OPLEIDING PB ORTHOPEDAGOGIE

Orthopedagogie

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**“See the child, before the disability” - UNICEF**

*Cultural differences and similarities on children with disabilities*

Bachelorproef van

Dessy Andwita Daulay

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# INTRODUCTION

My 2nd home, Indonesia, is an exotic country located in South East Asia that consists of more than 14.000 islands. According to statistics, it is ranked number 4 for the most populated country in the world. At the heart of this huge archipelago lies its capital city: Jakarta. A beautiful, crowded and vivid city illuminated by traffic lights; with scents of the street food and CO2 emissions. This all seems like a dream, but underneath all this beauty lies an ugly, hidden truth. A truth that I discovered when I went on an internship in the capital city.

Thanks to my university college, Karel de Grote-Hogeschool, I got the privilege to work at the Yayasan Sayap Ibu Bintaro. An organization/ orphanage specifically for children with multiple disabilities. While working with the children, I became more aware of the sad truth about Disabilities in Indonesia: there’s a lack of knowledge and awareness on people with disabilities here.

I was encouraged to further study this situation, because of the differences I noticed with my birthplace, Belgium. I used Pinto’s **Three-Step Method**, because it allowed me to view this problem from different perspectives. I went to research: 1) my standard and values, 2) Indonesia’s standard, values and codes; to then 3) come to a conclusion.

Here, you will read the result of my research. Enjoy!

Dessy Daulay

Jakarta, 7 juni 2018

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I would also like to thank all the people I met in Indonesia. Firstly, my family who welcomed me with open arms and took great care of me. For their support and words of advice. I’m grateful for you.

The *Yayasan Sayap Ibu Bintaro* organization for letting me be a part of their team for 5 months. For teaching me new skills, for helping me discover new talents and hobbies, for guiding me along the way, for teaching me the Indonesian language and make me feel more connected to my culture, and of course for the new friendships.

Finally, “out of sight, but not out of mind”. This goes out to my beloved little family who I had to miss for 5 months. To my mom and my 2 sisters, thank you for your unconditional love and support. Thank you for trusting me throughout this entire journey and for always believing in me. I’m eternally grateful for each one of you.

# SITUATION (Dutch)

Voor mijn laatste jaar als Bachelor studente Orthopedagogie, doe ik stage in een organisatie genaamd Yayasan Sayap Ibu in de regio Bintaro in Indonesië. Dit is een *Social Services Organization* en weeshuis voor kinderen met een meervoudige beperking gaande van kinderen met CP en bijkomende beperkingen tot kinderen met autisme, Downsyndroom,…

Deze kinderen werden ofwel door externe instanties (zoals het Sociale Departement van Indonesië,…) naar de Yayasan gebracht, ofwel door bewoners zelf die een kind hebben gevonden; of zelf een kind hebben met een beperking. Momenteel zijn er in totaal 36 kinderen die hier wonen.

De Yayasan is een non-gouvernementele organisatie en werkt nauw samen met andere organisaties, scholen of met (top)mensen. Ze zijn grotendeels afhankelijk van sponsors/ donaties van anderen. Daarom krijgt de organisatie heel vaak bezoek van mensen van buitenaf.

In deze organisatie werk ik als een soort leerkracht voor de kinderen en draai ik zo mee met het team. Als leerkracht zijn er steeds 3 klassen in de ochtend (8u30–11u) en 3 in de namiddag (13u30–15u30). Ieder kind wordt ingedeeld in een klas volgens hun leeftijd en beperking. Ieder klas heeft 2 leerkrachten.

Wanneer bezoekers naar de Yayasan komen, zijn meestal Pak Agus (mijn stagementor, *Head of the Child Service Unit* en *Principal of the Education Program*) en de leerkrachten degene die de gasten ontvangen en de kinderen bijstaan. Ik word er dikwijls bij geroepen.

Op een dag kwam er bezoek van een Islamitische Middelbare school. Het waren allemaal vierdejaarsstudenten. Ze verzamelden allemaal in wat ze hier ‘de aula’ noemen. Dit is een grote zaal waar de meeste ontmoetingen plaatsvinden. Ik moest mijn team van leerkrachten meehelpen met het begeleiden en brengen van een paar kinderen naar de aula: 5 kinderen met autisme en bijkomende beperkingen, 1 kindje met een meervoudige beperking en daarbij een beperkt visueel vermogen, 2 kinderen met het Syndroom van Down en 2 met Hydrocefalie (die beiden normaal kunnen functioneren) waren aanwezig.

Het was druk in de aula. Er waren een 40-tal leerlingen en ongeveer 4 leerkrachten. Toen ik met een kind (met autisme + bijkomende beperkingen) arriveerde, liet ik haar los en zat ik ergens op de grond, voor de deur van de aula. De mensen zaten in een kring en de meeste kinderen zaten in het centrum van dit cirkel.

Sommige kinderen dwaalden gewoon rond. Ik zag een leerkracht, van de middelbare school, een kind (die niet kon stappen) op het hoofd aaien en kriebelende bewegingen maken onder de kin van het kind. Ik zag leerlingen een kind trekken of dwingen om op hun schoot te zitten. Ik zag leerlingen hun gsm’s bovenhalen en de kinderen aangeven wat ze moesten doen voor de camera, mensen die lachen met of om het kind…

De leerkrachten van de middelbare school hielden aan het einde van hun bezoek een emotionele speech om de studenten erop aan te wijzen dat ze het goed hebben met hun leven en dankbaar moeten zijn met wie en wat ze hebben. Het was ook een soort sessie waar de kinderen moesten nadenken over hun daden. Tranen vielen overal.

Wat ik mij hier vooral bij afvraag is: *Welk beeld hebben deze mensen (Indonezen) van kinderen of mensen met een beperking? Hoe vaak komt het [in Indonesië] eigenlijk voor?*

# STEP 1: *Learn to know your own (culture-based) standard and values*

Shock, is the first emotion that I felt when I sat there in the aula, experiencing this situation. I was holding a child, who was sitting on my lap, (because otherwise he would walk to the door and exit the aula) and I remembered feeling very uncomfortable. During all the speeches, I saw how the students and the teachers interacted with the children. It was a shocking experience for me. It moved me. That’s why I chose this particular situation as a starting point of my research. I was mostly wondering why these visitors acted the way they did? How do they view these children? What do they know about them and/or (their) disabilities?...

As a result, I aim to study the image Indonesian people have on disability and what this means for the people with a disability themselves.

## Our image on and attitudes towards [children with] disabilities

This is not the first time a situation like this occurred at the Yayasan. A huge part of this organization depends on donations or sponsors. That’s one of the main reasons for the numerous visitors that come and go here. The first 30 minutes or even hour of their visit, everyone gathers in the aula. Everyone sits on the ground and is welcomed by my mentor, the Head of the Child Service Unit and the Principal of the Education Program, Pak Agus. He’s mostly the one who welcomes these visitors and gives them a formal and informative explanation about this organization and the children.

Some children are present during these visits. Not all of them are introduced in the aula. Only those who are able to go to the aula and who are available at the time the visitors arrive, are present. The children are also always assisted by 2, 3 or all of the teachers who work there (6 in total). I happen to be part of the teachers’ team, so they frequently call me to assist the children as well.

After the introduction and speech, the visitors are given some time to introduce themselves to connect and play with these children. Communication is one of the key rules at the Yayasan, and I understand why. They strongly advise to always communicate about who you are, what you’re going to do [with the child], about the place, etc (Yayasan Sayap Ibu Bintaro, 2018).

“Komunikasi itu yang penting. Selalu berkomunikasi dengan anak-anak” – Mbak Weni and Pak Agus, 2018. Some of these children are blind or have a visual impairment. If you step in their shoes, would you like it if something unexpected happened to you? Not knowing what’s going to happen to you or what/who lies in front of you? We have to persistently communicate with the children to avoid (Weningsih, 2013).

One day, we did a simulation where all the new employees (including me) were blindfolded. First, the teachers gave us objects to feel or food to eat, but in a rather hard way. They took us to places without telling us, pushing and pulling us everywhere,… At the end, one teacher introduces themselves to us and slowly guided us back to our meeting point. This is to see how it would feel if someone were to unexpectedly give, do something or take you somewhere without communicating with us.

This experience was a true eye opener. I previously understood why we always had to communicate with these children. But sometimes I too forget to communicate about the smallest of things with a child. It was after that simulation, that I started to communicate more frequently and became more transparent with a child. Even if it was verbal or non-verbal. That’s why communication is often the first lesson the team teaches these visitors.

Pak Agus helps these visitors introduce themselves to the children. This is a crucial, primary step. According to Pak Agus, these children must know who these new people are and why they came to visit them. They cannot continue their tour without a proper introduction.

I love to see the participation of these visitors. Even though some expressed their feelings of pity, high sense of compassion or even fear of approaching them, they’ll still try to overcome these feelings by trying to approach a child. It is either during the first introduction or after this, that I begin to notice the visitor’s change in behaviour. The visitors are slowly beginning to feel more relaxed or comfortable. That’s when the atmosphere starts to change.

Some of the children just wander around. Most of them just sit in the center looking around. Some do become quickly attached to these visitors or are so active [and present] that they want to draw the visitors’ attention. I saw people pulling the children, holding them tightly, laughing with them or at their behaviour. This may sound rude, but to me it all felt like a chaotic circus show. If these visitors know that a certain child likes to hang out with them or responds to their calls, they cling onto that specific child. They often suggest to do things they want to see the child doing. For example: smile ate the camera, wave to the camera, sing a small part of a song the child knows, give them their hand,…

If a child succeeds, they look impressed. If a child fails to do something the visitor asked, they try asking it again but eventually leave it. Not all visitors are like this, I know that. But most of the time, they behave like this.

There was a research conducted by Yazbeck et al. (in Thompson, Fisher, Purcal, Deeming & Sawrikar, 2011) on **community attitudes** towards people with a disability. They reported that there are 3 types of attitudes that people without a disability have towards people with a disability. These can be divided into **1 inclusive** and **2 exclusionary attitudes**:

The inclusive attitude involved an awareness of, and a willingness to engage with people with disability ‘as consumers, neighbours and friends’. […] The second attitude described (and the first of the two exclusionary attitudes) involved a lack of awareness of people with disability, even of their very existence, much less the difficulties they faced and their personal support requirements and ambitions. This encompassed a variety of individual attitudes, including paternalism. The final and most damaging attitude was discomfort with the ‘otherness’ of people with disability. This could lead to open hostility towards them, and exclusion and discrimination, both deliberate and covert (Thompson, et al., 2011, p. 9).

I would say visitors often show attitudes as described as ‘the second attitude’ in the previous paragraph. Although a few of them expresses their discomfort about these children with disabilities as well, especially very young children (last year of kindergarten or even elementary school kids), they put in effort to get to know the children with disabilities. That’s why it’s not the 3rd attitude.

Some of these people are blinded by the children their condition, that it’s hard to look away from it. Knowing that some of them sit in a wheelchair, knowing that some don’t communicate verbally, that some of those children wander around and don’t often sit still. When people notice these children their inabilities, the questions they ask are mostly about the children their conditions and what they’re unable to do, especially the “What?” “Who?” “How?” and “Why?”. The main thing I notice is that they come here with a lack of knowledge about these children, what they go through and what they need.

In my opinion, most visitors don’t know what to expect when meeting these children. But then again, how would they? Most of the time, the purpose of these visits is to become aware and learn about the place and the children. I cannot expect from each and every one going to the Yayasan, to be well prepared and educated.

They also have the tendency to talk about these children their conditions in front of the children. The teachers mostly mention their condition first and what it means for their learning skills and development. They mention these children ‘not being’ or ‘not functioning’ normally. This is degrading for the children. They are (perhaps unconsciously) belittling them. Some of the children understand us. But it isn’t a matter of understanding it or not. In my opinion, we shouldn’t talk about these children in front of them. I’m not the only one who noticed this. Mbak Weni (an Educational specialist) talked about this with me as well. Her opinion on this is that this is a problem, because it’s a form of humiliating the child in front of them. Only talking or noticing their inabilities and barely focusing on their positive traits could be damaging for their self-image, self-esteem or self-worth. According to her, this needs to stop happening. And I agree with her.

These visitors are curious. I can see that. And it’s good that they’re curious. Their willingness to know more about the children is present. Because if people stay ignorant or unknown about the existence of disabilities in their community or society, this will stay a problem. The road to an inclusive, open and understanding society will then be a long and difficult process (Tarahita & Rakhmat, 2017).

I got lucky that before I went to this place, I studied 2,5 years about what a disability is and what types of disabilities exists. I also learned how to approach certain people, what to do and what not to do. To become a (good) Socio Educational Care Worker. Mostly in the subject *Orthopedagogische Verkenning 2*, I learned about people with multiple disabilities. Although I found it hard to really understand this new concept, because I’ve never had any experience with children with a multiple disability, I learned that they are also people with abilities and that we need to help them find it and magnify the focus on it (Goossens, 2016).

That’s why I agree with the following quote: “It is clear, too, that disability should not be the only defining element of the individual, who should define himself or herself and be accepted as such“ (Burke, 2008, p. 11).

In addition, I want to bring out this quote as well. This quote, came from a woman I met during my internship, and it stuck with me throughout this entire journey: “Children with disabilities, are still children in the first place” – Weningsih, Educational specialist of Perkins International School for the Blind [Asia/ The Pacific], 2018.

Ms. Weningsih (also known as Mbak Weni) is an Educational specialist of the Perkins International school for the Blind, in Jakarta. She represents Asia and mostly travels around to America and Asia to inspect and supervise in organizations that work with children with a disability/MDVI (Multiple Disabilities and Visual Impairment). I met her at the Yayasan during one of my first weeks as an intern here. When she became aware of what I was doing, she immediately wanted to have a conversation with me about the children and how the team/ system works. During this conversation, she said the quote above and it stayed in my mind.

Remembering this quote, makes me approach a child differently. Where I was previously hesitant about certain actions, about how to approach a child, whether or not to always be serious (because I had the idea that one error, could lead to serious consequences), I became more relaxed with the idea to not take everything too seriously. As you get to know a child, you know what their qualities are, you learn their strengths, their talents, also their bad qualities, etc. But it doesn’t have to be a serious job. You’ll form an informal bond with these children that consists of unconditional love, humor and fun.

However, I also learned in college that we should indeed not only look at the disability. But we know that there’s a disability and we should take that in account. Because that’s what makes the child special (Hendrickx, 2016).

But despite all this, a part of me understands why the people react the way they do. I found a similarity between most of these visitors and me. Most of us feel scared or discomfort to get near a child. This feeling can be a result of the lack of understanding of a certain disability. SCOPE’s Aiden and McCarthy (2014, p. 3) says that “…many are concerned that they will do or say the wrong thing when talking to disabled people or about disability”, and I couldn’t agree more. I too felt this concern. I wanted to work with these children, but I was anxious of the idea that any wrong action (even the smallest), could cause severe consequences for a child. It took me about a couple of weeks (max. 2) to feel less concerned, open myself up and have courage to work with these children.

However, I did not distance myself from these children. My curiosity led me into educating myself more on how to approach and work with these children. I also had a good team who helped me bond with each child in the Yayasan. Most of them shared their experiences and first impressions, and after that I didn’t feel alone anymore. They told me that it’s humane of me to feel scared at first. “But if u have a heart and are willing to work with these children, you will feel differently afterwards”, the team says.

I also understand where the lack of knowledge comes from. Besides the lack of disability awareness across Indonesia in general, I partially also blame the home base for a lack of education on disability.

When I was younger, I used to think people with disabilities were helpless, incapable people. That’s why I mostly felt sorry for them. People in wheelchairs, people who looked differently (blind, amputated, with Down syndrome, etc.)... I put them all in 1 big category: *the handicapped*. My parents were huge contributors to this image I had.

As a child, I wasn’t well educated on disabilities. In our family, we didn’t talk much about it. I didn’t really know anyone with a disability. It was mostly people on the streets that I (not so often) saw who sat in wheelchairs, who were blind or had an amputated arm or leg. As a child, I frequently looked away from these people, because they looked rather scary and far from ‘normal’. My parents often made sure we don’t have to look at these people by hiding us behind them. They mostly told us to not pay any attention to them, but we had to pity them. “We can’t do much about their condition. Just make sure that u give something to them once in a while”, they often said.

There wasn’t any faith in believing people with disabilities could be stimulated or helped. They were doomed to live that way. I knew that hospitals were places where people could heal. I thought that could be a solution to their problem, but then there were the financial problems some of them face.

Years later, when I became older and because of my college education, I became more aware of the term *disability* and the various types of disabilities that exist. When I first heard this, I was shocked and mostly disappointed in myself that I didn’t know about this any sooner. But the more I educated myself, the more curious I became and eventually developed and grew new skills and mindsets to be able to work with people with disabilities. I see them from a different perspective now. The perspective where I see more potential and capabilities in each person and sources of motivation in failures.

In addition, I read a quote of UNICEF’s Executive Director Anthony Lake and want to add this, because I strongly agree with his words: “When you see the disability before the child, it is not only wrong for the child, but it deprives society of all that child has to offer… Their loss is society’s loss; their gain is society’s gain” (UNICEF, 2013). I acknowledge that these children have many potentials. They can be a huge contribution to society if we accept them. I’ve worked closely with these children and I’ve seen how they developed certain skills and have talent for certain things (such as cooking, shredding paper, sing, crafting, etc.).

These last words of Joyce Bender, CEO and president of the Bender Consulting Services (in The Jakarta Post) are words we should live by every day. She said that it’s possible for all of us that we might become part of the disabled community in the future. She believes that everyone is now temporarily able (Suryani, 2018, al. 2-3). This to see how we should take good care of one another as a society, no matter what our (dis)abilities are.

## The role of the Yayasan and relying on sponsors

I was constantly looking around. I saw the looks in my mentor and the teachers their eyes. To me, they looked very uncomfortable. They smiled, but it didn’t seem like genuine smiles of happiness. Some of the teachers were busy with playing or holding a child, that they didn’t fully pay attention on their surroundings.

But for the ones that observed the visitors, none of them made remarks or comments. Not even the Principal, who was the spokesperson and held the mic the entire time. Even he looked uncomfortable to me. My mentor once said that it’s “out of politeness that we let these people interact with the children. They come here to see the children and play with them, so that’s what they’re doing”.

I thought these visits were going to be informative, but fun. So that these people will become more aware of the existence of these children, of multiple disabilities and the existence of these kind of organizations. But I begin to think differently. People come to visit the place, see the children, they get a tour inside and around the building and afterwards give their donations either directly to the children (food, supplies, clothes, etc.) or just to my mentor instead (money). This doesn’t take a whole day. Some people come to visit for 1 or 2 hours, others an entire morning or afternoon.

If this is the case, then one day can consist of 3 visits from different groups or people. The children their schedule is also being interrupted then, but they mostly know beforehand when visitors are coming.

I’m very relieved to hear that this organization exists. I’m thrilled to hear their cooperation with other organizations or schools. This will expand the organizations’ and children’s network, and a lot of donations and support will be given to them. I support the teams here for thinking forward, for the sake of these children. This reminds me of an inspirational message my aunt frequently tells: “… dalam hidup itu, semua orang harus maju” (- Dyah Oetari, 2018), which means that in life, each person has to move forward. I too, would put the children in the center and think in terms of improving their lives. That’s one of the sole purposes of this organization.

And having sponsors or aid from outside is an important factor of income for the Yayasan. We see benefits for all parties: the children, the employees and the organization in general (Yayasan Sayap Ibu Bintaro, 2018).

#### Orphanage Tourism

I really do understand most of this. The Yayasan is a non-governmental, non-profit organization, so they do anything in their power to try and run everything themselves. In our culture, we are taught to always give back whenever we’re able to do so. My parents and family taught me this as well. “Always give back to those in need. Your reward will come later. In time”, is what they would say. So, I really do understand where these people are coming from.

However, over these past 5 months working here, I noticed the large amount of visits. Some weeks are very quiet, other times it’s flooding with visitors and that’s what mostly concerns me. Where I first thought this would be a good idea to make people aware of children with disabilities, I now begin to think this place is more like a charity case. Where people just come, take a look, give what they have and be gone.

Many researches and articles are beginning to doubt the intention and purpose of these visits. That’s where I came across the term “**orphanage tourism**”. Although the organization *Friends-International* describes this term and is primarily aimed for tourists that visit orphanages in Cambodia, I feel like this is applicable in the Yayasan’s situation. They describe this term as “tourists visiting children’s orphanages that includes a short performance or dance routine by the children, followed up with a request for a small donation” (Friends-International, n.d., al. 1).

They made a campaign to make people aware of the consequences of orphanage tourism. With the headline: “Children are not tourist attractions”. According to several reports, they believe these visits do more harm than good. These children have certain basic, human rights. These visits violate some of them. For example: they are taking away their right to privacy, due to these short visits. According to Friends-International, reports show that short visits can cause “harm to a child’s development and emotional wellbeing”. Because of these constant visits, the children won’t have much time for themselves. Their privacy is being violated (Friends-International, n.d.).

I strongly agree with this, because the children’s privacy was also my main concern. Some children are required in the aula to meet these guests, others stay in their rooms or have therapy or other activities in their schedule, that are crucial for them. But when visitors come, these things can be interrupted. The current activity is sometimes being paused so that visitors can take a look at the children. Some children are even heavily distracted with the arrival of these guests and sometimes have no clue what to do.

On a final note, I believe most of them come in with good intentions. They want to contribute in making the Yayasan even better for the children and they also want to make them happy. UNICEF explains that most people/tourists have the best of intentions, but only this is not enough (in Pitrelli, 2013).

## Visitors’ view on the team, young helpers & volunteers

On a final note, I also want to bring up something that my mentor likes to mention during these visits: *my* presence there. I’m most likely introduced to these visitors due to my background and reason for being there. I’m a student from Belgium who works at the Yayasan (either as a volunteer or as a community server in their eyes) for a period of 5 months.

Already hearing the ‘Belgium’ part, makes people look with full admiration at me. “Woah, so you travelled from afar to work with these kids? That’s so brave. You (must) have a good heart”, they mostly say. Some of them expressed their gratitude to me. They love that a young adult from a foreign country decides to work at this orphanage for 5 months. Some even find my decision heroic.

There are also young adults, who work in the Yayasan as caregivers, teachers and nurses. They are also being credited and acknowledged for their hard work and devotion. When looking at us, most of these visitors view us as heroes for these children, saviors or kind-hearted angels. Especially when you’re at a very young age.

It’s not that I’m against these labels. It’s truly a compliment when people see u that way. But I don’t associate or see myself as an angel, a savior or a hero at all. I’m doing something good, but I’m not the one who does all the work. I think the children do. I feel like it’s more the other way around. These children are my heroes. They’ve taught me new skills I didn’t knew I possessed before. They are the ones who touch our hearts with their inspirational stories of change and growth.

#### I am a Socio Educational Care Worker

According to a report of the Ohio State University, they state that people in general have an average amount of knowledge about people who work in the social sector. But the majority view these kinds of professions rather neutral or very positive (Cramer, 2015). Also, most of the people here continue to forget what I study. Even though I keep repeating that I work as an ‘intern Socio Educational Care Worker’, they still view or introduce me as a volunteer.

But still, they view volunteers as good people, because we voluntarily want to work somewhere. It was our own choice. Some people will say “When I was your age, I didn’t even think about doing this/ working here. So, good job to you!”.

To be honest, I am not that experienced. This is my very first time getting in touch and working with children with [multiple] disabilities. I had some knowledge, but I haven’t put these in use yet. At least, not for 5 months straight. I’m mostly thankful for these compliments, but whenever people try to label me as a ‘savior’ or ‘hero’, I convince them that I’m actually neither those things. I’m a student Socio Educational Care Worker for now and that’s how I actually want to be acknowledged for.

‘’…Wat dient hij [de ideale orthopedagoog] wel te zijn?

Hij dient een praktische studiosus te zijn die collegiaal dienstbaar wil zijn, iemand zonder eerzucht of statusbehoefte…’’. (Van Weelden, as cited in Hendrickx, 2016, p. 27)

I feel like this quote somewhat summarizes what I see in a socio educational care worker. We are available to those with (special) needs. What we do, we do out of passion. Our goal isn’t materialistic. Our goal is almost similar to that of our clients. To grow, to develop, to evolve. We aren’t chasing better equipment, resources, infrastructures, etc. for ourselves, but for those who need them the most.

But I think everyone has the heart to help these children. If you have the will, you’ll be able to do so. Yes, I travelled from afar to work here at the yayasan, but that doesn’t make me a superhero. I was passionate and dedicated about this internship abroad. I wanted to experience something new and challenge myself. I give myself some credit for that, but I’m still no hero.

If you work hard and have enough motivation, I believe that alot of people would also be willing to help [others]. “Because we human beings, are social beings… We survive here in dependence on others.”. (Dalai Lama XIV, 2008)

# STEP 2: *Learn to know the (culture-based) standards, values and codes of the other*

“… cultures differ in which physical and mental conditions are considered ‘disabling’”. (Kayama, M. & Haight, W.; 2014, p.1)

Somewhere in the first step, you’ve read how I defined a disability and where this definition came from. I collected a large amount of other definitions and people’s image, selected parts and formed my own image. That’s how my idea of a disability was created. But disability remains a broad term.

The definition of the World Health Organization is thoroughly known universally. They describe a disability as:

an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Disability is thus not just a health problem. It is a complex phenomenon, reflecting in the interaction between features of a person’s body and features of the society in which he or she lives (WHO, 2018, al. 1-2).

The Convention on Persons with Disabilities doesn’t have a clear definition. They do state that a disability is “conceptualized as the product of the interaction of persons with impairments with environmental barriers that hinder their full and effective participation in society on an equal basis with others”. (in Colbran, 2010, p. 44) They acknowledge the interaction between internal and external factors and don’t limit it solely to medical factors. (Adioetomo, Mont & Irwanto, 2014, p.5)

However, these clarifications or definitions might not be the same in every country or culture. So, before we get further into this research, we must firstly know how Indonesia defines a *disability*. To uncover whether there are differences and/ or similarities in how this specific country views a disability.

## Defining ‘*Disability’* in Indonesia.

According to the Japan International Cooperation Agency (2002, p.8; 2015, p. 3-1) Indonesia traditionally describes disabilities on the basis of the symptoms and functional classification. There used to be two sets of definitions: the medical and the legal definition. But since the law on People with Disabilities evolved, the definition changed with it. (Supriyanto, et al., 2017)

Byrne (2007) describes a disability in general terms saying that Indonesia acknowledges a disability as “a range of physical, intellectual, and psychiatric conditions which may range from mild to severe. However, disability is determined by the socio-cultural and physical environment”.

In the Law, People with Disabilities are referred to as *Penyandang Disabilitas*. This used to be “*Penyandang Cacat*”, but this term received a lot of criticism. It was a degrading term, that literally means “a disabled person”. As a result of Law No. 4 year 1997 and Law No. 8 year 2016 on People with Disabilities, this term changed from “*cacat*” to “*disabilitas*”. (Pawestri, 2017)

It is mentioned that in the *KBBI* (*Kamus Besar Bahasa Indonesia* or *The Great Indonesian Dictionary*) “*Penyandang”* is defined as a person who bears (in terms of ‘suffering’) something. “*Disabilitas*” on the other hand, derives from the English word *disability*. It indicates a defect or inability to perform normally. (Pawestri, 2017)

#### Law No. 4/1997 to Law No. 8/2016

If we look at the evolution of the definitions on People with Disabilities, the Indonesian Law No. 4/1997 on Persons with Disabilities should be mentioned. In this law, it is said that:

A ‘Person with Disabilities’ is every person who has a physical and/or a mental Impairment which can disturb or present a challenge for that person in functioning the way he or she should, who is (a) physically disabled; (b) mentally disabled; (c) physically and mentally disabled, where physically disabled means a disability which results in a disturbance to the way the body functions, among others, movement of the body, sight, hearing and the ability to speak; mentally disabled means a mental impairment and/or behavioural impairment, both inherent and as a result of disease/illness; physical and mental disability means a person who has both disabilities (in Colbran, 2010, p. 44).

However, according to Colbran (2010, p.44) this definition is problematic and incomplete: “Firstly, a person claiming to be a person with disabilities must prove that they cannot function ‘the way they should’”. Having no proof brings certain consequences to these people, such as having limited protection or no coverage from the government.

“Secondly, people with a psychiatric or psychological disability are not included and recognized as a person with a disability. (Colbran, 2010, p. 45)

This used to be the official definition that was frequently used and/or mentioned. Then, Law No. 8 year 2016 on People with Disabilities changed this definition. It is mentioned that Law No.4/1997 is no longer in use because it does not match with the needs of people with disabilities. That’s why it’s been replaced by this new law [No. 8/2016].

Law No. 8 year 2016 states that a person with a disability is every person with a long-term physical, intellectual, mental and/ or sensory disruption. Who faces certain barriers or difficulties in the interaction with their environment, to fully and effectively participate with other citizens, on an equal basis with others. (in Wibowo, 2016)

#### Categories and types of disabilities

As a result of various official statistical surveys, the Indonesian government also acknowledges 4 categories of disabilities, that eventually became 6 (JICA, 2015):

(a) visual impairment, (b) hearing impairment, (c) muteness, and (d) permanently damaged on specific parts of the body/ limbs or orthopedically impaired. They recently employed, adding two more categories: (e) mental disorders and (f) difficulty/impossibility to control behaviour of their own in everyday livings (JICA, 2015, p. 3-1).

In addition (to these definitions and categories), a disability can be divided in different types. According to the Rights of People with Disabilities under Article 4 of Law No. 8 year 2016 (as stated in Pawestri, 2017, p.169), there are 4 different types of disabilities. Which later on became 5:

1. People with physical disabilities: these are people who have limited motional function, amputation, paralyzed, weak or rigid bones, Cerebral Palsy (CP), complications due to the effects of a stroke or leprosy, and dwarfism.
2. People with intellectual disabilities: are those people whose brain function/ thinking processes are limited due to a low level of intelligence (below the average). This includes slow learners, people with dual disabilities (= disorder in growth and development of the intellect, sometimes accompanied by physical disabilities) and Down Syndrome.
3. People with mental disabilities: are the people who have a disruption of their thoughts, emotional and behavioural function.

Among them are also: (a.) psychosocial disabilities such as schizophrenia, bipolar, depression, anxiety and personality disorders;

(b.) developmental disabilities that affect the ability to social interactions, such as autism and hyperactivity.

1. People with sensory disabilities: these are the people with a disruption of any of the functions of their 5 senses, including visual impairment or blindness, auditive impairment or deafness, and/or disability in speech (or inability to be verbal) (in Pawestri, 2017, p. ).
2. As found in “BAB II: Tinjauan Pustaka” (n.d.) it says that people with multiple disabilities: are people with more than one disability. For example, someone with a physical and mental disability.[[1]](#footnote-1)

### Children with Disabilities

Children with disabilities are separately mentioned and also have their rights. The Indonesian Law No. 35 year 2014, article 1 paragraph 7 defines children with disabilities as:

Children who have physical, mental intellectual or sensory constraints for a long period of time who, in their interaction with their environment and the attitude of the society may find obstacles that make it difficult for them to fully participate in the equality and fulfillment of their rights (in Supriyanto, et al., 2017, p. 12).

This definition is reinforced by the children’s rights in the CRPD (the Convention on the Right of Person with Disability), stated in article 21 paragraph 1 that: The State, government, and regional governments must respect and fulfill children’s rights regardless of their physical/mental condition. (in Supriyanto, et al., 2017, p. 12)

In Indonesia, the word *Anak Tunaganda* is used to indicate a child with multiple disabilities. It means a child who has a combination of disabilities or impairments “of which causes such severe educational needs that they cannot be accommodated in special education programs solely for one of the impairments”. (Code of Federal Regulations, 1999, as cited in Snell, 2011, al. 2)

The Law No. 20 year 2003 on National Education System and governing special education services uses certain terms to describe a child with disabilities. A child with a disability initially became known as *Anak Luar Biasa* or *ALB* (= Exceptional Child). Under the Law No. 2 year 1989 these children have the right to an Exceptional Education (= *Pendidikan Luar Biasa* or *PLB*) in an Exceptional School (*Sekolah Luar Biasa* or *SLB*). (Supriyanto, et al., 2017)

Based on the Law No. 20 year 2003 the term “*exceptional”* was replaced with the term “*special*”. The children with special needs are now often referred to as *ABK* or *Anak Berkebutuhan Khusus*. Although this label changed, the term for the Special Education (SLB) remained the same (LINKSOS, 2015; Supriyanto, et al., 2017).

### DIFABEL, DISABILITAS and Impairment/ MDVI

Indonesia uses a variety of terms when it comes to disabilities, but it is important to know the meaning of and the differences between these words to avoid the incorrect use of these terms. We differentiate these 3 words: *difabel*, *disabilitas* and *MDVI*.

#### The difference between Difabel and Disabilitas

The explanation of both the terms *disabilitas* and *difabel* can be divided into how a person with a difable or a disability is described (*pengertian*), and what the definition (*definisi*) is.

“**Pengertian *difabel*** adalah seseorang yang memiliki kelainan fisik dan atau mental yang sifatnya mengganggu atau merupakan suatu hambatan baginya untuk melakukan kegiatan sahri-hari [sic.] secara layak atau normal”. (Maxwell J.C., in DefinisiMenurutParaAhli, 2016, z.p.)

This explanation describes *difabel* as a person who has a physical or mental disorder that is an obstacle for him/her to properly or normally perform daily activities.

“**Definisi *difabel*** adalah suatu kehilangan atau ketidaknormalan baik itu yang bersiffat fisiologis, psikologis, maupun kelainan struktur atau fungsi anatomis”. (WHO, in DefinisiMenurutParaAhli, 2016, z.p.; solider, 2017)

This definition says that *difabel* is either a loss or an abnormality of a physiological, psychological function, as well as structural differences or differences in anatomical functions.

A disability focuses more on the imbalance in the interactions between biological conditions and the social environment. There are people with physical, mental or a combination of both disabilities. (DefinisiMenurutParaAhli, 2016; Solider, 2017)

The reason for the existence of this new term, was to replace other terms which contained certain discriminatory elements (cacat, disable,…). The meaning and use of these words were inhuman. It distinguished people with disabilities from the “normal” people. (Muharam, 2014; LINKSOS, 2015)

The word *Difabel* derives from the English version *Difable.* It is an acronym from the words “differently able”. Though there’s a slight conceptual difference of meaning between these two terms, *Difabel* is considered a better term because ‘difabel’ people aren’t actually disabled. (Prasetyo, A.M., 2018)

Even though they made a new term, Indonesian people still tend to mix them. Some even see them as synonyms. And for others, this is still a new concept. What we also know is that the English translation of both terms remains the same: *disability*. In the law and other official documents, the word *difabel* is often used, but not that frequently. *Disabilitas* remains. (Muharam, 2014; LINKSOS, 2015)

#### IMPAIRMENT and MDVI

A term also used to indicate a person’s shortcomings is *IMPAIRMENT*. An impairment should not be confused with a disability. These are both different words, with different meanings.

According to the World Health Organization (2001, p. 1047) an *impairment* is “any temporary or permanent loss or abnormality of a body structure or function, whether physiological or psychological”. It can cause a defect in essential mental (memory, consciousness) or sensory functions, internal organs (heart, kidney), the head or the limbs. The difference is that a disability is more of an inability or restriction to perform an activity ‘normally’. It is often an effect from an impairment. (WHO, 2001)

There’s a specific kind of Multiple Disability called *MDVI*. This term originated from the English language and stands for *Multiple Disabilities and Visual Impairment.* In the literature, you will find another term with the same meaning, *VIMD*. This stands for Visually Impaired Multi Disabilities.

MDVI refers to a person with visual impairments and another disability. This secondary disability could be a restriction in auditive, intellectual, physical, emotional,... aspect. The extent to which these people experience limitations differs from person to person, but many of them can still hear or see something. (Weningsih, 2013)

There’s also another specific type of MDVI called *deafblind* (*tunanetra sekaligus tunarungu*). These people experience a major sensory loss, where 2 of their senses are damaged: their vision and hearing. These two senses play a huge role in processing information. In order to receive (outside) information, they depend on others who provide this info. (Weningsih, 2013)

As a result, they show certain characteristics such as “experiencing distorted perceptions of the environment, experiencing communication difficulties and experiencing barriers in maintaining interpersonal relationships with others”. (Weningsih, 2013, p. 5)

## Data and statistics on disabilities in Indonesia

Located in Southeast Asia, Indonesia is the largest archipelago in the world. With an estimated population of more than 260 million people, consisting of 1.128 ethnicities and 746 local dialects, it is ranked number 4 of the most populated countries in the world (worldatlas, 2017; Supriyanto, et al., 2017; worldometers, n.d.)

The WHO (2018, al. 2) states that “15% of the world’s population has some form of disability. This corresponds to around a billion people”. If we zoom in to Indonesia specifically, according to data found in a report by the Japanese International Cooperation Agency (2015) around 4,5 % of the Indonesian population have disabilities. However, this percentage has increased over the years. A recent report by Aprilina Pawestri (2017, p. 164-165) states that 12% of the Indonesian people have disabilities. This was a result of a survey conducted by the Central Bureau of Statistics (BPS) (Pawestri, 2017).

In another Indonesia Country Report (ICR) to the 2004 Workshop on Protection and Promotion of the Rights and Dignity of Persons with Disabilities state that there are around 1.480.000 people with Disabilities in Indonesia. We can subdivide this amount into different categories according to their specific disability: 162.800 (11%) with a physical disability, 192.400 (13%) are blind, 503.200 (34%) deaf, 348.800 (26%) with intellectual and mental disabilities, and 236.800 (16%) are people who have been affected by a chronic disease (e.g. leprosy or tuberculosis). These data however, are a result from researches of people with disabilities who live with their family or community. This does not include the people who live in institutions and is therefore not fully representative (Colbran, 2010).

According to a survey conducted in 9 Indonesian provinces, 299.203 people have disabilities and 10,5% (31.327 people) among them have severe disabilities. West Java is the province with the highest rate of people with disabilities with 50,9%. Gorontalo on the other hand, has the lowest rate with 1,65%. (Supriyanto, et al., 2017)

There are more male people with disabilities than female. About 57.96% of males have a disability. Age wise, the highest numbers of people with disabilities are the ones between the age of 18-60. If we look at the types of disability, most people deal with a physical disability which is 21.86%, there are around 15.41% of people with an intellectual disability, and lastly an estimated 13.08% are deaf or have some sort of hearing impairment. (Supriyanto, et al., 2017)

But despite all these data being published, Colbran (2010, p. 29) says that “there is no accurate and comprehensive data regarding PwDs [People with Disabilities] in Indonesia. Agencies collect data using different methods and criteria which results in widely different outcomes”. The existing percentages and numbers don’t accurately represent the amount of people with a disability in Indonesia. This is due to numerous of reasons mainly being: families who do not recognize, do not admit or hide a member with a disability; and a lack of knowledge, understanding and recognition of people with disabilities in Indonesia. (Colbran, 2010; Tarahita & Rakhmat, 2017)

As a result of these incomplete data information, the government does not have the right resources or policies that stem with the needs of people with disabilities. One of the first crucial steps towards improvement, is to improve their data collecting system.

In 2013, Indonesia was assisted by the World Health Organization and the United Nations Population Fund to make some changes. The Indonesian government (in Tarahita & Rakhmat, 2017, al. 6) made plans to improve their data collection, by redesigning their “comprehensive census questionnaires by including question variables that would provide more useful picture of the social and economic situation of the disabled communities”. But due to lack of finances, this census has been postponed. (Tarahita & Rakhmat, 2017)

## Stigma and Prejudgment

‘’Stigma is the big problem. People are looking down on them.’’

– Joyce Bender, president and CEO of Bender Consulting Services (2018, n.p.)

There’s still a negative stigma and judgment around people with disabilities in Indonesia. Most people still view them as an embarrassment to society, that’s why they’re often hidden and barely visible. In certain beliefs, they see disabilities as God’s punishment for their parents’ previous sins. For example: In Java and Bali, some people believe that a person with a disability is possessed by a supernatural spirit. They need to be exorcised in order to ‘be normal’. (Colbran, 2010; Byrne, 2007)

This can also be seen from another perspective. If we look at a matter of fate, some Indonesians view people with disabilities as unproductive, incapable people for whom ‘*nothing can be done’.* To most people, it is considered a sickness or weakness. They also believe that these people are a burden to those around them, because of their dependency. There’s a lack of empathy towards people with disabilities in Indonesia. (Colbran, 2010; Byrne, 2007; Wibowo, 2016)

Byrne (2007) also explains that they are “generally not encouraged to develop personally. They are not considered valuable members of their community and many remain housebound, uneducated and unskilled”. He adds that “these individuals are considered the responsibility of the family to be cared for as a dependent member of the family unit”. (Byrne, 2007, z.p.)

These stigmas and persistent judgment on people with disabilities negatively affect their lives. They’re often confronted with discrimination.

## Facing Discrimination

We’ve seen the lack of accurate data, the lack of acknowledgement and understanding of disabilities and the several stigma’s and prejudgments that exist around people with disabilities in Indonesia. As a result, these people face discrimination in their daily lives. Not only on micro level (e.g. their family), but also on meso and macro level (e.g. work environment, the government, gender discrimination).

### What is discrimination?

According to the Indonesian Law No. 8 year 2016 on People with Disabilities, *Discrimination* is: “any form of distinction, exclusion, restriction, harassment or excision of people with disabilities with the intention to deprive them from exercising or enjoying their rights [and recognition] as decent human beings”. (in Republik Indonesia, 2016)

### Discrimination on many levels

According to UNICEF’s report (2013) many children with disabilities experience exclusion in their early years. Most of them are unregistered after being born into this world. This also results in not getting any social services aid and legal protection. The chances of survival decrease this way. “For children with disabilities to count, they must be counted – at birth, at school and in life”. (Mr. Lake, in UNICEF, 2013, al. 9)

Angela Kearney, UNICEF Representative in Indonesia said that: “In many instances, families and communities are still ashamed if their children have a disability. These children are often locked away, excluded from school and community life rather than being supported and integrated,”. (UNICEF, 2013, al. 7)

There are even extreme cases where in some families, the member with a disability is tied up and brought to the back of the house. With the intention to isolate them from the outside world. In Indonesian terms, this is called *‘dipasung’*, meaning “to be held in stocks”. Some experience abuse, neglection, harassment, etc… within their families. Most children with a disability also live in poor families. They often cannot afford to send their child with a disability to an (official) institution, who can effectively help them (Byrne, 2007, al. 7).

**Education** is hard to access. Some children with disabilities are being denied in public schools because of their condition. Even getting into kindergarten can be a struggle. Many efforts have been put into establishing inclusive education for children with disabilities. But unfortunately, it’s still not entirely realizable. Only a few are able to have that ‘normal’ education. Others are required to go to special schools (the SLB, *Sekolah Luar Biasa*), but for some parents this is hard to accept.

But even if they’re allowed into these schools, the system does not work properly yet. Teachers still undermine some of these children their ability and intelligence, by teaching them preschool levelled curriculum over and over again. While not knowing that some of them are able to study with their age groups (Tarahita & Rakhmat, 2017)

Due to a lack of education, their future choices are very limited and finding a **job** can be a huge struggle. They’re frequently rejected by job opportunities, because people view their incapacities. But even if they’re hired, at their work environment itself, people with disabilities still face discrimination. There’s a lack of good resources or help to guide them into (preparing for) the working life. Employers are usually clueless on how to effectively help their colleague with a disability. Most of them are also underpaid, which makes them financially unstable (Tarahita & Rakhmat, 2017; Supriyanto, et al., 2017). “They generally do not earn a reliable income and therefore depend upon able-bodied family members to provide for their livelihood”. (Byrne, 2007, al. 6)

If we look at the differences between **gender**, girls and women suffer from double discrimination, because of their gender and their disabilities. They “continuously experience discrimination in fields of education, work, leadership participation, decision-making position…”. (Supriyanto, et al., 2017, p. 11) This makes them more vulnerable to violence, abuse and assault (Supriyanto, et al., 2017; Colbran, 2010).

Byrne (2007, al. 2) says that: “The general quality of life experienced by Indonesians [with disabilities] … is poor. Most people with disabilities in Indonesia go without government welfare, specialized medical treatment and assistive technology”. Particularly, those that live in isolation and poverty face a higher level of discrimination. In society, they often face stares in public places or even mockery from others. Sometimes, they’re even targets of jokes in television. People still have negative attitudes towards people with a disability. As a result of the social exclusion and discrimination, they can feel less motivated or confident in engaging with (physical) activities. In addition, this can bring stress and feelings of isolation which are some consequences for people with disabilities (Hi-Us, n.d.; Wibowo, 2016, Supriyanto, et al., 2017).

The lack of good policies that protect the rights and lives of people with disabilities also contributes to the marginalization and discrimination of these people. The government hasn’t taken any adequate actions yet to eliminate discrimination and exclusion. There’s no policy that states any punishment for the discriminative acts against people with disabilities and the violation of their rights (Supriyanto, et al., 2017).

Even though more needs to be done, the government continues to put in efforts to eliminate discrimination and make Indonesia more inclusive for people with disabilities.

## The road to INCLUSION and INTEGRATION

In the previous chapters, I’ve discussed the stigma, prejudgments and discrimination people with disabilities have to deal with daily and how this affects their lives: From social exclusion to being denied access to health, work or education, being humiliated at home or in public, etc. But Indonesia does not stay silent on this problem.

According to the International Disability and Human Rights Network (DAA, n.d., al. 2) a socially inclusive society means that it “must include independent living, fully inclusive education, and access to information, the environment, and all social systems”. The road to a more inclusive society is a long process. But let’s look at what Indonesia has done and plans to do.

In October 2011, Indonesia ratified the CRPD (Convention on the Rights of Persons with Disabilities). Supryanto, et al. (2017, p. 1) says that: “… Indonesia is now bound and obliged to implement the content of the CRPD in all sectors of life”. This also brought a change in the Indonesian law. While it took them 5 years to make this change, the government eventually replaced Law No. 4/1997 on People with Disabilities with Law No. 8/2016 on April 2016. This law helped change the way people perceive [people with] disabilities (UNESCO, 2014; Supriyanto, et al., 2017).

Indonesia now has about 17 laws regarding the rights of people with disabilities, such as Law No. 4/1997 on People with Disabilities, Government Regulation No. 43/1998 on Efforts to Improve their Social Welfare, Law No. 39/1999 on their Human Rights, etc. But unfortunately, these laws have not yet been optimally implemented by the Indonesian government (Liu & Brown, 2015; Wibowo, 2016).

### Education

Law No. 20 year 2003 on National Education System (in Supriyanto, et al., 2017, p.31-32) entitles all citizens to quality education. This includes children with special needs. As a result, the Ministry of Education divided two types of education aimed for people with Disabilities: special and inclusive education (Priebe & Howell, 2014).

The exceptional/special school (SLB) is a place meant for the education of children with disabilities. In this school, they’re categorized based on the type of disability. These schools are required to have space for the accessibility for wheelchairs, texts written in Braille alphabet,… All the necessary changes that corresponds with the needs of these children. Special schools exist for the various types of education: from elementary to high school (Ediyanto, Atika, Kawai & Prabowo, 2017; Priebe & Howell, 2014; Supriyanto, et al. 2017; Tarahita & Rakhmat, 2017).

On the other hand, the Circular Letter No. 380/G.06/MN, year 2003 (in Priebe & Howell, 2014, p. 5) defines an Inclusive Education as “education that welcomes the participation of children with disabilities to learn together with their peers in regular school”. In their eyes, all children are different. Therefore, the school puts in extra tools and effort to optimally help [and guide these children throughout their school career, according to their needs. (Priebe & Howell, 2014).

To summarize it all, inclusive education focuses on integrating children with disabilities into “mainstreams [sic.] classrooms but also providing accommodative curriculum”. (Tsaputra, A, S. & MA, n.d., p. 3)

Although Indonesia distinguished these two types of Education for children with disabilities, they aim for a more inclusive education, because the special education still had its flaws. In reality, these special schools cause more isolation, segregation and marginalization of these children. As a result, Indonesia is developing more inclusive education systems to eliminate further discrimination and separation between society and these children. But the amount of such schools is still relatively low (Ediyanto, et al., 2017; Tsaputra, et al., n.d.).

In these types of Education, the role and qualities of the teachers are of great importance. In Article 8 of Law No. 14/2005 on Teachers and Lecturers (in Supriyanto, et al., 20017, p. 36) they state that: “teachers must have academic qualifications, competence, certification as educators, physical and mentally health, as well as having the ability to realize the goal of national education”.

Inclusive Education would contribute into developing those capacities and skills for these children, needed for their future [work] lives. It can start a conversation about disability awareness and promote a diverse community with positive attitudes, participation and social inclusion (Afrianty & Soldatic, 2017).

### Employment

A lack of (high-) quality education can result in unemployment of people with disabilities. Many of them are being rejected from various job opportunities, because people still view them as incapable people for the job market. But even when they’re hired, they still face discrimination.

When it comes to job opportunities, there are certain stereotypical jobs people “assign” to certain people with disabilities. Such as becoming masseurs for the ones with visual disabilities, physical disabilities becoming tailors, people with hearing loss that should work in noisy places or that people with intellectual disabilities should weave. This is especially mentioned in The Minister of Manpower Decree No. 205/1999 on Vocational Training and Employment of Person with Disabilities (Supriyanto, et al., 2017).

To make the work environment more accessible and inclusive, Indonesia has taken some action and made certain laws and regulations.

Law 4/1997 protects and promotes People with Disabilities their right to work. It is stated that they work with a quota system, that is described in the following law:

Article 4, Paragraph 28 of Law No. 43/1998 on Efforts to Improve the Social Welfare of Persons with Disabilities (in Priebe & Howell, 2014, p. 6) states that “it is the responsibility of the private and public institution to provide employment opportunities and labour participation of PwDs, [wherein] on in every 100 employees should [be a] Person with a Disability”.

In article 28 of Law no 4/1997 a penalty is described to whoever fails in following Article 4. The sanction could either be a prison sentence of maximum 6 months or a maximum fine of Rp 200.000.000 (two hundred million Rupiah) (Colbran, 2010; Priebe & Howell, 2014).

In law No. 9/2003 however, it is stated that a company can terminate someone’s employment due to his/ her disability. If a person were to become permanently disable, they too could be terminated of further employment (Priebe & Howell, 2014; Supriyanto, et al., 2017).

But to shed some light in this situation, in December 2016, Indonesia signed and established the Indonesia Business and Disability Network (IBDN). This is a commitment made by 5 major companies across Indonesia whose goal is to promote diversity and inclusivity in the workplace. These companies are: *PT Bank Mandiri* (Persero) Tbk, PT *L’Oréal Indonesia*, PT *Standard Chartered Indonesia*, PT *TetraPak Stainless Engineering* and PT *Trans Retail Indonesia*. The IBDN was formed in partnership with several other organizations such as *disabled persons’ organization* (DPOs), the *Ministry of Manpower*, the *ILO* and the *National Social Security Provider for Employment* (BPJS Ketenagakerjaan) (ILO, 2016).

This Network’s mission is to “encourage business communities in Indonesia to be more inclusive and conducive for diversity…”. (ILO, 2016, al. 6) It could be a source of support for people with disabilities and companies in Indonesia, because of its numerous opportunities. Employers could share and learn from each other, people with disabilities can become more aware of the employment opportunities and this could put a spotlight on their capacities, interests and talents.

At the base of this Network, there are 4 commitments. These are:

1. Foster efforts aimed at preparing the business sector to be more inclusive (covering among other following areas: infrastructure, mindset and policy, accessibility, reasonable accommodation, education & training, and awareness raising through exchange of information);
2. Facilitate active roles and preparedness of people with disabilities to work (covering among other following areas: mindset, skill, communication, reasonable accommodation, education and training, and awareness raising);
3. Carry out merit-based recruitment of people with disabilities using mechanism that are equal and friendly with diversity;
4. Encourage creative programs which can improve both company’s competitiveness and the independence of people with disabilities (ILO, 2016, al. 7).

Although Indonesia is planning on moving towards a more inclusive work environment, it still lacks the enforcement and practices of certain laws, the employment policies needed to support people with disabilities, guaranteeing security and safety systems in the work environment, etc.

Tarahita & Rakhmat (2017, al. 9) concluded that the mutual benefits of employing people with disabilities is that: “People with a disability in Indonesia will be empowered and independent if they are able to work and have a stable source of income. In this way, their financial and social strata will also be lifted, and Indonesia will become a better country”.

### Health Care

Article 139 of Law No. 36/2009 on Health (in Supriyanto, et al., 2017, p. 33) states 2 things:

1. Health maintenance efforts of the disabled shall be aimed at maintaining healthy life and be socially and economically productive, as well as having dignified lives.
2. The Government shall ensure the availability of health care facilities and facilitate to enable them live independently and socially and economically productive lives.

In this law, they also included Mental Health which state that every person has the right for protection and mental health services (Supriyanto, et al., 2017).

In Article 1 of the Government Regulation No. 36/1980 on Social Welfare for people with disabilities it says that “medical and social rehabilitation and a social fund to support poor PwD’s must be provided. This, according to the financial resources of the government”. (Priebe & Howell, 2014, p. 7)

Article 4 in Law No. 43/1998 on Efforts to Improve the Social Welfare of Persons with Disabilities states that “the government should provide equal opportunities, rehabilitation, social assistance, and government assistance to improve the welfare of PWDs”. (Priebe & Howell, 2014, p. 7)

It should be taken in account that these laws have not been fully implemented. Some People with Disabilities still face discrimination on this aspect and are being denied access to health care or health insurance. They still deal with unfriendly service and are not given the right support that help them improve. Also, health insurance held by the state does not guarantee their protection of their rights (Supriyanto, et al., 2017).

### More needs to be done…

Although, Indonesia has made these several changes and has taken certain actions, there’s still more that can and needs to be done. All these new regulations are one small step towards an open, diverse and inclusive society for people with disabilities. In reality, all facets of society need to come and work together to realise that kind of society. Whether it’s the government, the Indonesian citizens themselves, health institutions, schools and/ or companies.

They also work with several, international companies to reach the goal for a more inclusive society. For example, over the year, Indonesia has been cooperating with the Australian government to help make these improvements. Together, they made programmes[[2]](#footnote-2) that aim to reduce poverty and build more resilient economic growth. Some of these programmes include fighting for more justice for women, the poor, people with disabilities and vulnerable children. For example: More Gender equality and women’s empowerment, more practices of the Disabilities Human Rights, etc (Australian Government, n.d.).

## Establishing the Yayasan Sayap Ibu (Bintaro)

As a result of the disability movement (in this case specifically for children with disabilities), the *Yayasan Sayap Ibu Bintaro* was established. It is one of many Social Services organizations in Indonesia that provides shelter, care, guidance and support for (families of) children with disabilities. It took a long time to visualize and build this orphanage. It was eventually established in 2005.

In Indonesia, there’s a total of 4 Yayasan Sayap Ibu: 1 in Banten, 2 in Yogya and 1 in Surabaya. The first ever YSI was established in Yogyakarta.

The Yayasan Sayap Ibu Bintaro is currently fostering approximately 391 children. Of which 36 live in the orphanage and 355 still live with their parents or a close family (Yayasan Sayap Ibu Bintaro, 2018).

### Introducing the staff

The Yayasan currently has an organizational structure of 7 core managers and executives. There are: 1 manager, 33 nurses & caregivers, and 38 staff & therapists (Yayasan Sayap Ibu Bintaro, 2018).

According to an interview with Pak Agus, many staff members didn’t come here with an educational background in the social sector. Most of them started off as volunteers, without any (professional) knowledge [of these children their condition and the whole system] and skills.

The Yayasan recruits their staff by actively searching for them in different places/ areas. Most of these people are young adults, with no experience in the social sector. When accepted to this job, they will firstly be trained and guided, so they know how to take care of a child. Most of them also learned these skills in an autodidactic way.

### Vision, Mission and Slogan

The Yayasan holds a very dear ***vision***, which states that: Every child has the right to a decent, dignified life. Neglection is not tolerated. The organization has 'an eye on a sustainable, holistic well-being' of the children. They make efforts so that children receive the necessary care, love and affection. (Yayasan Sayap Ibu Bintaro, 2018)

There are 7 ***missions*** that can be described as follow:

1. Professional sponsorship, Care and Education are provided for children with a disability, both in the Institution itself or within the child’s network (e.g. family);
2. Effective and optimal Physical, Psychological & Social Rehabilitation;
3. Providing optimal social services;
4. Providing quality social services;
5. Stimulating children to become independent;
6. Child protection & care since the womb;
7. Establish an active partnership (inter)nationally (Yayasan Sayap Ibu Bintaro, 2018, p. 7).

Their ***goal*** for each child here is so that: “Every child can live independently and get the same rights as children in general. They can maximize their potential […] to work. And have the social competence to economic independence that makes their life happier, healthier and prosperous”. (Yayasan Sayap Ibu Bintaro, 2018, p. 7)

They also have a **slogan**: *To Live, To Play, To Work, To Love.* Each employee, volunteer or other worker here has to keep this slogan in the back of their minds and act on it. Because certain children’s rights are included in there.

*To Live* means having the right to live like a child, as every other child in the world. *To Play* is essential during the childhood. Because “childhood is playing and learning”. (Yayasan Sayap Ibu Bintaro, 2018, p. 8) *To Work* is training and guiding the child as early as possible as a preparation for their future (working) lives. And lastly, *To Love* which indicates sharing each other’s love and affection. (Yayasan Sayap Ibu Bintaro, 2018, p. 8)

### A slight shift in wording

Recently, there have been comments about the description of the Yayasan. External people noticed the use of a term that had a rather negative connotation.

As a result, the Yayasan made a slight change in wording their description. What previously was: “Penyantunan & Rehabilitasi Anak **Cacat** Terlantar” became “Penyantunan & Rehabilitasi **Disabilitas** **Ganda** Terlantar”. (Yayasan Sayap Ibu Bintaro, 2018)

The first description briefly means “Aid (or sponsorship) and rehabilitation for abandoned, disabled children”. Whilst the second one translates into “Aid (or sponsorship) and rehabilitation for abandoned children with multiple disabilities”.

### The Education Program

Around 2015, the Education Program was introduced to the Yayasan. These new changes were made by the arrival of Mbak Weni, an Educational Specialist at the Perkins School for the Blind. She made sure different types of classes were made, that corresponds with the different types of disabilities. Templates for Individual Lesson Plans have been made and trainings were given. The Yayasan transformed into a special education school, but it has not reached that level yet (Yayasan Sayap Ibu, 2018).

It is important to know the strategies they live by. It’s called “Strategi belajar anak-anak sekolah khusus YSIB”, which means the learning strategies for the children of this special school:

1. Kembangkan komunikasi. = Communicate!,
2. Hand under hand. = Hand under hand, a technique to help or guide a child in executing a certain activity,
3. Kembangkan pemahaman konsep. = Develop an understanding of concepts. This can be reached by always communicating!,
4. Dorong kemandirian = Encourage their independence,
5. Gunakan kurikulum dan akademis fungsional = Use a curriculum and a functional academic,
6. Kembangkan kegiatan rutin dan antisipasi = Develop routine and anticipatory activities,
7. Kesempatan memilih = Give them the opportunity to choose,
8. Beri Bantuan secukupnya (task analisis, wait and see, circle) = Give enough help,
9. Kerja sama dengan keluarga = Cooperate with family,
10. Kembangkan dokumentasi = Document events,
11. Siapkan transisi = Prepare the transition (Yayasan Sayap Ibu Bintaro, 2018)

Whether you’re a teacher, a caregiver, a nurse or an office person, everyone needs to use these strategies when it comes to helping or guiding a child (Yayasan Sayap Ibu Bintaro, 2018).

### The Role of donators/ sponsors

Due to being a non-governmental and non-profit organization, they rely on the donations of sponsors or visitors. This is the Yayasan’s primary source of income, the main reason why donators and sponsors are crucial. Most of them, donate supplies such as food (rice, grain, cookies, milk, vegetables, etc.), school materials for the kids, clothes, shoes, money, etc… (Yayasan Sayap Ibu Bintaro, 2018)

A lot of these donations are stored in a safety space, where they keep track of everything. These supplies are not only meant for the children living at the orphanages. They share these with the other children with disabilities who still live with their families.

Besides these donations, the Yayasan welcomes its doors to visitors. It is required to make an appointment to plan these visits, due to a full schedule. Some weeks are full of visits, some weeks are quieter. Weekends are mostly scheduled for visits, because of the amount of free time some of these children have (Yayasan Sayap Ibu Bintaro, 2018).

#### Their intentions

According to an interview with Pak Agus, most visitors come here to “mencintai dan menkasihi”, which means that they come to “love and give”. People go here with good intentions. But he also says that sometimes the giving is too much, which creates a flood. It’s overflowing with donations and that’s not good.

He adds by saying that their vision is that “mereka punya hati dan memberikan empathy, tapi mereka tidak bawa empathy yang terlalu besar membuat excitement anak-anak menjadi perlebihan dan anak-anak menjadi liar, wild and need more attention”.

He states that visitors view themselves as people with a big heart and they have empathy towards these children, but in reality, they don’t have that much empathy as they thought they would. Instead, they make these children excessively exited, children lie, become wild or have this need for attention in the presence of these visitors.

### Other organizations in Indonesia

The Yayasan Sayap Ibu’s are not the only orphanages/ organizations that aim for the support and help of children/ people with disabilities. Thankfully, there are many other organizations and even schools across Indonesia meant for them.

Family members of people with a disability can go to these specific organizations to get well informed or get the help they need.

On the website of the Disability Rights Fund (DRF), you can find a list with organizations that’s either meant for helping people with a specific disability or meant for helping people with disabilities in general. You can find the names and a little description of these organizations in the webpage of the Disability Rights Fund[[3]](#footnote-3).

There are also a couple of schools available for children with disabilities. One of the most known schools is the Rawinala School for Multiple Disabilities. This school works closely with Yayasan Sayap Ibu Bintaro by exchanging knowledge, strategies or skills (Yayasan Sayap Ibu Bintaro, 2018).

# STEP 3: *Think how you will handle in the given situation with the observed differences in standards and values*

“It is *not* about disability as a problem; it is about making disability accepted and understood” (Burke, 2008, p.11).

This research doesn’t end here. If I had more time to research this topic any further, I would have wanted to know more about the gender differences, what part religion plays in the perception on and attitudes towards people with disabilities, more/future sensibility or awareness movements on disability in Indonesia, etc. I would have also been interested in visiting other organizations that work with people with disabilities, to see how they operate there and how their methods differ from the organization I worked with. But after collecting all this information, this is what I can conclude:

There’s still a lack of Disability awareness in Indonesia. Although the country has ratified the CRPD in 2011, which supposed to reinforce more Disability Rights, but resulted in many changes in laws and regulations for people with disabilities, it has not been effectively implemented yet. Flaws in these systems and regulations still causes certain violations of these people’s rights. Stereotypes, stigma’s, prejudgment and discrimination on people with disabilities will continue to exist.

One of the main factors contributing to these problems is the inaccurate and incomplete data collection on people with disabilities. The existing data differs from study to study and organization to organization, due to hidden, isolated or even non-registered children/people with disabilities. “For children with disabilities to count, they must be counted – at birth, at school and in life”, says Mr. Lake (in UNICEF, 2013, al. 9). Though Indonesia is finding a solution to this problem, it’ll still take a while before they have accurate data that correctly represents people with disabilities in Indonesia.

Indonesia’s perception on people with disabilities also needs to change. The public still has a negative attitude towards people with disabilities, which results in discrimination, a persistent stigma around them and more social exclusion.

For example, take my situation that I described at the very beginning of this scription. During my time that I worked at the Yayasan, I saw most of the visitors looking down at the children, being too cautious or sometimes even reckless when approaching them, making degrading comments in front of the children,… This is all due to a lack of knowledge of and ‘exposure’ to people with disabilities in general. That’s why I feel most visitors will continue to show these kinds of behaviour.

The mentality that people with disabilities are incapable people also needs to be eliminated. They need to be more acknowledged and accepted into society, because their capacities and talents could be a huge contribution to society. For example, at the workplace.

To reduce the gap between people with and without a disability, Indonesia needs to put in more effort into creating an inclusive, diverse and conducive society for these people. More movement towards disability awareness is what I would also advise to Indonesia. There are a number of actions that Indonesia could take. Such as, changing the infrastructure to become more disability-friendly, providing improved special education or even inclusive education for children with disabilities, improving the accessibility to employment and healthcare, the ability to participate in society and its numerous (outside) activities, etc.

These are not the only measures that should be taken in order to reach this kind of society. There are of course more ways, but these are just some suggestions. It’s a long list, but with help from all facets of society I believe Indonesia could improve in becoming an inclusive society for all its people.

# STEP 4: *ACTION*

This 4th and last step was added by my university college. As a result of this research, I planned a conversation with my internship mentor (also the *Head of the Child Service Unit and Principal of the Education System*) and one of the *Head of the Development Unit*. The goal was to exchange the information I found in my research and what this could mean for the Yayasan. But unfortunately, due to a tight schedule, I wasn’t able to have this conversation with the people I had in mind. Instead, I could meet with the manager of the Yayasan. Which is a bigger deal than I had previously thought.

On Thursday afternoon, 31st May 2018 at around 16:11, I had a conversation with the Manager of the Yayasan Sayap Ibu: Ibu Tuti. It is important to know that Bu Tuti went away to Boston for 9 months and just recently came back. In Boston, she joined an educational program with the Perkins School for the Blind. The goal was to get more knowledge and pass this on to the Yayasan.

I started the conversation with explaining the topic of my research and what this could mean for the Yayasan. “My scription is about the image Indonesian people have on people with disabilities”, I said. I added that “I chose a situation, here in the Yayasan, that started this research. My situation is about one of the visitors who come here. I have experienced a lot of these visits and came to notice something”.

She was curious of the title of my research and asked about it. When I showed her the title, she seemed impressed. “Good… But why is *UNICEF* there?”, she asked.

“Oh, that’s because it’s a quote that a member of UNICEF said”, I replied. Also explaining that I found the title very suitable for my scription topic. I went back to my situation and explained further how I understand the numerous of visits the Yayasan has. Their source of income are these visitors and sponsors. Without them, this place cannot move forward.

BUT during these visits, I see a certain pattern. Most of them, still act rather odd around the children. They notice their condition, their disability faster, but I know that that’s normal. This may be their first time interacting with someone with a disability. Let alone, children with multiple disabilities.

But I notice that they frequently ask questions about what the children are unable to do. I also acknowledge how the team works so hard to stimulate and motivate these children into becoming more independent, confident and believing that they’re capable of doing anything. When these visitors come, I feel as if the atmosphere suddenly changes. Some still belittle these children, treat them like fragile, little human beings.

Others also only come to visit once to take pictures, invade their privacy… I feel as if the children feel lost, because these visits also interrupt their (learning) schedule.

Bu Tuti sees where I’m coming from. She stated how she understands my analyzations and how she also notices these situations. “That’s one of our biggest problems right now. We actually have certain rules during these visits. They’re all written down, but there’s a lot of them. One of those rules is that visitors may not enter the children’s rooms. Nine months ago, before I left, this was the case. Even though the rule was there, people didn’t listen. And now, 9 months later, it’s still the same. During a meeting, I’ve talked about this, but I understand my colleagues”.

She explained that her colleagues told her that if there were any stricter limitation to these visits, not a lot of visitors will come. And that’s what they want to avoid.

I stated my understanding for their statements. They are also thinking for the sake of the children. The more visits, the more people know about the place and are aware of disabilities, the more donations, the more (right) resources there are for the children to grow and evolve.

I asked Bu Tuti what her opinion is on this situation. She repeated that: “it is truly one of our biggest problems here”. For now, they don’t know how to deal with that problem, but they are thinking of ways to make it better for the children. “What do u suggest?”, she asked me.

Well, I explained to her that I had certain actions in mind. But due to lack of time and good preparations, I couldn’t execute them.

These actions included:

* Making my own version of a flyer/ brochure for the Yayasan. I would design it, so it would raise more awareness not only about the existence of the Yayasan, but also the existence of people/ children with disabilities across Indonesia. With statistics and facts about disability in Indonesia in general, and a little inside look of the Yayasan.
* Going out to a place where they’ve never been and distribute these flyers/brochures as well. One of the objectives is to take the children somewhere (fun, adventurous or educational) they’ve never been before. Another objective is so that the children are exposed to the outside world and for Indonesia to become more aware that children with disabilities exist and are able to participate.
* I saw that my internship place did a simulation, where some visitors were blindfolded so they could feel how it is to not be able to see. I was inspired and searched more of such activities, but with other disabilities. For example: autism, hearing impairment, communication disorder, etc. I found a *Disability Awareness Packet* (2006) with several activities to do with future visitors. I also find some activities on Pinterest or other Disability awareness sites and selected the ones that corresponds to the children’s condition (autism, communication disorder, etc.).

I briefly explained these actions, but when Bu Tuti heard the last one, she explained that the Yayasan have some backup activities that they’ve written down and plan to do once with visitors. These, however, are activities to stimulate a bond between the visitors and the children. They are interactive activities. Fun games to do.

The purpose of the activities that I’ve looked up, are activities to make these people more aware of the different disabilities. To try and step into the shoes of these children, just to understand a little bit more about what it means to have that certain disability.

Due to so little time, we had to wrap up this conversation. Bu Tuti suggests that we continue this conversation on another day. Somewhere next week. She found the topic of my research very interesting and wants to see/read what I’ve found. We can and will discuss this problem furthermore and hopefully come with a solution. Cause both of us have one thing in common: we put the children central and are foremost concerned about their rights and well-being.

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# APPENDIX 1: Interview

## Interview: Bintaro, Pak Agus, *Head of the Child Service Unit* en *Principal of the Education Program*, Held on the 28th of May 2018 at 14:20

*Introduction*: The Indonesian language was thoroughly used during this interview. Before we began, I explained to Pak Agus what my topic of my scription was and how I came to that topic. I then started by asking the question “What do you know about the Indonesian image on disability?”.

**Pak Agus:** “Ja? Uuuhh… Disabilitas image uuuuhh… They are so uuhh… Mereka mengankap disabilitas adalah sesuatu sangat huruf”.

**D:** “Sangat apa?”

**Pak Agus**: “Sangat huruf, sangat jelek, sangat ‘worse’. Gitu jadinya. Ja, uuhhh… Bawa kecacatan merupakan suatu putukan, sutau dosa, suatu… Suatu, apa? Buah dari perbuatan mereka gitu, jadi kesadaran. JAdi, kesadaran apa?.. Kesadaran mereka tentang uuuhh… Dan pengetau tentang disabilitas itu sangat minim. (\***inaudible**\*).. Membuat mereka berfikirnya uuh, suatu yang sangat mengakutkan, suatu yang sangat uuuh… menjijikan. Uuhh, suatu yang sangat.. Apa?.. Sangaat… uuuhh… Bener-bener, buat satu keluarga pun yang didi betulan dikarniin anak spesial (\***inaudible**\*)… They have uuuh… family disability. One of.. There are, disability itu merupakan berbanyak sangat-sangat berat.”

“Karena munkin juga, minimnya pertahuan, minimnya sosialisasi, minimnya kayak uuh.. Information. Kemudian, belom ada, belom ada orang yang bertangung jawab.. We are not for, for government juga mereka belom punya peranan yang nyatah. Jadi government so.. don’t have uuh… uuuh.. action for them!”

**D:** “Ooh, iya.. Ini kan Yayasan, non-governmental ya?”

**Pak Agus**: “Yes”

**D:** “Jadi income nya dari sponsor, dari ini…”

**Pak Agus**: “Iya, ya.. This is uuh.. Non-government, non-profit uuh.. organization. Sayap Ibu yang mendirikan adalah… Salah istri pahlawan nasional. Heroisch for me. Namanya Ibu Johana Sunarti Nasution. Ibu Johana from Holland. Holland people, like you.”

**D**: “Kok.. masih.. Orang Indonesia ya?”

**Pak Agus**: “Uhhh, Namanya. Uhh no no no. Dia really really Holland, but uuhh married with man of Indonesia, jadi name. Namanya dirubah. Johana blablablabla get married jadi Johana Nasution.”

**D:** “Oohh, oke. Uhh, iya juga ini. Apa? Siapa yang establish ini, Yayasan? Siapa yang bikin Yayasan ini?”

**Pak Agus**: “Uuhhh, pertama yang mendirikan adalah Ibu Sulistina Sutomo. This is wife from heroes also. Uuh, first uuhh Yayasan ini berdiri at Yogyakarta. We have yet.. In Indonesia we have 4 Sayap Ibu: In Jakarta, in Banten, here, in Yogya.. In Yogya we have.. Punya 2 Sayap Ibu. Terus yang terakhir, Surabaya.”

**D:** “Ooh.. Oke! Itu semuanya dari Ibu itu?”

**Pak Agus**: “Uuuh, awalnya tidak. Awalnya ibu Sulistina Sutomo hanya mendirikan yang di Jakarta terus penimpung Kembangan nya di Yogya dan.. Masing-masing cabang, branch, mereka lahir kemudian tertahap. Sustainable.”

**D:** “Oohh, tapi kok. Yang lainnya kan. Uuhh.. Yang di Jakarta kan anak-anak normal..”

**Pak Agus**: “Iya”

**D:** “Kok ini disabilitas?”

**Pak Agus**: “Oohh ceritanya begini. Kalo, kenapa disini disabilitas? Dulu Yayasan ini adalah uuhh… Little place from Jakarta. Jakarta, itu dulu special place for children and not normal children, uhhhm.. together, because vision Ibu Johana Sunarti Nasution not good. Not good uuhh, tidak baik menyantukan mereka dalam satu .. Satu tempat karena uuhh.. Masing-masing punya kebutuhan beda. Yang normal punya kebutuhan beda, yang disabilitas they have a need uuuh… different gitu. Dan akhirnya yang disabilitas di pindah ke Bintaro pada tahun 2005. Two thousand and five, sama Ibu Johana itu. Jadi kalo, munkin kalo Sayap Ibu disini terus.. Iya kayaknya karena Ibu Johana itu. Karena yang vision nya untuk memisahkan anak-anak disabilitas sama normal itu dari dia.”

**D:** “Oke! 2005? Ini..”

**Pak Agus**: “Iya 2005, ya!”

**D:** “… Ini Yayasan udah ada..”

**Pak Agus**: “Iya! Dulu pertama kali hanya 10 anak, salah satu Ubay, Ucup, Nurul, Rizky, Budi, Dini. Ada almarhum Rayhan, almarhum Inez, almarhum Popo. Dulu pertama kali punya anak 5 dan kita menkontrak rumah di deket GIANT sana.”

**D:** “Ooh.”

**Pak Agus**: “Ya really, first we.. We ask them.”

**D:** “Terus waktu punya Yayasan ini, uuh staff nya. Employee nya, gimana dating gitu? How did they come here? Uuhh, gimana process, uuh.. Hire the staff. Kan ini semuanya masih muda. Kayaknya backgroundnya. Background educationnya bukan social atau nurse..”

**PA:** “Iya”

**D:** “Semuanya kan?”

**Pak Agus**: “Uuuuh jadi dulu, pertama kali terbentuk 10 anak itu hanya 4 perawat.. Dan itu, perubahan ini keliatan.. Munkin kalo kamu, kalo Dessy looking now. Looking sekarang, gitu kan? Itu, yang seperti ini itu tahun 2013. Sebelumnya itu, uuh, tidak.. Belom terorganise dengan baik seperti sekarang. Jadi 2013 udah mulai.. Atau munkin kita realisasinya dari 2012 seja one of volunteers from Holland, Daanike, come here gitu. Mulai menatah. Yang merintis itu, dia. Yang merintis.. uuuhm…”

**D**: “Itu volunteer?”

**Pak Agus**: “Iya!”

**D:** “Bukan Daanike?”

**Pak Agus**: “Daanike itu volunteer”

**D:** “Oooh ooh, oke!”

**Pak Agus**: “Daanike itu volunteer. What do u think about her?”

**D:** “Kirain ya, apa? One of the makers of the Yayasan.”

**Pak Agus**: “Boardmembers?”

**D:** “Iya”

**Pak Agus:** “No, dia really volunteer. Jadi dia dari bel.. Dunia lain. Dia adalah one of.. I think if I talk about uuuhh.. Who is person special. One of Daanike. Number two, Mbak Weni. I think, big contribution. Yah. Minimal mindset, minimal idea gitu. Dua orang itu secara pribadi. Kalo orang lain ngak tau. Kalo aku bilang, beda.. Kalo aku talk about uuuh audience gitu uuh… So thank you for Daanike. Daanike one of person special for Sayap Ibu. Also Mbak Weni juga special. Special, karena big contribution”.

**D:** “Ooh iya. I see”.

1. As found in following PDF file: *BAB II: Tinjauan Pustaka* <http://digilib.unila.ac.id/5849/14/BAB%20II.pdf>. This file has no author nor a date. It is part of a report, but the source isn’t mentioned. Therefore, I mention the link and title, because this document contains a lot of useful information. [↑](#footnote-ref-1)
2. All these programmes, their objectives and goals are described in the following link: <http://dfat.gov.au/geo/indonesia/development-assistance/Pages/inclusive-society-in-indonesia.aspx> [↑](#footnote-ref-2)
3. On the following link: <http://disabilityrightsfund.org/countries/indonesia/page/7/> [↑](#footnote-ref-3)