groups which are stigmatized within society or had less opportunities in history (Shore et al., 2011) and the organization will value the contributions of all employees (Gonzalez & DeNisi, 2009; Leslie & Gelfand, 2008; McKay et al., 2009). The second antecedent in the framework of Shore et al., (2011) is inclusive leadership because direct supervisors can have a strong impact on the experiences of employees, especially in diverse groups. Direct supervisors can have a strong impact on the experiences of employees, especially in diverse groups. Therefore, it is another factor in the framework of Shore et al., (2011). To become more inclusive, the top management of an organization should take the lead in hiring people with an occupational disability and must propagate this vision (Lengnick-Hall et al., 2008). The management or manager plays an important part in the development of an inclusive culture. Necessary competencies of managers are valuing diversity, adjusting norms and values and openness to experiments (Lirio et al., 2008). Leaders are important in creating an organizational culture of inclusion because leaders can establish a story which supports inclusion and actively engages existing resistance towards inclusion or diversity (Wasserman et al., 2008). Thirdly, inclusive practices are emerged to enhance inclusion, such as participation in decision making, information access (Nishii, 2010), the facilitation of communication (Janssens & Zanoni, 2007) and conflict resolution procedures (Roberson, 2006). The contextual antecedents influence the employee perceptions of work group inclusion which may result in several outcomes such as high-quality relations with group members and supervisors, job satisfaction, intention to stay, job performance, organizational citizenship, organizational commitment, well-being, creativity within the workplaces and career opportunities (Shore et al., 2011).

### 3.5 Conceptual Framework

The aim of this study is to explore how boards can become more inclusive in order to create more suitable workplaces for people with a MID on a larger scale. The model (Figure IV) used for this research is based on the 4 phases of inclusive climate as proposed by Pless & Maak (2004), on the interrelated categories of inclusion by Farrell (2004), disability mainstreaming by UNWRA (2013) and the framework of inclusion as proposed by Shore et al., (2011). The concept of belonging is included in this framework, instead of the achievement category of Farrell (2004). Achievement solely refers to the

subjective extent to which PwDs learn and develop positive views of themselves while belonging is seen as a key aspect of social inclusion (Garbutt, 2009). This approach of concepts will be used as the ‘lens’ through which the data will be ordered and eventually analyzed. Therefore, operationalization of inclusive leadership, inclusive climate, the different categories of inclusion and disability mainstreaming is needed. The concepts that were thought to be most significant for this research are included in the conceptual framework. A short delineation will follow which will result in a set of sub research questions to further guide the research.

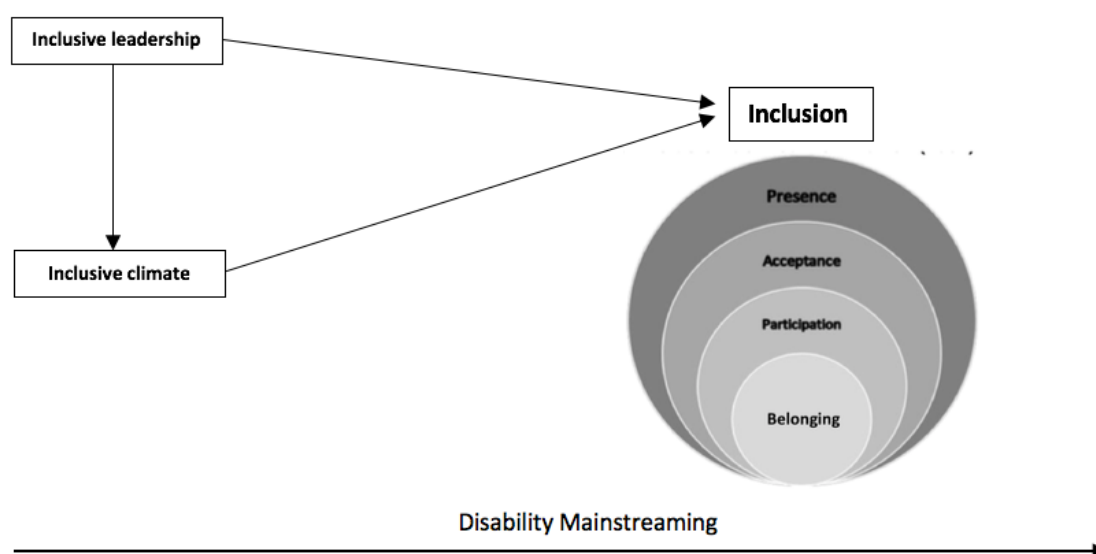


Figure IV – Conceptual Framework

### 3.5.1 Inclusive leadership

The first concept focuses on inclusive leadership. Inclusive leadership is about involvement in the hiring process, who decided to hire a PwDs and their motives. Moreover, strong impact on the experiences of employees referring to the perceptions of the board members on the functioning of the chairman is part of inclusive leadership. Inclusive leadership furthermore entails the establishment of a story which supports inclusion by attempts to create an inclusive climate

### 3.5.2 Inclusive Climate

Inclusive climate is the second concept which is divided into four phases. The first phase is about raising awareness, creating understanding and encouraging reflection. In this phase, the importance and relevance of inclusion is emphasized. In the second phase, a vision of inclusion is developed which refers to the vision of the board on inclusion. Rethinking key management concepts and principles is the third phase and is about the changes discussed in order to become inclusive. Within the last phase



refers to the changes made in organizational processes and structures. Hence, the HR systems and processes are adapted.

### 3.5.3 Disability mainstreaming

The third process is disability mainstreaming, a process of assessing and addressing the possible impact of any planned action on PwDs. Disability mainstreaming entails the permanent adjustments made to function as inclusive board. Moreover, disability mainstreaming focusses on how the progress of PwDs and the functioning of the board is measured.

### 3.5.4 Outcomes: inclusion

The last concept in the conceptual framework is inclusion. Inclusion is not only about being present but consists of three other categories that are interrelated. However, the first category of inclusion is presence. Presence is about the extent to which PwDs attend board meetings and board activities. The extent to which fellow colleagues welcome all PwDs as full and active members in their board refers to the second category of inclusion: acceptance. Participation is the third category and focusses on which degree PwDs contribute actively in board activities and co-create decision. The extent to which PwDs feel like they belong to the group refers to belonging, the last category of inclusion.

## 3.6 Sub questions

To answer the research question *“What lessons can be learned from a board with a board member with a mild intellectual disability regarding feelings of inclusion?”* the following sub-questions can be derived from the conceptual framework.

- \* What are the adjustments (on individual and organisational level) made before becoming an inclusive board and what are the current practices?
- \* What is the role of the chairman in relation to the inclusiveness of the board?
- \* What are the facilitators and barriers for a board with a board member with a MID?

## 4. Methods

This chapter will explain how this research was conducted and what tools were utilized. Furthermore, the section will discuss the research design, the research population, the instruments that were used, the data collection and the data analysis. Finally, it will discuss the validity and reliability of this research.

### 4.1 Research design

No earlier research has been conducted about how to make boards more inclusive and what contributes to a successful placement of someone with an intellectual disability in an administrative function.

To gain insight into the functioning of the board and their behaviors and systems a case study with a qualitative approach was carried out (van Teijlingen, 2014). The case study includes the board members of SPZ who have experience working together with a board member with an intellectual disability. The qualitative research included semi-structured interviews using two different topic lists (annex 1 & 2) a subsequent thematic analysis and participant observation. Semi-structured interviews are an open-ended interview technique, which follow a general script and cover a list of topics (Gray, 2014). A semi-structured interview is seen as particularly useful when exploring someone's perspective towards a topic (Van Teijlingen, 2014). The use of a semi-structured method gives the interview direction but also leaves room for emerging topics and results in an in-depth understanding of the board member's perceptions (Green & Thorogood, 2014). With the use of probing, new leads can be followed (Verhoeven, 2014). Furthermore, semi-structured interviews allow the respondents to discuss their experiences in greater detail and length and gives the interview the possibility to ask new question while elaborating on the given answers, resulting in fully covered topics (Gravetter & Forzano, 2018; Gray, 2014; Green & Thorogood, 2014). This interview used a responsive evaluation approach in which evaluation is not exclusively focusing on the assessment of the effectiveness of (policy) programs and interventions (Abma & Stake, 2001; Guba & Lincoln, 1989; Stake & Abma, 2005). Responsive evaluation also focused on engagement among and with stakeholders and the issues of stakeholders. The aim of responsive evaluation is to increase both personal as mutual understanding of all stakeholders (Abma, 2006). The non-participatory observation method was used with the aim of gaining more familiarity with the board members and their practices (Gray, 2014). Hence, a board meeting was observed, and field notes were made.

### 4.2 Research respondents

The research respondents were the board members of SPZ. Board members were considered for participation if they had been together in the board of SPZ with a board member with a MID. The research participants were, following the criteria above, selected through purposive sampling (Etikan et al., 2016; Gravetter & Forzano, 2018; Gray, 2014). The purposive sampling technique is a non-random

technique, the researcher decides what needs to be known and will search for people who can provide this information (Bernard, 2017). Purposive sampling involves both the identification as the selection of groups of individuals that are proficient and well-informed with a phenomenon of interest (Cresswell & Clark, 2017). The respondents were recruited with help of one board member, who shared the contact details of the other board members. All board members were approached and if they agreed to participate, interview appointments were made.

### 4.3 Data collection

The interviews were conducted face-to-face which helped to establish a trusting relationship between interviewer and respondent and rapport was built through polite and respectful behavior of the interviewer. Furthermore, the interviewer made an appropriate appearance, used proper and understandable language and was listening empathically. Emphatic listening encourages the participant to open up, which result in richer data (Bernard, 2017). Furthermore, a face-to-face interview allows more time to go in-depth in the subjects (Gravetter & Forzano, 2018; Gray, 2014).

The data was collected by recording the interviews. The recordings allowed the author to transcribe and code the collected data. The interviews were literally transcribed, so no information was missed. The transcripts were imported in the coding program MAXQDA.

The interviewees were asked to choose the location in which the interview would take place to ensure that there were comfortable during the interview and shared all the information they thought was essential and relevant for the study (Herzog, 2005). Green & Thorogood (2014) state that interviewing in a natural environment, such as someone's workplace or home results in an increase of quality of the research because the data will be collected in a relevant context. Before the start of each interview, the participants were asked to sign an informed consent (annex 3). The importance of recording the interview was explained and the participants were asked for permission to record. (Bryman, 2012). The interviewer received permission from all board members to attend a board meeting. Hence, a board meeting was observed, and field notes were made.

#### 4.3.1 Interview design

The interviews started with a light conversation in which the respondent could get used to the situation, some demographics details were established and insight in the respondent's function within the board was gained. The interview was held with a topic list based on the conceptual framework (annex 1) to ensure all relevant topics were covered. A different topic list was developed for the board member with a MID (annex 2). Further probing questions were asked based on the given answers. The interviews were completed by ending with a summary of what has been said and by providing more information about the further research and the ethical considerations. (Fox, 2009).

#### 4.4 Data Analysis

The data was analyzed by using an inductive approach because the identification of themes was based on the conceptual framework. However, in case of identifying themes which did not fit one of the existing codes could give rise to a new concept. The data was analyzed with use of a thematic analysis (Braun & Clarke, 2006). The aim of thematic analysis is identifying returning themes which are important and say something about a specific topic or issue and to determine the overarching themes common to each interview (Braun & Clarke, 2006).

The data was coded in 3 phases. Prior to these phases, a coding tree will be created based on the existing theory. The first phase was open coding. During this phase the data was categorized, and the coding tree was extended with emergent codes (Boeije, 2010). Emergent codes are the new codes which include the unexpected information emerging from the interviews (Gilgun, 2014). The interviews were open coded to investigate which themes were emerging, so adjustments could be made to the topic list for future interviews (Gray, 2014). The second phase in analyzing data is axial coding. During the axial coding phase, connections between categories were made. Within this phase was also checked if all fragments were coded correctly and if codes were missing or duplicated. During the axial coding phase, the amount of master codes might decrease as result of becoming a sub code (Boeije, 2010). The last phase of the coding process is selective coding. During this phase, there was searched for relationships and for explanations for relationships in order to answer the research question. After the merging of all codes, recurrent similar and interesting codes were identified and sorted into potential themes. Afterwards, the potential themes were refined. Subsequently, a definitive list of all themes was identified in which all themes were named and identified. The essence of every theme in relation to the data will be formulated. Thereafter, the most recurring themes and most remarkable result were selected to report (Braun & Clarke, 2016).

#### 4.5 Credibility and dependability

The extent to which the study's findings are trustworthy and believable for others refers to credibility. Dependability is the extent to which the findings are consistent in relation to the context in which they were generated (Frambach et al., 2013; Gray, 2014). Prior to the interviews in this research, the interviewer participated in an interview training and developed the interview design together with an experienced qualitative researcher, contributing to the inter-respondent consistency which increased the dependability of the results (Marsden & Wrights, 2010). In this research there is inter-judge reliability as a result of the interviews which were transcribed by one researcher and every transcript was reviewed by a second researcher to check for true value of evidence and ethical implications. This increased the transferability and credibility of the researcher (Green & Thorogood, 2014). At the end of the interview, the interviewer did summarize the main concepts mentioned by the respondent to ensure right interpretation of the words. Furthermore, the interviewee was given the option to receive a summary of

the transcript after the interviews for a member-check resulting in an increase of confirmability (Birt et al., 2016; Frambach et al., 2013).

#### 4.6 Ethical considerations

Before the interviews took place, the respondents were informed about both the purpose, and the content of the research and informed consent was obtained (annex 3). Informed consent guarantees voluntary participation of the participants and granted the researcher to use the collected data for the research. The voluntary participation was based on a complete understanding of the possible benefits and risks that participation in the research entailed (Gravetter & Forzano 2018, Gray, 2014). A different informed consent (annex 4) was used for the board member with a MID to ensure she also understood what she was signing for. The informed consent was in Dutch, considering all the participants understand, write and speak Dutch fluently. All participants were given the freedom to withdraw at any moment in the research and to exclude their disclosed information from the research. In order to preserve privacy of all respondents, the data is treated with consideration. Any personal details regarding the identity of the respondents is excluded from the transcript. There will be limited access to data and audio tapes, and transcripts are destroyed after finishing this research.

## 5 Results

In this chapter, the themes that derived from the data analysis are described. First, an in-depth description of the case is given (5.1), including a better understanding of the key participant in this study, to familiarize with her character and background. For all respondents, fictitious names are used. Then in subparagraph 5.2, the most recurrent themes and lessons learned from this case are presented. In subparagraph 5.3 the results in line with the conceptual framework are described in order to answer the research question: *“What lessons can be learned from a board with a board member with a mild intellectual disability regarding feelings of inclusion?”*

### 5.1 Case description

#### 5.1.1 Organization

To understand how inclusion is established in this particular case, it was important to understand, to a better degree, what sort of organization SPZ actually is. Of course, SPZ’s main objective is to support projects which focus on helping people with an intellectual disability and which give them the opportunity to develop themselves and they seem to try to achieve this by meeting together 6 times a year. The board members do not receive any salary from the foundation but do receive a yearly compensation for their expenses. The board member with a disability is not an exception. However, it turns out, the board duties are performed during her working hours, for which a salary is received. Both the management assistant, which is a freelancer, and the coach do receive salary from the foundation. Most board members have a background in social pedagogy or social work. As mentioned by 4 respondents, the motive of SPZ is really to include their own target group as part of the decision-making processes hence the board decided 2.5 years ago to hire a board member with a MID.

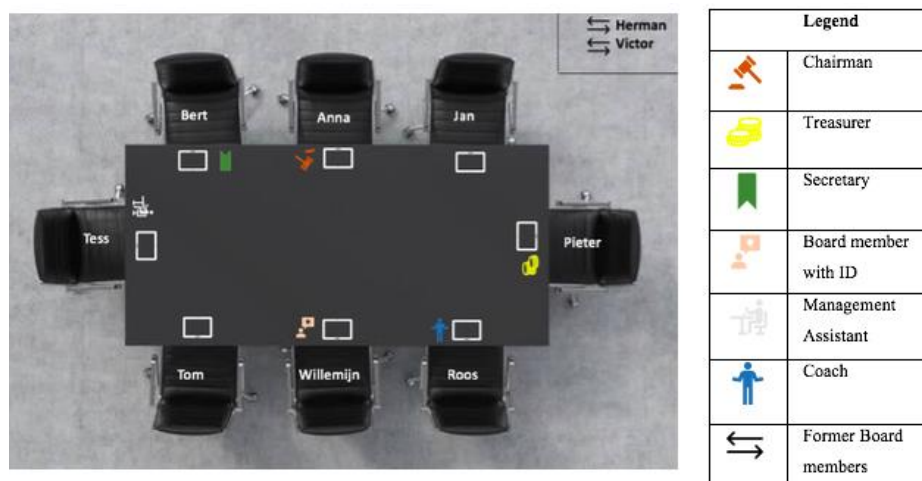


Figure V: a visual representation of the board members

In terms of specific backgrounds, four of the board members had their education in the social pedagogical field, including Bert (left, up), board member since 2009 and Jan (right, up), board member

since 2017. Also, Anna (middle, up) has a background in the social pedagogical field and is a board member since 2018 and chairman since the beginning of 2019. Anna has also personal experience with intellectual disabilities. The last board member with a social pedagogical background is Tom (left, bottom). Tom is a board member since 2013 and was intensively involved in the hiring process of Willemijn. Tom is the only board member not included in this research because there was no possibility to interview him. Willemijn (middle, bottom) is 33 years old and has a MID. She joined the board in 2016 and represents the target group in various organizations, foundations and initiatives. Roos (right, bottom) is not an official board member but is the coach of Willemijn since the beginning of 2016. Roos (left, middle) has professional and personal experience with intellectual disabilities. Pieter is the treasurer of the board since 2009 and has a background in finance. Lastly, Tess is also not an official board member but works freelance as the management assistant of the board since 2009. Tess has a background in humanistics.

Victor and Herman are both former board members and left the board in December 2018. They both were board members since the start of the foundation in 2009. Victor was an entrepreneur and has a 41-year-old daughter with an intellectual disability. Herman is 76 years old and has been chairman of the foundation since 2009. He became honorary chairman when he left the board in 2018. He had a career as mayor in two different municipalities.

#### 5.1.2 Board member with a disability

The board member Willemijn has a mild intellectual disability and is diagnosed with PDD-NOS. Willemijn explains having problems with learning, her experience can differ from others because it is harder to separate fiction from non-fiction. Furthermore, she expressed to experience difficulties with maintaining social contacts and expressing deeper emotions. Also, nonverbal communication is a pitfall and feeling emotions of others is harder on Willemijn.

*“I have no partner, I have no children. Love, anger, things like that, the emotions at the bottom of the iceberg are very difficult for me. And difficult to express, but also difficult to deal with from other people.” (Willemijn)*

She followed special education and finished a course as administrative assistant. Afterwards, she worked in a social work place, which she did not like much. At some point, she started working for an organization which defends the interests of people with disabilities and supports them among others with coaching. At this organization, Willemijn has a permanent contract and works for 32 hours a week. Her main task is representing the target group in several organizations and board functions. During her work, she receives guidance from a coach.

*“And some things she [the coach] helps me with because for her it is just easier because she can better distinguish main issues and side issues in projects where I then think along with that we approve or not approve. So, she [the coach] does a lot of preliminary work in that because that is hard when you have to make decisions and you have to make your point. And well, she supports me in that. And my role really is as an experience expert, the projects that are being applied for have that sense, they really are for the people [PwDs] themselves.” (Willemijn)*

### 5.1.3 Coach

When Willemijn started her function as board member, her coach (Roos) was hired by the foundation to guide Willemijn. Roos supports Willemijn while preparing for meetings. Roos is also present for support during the board meetings. The coach is not a board member but solely hired to coach. This consists among other of pre-reading all applications and summarizing them for Willemijn.

*“And there are a lot of them, there are a lot of pieces of text and I really read differently than she does. I can separate main issues from side issues faster, I see faster this is the core, that's what it's about. For her it is a broth of letters and sentences, it is much more difficult for her to separate everything.” (Roos)*

The board members describe the job of the coach as helping to structure the subsidy proposals. The board members share different opinions about the coach. Five of the respondents thought that the coach was essential for the success of the board member with an ID and are convinced coaching is a requirement for an inclusive board.

Victor: *“Sometimes the coach said, we discussed this in the preliminary meeting and I found that too compelling. Willemijn must form her own opinion. Then I think how independent is this [Willemijn's opinion]? That is a question that you encounter.”* However, Victor agrees Willemijn will always need coaching.

Three respondents felt that Willemijn could work without coaching during the meetings. At the same time, they all agreed coaching is essential in preparing the meeting. Thus, during the board meetings Willemijn could participate without a coach. Pieter thought it might increase the participation of Willemijn during the meetings. There is a possibility that Willemijn could speak more freely during the board meetings without a coach because she is now sticking to the prepared notes.

Three board members also point out that they are convinced Roos never speaks for Willemijn.

*“Sometimes Roos gives her own opinion but then it is also clear that it is her own opinion.” (Tess)*

Willemijn also believes coaching is essential for her to participate actively in a board (see box 1).



**Box 1:**

Willemijn and Roos work together for almost 12 years. This collaboration started with a preliminary process in which trust was gained and a bond was built. Willemijn and Roos are used working together. Willemijn functions better when she is working together with Roos and she is used to always do things together.

A few years ago, Willemijn started working in another board without a coach. She is not very enthusiastic about this position because Willemijn has the feeling she cannot fully function without Roos present. Without coaching Willemijn has the feeling she has less support and is taken less seriously as a board member. She feels insecure without Roos present.

In her board function with SPZ, Willemijn receives constant coaching from Roos, during the preparation and the meetings themselves. The presence of Roos gives Willemijn the feeling she is taken more seriously and is a better version of herself as board member. Roos always helps Willemijn by prereading the research proposals and highlighting main and side issues. Furthermore, Roos provides guidance and coaching in how Willemijn should fulfill her role as board member. Willemijn is very positive about her collaboration with Roos because it gives her a better role as board member. When Roos helps her during the preparation of the board meetings she goes to the meetings with confidence.

Source: interview Willemijn (April 2019)

#### 5.1.4. Recruitment process

In 2016, when there was an open function, the board started a search for a board member with an ID. The main reason to include a board member with a MID in the board was to make the voice of the target group heard. The board was looking for someone who could represent the target group and who was able to distance herself from her own views, on behalf of the target group.

*“But we still missed a bit of what the handicapped person wants, and we gradually noticed social developments that people with a disability could very well make clear what they needed and what they wanted.” (Bert)*

The aim was to find someone with a MID who could be an equal board member. Requirements in advance where a board member with a MID who could contribute in conversations, could participate in all discussions, could make decisions and was willing to take legal responsibility. The function was created, there was no open interview process, but a specific person was searched for the position. Three board members of SPZ went for a meeting with the foundation Willemijn was working for and told them about what kind of board member they were looking for. Two board members of SPZ already knew Willemijn from other organizations or board functions and suggested her because they knew about her ability of representing the target group. Willemijn was known for her ability to contribute in discussions and represent the opinion of the target group instead of solely her own experiences. Eventually, Willemijn was hired after a few conversations with her coach, 3 board members of the foundation and the director of the organization Willemijn was working at.

### 5.1.5 Board meetings

The board of SPZ meets 6 times a year and these meetings take approximately 2 hours. The chairman and management assistant explained that they set the agenda for these meetings together. The agenda is always more or less the same. The meetings take place in a rented meeting room because SPZ does not have a physical office. Box 2 is a narrative about the board meetings of SPZ. The box gives an in-depth description of an average board meeting and helps to create understanding of the functioning of the board with a board member with an ID during their board meetings. To give an impression about how the collaboration is going, see box 2.

#### **Box 2:**

One by one, all board members enter the meeting room. Everyone shakes hands when entering the room. Seats around the conference table are chosen randomly: *"you are sitting here all alone, I will take the seat next to you."*

Except for the chairman and Willemijn, they pick their seats with premeditation to sit opposite one another or side by side. The meeting starts with the opening and announcements. Willemijn and Roos share a tablet during the meetings which Roos controls. Roos takes notes for Willemijn during the meeting. Roos sometimes whispers some extra **explanations** to Willemijn in between discussions. Especially during discussions which were not on the agenda and **could not be prepared**. Some discussions go **very fast** because board members are keen on sharing their opinions with the rest of the board. These are harder to follow for Willemijn and she is not really contributing to these discussions. However, overall there is attention for Willemijn and the other board members are waiting for her opinion. During the discussion over finances, Anna gives an extra explanation of some numbers for Willemijn. When the applications for subsidy are discussed, everyone listens carefully and with extra attention to Willemijn's opinion: *"if she [Willemijn] has a real critical opinion about a project, I always think, we must honor this opinion."* Anna or other board members ask for her opinion about the projects. Her opinion is mostly formulated and explained clearly, with **her notes** from the preparation with Roos in front of her. Willemijn and Roos are asked to leave the meeting due to a conflict of interest in one agenda item. When they both left the room, the discussion continues on the same pace as before. After a few minutes Roos and Willemijn are re-invited for the meeting. Willemijn enters the meeting room with a joke: *"And, we are back after the commercial break"*.

Willemijns' contributions and presence are valued by all board members. All parties are enthusiastic about this collaboration.

Source: observations board meeting and interviews respondents (2019)

During the meetings, Roos gives extra explanations to Willemijn in between discussions. These extra explanations are especially necessary when subjects are discussed which were not on the agenda and could not be prepared. The contribution of Willemijn, during the conversations or discussions which are not prepared, is very little. There is also a difference in the attitude of the board members. As mentioned in box 2, overall there is attention for Willemijn, and her colleagues wait for her to share her opinion. However, in discussions in which a strong personal opinion exists among the board members, the conversation goes faster, and the main focus is convincing the others hence taking Willemijn into account fades a bit to the background. Nevertheless, Roos is ready to interfere for Willemijn when needed. Willemijn prepares the meetings with Roos very carefully and makes notes during this preparation. These notes help her with sharing her opinion during the board meetings.

## 5.2 Lessons learned

In this subchapter we will discuss the lessons learned from this best practice case. The lessons are divided in procedural lessons and practical lessons.

### 5.2.1. Procedural Lessons

#### 5.2.1.1 Trial period and evaluation

The first lesson learned of this case study is the importance of a trial period and evaluation afterwards. The board membership started with a trial period of 1 year. All board members present in the board at that time mention the trial period and the added value of it. The trial period was used to see how an inclusive board would work in practice, without any formal responsibilities. The trial period was not only introduced for the board but also for the board member with an ID. Willemijn emphasized the added value of a trial period during the interview because she really had the feeling when she signed her contract, everybody was in favor of her becoming a board member. A board function comes with a responsibility, as official board member you are jointly and individual responsible if something goes wrong with the funds. The trial period gave the opportunity to experience how it works in practice, without the pressure of legal responsibilities. After evaluation with all stakeholders involved, the board position was formalized. Herman, the chairman in the period Willemijn was hired, emphasizes the importance of a trial run because the board function should result in an interaction. Both sides should be considered in the evaluation.

*“Yes, I would always do that [trial period]. That is from two sides. You must also give the person who comes in a chance. Suppose she would say I do not feel at home on this board at all, it just seems like I'm sitting there for show. Then it starts to work against her, then it becomes counterproductive. See, I have a limitation. Talking about quality of life, talking about inclusive society, you should look at that board. Then it starts to work counter-productively.” (Herman)*

#### 5.2.1.2 Affinity with the subject

In order to increase the participation of a board member with an ID it seems vital to include a board member with affinity for the activities of the board. The inclusion of a board member is easier and more obvious when it relates to the life of the person with an ID. When Willemijn feels more at home in a subject, she contributes more during the meetings.

Willemijn: *“You must have a certain interest in it [the subject]. But if you have the motivation for it, and you like the subject, so if you are really interested in the subject, I would definitely recommend it if you get that opportunity within an organization.”*

#### 5.2.1.3 Practical expertise and expert knowledge

Willemijn's main task within the board of SPZ is being a representative of the target group. She was hired in order to make the voice of the target group heard. Additionally, it became clear through the interviews because it was mentioned by all board members, that it is necessary to speak for all people with an ID and not solely refer to personal experiences. Possessing only experiential knowledge ('being familiar with') is not enough to be a representative for the target group since this will result in a contribution of own perspectives instead of those from the entire target group. The ability to speak for an entire group requires also practical knowledge ('knowing how') and expert knowledge ('knowing that').

*"If Willemijn would quit and we must find a replacement, then I think that it is very important, that someone is capable of taking distance of their own conceptions and can speak for the entire target group, like she [Willemijn] does." (Bert)*

### 5.2.2 Practical lessons

#### 5.2.2.1 Stick to the agenda

Like mentioned before, Willemijn always prepares the board meetings with Roos. It is harder for Willemijn to represent the target group if she could not prepare the subjects. It is difficult for Willemijn to spontaneously say something if something comes up in the meeting that is not prepared. Victor: *"Within a board, from time to time, I think you sometimes mention things that are not on the agenda. And then you notice that there is a gap now and then. You actually have to maintain the process and we don't always do that".*

#### 5.2.2.2 Attention for needs

To make participation possible, it is important to pay attention to the needs of the person with a MID. As mentioned before, the extended explanations of agenda points and extra summaries of some subjects were necessary for Willemijn to understand the subjects. As a board member, you receive a tablet in order to prepare the meetings and have access to all proposals. In the first two years of her board function, Willemijn still printed all the proposals prepared the meetings on paper with her coach, Roos. However, since a year she stopped printing the proposals and also uses the tablet. Another need of Willemijn is guidance via coaching. The board of the foundation pays attention to this need. Herman: *"And in support, we said, we are willing to pay for the support she needs to develop. Because Roos must of course be paid."* A fulfillment of the needs is relevant to ensure an equal playing field for persons with an ID.

### 5.3 Inclusion

According to all board members, the management assistant and the coach are working together in an inclusive board. As mentioned in the theoretical background, there are several levels of inclusion, which will be further discussed in this subparagraph.

#### 5.3.1 Inclusive leadership

Inclusive leadership is necessary to achieve inclusion. During the interviews, the relevance of the role of the chairman is mentioned the most of all subjects. The chairman is responsible for the order and direction of the meetings and to make sure the board member with a MID is able to say what she wants to share.

*“And the person of the chairman is very important also for the coloring of a board, because a chairman has a separate role.” (Jan)*

Herman was also involved in the hiring process of Willemijn. The seat position of the chairman is chosen with premeditation, so that it is a favorable position in relation to Willemijn, preferably across the table from her, or next to her. Herman always summarized the subjects for Willemijn and always asked her if everything was clear. Herman gave a more elaborate explanation about every subject on the agenda and had the patience to explain everything extensively in the meetings.

*“Yes, perhaps in the beginning, Herman was more focused on explaining to her what we were doing. Herman always did that very nicely, with the beeping system. Had you received and sent documents, and only if you wanted to say or know something about it then you had to beep. The beeping system, he first explained to Willemijn what it was. But that is no longer the case now, she knew what it was after two times.” (Pieter)*

#### 5.3.2 Inclusive Climate

The creation of an inclusive climate is essential for inclusion and happens in four phases. Firstly, it is important to raise awareness, which is done by explaining the motives of why Willemijn was hired.

*“There was previous representation from the parents [of PwDs], but we still missed a bit of what the disabled person wants, and we gradually noticed social developments. Hence, that people with a disability could very well make clear what they needed and what they wanted” (Bert)*

Secondly, all board members agreed it was needed to include the target group in the decision-making process. Afterwards, they started the search for a board member with a MID. During the interview with

Willemijn it became clear she works together with a coach. In comparison with the board members, the coach needs to receive a salary.

*“And we always said, Willemijn, we [SPZ] will pay for it [the coach], you will work together with someone that coaches you.” (Herman)*

As mentioned above, Willemijn had a trial period of one year. This trial period was specially introduced for her, none of the other board members had a trial period. The trial period and the willingness to hire a coach are both examples of phase 4 when creating an inclusive climate, because organizational structures are adapted.

### 5.3.3 Disability mainstreaming

Disability mainstreaming is an important strategy to reinforce inclusion. Disability mainstreaming helps to address the possible barriers that will exclude PwDs of their human right to perform labor. Disability mainstreaming entails the permanent adjustments made to function as an inclusive board. Moreover, disability mainstreaming focusses on how the progress of PwDs and the functioning of the board is measured.

All respondents, except for Willemijn and Roos, were asked if they changed anything individually and as a board before the start of Willemijn as board member. All respondents agreed, not a lot of adjustments were made.

*“Well, actually not, no. No, of course we all tried to express ourselves in such a language and formulation that you can understand.” (Bert)*

*“No, not specific. I think I just stayed myself.” (Victor)*

The board did not have the feeling they had to change their working methods when Willemijn entered the board and both Willemijn and Roos also did not ask for specific changes. Hence, the duration of the meetings and the agenda remained the same. Moreover, the information package all board members receive before the start of their term as board member was the same for Willemijn as for everybody else. However, the management assistant Tess did ask Willemijn if change was needed.

*“I have thought about it and I have asked. But Willemijn said no, you don't have to do anything else, you don't have to. What I have tried, but I often forget about that, is to try to keep writing understandable. So not those very long sentences in a report.” (Tess)*



Herman was chairman of the board when Willemijn joined the board. He explained he did not make a lot of adjustments but changed the setting of the meeting a bit, as explained in box 3.

**Box 3:**

Herman felt a responsibility as chairman to make sure Willemijn understood everything during the board meetings. He told the board in the beginning that he would **summarize** a bit more for Willemijn. Both Willemijn and Roos experienced this extra summarizing as pleasant.

After an agenda item Herman would make a summary about what was discussed. *“we have now discussed this with each other, we have now learned this, that means this is the core that we are going to decide on. That, that and that and that, I summarize that, and then I said, that was at the beginning, at the end it was no longer necessary at all, but then I caught myself saying Willemijn is that clear for you”*

Herman explained that in the beginning a lot of attention was paid to extra summarizing. But after a while, this became less necessary.

Herman is as chairman also responsible for **evaluating the functioning** of the board.

Source: Interview respondent Herman (April 2019)

Disability mainstreaming also entails the measurement of the progress of PwDs and the functioning of the board. Within the board of SPZ, there is an evaluation after every year about the functioning of the board and what things should change. Furthermore, the trial period of Willemijn was evaluated both with and without her present.

#### 5.4.4 Outcomes: experience of inclusion

In the theoretical background, different interrelated categories of inclusion are discussed. The interrelated categories as mentioned in the framework are presence, acceptance, participation and belonging, and this study was also aimed at learning to what extent we could speak of true inclusion in SPZ. The first category of inclusion is presence, which indeed was practiced in SPZ. Willemijn is always present during the board meetings and attends other board activities to the same extent as other board members. Willemijn is accepted as dignified board member by all respondents. Acceptance is the second category of inclusion.

*“Yes, I see her [Willemijn] as a dignified board member, and the other board members do too.” (Anna)*

The third category of inclusion is participation and refers to the degree PwDs contribute actively in board activities and co-create decisions. According to most board members, Willemijn especially actively contributes during the approval of the subsidies for the proposals. Her opinion and the way she represents the target group is unique and very valuable according to all board members. However, as mentioned above, Willemijn experiences difficulties with contributing in discussions about topics that were not part of the agenda. Furthermore, her financial knowledge is too little to actively contribute in the discussions about investments and the financial situation of the foundation.

*“A board member with an intellectual disability definitely adds value. However, the contribution is always the same; she always asks what the benefits for the target group are.” (Pieter)*

Belonging is the last category of inclusion. As mentioned above, Willemijn is an official board member and registered at the Chamber of Commerce. She also feels like she is a real member of the board and has the feeling her contribution has grown over the years she is a board member.

*“Yes, we [Roos and Willemijn] are fully involved as board members. We are also invited for the farewell of Herman. I am also fully involved in that, it is not that I am not invited for those things. No, it really is in the whole, also the dinner, also the party, also the thank you moment. And really, it is a very serious thing that you really see people with an ID are really involved. It is not just once, but now they are really coming to me and they are going to ask things from you want to take a look at the website. There are also real questions from them to me.” (Willemijn)*

Performing valued social roles in combination with enjoying reciprocal relationships leads to a subjective sense of belonging to a group. Several board members emphasized the ability of Willemijn to give a personal speech during several farewell meetings.



## 6. Discussion

The aim of this research was to explore how boards can become more inclusive in order to create more suitable workplaces for people with a MID on a larger scale.

The research question of this study was: *“What lessons can be learned from a board with a board member with a mild intellectual disability regarding feelings of inclusion?”* To answer the research question, sub-research questions were composed, and an attempt was made to answer these using a qualitative research method. This chapter will elaborate on the results as described in the result section, comparison with other literature, the limitations of the research, and gives recommendations for future research.

### 6.1 Key Findings

There are several lessons that can be learned from this case study. Firstly, a trial period and additionally an evaluation of this trial period is very valuable and increases the chances of successfully become an inclusive board. Furthermore, it is important that the PwDs have affinity with the activities of the board. Thirdly, the board member should not only possess experiential knowledge, but in order to represent the target group, practical expertise and expert knowledge are also needed. According to Schippers (2012), the possession of solely experiential knowledge is not sufficient to represent the target group. The difference between the needed knowledge is also explained by Caron-Flinterman et al., (2005) in which they establish three different parts of knowledge and emphasize the relevance of the information part of knowledge which can be made explicit (expert knowledge) and the competence part knowledge, consisting of skills and capacities (practical knowledge). During the board meetings it is important for the board member with a MID to stick to the agenda, because it is harder to elaborate on subjects that could not be prepared. Lastly, the board should have attention for the needs of the board member with a MID in order to successfully function as an inclusive board.

In general, we can speak of the creation of an inclusive climate which was partially a result of the inclusive leadership of the chairman. Disability mainstreaming was partly happening in this case study. It was remarkable that not too many adjustments were made when the board member with a MID started with her function. However, some small adjustments were made. Furthermore, several evaluation moments took place within the board, about the functioning of the board member with a MID and the functioning of the board in general. The four interrelated categories of inclusion were all discussed in all interviews. Even though Willemijn was unable to contribute to all discussions during the meetings, she is still seen as a dignified board member by all other board members. There is participation, however her contribution is less when discussing other subjects rather than representing the target group. The last category of inclusion is belonging. The feeling of belonging is subjective, but as mentioned in the results section, interpersonal and reciprocal relations and a feeling of belonging was experienced by all

members in the board of SPZ. Lastly, the importance of coach was evident. However, the opinions among board members about when the coach was needed were divided.

## 6.2. Comparison with literature

In this case study the role of the coach was mentioned multiple times. It became evident how important the role of the coach was for Willemijn. Drawing from this study, indeed the contribution of the coach seems vital for the functioning of the board member with an ID. Still, the opinion of the board members about how and when the coach works to support people with MID were divided. Several board members were convinced the coach is needed. However, other board members thought the coach is only needed in the preparation for the board meetings. The opinions about coaching are not only divided within the board. In both literature as society it remains unclear what inclusion entails. Participation mainly seems to mean that PwDs should be able to integrate into regular settings (WHO, 2011). Nevertheless, it remains unclear if participation is about acting independently or being able to participate as result of needed support. Carter et al., (2008) emphasize the risk of a coach. The constant presence of an external helper may cause stigma and be of hinder when creating social connection. However, Gilson & Carter (2016) explain that a coaching method is needed to learn relevant job tasks and to become more independent. Sorée (2010) emphasizes that support including coaching, guidance and tools aims to build a bridge between the individual's limitation and society hence contributes to the reduction of one's handicap. This relates to other studies which state that in order to function as a board member, people with an occupational disability need guidance and support during their work and point out that coaching is one of the most important activities in order to become inclusive (Borghouts & Freese, 2016; Storey, 2003).

Remarkable is the fact that all board member state that no organizational changes were made before the arrival of Willemijn. Nevertheless, Willemijn needs a coach to function in the board and help her prepare the board meetings. If the board could, for example, already sent summaries of the subsidy proposals, the coach might not be needed or needed less. = Self-stigma can occur in minority groups (Herek et al., 2009; Mak & Cheung, 2010). Self-stigma is experienced when you are aware of the assumed existing (negative) prejudices that exist about your stigmatized group and agree with them. A part of self-stigma is applying the stereotyping on yourself (Corrigan et al., 2006; Watson et al., 2007). Not being able or willing to indicate a need may be a consequence of self-stigma (Vogel et al., 2007).

To ensure that full participation is possible, the idea of integrating into existing structures must be abandoned; it makes more sense to look at what is needed to realize optimal participation, for inclusion. This can be explained with the capability approach of Amartya Sen (1992), often used to analyze the link between disability, gender discrimination and poverty (Welch, 2002). Within his approach, Sen focuses on the type of life people are able to live, within their capability to achieve and accomplish. (Mitra, 2006). Sen emphasized the capability of individuals to achieve the kind of lives they

have reason to value. Policies should focus on what people are able to do and be and on removing obstacles in their lives resulting in more freedom to have the capability to achieve the kind of lives they have reason to value (Sen, 1992; Robeyns, 2005). In order to have these capabilities, equity is needed. Still, there is an ongoing discussion about equity versus equality. Equality exists when we treat all social groups the same. But, equity is about giving everyone what they need in order to be successful (McLaughlin, 2010). The trial period and the coach are examples of this equity principle. Both are mentioned as necessary in order to successfully function as an inclusive board.

Removing obstacles corresponds to disability mainstreaming, an important strategy to reinforce inclusion by addressing possible barriers that will exclude PwDs (UNWRA, 2013). Mainstreaming could profit from the concept of universal design (UD). A UD is defined by the Center for Accessible Housing (1995) as “the design of products and environments that can be used and experienced by people of all ages and abilities, to the greatest extent possible, without adaption”. The aim of UD is related to making the use of products and environments easier by reducing their complexity and decrease an individual’s reliance in their capabilities to interact with the product of environment (Imrie, 2012). A benefit of a UD is that it integrates accessibility from the beginning of the process hence adaption is less needed or noticeable (Story, 1998). A UD has the potential of reducing stigmatizing and self-stigma because different needs are less noticeable. In the case of the board of SPZ, an example of UD would be summarizing the subsidy proposals. This would make the assessing applications easier for all board members, including the person with an ID.

### 6.3 Limitations

The first limitation of this research is of the limited transferability. The research solely focused on one case, which can limit the generalizability of the research resulting in a decrease in the transferability (Gray, 2014). Nevertheless, the purpose of this study was an explorative study of one practice which gave the possibility to go in depth in this case. Within the result section, a thick description is given in order to increase the transferability of the research (Lietz & Zayas, 2010).

A decrease in credibility due to the likelihood of interview bias is considered as the second limitation of this research (Gray, 2014). The interviewer participated in an interview training prior to this research, however she lacked experience in the field. Lack of experience could influence the answers given by the respondents due to inconsistency in the manner questions were asked. Nevertheless, several interviews were conducted together with a postdoc with years of experience in qualitative research. Furthermore, the interviews were very extensive and there is no reason to believe that relevant elements have not been revealed.

Lastly, translation could also be a limitation in this research. The researcher and all respondents were native Dutch speakers; hence all interviews were conducted and transcribed in Dutch. The citations had to be translated since the report is written in English. This may have resulted in translation bias and a

decrease in cross-cultural validity (Peters et al., 2014), nevertheless semantic equivalence was tried to be attained by the researcher. The citations from the interviews were translated after finishing the transcripts and member-checks, with respect to the meaning of the original quote. To mitigate this bias, the translations and transcripts were checked by another researcher (Van Nes et al., 2010).

## 7. Conclusion and Recommendations

### 7.1 Conclusion

The aim of this research was to gain insight into how a board with a board member with a MID functions effectively to create suitable workplaces for people with a MID in board functions on a larger scale. The lessons that can be learned from this board are that a trial period and evaluation are valuable for successful inclusion. The board member with a MID needs affinity with the subjects of the organization and should have practical experience, experiential and expert knowledge. There must be attention for the needs of the board member with a MID and the board members and chairman need to try to stick to the agenda.

Despite that the board member with a MID cannot fully participate on all subjects during the board meetings, the results show in conclusion that the board of SPZ is an inclusive board. Inclusion is not solely about participation. Inclusion also entails presence, acceptance and belonging. All board members experience this board as inclusive, and that is the goal. The aim of inclusion is to contribute to quality of life. Working results in the feeling of belonging. In order to establish inclusion, attention for needs with consideration of the equity principle is necessary. However, this might not be needed if disability was mainstreamed and more workplaces were created according to a universal design.

### 7.2 Recommendations

As mentioned before, several lessons can be drawn from this inclusive board in order to create suitable workplaces for people with a MID in board functions on a larger scale. Therefore, these recommendations will focus on future research. This study took one case into account. Future research should focus on other cases which increases the transferability of the results. Within this research stigma and self-stigma was mentioned but not a lot about this phenomenon in combination with board functions is known. In order to increase inclusion in board functions, future research should look into how to decrease stigma with respect to participation.

Universal design can be seen as a solution for mainstreaming disability. However, little is known about how to create a board according to a universal design. Future research should look into how to design a board and board meetings.

## References

- Abma, T. A. (2006). The practice and politics of responsive evaluation. *American journal of evaluation*, 27(1), 31-43.
- Abma, T. A., & Stake, R. E. (2001). Responsive evaluation: Roots and evolution. In J. C. Greene & T. A. Abma (Eds.), *Responsive evaluation: New directions for evaluation*, No. 92 (pp. 7-22). San Francisco: Jossey-Bass.
- Adelmeijer, M. H. M., Schenderling, P. J., Heekelaar, M. S., Oostveen, A., & Beerepoot, R. (2015). *Onderzoek Participatiewet bij werkgevers: rapportage fase 1 (peiljaar 2015)*. Utrecht: Berenschot Groep B.V.
- Ager, A., Myers, F., Kerr, P., Myles, S., & Green, A. (2001). Moving home: Social integration for adults with intellectual disabilities resettling into community provision. *Journal of Applied Research in Intellectual Disabilities*, 14(4), 392-400.
- Allison, M. T., & Hibbler, D. K. (2004). Organizational barriers to inclusion: Perspectives from the recreation professional. *Leisure Sciences*, 26(3), 261-280.
- Baart, I., & Maier, R. (2016). Disability Studies. *Disability Studies in de Lage Landen*, 12.
- Barr, O., & Gates, B. (Eds.). (2018). *Oxford handbook of learning and intellectual disability nursing*. Oxford University Press, US
- Beadle-Brown, J., Leigh, J., Whelton, B., Richardson, L., Beecham, J., Baumker, T., & Bradshaw, J. (2016). Quality of life and quality of support for people with severe intellectual disability and complex needs. *Journal of Applied Research in Intellectual Disabilities*, 29(5), 409-421.
- Bernard, H. R. (2017). *Research methods in anthropology: Qualitative and quantitative approaches*. Rowman & Littlefield.
- Biklen, D. (1992). Facilitated communication: Biklen responds. *American Journal of Speech-Language Pathology*, 1(2), 21-22.
- Bilimoria, D., Joy, S., & Liang, X. 2008. Breaking barriers and creating inclusiveness: Lessons of organizational transformation to advance women faculty in academic science and engineering. *Human Resource Management*, 47: 423-441.

- Birt, L., Scott, S., Cavers, D., Campbell, C., & Walter, F. (2016). Member Checking: A Tool to Enhance Trustworthiness or Merely a Nod to Validation? *Qualitative Health Research*, (26)13, 1802-1811.
- Blankman, M. K., & Vermariën, M. K. (2015). Conformiteit van het VN-Verdrag inzake de rechten van personen met een handicap en het EVRM met de huidige en voorgestelde wetgeving inzake vertegenwoordiging van wilsonbekwame personen in Nederland.
- Boeije, H. (2010). *Analysis in qualitative research*. London: Sage
- Bonaccio, S., Connelly, C. E., Gellatly, I. R., Jetha, A., & Ginis, K. A. M. (2019). The Participation of People with Disabilities in the Workplace Across the Employment Cycle: Employer Concerns and Research Evidence. *Journal of Business and Psychology*, 1-24.
- Bone, K. M. (2017). Trapped behind the glass: crip theory and disability identity. *Disability & Society*, 32(9), 1297-1314.
- Borghouts-van de Pas I. (2014). De gevolgen van de voorgenomen Participatiewet voor jonggehandicapten. *Tijdschrift Recht en Arbeid*, Jaargang 6 juni/ juli 2014(6/7), 10-16.
- Borghouts, I., & Freese, C. (2016). Inclusief HRM: (hoe) past de participatiewet in de organisatie-en HR-strategie. *Tijdschrift voor HRM*, 7, 1-20.
- Braddock, D., & Bachelder, L. (1994). The glass ceiling and persons with disabilities.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.
- Browder, D. M., Spooner, F., Lo, Y. Y., Saunders, A. F., Root, J. R., Ley Davis, L., & Brosh, C. R. (2018). Teaching students with moderate intellectual disability to solve word problems. *The Journal of Special Education*, 51(4), 222-235.
- Bryman, A. (2012). *Social Research Methods (4th Edition)*. New York: Oxford University
- Caron-Flinterman, J. F., Broerse, J. E., & Bunders, J. F. (2005). The experiential knowledge of patients: a new resource for biomedical research?. *Social science & medicine*, 60(11), 2575-2584.

Çelik, S. (2015). De business case van diversiteit in de publieke context: de verbindende overheid. Tijdschrift voor HRM.

Center for Accessible Housing. (1995). Accessible environments: Toward universal design. Raleigh: North Carolina State University.

Centraal Bureau voor de Statistiek (2015). Een op de drie arbeidsgehandicapten heeft betaald werk. Retrieved from:  
<https://www.cbs.nl/nl-nl/nieuws/2015/05/een-op-de-drie-arbeidsgehandicapten-heeft-betaald-werk>

Centraal Bureau voor de Statistiek (2017). Met arbeidshandicap vaak niet actief op arbeidsmarkt. Retrieved from:  
<https://www.cbs.nl/nl-nl/nieuws/2016/29/met-arbeidshandicap-vaak-niet-actief-op-arbeidsmarkt>

Claes, L. (2014). Mensen met een verstandelijke beperking in een vastgelopen situatie: onderzoek naar levenstrajecten vanuit een kruisbestuiving van de theoretische perspectieven. *Disability Studies en Social & Cultural Geography* (Doctoral dissertation, Ghent University).

Cobigo, V., Brown, R., Lachapelle, Y., Lysaght, R., Martin, L., Ouellette-Kuntz, H., ... & Fulford, C. (2016). Social inclusion: A proposed framework to inform policy and service outcomes evaluation. *Inclusion*, 4(4), 226-238.

Corrigan, P.W., Watson, A.C., & Barr, L. (2006). The self-stigma of mental illness: Implications for self-esteem and self-efficacy. *Journal of social and clinical psychology*, 25(8), 875-884.

Crawford, C. (2003). Towards a common approach to thinking about and measuring social inclusion. Toronto, Ontario: L'Institut Roehrer Institute.

Creswell, J. W., & Clark, V. L. P. (2017). Designing and conducting mixed methods research. Sage publications.

Crews, D. E., & Zavotka, S. (2006). Aging, disability, and frailty: implications for universal design. *Journal of physiological anthropology*, 25(1), 113-118.

Cummins, R. A., & Lau, A. L. (2003). Community integration or community exposure? A review and discussion in relation to people with an intellectual disability. *Journal of applied research in intellectual disabilities*, 16(2), 145-157.

Davis, L. J. (2002). Bending over backwards: Disability, dismodernism, and other difficult positions (Vol. 26). New York: New York University Press.



Den Besten, C. & Van Vulpen, A. (2009). *Begeleid ontdekkend leren*. Amsterdam: Boom/Nelissen.

Downey, S. N., van der Werff, L., Thomas, K. M., & Plaut, V. C. (2015). The role of diversity practices and inclusion in promoting trust and employee engagement. *Journal of Applied Social Psychology*, 45(1), 35-44.

Eerten, M. V. (2007). *Vele gezichten van de Wmo, maatschappelijke ondersteuning tussen wet en werkelijkheid*, 's-Gravenhage.

Elfil, M., & Negida, A. (2017). Sampling methods in Clinical Research; an Educational Review. *Emergency*, 5(1), 52.

Etikan, I., Musa, S. A., & Alkassim, R. S. (2016). Comparison of convenience sampling and purposive sampling. *American journal of theoretical and applied statistics*, 5(1), 1-4.

Farrell, P. (2004). School psychologists: Making inclusion a reality for all. *School Psychology International*, 25(1), 5-19.

Feldblum, C.R. (1991). Employment protections. In J. West (Ed.), *The Americans with Disabilities Act: From policy to practice* (pp. 81-110). New York: Milbank Memorial Fund.

Fox, N. (2009). *Using Interviews in a Research Project*. National institute for health research.

Gabel, S. L. (Ed.). (2005). *Disability studies in education: Readings in theory and method* (Vol. 3). Peter Lang.

Frambach, J. M., van der Veluten, C.P., & Durning, S.J. (2013). AM last page: Qualitative criteria in qualitative and quantitative research. *Academic Medicine*, 88(4), 552.

Garbutt, R. (2009). Social inclusion and local practices of belonging. *Cosmopolitan Civil Societies: An Interdisciplinary Journal*, 1(3), 84-108.

Goldin, E. D. V. (2012). *Invisible to myself: Trigger words and the invisibly disabled identity*. University of Colorado at Denver.

Gonzalez, J.A., & DeNisi, A.S. 2009. Cross-level effects of demography and diversity climate on organizational attachment and firm effectiveness. *Journal of Organizational Behavior*, 30: 21-40.

Goodley, D., Hughes, B., & Davis, L. (Eds.). (2012). *Disability and social theory: New developments and directions*. Springer

Goodley, D. (2016). Disability studies: An interdisciplinary introduction. Sage.

Goodley, D. (2017). Disability studies: An interdisciplinary introduction. Sage.

Gilgun, J. F. (2014). Deductive qualitative analysis as middle ground. In: Deductive qualitative analysis and grounded theory: a reader. Chicago School Traditions Volumes 1 and 2, hoofdstuk 12: 168-187.

Gilson, C. B., & Carter, E. W. (2016). Promoting social interactions and job independence for college students with autism or intellectual disability: A pilot study. *Journal of autism and developmental disorders*, 46(11), 3583-3596.

Gravetter, F. J., & Forzano, L. A. B. (2018). Research methods for the behavioral sciences. Cengage Learning.

Gray, D.E. (2014). Doing research in the real world. Thousand Oaks, California: SAGE.

Green, J., Thorogood, N. (2014). Qualitative Methods for Health Research (3rd edition). Los

Greenwood, R. & Johnson. V.A. (1985). Employer concerns regarding workers with disabilities. Arkansas Research and Training Center in Vocational Rehabilitation.

Greenwood, R., Schriener, K.F., & Johnson, V. (1991). Employer concerns regarding workers with disabilities and the business-rehabilitation partnership: The PWI practitioners' perspective. *Journal of Rehabilitation*, 57, 21-24.

Griep, Y., Kinnunen, U., Nätti, J., De Cuyper, N., Mauno, S., Mäkikangas, A., & De Witte, H. (2016). The effects of unemployment and perceived job insecurity: a comparison of their association with psychological and somatic complaints, self-rated health and life satisfaction. *International archives of occupational and environmental health*, 89(1), 147-162.

Griffin, C., Hammis, D., Keeton, B., & Sullivan, M. (2003). Making self-employment work for people with disabilities. Baltimore: Paul H. Brookes.

Guba, E. G., & Lincoln, Y. S. (1989). Fourth generation evaluation. Newbury Park, CA: Sage.

Hall, S. (2009). Being at home: space for belonging in a London caff. *Open house international*, 34(3), 81-87.

- Hallah, D. P., Kauffman, J. M., & Pullen, P. C. (1997). *Exceptional learners: Introduction to special education* (7th ed.). Boston: Allyn and Bacon.
- Hayward, K. A. (2005). A hierarchy of disability: Attitudes of people with disabilities toward one another.
- Herek, G. M., Gillis, J. R., & Cogan, J. C. (2009). Internalized stigma among sexual minority adults: Insights from a social psychological perspective. *Journal of Counseling Psychology*, 56(1), 32.
- Hernandez, B., Keys, C., & Balcazar, F. (2000). Employer attitudes toward workers with disabilities and their ADA employment rights: A literature review. *Journal of Rehabilitation*, 66: 4-16.
- Herzog, H. (2005). On home turf: Interview location and its social meaning. *Qualitative sociology*, 28(1), 25-47.
- Holt-Lunstad, J., Smith, T. B., & Layton, J. B. (2010). Social relationships and mortality risk: a meta-analytic review. *PLoS Medicine*, 7.
- Imrie, R. (2012). Universalism, universal design and equitable access to the built environment. *Disability and rehabilitation*, 34(10), 873-882.
- Janssens, M., & Zazoni, P. 2007. What makes an organization inclusive? Work contexts and diversity management practices favoring ethnic minorities' inclusion. Paper presented at the Academy of Management conference, Philadelphia, PA.
- Jones, M. K. (2008). Disability and the labour market: a review of the empirical evidence. *Journal of Economic Studies*, 35(5), 405-424.
- Kessler, R. C., Turner, J. B., & House, J. S. (1988). Effects of unemployment on health in a community survey: Main, modifying, and mediating effects. *Journal of social issues*, 44(4), 69-85.
- Khan, N., Korac-Kakabadse, N., Skouloudis, A., & Dimopoulos, A. (2019). Diversity in the workplace: An overview of disability employment disclosures among UK firms. *Corporate Social Responsibility and Environmental Management*, 26(1), 170-185.
- Klimoski, R., & Donahue, L. (1997). HR strategies for integrating individuals with disabilities in the workplace. *Human Resource Management Review*, 7: 109-138.
- Kröber, H. (2008). Care for persons with ID and inclusion. *Journal of Intellectual Disability Research*, 52(8-9).

- Lemay, R. (2006). Social role valorization insights into the social integration conundrum. *Mental Retardation*, 44(1), 1-12.
- Lengnick-Hall, M. L., Gaunt, P. M., & Kulkarni, M. (2008). Overlooked and underutilized: People with disabilities are an untapped human resource. *Human Resource Management*, 47: 255–273.
- Leslie, L.M., & Gelfand, M.J. 2008. The who and when of internal gender discrimination claims: An interactional model. *Organizational Behavior and Human Decision Processes*, 107(2): 123-140.
- Lietz, C. A., & Zayas, L. E. (2010). Evaluating qualitative research for social work practitioners. *Advances in Social Work*, 11(2), 188-202.
- Lindsay, S., McDougall, C., Menna-Dack, D., Sanford, R., & Adams, T. (2015). An ecological approach to understanding barriers to employment for youth with disabilities compared to their typically developing peers: views of youth, employers, and job counselors. *Disability and rehabilitation*, 37(8), 701-711.
- Lirio, P., Lee, M. D., Williams, M. L., Haugen, L. K., & Kossek, E. E. (2008). The inclusion challenge with reduced-load professionals: The role of the manager. *Human Resource Management*, 47(3), 443-461. doi:10.1002/hrm.20226.
- Llewellyn, A., & Hogan, K. (2000). The use and abuse of models of disability. *Disability & Society*, 15(1), 157-165.
- Lucas, R., Clark, A., Georgellis, Y. & Diener, E. (2004). Unemployment alters the set point for life satisfaction. *Psychological Science*, 15, 8-13.
- Mace R (1998) Universal design: housing for the lifespan of all people. U.S. Department of Housing and Urban Development, Washington D.C.
- Mak, W. W., & Cheung, R. Y. (2010). Self-stigma among concealable minorities in Hong Kong: conceptualization and unified measurement. *American Journal of Orthopsychiatry*, 80(2), 267.
- Marsden, P. V., & Wright, J. D. (2010). Handbook of survey research. *Emerald Group Publishing*.
- McKay, P.F., Avery, D.R., & Morris, M.A. 2009. A tale of two climates: Diversity climate from subordinates' and managers' perspectives and their role in store unit sales performance. *Personnel Psychology*, 62(4): 767-791.

- McKee-Ryan, F., Song, Z., Wanberg, C. R., & Kinicki, A. J. (2005). Psychological and physical well-being during unemployment: a meta-analytic study. *Journal of applied psychology*, 90(1), 53.
- McLaughlin, M. J. (2010). Evolving interpretations of educational equity and students with disabilities. *Exceptional Children*, 76(3), 265-278.
- Meekosha, H., & Shuttleworth, R. (2009). What's so 'critical' about critical disability studies?. *Australian Journal of Human Rights*, 15(1), 47-75.
- Ministerie van Sociale Zaken en Werkgelegenheid (2013). Nader rapport wetsvoorstel invoering participatiewet. Retrieved from: <https://www.nji.nl/nl/Download-NJi/Nader-rapport-wetsvoorstel-invoering-participatiewet.pdf>
- Mitra, S. (2006). The capability approach and disability. *Journal of disability policy studies*, 16(4), 236-247.
- Mohr, G., Otto, K., Antoniou, A. S., & Cooper, C. (2011). Health effects of unemployment and job insecurity. *New directions in organizational psychology and behavioral medicine*, 289-311.
- Mowday, R.T., & Sutton, R.I. 1993. Organizational behavior: Linking individuals and groups to organizational contexts. *Annual Review of Psychology*, 44: 195-229.
- Nishii, L. H. (2013). The benefits of climate for inclusion for gender-diverse groups. *Academy of Management Journal*, 56(6), 1754-1774.
- Nishii, L. H., & Rich, R. E. (2014). Creating inclusive climates in diverse organizations. *Diversity at work: The practice of inclusion*, 330-363.
- Oliver, M. (1996). The social model in context. In *Understanding disability* (pp. 30-42). Palgrave, London.
- Perenboom, R. J., & Chorus, A. M. (2003). Measuring participation according to the International Classification of Functioning, Disability and Health (ICF). *Disability and rehabilitation*, 25(11-12), 577-587.
- Pless, N., & Maak, T. (2004). Building an inclusive diversity culture: Principles, processes and practice. *Journal of Business Ethics*, 54, 129-147.
- Putter, I. D., Cozijnsen, R., & Rijken, M. (2015). Het vergroten van arbeidsparticipatie onder mensen met een chronische ziekten of beperking: een werkwens alleen is niet voldoende.

Ras, M., D. Verbeek-Oudijk en E. Eggink (2013). Lasten onder de loep. De kostengroei van de zorg voor verstandelijk gehandicapten ontrafeld. Den Haag: Sociaal en Cultureel Planbureau.

Ravaud, J. F., Madiot, B., & Ville, I. (1992). Discrimination towards disabled people seeking employment. *Social Science & Medicine*, 35(8), 951-958.

Rijksoverheid. (2016, November 14). Participatiewet. Retrieved from: <https://www.rijksoverheid.nl/onderwerpen/participatiewet>

Rioux, M. H., Crawford, C., Ticoll, M., & Bach, M. (1997). Uncovering the shape of violence: A research methodology rooted in the experience of people with disabilities. *Doing disability research*, 190-206.

Riviere, H. (2016). Using Student Engagement Theory To Explore Inclusion For Pupils With SEN In Mainstream Schools In England.

Roberson, Q. M., & Stevens, C. K. (2006). Making sense of diversity in the workplace: Organizational justice and language abstraction in employees' accounts of diversity-related incidents. *Journal of Applied Psychology*, 91(2), 379.

Robeyns, I. (2005). The capability approach: a theoretical survey. *Journal of human development*, 6(1), 93-117.

Roulstone, A., & Williams, J. (2014). Being disabled, being a manager: 'glass partitions' and conditional identities in the contemporary workplace. *Disability & Society*, 29(1), 16-29.

Schalock, R. L., Verdugo, M. A., & Braddock, D. L. (2002). *Handbook on quality of life for human service practitioners*. Washington, DC: American Association on Mental Retardation.

Scheid, T. L. (1999). Employment of individuals with mental disabilities: Business response to the ADA's challenge. *Behavioral Sciences & the Law*, 17(1), 73-91.

Schipper, K. (2012). Patient participation & knowledge.

Schmelkin, L. P. (1984). Hierarchy of preferences toward disabled groups: A reanalysis. *Perceptual and Motor Skills*, 59(1), 151-157

Schur, L., Colella, A., & Adya, M. (2016). Introduction to special issue on people with disabilities in the workplace.

- Shakespeare, T. (2006). The social model of disability. *The disability studies reader*, 2, 197-204.
- Sheeran, P., Abrams, D. & Orbell, S. (1995). Unemployment, self-esteem, and depression: a social comparison theory approach. *Basic and applied social psychology*, 17, 65-82.
- Sen, A. (1992) *Inequality Re-examined*. Oxford: Clarendon Press.
- Sen, A. (1999) *Development as Freedom*. New York: Alfred A. Knopf.
- Shore, L. M., Randel, A. E., Chung, B. G., Dean, M. A., Holcombe Ehrhart, K., & Singh, G. (2011). Inclusion and diversity in work groups: A review and model for future research. *Journal of management*, 37(4), 1262-1289.
- Smith, B., & Bundon, A. (2018). Disability models: Explaining and understanding disability sport in different ways. In *The Palgrave handbook of Paralympic studies* (pp. 15-34). Palgrave Macmillan, London.
- Sorée, V. (2010). Het Verdrag van de Verenigde Naties inzake de Rechten van Personen met een Handicap als sleutel tot meer Kwaliteit van Bestaan. *Ethiek & Maatschappij*, 13(4), 141-161.
- Stake, R. E., & Abma, T. A. (2005). Responsive evaluation. In S. Mathison (Ed.), *Encyclopedia of evaluation* (pp. 376- 379). Thousand Oaks, CA: Sage.
- Stewart, R. (2004). The “Really Disabled”: Disability Hierarchy in John Hockenberry’s ‘Moving Violations’. *Review of Disability Studies: An International Journal*, 1(2).
- Story, M. F. (1998). Maximizing usability: the principles of universal design. *Assistive technology*, 10(1), 4-12.
- Thomas, A. (2000). Stability of Tringo's hierarchy of preference toward disability groups: 30 years later. *Psychological Reports*, 86(3\_part\_2), 1155-1156.
- Thomas, C. (2007). *Sociologies of disability and illness: Contested ideas in disability studies and medical sociology*. Macmillan International Higher Education.
- Tringo, J. L. (1970). The hierarchy of preference toward disability groups. *The Journal of Special Education*, 4(3), 295-306.

Uitvoeringsinstituut Werknemers Verzekeringen (2019). Retrieved from:  
<https://www.uwv.nl/werkgevers/werknemer-met-uitkering/werknemer-heeft-wajong-of-valt-onder-participatiewet/index.aspx>

Unesco. (2005). Guidelines for inclusion: Ensuring access to education for all. Unesco.

Van Gennep, A., & Ruigrok, H. (2002). Tussen deinstitutionalisatie en integratie: op weg naar inclusie. *Nederlands Tijdschrift voor de zorg aan verstandelijk gehandicapten*, 2, 104-119.

Van Lierop, B. & Van Soest, K., (2008). Job carving: succesvolle aanpak om nieuwe banen te creëren. *Maandblad Reïntegratie*, 8, 24-26.

Van Nes, F., Abma, T., Jonsson, H., & Deeg, D. (2010). Language differences in qualitative research: is meaning lost in translation?. *European journal of ageing*, 7(4), 313-316.

Van Ogtrop, J. (2009). Wet-en regelgeving van gezondheid en participatie–sociale constructie van gezondheidszorgbeleid. In *Ontwerp van zorgtrajecten/zorgketens* (pp. 60-70). Bohn Stafleu van Loghum, Houten.

Van Teijlingen, E. (2014, December). Semi-structured interviews. In PGR Workshop December.

Veenhoven, R. (2018). Het effect van werk op geluk en van geluk op werk.

Vogel, D. L., Wade, N. G., & Hackler, A. H. (2007). Perceived public stigma and the willingness to seek counseling: The mediating roles of self-stigma and attitudes toward counseling. *Journal of Counseling Psychology*, 54(1), 40.

Vornholt, K., Uitdewilligen, S., & Nijhuis, F. J. (2013). Factors affecting the acceptance of people with disabilities at work: a literature review. *Journal of occupational rehabilitation*, 23(4), 463-475.

Wasserman, I. C., Gallegos, P. V., & Ferdman, B. M. 2008. Dancing with resistance: Leadership challenges in fostering a culture of inclusion. In K. M. Thomas (Ed.), *Diversity resistance in organizations*: 175-200. New York, NY: Taylor & Francis Group/Lawrence Erlbaum Associates.

Watson AC, Corrigan PW, Larson JE *et al.* Self-stigma in people with mental illness. *Schizophr Bull* 2007;**33**:1312-8.

Weick, K.E. 1979. Cognitive processes in organizations. *Research in Organizational Behavior*, 1: 41-75.



Western, J., McCrea, R., & Stimson, R. (2007). Quality of life and social inclusion. *International Review of Sociology—Revue Internationale de Sociologie*, 17(3), 525-537.

Woittiez, I., Eggink, E., Putman, L., & Ras, M. (2018). An international comparison of care for people with intellectual disabilities. Den Haag: SCP.

Woittiez, I., Putman, L., Eggink, E., & Ras, M. (2014). Zorg beter begrepen. Verklaringen voor de groeiende vraag naar zorg voor mensen met een verstandelijke beperking. Den Haag: SCP.

Wolfensberger, W. (1998). A Brief Introduction to Social Role Valorization: A High Order Concept for Addressing the Plight of Socially Devalued People, and for Structuring Human Services. Syracuse University.

Wolfensberger, W., & Thomas, S. (2005). Introductory social role valorization workshop training package.

Wolfensberger, W., Thomas, S., & Caruso, G. (1996). Some of the universal “good things of life” which the implementation of Social Role Valorization can be expected to make more accessible to devalued people. *International Social Role Valorization Journal*, 2(2), 12-14.

Wouters, J., Brems, E., Smis, S., & Schmitt, P. (2010). *Accountability for human rights violations by international organisations*. Intersentia.

Zijlstra, F. R., Mulders, H. P., & Nijhuis, F. J. (2012). Inclusieve Organisaties-Op weg naar duurzame arbeidsparticipatie. *Tijdschrift voor Arbeidsvraagstukken*, 28(1), 21-29.

Zheng, Q., Tian, Q., Hao, C., Gu, J., Tao, J., Liang, Z., ... & Hao, Y. (2016). Comparison of attitudes toward disability and people with disability among caregivers, the public, and people with disability: findings from a cross-sectional survey. *BMC public health*, 16(1), 1024.

## Annex 1

Topiclijst (oud-) bestuursleden SPZ

### Introductie

- Voorstellen
- Doel van het onderzoek
- Opnemen interview
- Informed consent
- Vragen vooraf respondent

### Achtergrond

#### Kan je misschien eerst iets over jezelf vertellen?

- **Functie:** Zou u wat meer kunnen vertellen over uw functie binnen het bestuur van SPZ?
  - o Hoe lang bent u al werkzaam binnen SPZ?
  - o Is het een vrijwillige functie? (Geen financiële compensatie)?
  - o Hoe is het idee ontstaan om een ervaringsdeskundige in jullie bestuur te betrekken?
    - Hoe is dit in zijn werk gegaan? → Vacature/specifiek persoon
    - Waarom wilden jullie een ervaringsdeskundige in het bestuur?
    - Kan je vertellen hoe dat proces verlopen is?
    - Hoe kijk je daarop terug?
  - o Hoe heeft u uzelf voorbereid om samen te werken met iemand met een verstandelijke beperking?

### Support & Acceptatie

- o Kan je iets vertellen over de taken van de verschillende bestuursleden?
- o Als we specifiek kijken naar Ellis, wat zijn haar taken binnen het bestuur?
  - Kan je iets vertellen over hoe dit takenpakket tot stand is gekomen?
  - In hoeverre hebben jullie samen besproken wat haar taken worden?
  - Wie maakt de afspraken?
    - Waarom en hoe?

### Attitude:

- o Hoe ervaar je het bestuur met een ervaringsdeskundige?
- o Wat maakt dat dit (niet) goed werkt?
- o Zijn er dingen die jij anders zou willen doen?

### Participatie

- o Hoe ziet een vergadering eruit?
  - Is iedereen de hele vergadering aanwezig?
  - Hoe wordt de agenda bepaald?
- o Zijn er verschillen tussen bestuursleden? (Tijd/functie/aanwezigheid)
- o Zou je Ellis omschrijven als een volwaardig bestuurslid?

- Wat maakt dat ze dat (niet) is?
- Hoe zijn de verhoudingen binnen het bestuur?
  - Taakverdelingen
  - Ik begreep dat het een vrijwillige functie is. Betekent dit dat Ellis ook niet wordt betaald?
    - Is dat besproken?
  - Hoe zijn de verhoudingen t.o.v. de ervaringsdeskundige?

## **Disability Mainstreaming**

### **- Barriers**

- Zijn jullie dingen anders gaan doen op voorhand? /Hebben jullie je destijds voorbereid op de komst van Ellis? (ik kan me voorstellen dat er aanpassingen gedaan zijn, zoals bij iemand een lichamelijke beperking: drempel)
- Houden jullie er nu rekening mee? (indien ja, Op welke manier?)
- Jullie werken nu bijna 3 jaar samen begreep ik; is de samenwerking nu anders dan in het begin? (kan je dat uitleggen?)
- Waren er ook dingen die lastig waren?
  - Hoe zijn jullie daarmee omgegaan?
  - Hoe is dat nu?

## **Emancipation**

- Waarom werkt het hier?
- Wat jullie hier doen, is dat ook mogelijk bij andere besturen?
- Wat is er nodig om dit breder toe te passen?
- Zijn er dingen die anders kunnen/ Zijn er dingen die je achteraf anders zou hebben gedaan (afhankelijk van of je met oud-bestuurder spreekt).
- Zou je het samenwerken met een ervaringsdeskundige met een LVB aanraden aan andere besturen?

**We hebben al veel besproken maar ik heb eigenlijk nog een laatste vraag.**

**‘Zou je het samenwerken met een ervaringsdeskundige met een LVB aanraden aan andere besturen? (En waarom?)**

**Zijn er verder nog dingen die u graag zou willen toevoegen?**

**Heeft u nog vragen?**

**Bedankt voor uw deelname.**

#### Introductie

- **Voorstellen**
- **Doel van het onderzoek**
- **Opnemen interview**
- **Informed consent**
- **Vragen vooraf respondent**

#### Achtergrond

##### Kan je iets over jezelf vertellen?

- Zou je mij ook wat meer kunnen vertellen over jouw licht verstandelijke beperking?
  - Wanneer heb je deze ontdekt?
  - Met welke dingen heb je de meeste moeite?
- **Functie:**
  - Zou je wat meer kunnen vertellen over functie binnen het bestuur van SPZ?
  - Hoe lang ben je al werkzaam bij SPZ?
  - Kan je iets vertellen over hoe je aan deze functie bent gekomen?
    - Sollicitatie, ervoor benaderd/gevraagd, proefperiode?
- **Participatie**
  - Wat zijn uw taken als bestuurslid bij SPZ?
  - Wat vind je van je taken als bestuurslid?
    - Zijn er taken die je lastiger vindt? Welke?
  - 
  - U gaf aan 2/3 jaar in het bestuur te zitten, Zijn je taken nu anders dan in het begin?
- **Prestatie**
  - Ik hoorde dat je naast ervaringsdeskundige bij SPZ ook ervaringsdeskundige bent bij ZoMw, zit er verschil tussen de functies?
    - Kun je hier een voorbeeld van noemen?
  - Wat heb je het meeste geleerd sinds je begonnen bent als ervaringsdeskundige bij SPZ?
  - Welke dingen wil je nog graag leren als ervaringsdeskundige?
    - Is dit mogelijk binnen SPZ?

## **Disability Mainstreaming**

### **- Barriers & Acceptatie**

- Je bent de enige ervaringsdeskundige in dit bestuur, hoe vind je dat?
- Kan je iets vertellen over de samenwerking met je collega's?
- Heb je het gevoel dat er rekening wordt gehouden met jou?
  - Kan je een voorbeeld geven?
  - Hoe vind je dat?
- Zijn er dingen die je zou willen veranderen? (in de samenwerking?/aan de functie?)
- *Excuuuustruus? Wat maakt dat dit (niet) zo voelt?*

### **- Support**

- Hoe ben je aan deze functie gekomen?
- Heb je nog speciale trainingen of coaching gehad voor dat je begon bij SPZ?
- Je hebt een coach voor jouw werkzaamheden:
  - Hoe kom je aan deze coach? (Toegewezen, zelf kiezen)
  - Wat zijn de taken van de coach? Waarbij wordt t je ondersteund?
    - Hoe vind je dat?

### **- Emancipation**

- Wat is volgens jou de beste manier om meer ervaringsdeskundige aan het werk te krijgen binnen besturen?
- Zijn er dingen die je graag anders zou zien of zou willen veranderen?

## **Compensatie:**

- Ik begreep dat dit jouw baan is, geldt dat ook voor je functie bij ZonMw?
  - Wat vind je hiervan?
  - Heeft het feit dat je (onbetaald) bestuurder kan zijn invloed op andere dingen?

**We hebben al heel veel besproken. Ik heb eigenlijk nog maar één vraag. Zou je andere mensen met een LVB ook aanraden om bestuurslid te worden? Kan je dat uitleggen?**

**Zijn er verder nog dingen die u graag zou willen toevoegen?**

**Heeft u nog vragen?**

**Bedankt voor uw deelname.**

## Annex 3

### Informed consent verklaring



#### TOESTEMMINGSFORMULIER (Informed consent)

**Betreft:** *onderzoek naar inclusieve besturen*

Ik verklaar hierbij op voor mij duidelijke wijze te zijn ingelicht over de aard, methode en doel van het onderzoek.

Ik begrijp dat:

☐ ik mijn medewerking aan dit onderzoek kan stoppen op ieder moment en zonder opgave van reden

☐ gegevens anoniem worden verwerkt, zonder herleidbaar te zijn tot de persoon

☐ de opname vernietigd wordt na uitwerking van het interview

Ik verklaar dat ik:

☐ geheel vrijwillig bereid ben aan dit onderzoek mee te doen

☐ de uitkomsten van dit interview verwerkt mogen worden in een verslag of wetenschappelijke publicatie

☐ toestemming geef om het interview op te laten nemen door middel van een voice-recorder

Handtekening: .....

Naam: .....

Datum: .....

**Onderzoeker** Ik heb mondeling toelichting verstrekt over de aard, methode en doel van het onderzoek.

Ik verklaar mij bereid nog opkomende vragen over het onderzoek naar vermogen te beantwoorden.

Handtekening: .....

Naam: .....

Datum: .....

## Annex 4

### Informed consent verklaring

vrije Universiteit amsterdam



#### TOESTEMMINGSFORMULIER (Informed consent)

**Betreft:** *onderzoek naar inclusieve besturen*

Ik verklaar hierbij dat mij verteld is waar het onderzoek over gaat.

Ik begrijp dat:

O ik op ieder moment met dit onderzoek kan stoppen, ook zonder reden

O het onderzoek anoniem is

O de opname vernietigd wordt na uitwerking van het interview

Ik verklaar dat ik:

O vrijwillig mee doe aan dit onderzoek

O de uitkomsten van dit interview verwerkt mogen worden in een verslag of wetenschappelijke publicatie

O toestemming geef om het interview op te laten nemen door middel van een voice-recorder

Handtekening: .....

Naam: .....

Datum: .....

**Onderzoeker** Ik heb mondeling toelichting verstrekt over de aard, methode en doel van het onderzoek.

Ik verklaar mij bereid nog opkomende vragen over het onderzoek naar vermogen te beantwoorden.

Handtekening: .....

Naam: .....

Datum: .....

