

**Understanding the Integration of Children with Disabilities:
Reflections on the Experiences of Sesobel Organization in Lebanon**

Research Paper presented by:

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Disclaimer:

This document represents part of the author's study programme while at the International Institute of Social Studies. The views stated therein are those of the author and not necessarily those of the Institute.

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Dedication:

This research is dedicated to my aunt who inspired me with her resilience and life experience to contribute, even though a small contribution, to the cause of people with disabilities. This research is also dedicated to all extraordinary children out there fighting daily with their unique abilities and brilliance, the harsh ordinary.

Keep on fighting heroes!

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List of Acronyms

CRC	Convention on the Rights of Children
CRPD	Convention on the Rights of Persons with Disabilities
CWDs	Children with Disabilities
IEP	Individualized Educational Plan
PWDs	People with Disabilities
UN	United Nations
WHO	World Health Organization

Abstract

The number of children with disabilities around the world is estimated around 240 million out of the total number of people with disabilities and they are one of the most marginalized groups. Yet, despite the urgency of the situation they are still not highly included in programs that aims to promote inclusion of people with disabilities. Moving to the Lebanese context, the rights and needs of children with disabilities are not properly met due to several factors creating barriers and challenges for them to be included in the society. This study focuses on the integration process of children with disabilities addressed by the Sesobel organization in Lebanon. This study highlights the practices and ways adopted by the Sesobel organization to navigate this limited environment. Hence, the main question asked is How does the Sesobel organization address the integration process of children with disabilities into Lebanese society? The question addressed is answered through the analysis of the data collected after conducting semi-structured interviews with five participants of the organization in addition to personal observations on site. Moreover, the analysis was addressed through the following concepts: integration and disability, religion and faith-based organization, and models of disability. Following the analysis, it was noted that the socioeconomic situation and status determine the quality of the service and impact the integration process. Moreover, the integration process of children with disabilities goes beyond education, as such Sesobel sets an individualized educational plan according to each child's disability that covers medical follow-up, educational learning with the implementation of an adjusted curriculum according to each child's disability and functional/skills learning where children with disabilities are taught skills that allow them to effectively participate in the society. Also, the family's participation is crucial for the betterment of the process outcome, this research highlights two important factors in relation to the family's participation: information exchange between the family of a CWD and the professionals and the acceptance of the family of their child's disability. Additionally, this research underlines the religious (Christianity) influence on the Sesobel organization's mission through the incorporation of religious practices as part of the integration process. Lastly, this research emphasizes that integration process goes beyond the CWDs seeking integration programs, it is related with the society's awareness as well, hence, the Sesobel organization works at the level of the society to promote inclusion by spreading awareness through campaigns about the topic of disability and through engaging children with disabilities in different activities.

Relevance to Development Studies

This paper was influenced by the current discourse about the necessity of promoting inclusive environments for children with disabilities to ensure their effective participation in the society. The effective inclusion of children with disabilities aligns with ensuring their inherent dignity, self-worth, and perceiving them as equal as other individuals of the society as well as promoting for equal opportunities that meet with their needs and capabilities.

Keywords

Children with disabilities - Social integration - Lebanon - Religion - Family - Sesobel

Chapter 1: Introduction

In the following section I am presenting an overview about the situation of integration of children with disabilities (CWDs) and how they are still not highly covered by inclusion programs worldwide. I will discuss the different international conventions recognizing the rights of CWDs as a response to the urgency of the situation. Additionally, I will present the situation of CWDs in the Lebanese context, highlighting the different factors (political, religious, economic, and social) making the state incapable of addressing the specific needs of CWDs. Additionally, those factors are translated into different barriers challenging and pushing them towards looking for alternative initiatives in order to get integration services. Lastly, I will research one of the alternatives chosen by several Lebanese families, the Sesobel organization and try to look how this organization is addressing its integration process within this limited environment.

1.1. General overview

The 'World Report on Disability' prepared by the World Health Organization (WHO) and the World Bank in 2011, mentions that the number of people with disabilities (PWDs) around the world exceeds the 1 billion people. PWDs experience life differently across the world, and their experiences are shaped by several factors. For instance, in addition to the type of impairment of each individual with disability, their personal factors along with the environmental ones must be taken into account as well (World Health Organization & World Bank, 2011).

The previous statement pushes us to realize that the task of participating in the society can't be burdened solely upon the person with disability, and that the environment where an individual with disability is present, either facilitates or hinders their participation (World Health Organization & World Bank, 2011). Therefore, it is necessary to address the different barriers presented within the society and challenging PWDs to integrate. Therefore, to fix the root causes of the creation of inequalities leading to the social exclusion of PWDs.

Nearly 240 million out of the total number of PWDs around the world are children, they are considered among the most marginalized groups, and yet, they are still not highly covered by inclusion programs aiming to promote inclusivity for PWDs (UNICEF, n.d.). As such, within the framework of international human rights law, several international treaties were launched acknowledging the rights of CWDs. These treaties were drafted throughout the years in response to the seriousness of the situation of CWDs (Beckett & Callus, 2023).

In 1989, the United Nations (UN) Convention on the Rights of Children (CRC), explicitly recognized in its article 23 the rights of CWDs "to enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community" (ohchr, 1989). However, the most significant progress in the realm of the international codification of the rights of CWDs rights was highlighted in 2006 by the UN Convention on the Rights of Persons with Disabilities (CRPD), which, through different articles such as Article 7, articulated the rights of CWDs insisting on making their interest as a priority (ohchr, 2006).

The CRPD created a connection between disability and human rights concepts allowing us to approach PWDs from a human rights perspective and framework (Beckett & Callus, 2023). The importance of approaching CWDs from a human rights perspective allows fostering a more

inclusive environment for them as well as promotes for more equitable and just society for everyone. It allows to break the discriminatory societal norms and attitudes by emphasizing that CWDs have an inherent dignity that must be respected and a worth that must be valued regardless of their abilities.

According to Beckett and Callus (2023: 17-18):

“Within Article 3, through substantial principles, the CRPD delineates the human rights model of disability. It includes respect for inherent dignity, individual autonomy, including the freedom to make one’s own choices, and independence of persons; non-discrimination; full and effective participation and inclusion in society; respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; equality of opportunity; respect for the evolving capacities of CWDs; and respect for the right of CWDs to preserve their identities.”

In conclusion different international treaties including the CRPD, in addition to articulating dignity, autonomy, and self-reliance of CWDs, recognized their crucial empowerment and development by advocating access to quality education, support and services, and skill improvement ensuring their effective participation in society (ohchr, 2006). By ensuring the participation of CWDs in the society, we are ensuring their engagement in different life situations and activities hence, helping them to establish a meaning in life (Law et al., 2006).

1.2. Situating Disability in the Lebanese Context:

Lebanon joined the CRC, by signing it on the 26th of January 1990 and then ratified it on the 14th of May 1991 (United Nations Human Rights Treaties Bodies, n.d.). Being a State Member of the CRC, requires from the Lebanon the implementation of several actions to ensure decent living conditions for children in general including CWDs tackled in article 23 of the convention. Moreover, Lebanon has signed the CRPD, but hasn’t ratified it yet (Solidar, 2015). Therefore, Lebanon has declared internationally its will, to work on the implementation of the adequate measures to ensure the protection of CWDs’ rights. Domestically, as a response to this international commitment, the Lebanese government and Parliament passed in the year 2000 the law 220/2000 concerning the rights of PWDs. This law is influenced and shaped by the ‘Standard Rules on the Equalization of Opportunities for Persons with Disabilities’ (Damaj, 2014). According to Law 220/2000, the government shall ensure the integration of PWDs into society by adopting a rights-based approach. Also, this legislation consists of diverse rights that concern PWDs such as the right to education and sports, the right to employment and social benefit, the right to health care, and others (Unesco - Beirut, 2013)

However, the implementation that provides proper support to PWDs has been falling short. There is a systematic lack of provisions for rights, resources, and services for PWDs in Lebanon, due to inaction by the state (Solidar, 2015; Combaz, 2018). This situation is a result of several factors, starting with the fact PWDs are under-documented and there are no official statistics about them (Central Administration for Statistics in Unesco - Beirut, 2013). Moreover, several factors contributed to making Lebanon a limited environment for the implementation of measures that meet CWDs needs.

The different factors are the following:

Political factor:

The sectarian civil war that was entangled from 1975 until 1990 due to its correlation with regional events (Merrifield & Centre for Lebanese Studies, 2022). Additionally, a series of twelve political assassinations from 2005 until 2009 destroyed the Lebanese infrastructure (ALJAZEERA, 2008) and made the situation more exacerbated. Moreover, the number of extended periods where the government where either changed or only existed in a caretaker role (Merrifield & Centre for Lebanese Studies, 2022) along with the country functioning for around two years without a president (Nakhoul & Perry, 2016) made the Lebanese governments not being capable of executing their required tasks and falling short in the implementation of proper legislation that protect the rights of CWDs.

Religious Factor:

According to Merrifield & Centre for Lebanese Studies (2022:2), Lebanon has “eighteen religious’ affiliations” shaping its identity on the cultural and national level. The country is ruled by a confessional democracy where religious groups are presented via political positions in the government (Merrifield & Centre for Lebanese Studies, 2022). Which makes the religious groups in the Lebanese context very powerful in terms of decision-making and influential in the daily life social norms (Merrifield & Centre for Lebanese Studies, 2022). Therefore, as Abou Assali (2012) noted, it is difficult to put into practice any idea that is seen as threatening to a traditional religious belief.

Based on what is previously mentioned, it is important to note, that one of the forms of the religious presence in the decision-making is throughout the local faith-based organizations. According to Jawad (2009:144-145), the Lebanese government, by being aware to the remarkable influence of religion on the societal norms, as well as the government’s ‘productivist’ perception of the social policy, promotes for the faith-based organizations with their mission of aiding the other in need, to be actively present.

Economic Factor:

The long period of war, many conflicts, in addition to the different assassinations that happened since 2005 to 2009, has led to the destruction of the Lebanese infrastructure (Merrifield & Centre for Lebanese Studies, 2022). Which was translated into the lack of basic services and affected the access of people to their basic needs. Moreover, the lack of job opportunities, as well as the disparity between how much a Lebanese individual earn and how much they spend (Hess, 2011), are other indicators of the difficult economic situation in Lebanon.

Additionally, as per the year 2013, “27% of the Lebanese population lives below the poverty line” (Unesco - Beirut, 2013:13). All these factors previously mentioned, pushed a lot of educated Lebanese citizens to emigrate looking for a better opportunity outside of the country (Merrifield & Centre for Lebanese Studies, 2022). As a result of the Lebanese failed economy, Lebanese diaspora became an important supporter to the Lebanese people and economy through their remittances. In year 2010, the worth of the remittances sent by the Lebanese living abroad was 22% of the country’s GDP, which was equivalent to 8.2 billion dollars in 2010 (World Bank, 2011).

Social/Cultural Factor:

The Lebanese culture is known for its collectivism (Hofstede, 2001; Joseph, 1993; Khalaf & Khalaf, 2009; McCabe et al, 2008) where “the primacy of the family over the person [...] the sense of responsibility for and to others, (and) the experience of oneself as an extension of others and others as an extension of oneself” (Joseph, 1993:479). Therefore, the interest and goal of the group are prioritized over the interest of the individual.

In addition to the previously mentioned factors, it is worth mentioning that they are not the only main reason behind hindering the integration of CWDs in the society. Despite the fact that the Lebanese government has domestically adopted the law 220/2000, however, the adopted definition of disability relies on an “outdated medical definition” (Lakkis et al., 2015:10-12) that does not address properly the concept of disability. Which amplifies the problems/barriers faced by CWDs leading to socially excluding them.

The following is the definition of a disabled person, adopted until this day by the Lebanese government:

“A disabled person is defined as a person whose capacity to perform one or more vital functions, independently secure his personal existential needs, participate in social activities on an equal basis with others, and live a personal and social life that is normal by existing social standards, is reduced or non-existent because of a partial or complete, permanent or temporary, bodily, sensory or intellectual functional loss or incapacity, that is the outcome of a congenital or acquired illness or a pathological condition that has been prolonged beyond normal medical expectations” (Unesco - Beirut, 2013: 8).

As per the previous sentence, disability is created as a result of a congenital or acquired disease, that has not improved with treatment (Merrifield & Centre for Lebanese Studies, 2022). Moreover, this definition uses vague language such as vital functions, and existential needs, and defines them in addition to impairment as something abnormal or deviant to the existing social norms (Ibid.)

A person with a disability meeting the above-mentioned definition is allowed to receive a disability card that allows full medical coverage after registering with the Ministry of Social Affairs and “the total number of PWDs registered is 80.703” (Unesco - Beirut, 2013:9) on a total population of 4 million where PWDs are estimated to be 15 percent of the total population (Unesco - Beirut, 2013:10). However, Damaj (2014) considered this card as another barrier to be faced by the PWDs as it is contributing to segregation and disabling identity labeling that will not help PWDs integrate into society.

In conclusion of what was previously mentioned, several factors have transformed Lebanon into a limited environment for the implementation of measures that promote inclusivity for CWDs and meet their needs. Therefore, this situation is translated into different examples of barriers to be faced by these group on different levels, hence, increasing their vulnerability. More details about these examples shall be provided in the next section.

1.3. Problem Statement and Research Objective:

Several barriers such as the lack of investment in human development and the social perception face CWDs in the Lebanese context. For instance, according to (Wehr et al., 2012), disability is associated with the concept of haram, which is in a religious context forbidden or accursed.

Moreover, in the Lebanese context, haram is also a way to feel bad for someone, it is also used to pity someone, and used in cases of highlighting an “unfortunate situation” (Khalife, 2016).

The Lebanese government has failed to put into practice policies that protect CWDs and ensure their inclusion in the educational system, even though the law 220/2000 emphasize it (Unesco - Beirut, 2013:14). The Lebanese governments have made a small progress in making the education system more inclusive for CWDs in terms of accessibility. For instance, only five government schools in Lebanon have been made accessible to people with physical disabilities (Unesco - Beirut, 2013). Moreover, “With regards to technical education and vocational training (TVET), most of governmental vocational institutions are not accessible to students with disabilities.” (Unesco – Beirut, 2013:15). As a result of inaccessible educational institutions, 85 percent of CWDs did not complete their primary education as reported by the Lebanese government in 2002 (Combaz, 2018).

The Lebanese Physical Handicap Union conducted a survey in 2009 on the Lebanese accessibility standards for public buildings for people with physical disabilities. The results showed that only “few schools in Lebanon are accessible” (Human Rights Watch, 2018:31) to PWDs which indicates that buildings including schools are not being adapted to become. Moreover, there is a lack of financial support to address the needs of special education as such “neither resources nor training have been provided to school” (Unesco – Beirut, 2013:14-15) leading to making their integration process into society more difficult. In Lebanon, PWDs have very little or unequal access to education as a matter of fact, “there is a problem convincing school managers of the feasibility and value of inclusion, together with the shortage of qualified and trained professionals” (Khochen & Radford, 2011:140). Unfortunately, Lebanese law does not fine schools for not implementing the clauses of law 220/2000 as Khochen & Radford (2011) highlighted. This is another factor hindering the integration of CWDs into society and making them feel left behind and push their parents to look for alternatives.

Several research have studied the disability topic in the Lebanese context highlighting the situation and barriers faced by PWDs as it is previously mentioned. However, there are no studies focusing on CWDs specifically, or on alternative initiatives provided by other actors, chosen by their families in order to get assistance for integrating them into the Lebanese society. I aim to look at the Sesobel organization, one of the longest lasting organizations selected by the Lebanese families with a child with a disability as an alternative initiative. The Sesobel organization, is a Christian and very well-known organization at the Lebanese level where a person with disability is perceived as “a child of God.” (Sesobel, n.d.). Sesobel has been helping CWDs since 1976 to meet their different needs on different levels to ensure their social integration (Sesobel, n.d.). More information about the organization (mission, staff number, etc.), the selection of the research location shall be provided in the following chapters (chapter 3 & 4).

Therefore, this research focuses on how the Sesobel organization, is navigating this limited environment to execute its mission of preparing CWDs for integrating into the Lebanese society by addressing the integration process from the lens of improving the well-being of children and not focusing solely on the medical aspect.

1.4. Main Research Question:

How does the Sesobel organization address the integration process of children with disabilities into Lebanese society?

To answer this question, I am addressing the following sub-questions:

- 1- What is the pedagogy adopted by the Sesobel organization to address the integration process of children with disabilities?
- 2- How does religion and family engagement influence the integration process of children with disabilities addressed by the Sesobel organization?
- 3- What are the other practices in addition to the pedagogy, adopted by the Sesobel organization to address the integration process of children with disabilities?

Chapter 2: Theoretical framework:

In the following chapter, I am defining the integration and relating it to the CWDs along with the actors and factors involved during this process. Additionally, I am highlighting the impact of religion (Christianity) on the decision-making, mission, and provided services of a faith-based organization in relation to the disability. Lastly, I am presenting the three models of disability, definition, importance and influence on the way disability is perceived along with the critiques related to each model.

2.1. Integration and Disability:

According to the Gill (1997), integration is an everlasting concept in human growth / development, and it is usually defined as an act of merging into a whole. In most classic theories of personality development, integration appears, and is associated with positive outcomes “such as maturity, psychic comfort, and emotional health” (Gill, 1997:39). However, once we talk about the concept of integration in the context of disability, it is important to be aware to the fact that the meaning of integration for PWDs is that they want to be part of the society, to be seen, and treated similarly to other individuals, as such, the concept of integration is a very crucial one as van de Ven et al., (2005) noted.

Back in the days, PWDs were seen as a minority that get to be marginalized if they did not abide by the norms set by the majority in the society, (van den Heuvel, 1976). Therefore, the concept of integration became controversial (Myers et al., 1998) and required a clear definition that is accepted by the individuals with disabilities themselves (van de Ven et al., 2005). However, (Willer et al., 1993; Dijkers,1999) noted that there is no reference to the conceptual definition of integration while it is being used during research or in government policies, hence, there is no clear definition of it. The absence of a clear definition of the concept of integration, can lead, according to Oliver (1998) to misuse as it is the case for the concept of ‘disability’. Moreover, van de Ven et al., (2005) referred to the confusion of defining integration and its characteristics with the community integration that is defined as “integration into a home-like setting, integration into a social network, and integration into regular productive activities” (van de Ven et al., 2005:312). This definition allows us to understand the importance of taking into considerations the different aspects of the integration, such as “living situation, rights, interaction partners, roles, freedom of action, power, degree of segregation from society, and so on” (van de Ven et al., 2005:312).

Moving to CWDs, their integration in the society was highly present in different international conventions such as the Convention on the Rights of the Child CRC, where in its article 23 advocates for an active participation and a self-reliance of children with mental or physical disabilities in the community. Moreover, article 23(3) of the CRC highlights the importance of providing CWDs with the required opportunities such as access to healthcare and rehabilitation services, education, and employment. Whatever allows their “fullest possible social integration and individual development, including his or her cultural and spiritual development.” (ohchr, 1989). Based on what is mentioned previously, I will look at the integration process of CWDs in Lebanon in terms of actions that are being taken along with the different personal and contextual conditions involved in this process, on the level of their community, family, and education place. Hence, the adoption of the following definition of integration by (Rodrigues & Garro-Gil, 2015:1323): “the actions towards integrating children and young people with special needs in mainstream education and community”.

During this process, several aspects must be acknowledged and their relation to the process must be identified according to Leliuguene & Kausyiene, (2012:104)

(a) the physical, that takes into consideration the obstacles and barriers within the environment hindering the child with disabilities to meet their basic needs;

(b) the functional, that refers to the overall quality of life of a child with a disability within the environment;

(c) the social, that refers to fostering a sense of belonging to a child with a disability by developing their social and individuals' skills and ensuring a good and positive society's attitude; and

(d) the public, that refers to the fulfillment and acknowledgement of the social role of a child with a disability and their participation in the society

2.1.1. Parental involvement in the integration process of CWDs:

During the integration process of CWDs, parents must get actively involved for the betterment of the process. The importance of parental involvement and the role of families have become increasingly recognized (Spann et al., 2003). Without consideration for the parents' perspectives, the paraprofessional programs adopted by the professionals may promote ideas that do not meet with the child's disabilities and needs; hence, they won't be helpful (Prezant & Marshak, 2006:32).

According to Cross et al. (2004), the relationship between the parents of the child with a disability involved in an integration progress and the staff members providing the assistance during the process is very crucial for a successful experience. Therefore, Turnbull & Turnbull (2001), looked at the relationship between them as one relationship where both sides collaborate to enhance the practical skills of the child as well as making the child's growth stronger. Moreover, Cross et al. (2004:176), noted that, taking the children's needs and disabilities seriously is a key element, where both parties of the parents-provider relationship should exchange information for the best interest of the child. An example is the sharing of information about the daily routine of the child by their parents with the staff to create an individualized plan that meets each child's needs and disabilities (Cross et al., 2004). On the other hand, the staff members are the ones who explain and share clarifications with the parents of the medical and health situation of the children (Ibid). Additionally, parents and employees accepting the kids for who they are and not to having what the author called a "fix it mentality" is an important aspect about this relationship according to Cross et al., (2004:177). Instead, both groups must agree on making the necessary adjustments and accommodations for any requirements of the child in order to build up their skills as well as addressing the expectations for the child.

However, while looking at the relationship between the parents of the child with disabilities and the staff providing the service, one should take into consideration, according to Prezant & Marshak (2006), the type of help being provided. Kerr (1984) addressed to what extent the parents and the service providers are agreeing on the type of help provided to the child with a disability and said that "help is not a simple common-sense phenomenon rooted in the good intentions of the helper" (Kerr, 1984:151) as quoted in Prezant & Marshak (2006:31). However, some help can provide options; however, some other help could be considered as 'oppressive' (Prezant & Marshak, 2006:31).

To address the complexities of helping and its social, political, and psychological impact Kunc et al. (1994) mentioned the necessity of differentiating between the help provider and the help receiver. The following quote by Beatrice Wright shows the importance of proper help:

“Too much help can be a disabling force. [...] Too much help, even when enthusiastically given, is fundamentally disempowering.” (1983:311).

This quote makes us reconsider the idea of giving help. The identification of the unmet need is important. However, it is not the only thing. The service providers must also understand the nature and type of the help they are providing. This is important, because according to literature such as Marshak & Seligman, 1993; and Wright, (1983), the reaction of the recipients of help, that is most of the time influenced by social norms that expect the recipients of help, especially, PWDs to be grateful of this help even though if it does not align with their needs. Therefore, the nature of the provided service that is not meeting the needs of the recipients (in this case CWDs) is not being improved due to the ‘fake’ reaction of the recipient, which affects the purpose/outcome of why this service was implemented in the first place.

2.1.2. Other important factors during the integration process:

The first such other factor is the staff involved in the implementation of the integration process and the way they impact it. According to Farrell (1997), it is essential that the staff are being exposed to ongoing training, as well as collaborating with other teachers so their instructions get more suitable for the children’s requirements, and hence, for a better and effective implementation of the integration process. Outsourcing the training of the staff involved in the integration process by including supporter workers allows both actors to collaborate planning individualized programs using “systematic and structured teaching techniques” (Farrell, 1997:3). Many authors such as Rouse & Florian (1996), or Howlin (1994), have argued the need for teachers to be trained and assisted by other support workers in order to be able for them to do their jobs. Lorenz (1993) proposed that the adopted training must be skills-based and incorporate whole school approaches according to Balshaw’s (1991).

On the other hand, many authors highlighted the negative impact of support staff on the integration process of CWDs and that it can hinder them in the mainstream context. For instance, Pedlar (1990) and Lewis (1995) saw that the presence of an overprotective support staff can impede the social engagement of CWDs and their interaction with their environment. Moreover, Slee (1991), Philsps (1994), and Lincoln et al., (1992) argue the same idea, that the presence of support workers while CWDs are socially engaging, for too much time might act as a barrier to it. According to Stainback et al., (1994) this presence could be seen as forcing children to engage hence, losing the factor of freedom to decide to do so. It also, affects to what extent CWDs are included (Farrell, 1997). Therefore, according to Lewis (1995), support workers must be as quoted by Farrell (1997:4) “detached but vigilant observer”.

The second factor is the curriculum, according to Farrell (1997:6), many schools dealing with children who have SLD, in order to make their integration easier, they changed the available curriculum according to children’s impairment. However, the author notes that this adjustment can work with certain type of disability, for instance, the moderate and mild learning difficulties, however, it does not work or facilitate the integration of children with severe disability. Farrell (1997) shared an example of a 15-year-old child with severe disability that does not allow them

neither to communicate, feed themselves, nor using the bathroom, therefore, the national curriculum even if it is adjusted, would still not enough because it does not provide materials that allow the development of self-help and independence skills.

2.2. Religion and disability:

According to Bielefeld & Cleveland (2013), in order to understand how faith-based organizations work, it is important to understand how religion influences their work and services provided. As such, researchers adopted three classification systems or typologies allowing them a better understanding of faith-based organization: “organizational control, expression of religion, and program implementation” (Bielefeld & Clevel, 2013:446). Bielefeld & Clevel (2013), presented the three categories previously mentioned as the following:

- (a) the first category, which is the organizational control includes financial mechanisms and dynamics of the management and decision making within the faith-based organization;
- (b) the second category is the expression of religion, that looks into how religion is presented within the faith-based organization in relation with several factors, such as “the self-identity of the organization, religiosity of participants, and definitions of outcome measures” (Bielefeld & Clevel, 2013:447);
- (c) the third and last category is the program implementation by the faith-based organization that goes deep in studying the type of services provided by the organization in relation to the religious elements while the service delivery, as well as the religious activities nature (voluntary or mandatory).

Bielefeld & Clevel (2013) noted that the way the organization perceives the provided services as well as the service delivery is very much influenced by religious traditions, and it requires to be managed in order to be sustained. However, each religion (Christianity, Islam, and Judaism) with its unique and different principles, influences differently the principles of the sponsored organization and the way that each religion influences the provided services is based on to what extent it motivates the faith-based organization to be engaged or not with the larger community (Bielefeld & Clevel, 2013).

Caspary (2012), examined how the social norms and attitudes perceive an infant with a disability. For instance, a newborn with a disability, in the late antiquity, was sentenced to death. Stiker (1993) noted that babies born with impairment were always considered to have supernatural power, were named monsters, were bad luck for their families, and seen as causing harm for the society. Therefore, according to Caspary (2012), previously an individual’s importance was limited to their capabilities of contributing to the society. Therefore, a child’s worth was determined by what they can give to the society once they get older. The life of any person at that time was only associated with their potential, and childhood did not have any importance of its own, to get criticized as Rist (1996), noted.

As the research is about the integration process provided by Sesobel, which is a Christian organization, I will highlight how disability is perceived by the Christian norms.

Christianity with its genuine values based on gratitude and recognition of the life of humans was key in changing this perception and the attitude towards people (Caspary, 2012). The fact that

Christianity refused limiting a person's worth to their bodies and abilities to contribute to the public good, allowed to the existence of public organizations and institutions for charity for marginalized groups (Casparly, 2012).

Additionally, it was noted by Casparly (2012), that the church believes that Christians and the community, must be aware and act upon the struggles of other human beings, and addressed disability and impairment from that perspective. The New Testament plays the role of guidance in Christianity, and requires responding to poverty, diseases, and disability with "an attitude of love of humanity" (Casparly, 2012:29). As suggested by Casparly (2012) the behavior is directly linked to the Christian ideology that humankind has been created in the name of God. To this end, the seemingly befitting response to this is that the suffering of humans is seen as a form of charity.

Thus, for this research, I will be looking at how the concept of disability is perceived through a religious lens (Christianity), and how Christianity is shaping the integration services of Sesobel as well as the staff providing these services.

2.3. Models of Disability:

It has been acknowledged within the literature that the main models used to approach disability are the medical/individual, the social, and the human rights-based models. The three models have an important influence as they present both different and contrasting views about disability and the related policy implications. Identifying disability as well as measuring it affects the way it is approached, treated, and improved and has implications for the way of creating and analyzing empowering policies and programs related to CWDs (Trani et al., 2011). This impacts the outcome underlying the link between the needs and interests of CWDs with the main purpose of the policies.

2.3.1. The medical model:

Several definitions of the medical model show that, according to this model, disability is considered a personal feature of the individual with a disability. According to Marks (1997), the medical model locates disability within the individual. From this perspective, a comparison between a disabled person/child with a 'normal' person/child is created, stemming from the fact that a child with a disability has an impairment reducing their quality of life and social participation (Trani et al., 2011). In addition to being exposed to stigmatization and discrimination, PWDs are categorized and labeled according to the type of impairment they have, and the latter is considered the main and only limitation, hence, making the individual with a disability "deviant from the norm" (Trani et al., 2011: 248).

Silvers (1998) noted that, according to the medical approach, the consequence of treating and fixing the disability will help the individual to adapt and function despite the disability. As such, the medical model is strongly oriented towards 'rectifying' a personal feature through medical interventions by focusing purely on the body and neglecting other factors. Moreover, the medical approach "fails to acknowledge the cognitive and emotional factors shaping illness and disability" (Marks, 1997:87), and the "factors shaping the degree of disability experienced include the nature of the built environment, social hierarchies, legislations, attitudes and images, technologies, aesthetics, and language and culture" (Ibid). Finally, the so-called medical view of disability, as disability scholar Liz Crow (1996) noted, considers it a functional limitation causally related to an

impairment that will determine the root cause of any disadvantage experienced by the person with a disability.

Limitations of the medical model:

Marks (1995) noted that a consequence of the medical approach is that disability is considered solely a medical problem. Therefore, PWDs are considered occupying a position between health and illness or a “liminal position” as Murphy et al., (1988:238), called it. As a result, “disabled people violate the norms of the ‘sick role’ by neither withdrawing fully from social activities nor in returning to ‘normality’ and full social activity” (Marks, 1997: 86). Another impact resulting from the adoption of the medical approach is the feeling of exclusion and pressure to fit the norms (Goering, 2015). Pitying attitudes towards PWDs “incredulity if they speak about anything positive related to living with their conditions” (Goering, 2015:134). Moreover, the “unwelcome reception in the world, in terms of how physical structures, institutional norms, and social attitudes” (Goering, 2015:134) makes their experience more difficult and tends to exclude them from society most of the time. Therefore, policymaking will only focus on existing barriers directly linked to the impairment instead of reflecting on ensuring the full participation of CWDs whilst removing existing barriers.

2.3.2. The social model:

The social model is another model to approach disability. However, this model opposes the medical one. It is about switching the focus from the physical limitations of a particular individual with a disability to the way the physical and social environment is limiting this category of people from participating in society (Oliver, 1981). From this perspective, the health limitations are not ignored but are associated with the type of disability in addition to the social barriers preventing them from executing functioning in a similar way as a non-disabled person.

Shakespeare (2013) noted that the social model is formed by a set of dichotomies that mainly focus, first, on the differentiation between impairment as individual and private versus disability as structural and public. This means that impairment is related to physical, social, and emotional limitations, whereas disability is understood as social exclusion. Second, the focus is on the rejection of the medical model and considering disability as a social creation. Hence, disadvantages experienced by PWDs are caused by society. A third element is the conviction that civil rights are the tool to solve the disability problem instead of pity and charity. Therefore, there is a necessity of changing the design of social arrangements in order to control and defeat disadvantages that are hindering the participation of PWDs in societies (Oliver, 1996). This change is on the political, cultural, social, legal, and structural levels.

Limitations of the social approach:

According to Trani et al. (2011), policymaking adopting the social model of disability approach only addresses the impairment on a sole basis along with the social barriers within the environment creating a disabling situation. However, there is a necessity to promote equal opportunities for equal and efficient participation of PWDs in society.

2.3.3. Human Rights-based Model:

After shifting from the medical model to the social model of disability where the latter was used to criticize the medical model, the human rights-based model of disability became more prominent

in the slipstream of the adoption of the CRPD. It is an alternative to the social model that was criticized in the disability's studies literature (Degener, 2017). Even though many models were developed following the social model of disability, the human rights-based model is a better alternative (Oliver, 2013). According to Degener (2017), most of the state parties to the CRPD adopted the traditional medical model of disability; and hence, their understanding of disability was an illness that must be cured and rehabilitated. "Disability is seen as a deviation from normal health status" (Degener, 2017:42) and as a result, PWDs were excluded because of their impairment.

The human rights principles claim that every individual has the right to legal protection and recognition, regardless of their situation/disability (Degener, 2017). Hence, a human rights-based approach validates their legal status, agency and autonomy. This aligns with the purpose of the CRPD articulated in article 1: "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their dignity." (ohchr, 2006). In other words, the human rights model of disability challenges the assumption that a disability/impairment of a person necessarily restricts their capacity for human rights (Degener, 2017). Moreover, it considers the different identities and how they shape the experience of disability in relation to their integration process (Degener, 2017)

PWDs, through the lens of human rights-based approach, are given the priority in the decision-making in relation to anything that could impact them. Thus, their inherent dignity as individuals is highlighted, as Quinn & Degener (2002) noted, and the society is considered as the primary source of the 'problem' rather than that the problem is being located in the person themselves.

Additionally, the rights-based approach allows the equal participation of PWDs in the society by channeling societal resources towards working according to their needs. Hence, it ensures their inclusion in the different regular structures of employment, social services, education, and others. (United Nations, 1993). By seeing PWDs as subjects with equal rights as other citizens (Browne & Millar, 2016), we are questioning the "social impulse to rank people in terms of their usefulness and to screen out those with significant differences" (Quinn & Degener, 2002:10) on various levels of their lives: social, personal, infrastructure, and others (Verdonschots et al., 2009).

This approach allows me during my research to look at the integration process beyond only its individualistic approach aiming to improving the personal skills of CWDs, but also to examine this process from a holistic structural perspective. According to Quinn and Degener (2002), the human rights model of disability is strongly connected with the social model of disability, since the social construction of disability is given high attention throughout the laws and policies from a rights standpoint. Moreover, according to Nussbaum (2006), the human rights perspective considers that a minimal threshold of human capabilities must be preserved, as humans' capabilities highly depend on external factors that can be improved and adjusted by public policies. Lastly, the rights-based approach refuses the notion that barriers of individuals with disabilities to participate in society are because of their impairment/disability rather than considering external factors that hinder this participation such as governmental policies, environmental obstacles, and access to social supports (UNICEF, 2007). According to Dowling & Dolan (2001:24): "The individual is being disabled, not by their impairment, but by the failure of society to take into account of and organize around difference" thus, disability is perceived as an outcome of an interaction between disability and the expected social defined roles (Browne & Millar, 2016).

Limitations and critiques:

According to Fineman (2008); Fraser (2003); and Gatens (2004) the first limitation is in relation of how rights are defined within each society taking into consideration the related complexities, contexts, and experiences shaping each society. The second limitation is some proclaimed rights are ineffective within a certain context due to the lack of the right mechanisms and resources in place to ensure the adequate implementation of these rights, as well as holding accountable the violators in case any violation takes place ((Gatens (2004); James (2003); and O’Neill (1996)).

Lastly, Browne & Millar (2016), referred to always questioning the understanding of the human rights-based approach in relation to the context and social facts where the integration process is being implemented while including people with wide range of personal and social conditions.

The concepts elaborated above will allow me to look at the integration process of the Sesobel organization beyond its individualistic approach at the level of the child with a disability. However, I will look at the different aspects and the different actors involved in the implementation of the integration process. Moreover, I will be able to identify if the integration services provided by the Sesobel organization are meeting more than the medical needs of a child with a disability to touch upon the skills and functions that allows them to enjoy their rights of participating in the society. Moreover, it allows me to look at how disability is perceived more than its medical aspect by addressing the several barriers limiting the CWDs from engaging effectively according to their capabilities. Moreover, to understand how Christianity’s values are being translated into practices during the integration process and to what extent they are shaping the perception of disability and the mission of the organization. In the next chapter, more information about the data collection process shall be provided.

Chapter 3: Methodology

I looked at the process of integration of CWDs addressed by the Sesobel organization. A Lebanese organization that aids CWDs and their families. It was founded in 1976, one year after the long Lebanese civil war, by Yvone Hachem (Sesobel, n.d.). As per the organization's website, it adopts a global approach to address integration through programs that support the CWDs and their families as co-partners as well. Moreover, the organization puts a lot of effort into overcoming the obstacles faced during the integration process (Sesobel, n.d.). Two other organizations were founded following Sesobel to continue the assistance of adults with disabilities: Anta Akhi, cares for PWDs as they age, it was founded in 1992, and Handicap et Vie en Englise, founded in 2000 that works on the level of acceptance of PWDs in church life (Sesobel, n.d.). More information shall be provided about the organization in chapter four.

During the research, the policies, pedagogy, and other resources, practices, and the staff body of Sesobel were researched in order to understand more about how the process of integration of CWDs is being addressed in the Lebanese context. I was trying to identify, through the different practices of the Sesobel organization, to what extent, they are going beyond the medical aspect of disability by addressing and referring to the cognitive and emotional factors (Marks, 1997:87) and different identities (Degener, 2017:49) of each child with a disability shaping their experiences.

I had a contact person who helped me to get in touch with a woman working at the headquarters of Sesobel, who facilitated my access to the organization. Before starting the fieldwork, I filled in a document shared by the organization, where personal details were collected: name and last name, education background, name of the university I study in, the person who put me in contact with the organization, the reason behind visiting the premises of the organization, and the topic of my research. Moreover, I was asked to share with the organization, a letter from my university confirming my enrollment in it, as well as an interview consent form that I had to sign, and to approved by the organization before sharing it with the participants in the research.

I visited several times one of the organization branches located in Jezzine area, from mid-July until the end-July. However, I only visited the headquarters in Mount Lebanon once. To conduct the research, I adopted a qualitative approach, where the participants were the subjects of in-depth semi-structured interviews. In the following section, I shall provide an explanation of the importance of the areas chosen, the selection of participants process, my positionality, and the limitations I encountered.

3.1. Selection of research area

The research was conducted at the headquarters of the Sesobel organization and in one of its branches. The headquarters is in Ain Al Rihany, in Mount Lebanon which is about 18 km Northeast of Beirut (Lebanon's capital city). With an estimated two million persons as of December 2022, this area is known to be the center of the Lebanese cultural, economic, social, and political activities (UNHCR, Lebanon, n.d.).

The branch is in Jezzine, in the South of Lebanon which is about 70 km South of Beirut (Lebanon's capital city). Doing part of my fieldwork at the headquarters of the Sesobel organization was crucial for me as a researcher. It allowed me to be at the heart of the activities of the organization and its work. This choice provided me with a comprehensive perspective and a thorough viewpoint on the dynamics and the process of the decision-making of the organization.

On the other hand, my selection of the branch's location in Jezzine was made due to my acquaintance with the area. This made it easy to understand the cultural, social, and economic context in which the branch operates. Therefore, dynamics were explored, giving me insightful information about the experiences of both workers and beneficiaries in a different setting from the headquarters. This shall be more elaborated in chapter four of the document.

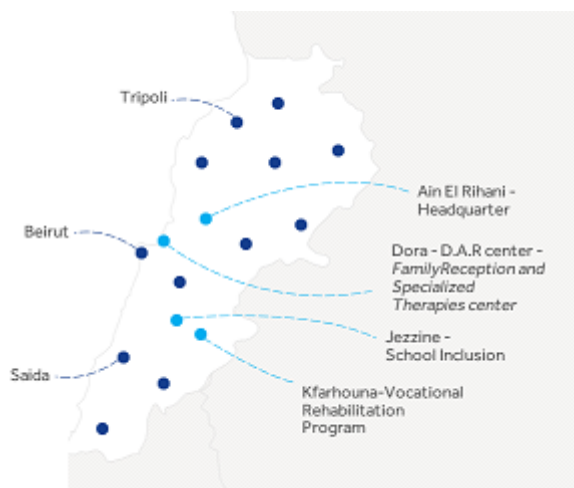


Figure 1

a picture showing the different locations where the Sesobel organization operates. Taken from the Sesobel organization website.

3.2. Selection of participants and data collection

During the research the chosen sample needed “to relate to the phenomena that the research is trying to highlight” (King et al., 2019:56). I interviewed five staff members who were already preselected by the Sesobel organization.

The following table shows the participants selected during the research:

#	<i>Job position</i>	<i>Location</i>	<i>Engagement Period</i>
1	Special educator	Branch	>15 years
2	Special educator	Branch	>15 years
3	Speech therapist	Branch	1 year
4	Head of pedagogy department	Headquarters	>15 years
5	Head of physiotherapy department	Headquarters	>15 years

The participants identified themselves as Lebanese women. Three worked at the branch and the other two worked at the headquarters of the organization. All the three women working at the branch: come from the region in which the branch operates, were very familiar with the context of this region and its dynamic, and their relationships with the families of the children they are assisting went beyond parents-service provider relationship due to this acquaintance.

Two of them were part of the foundation team of the branch, married, in their 40s, and had a very direct and realistic approach about their work and life in general. The third staff was a new member of the team who recently graduated from the university, around 25 years old. While she had only

joined the team recently, she was very active and engaged. The last two participants working at the headquarters, also come from the region in which the headquarter operates, are in their 40s, and have a long experience with the organization. However, had a more formal and sophisticated language while talking to me about their profession at the organization.

It is worth to mention that since my sample was limited in terms of the number of participants, and for the sake of anonymity of the participants, I am not revealing any detail that might expose them during the analysis of the findings. Hence, I am settling for referring to them as “individual interviews” once they are being quoted.

3.3. Research process:

The primary data were collected from 21 July to 31 July 2023 and analyzed for conclusions and recommendations on the topic. In-depth, semi-structured interviews were done with the staff members of the organization. Semi-structured interviews are a “scheduled activity” (Bernard, 2011:156) with a prepared script (that shall be found in Appendix 1 of the Appendices section) including the topics I am focusing on. It was a thematic and inductive analysis as I posed my questions in a way that aligned with the main research question and the three sub-questions addressed to answer the main one.

The interviews were recorded in Arabic they were the main resource generating findings. I conducted the translation and transcription at a later stage. However, I also supported my arguments and findings by going back to the notes I wrote in my notebook about any observations that seemed important to me. Moreover, the presentation’s notes that I attended on the first day where an overview about the organization was provided were also checked for reference.

However, I adopted an unstructured format while interviewing my participants, allowing spontaneity and space for the staff members to share their personal experiences, hence, allowing me to be fully in control of what I wanted “to receive without exercising excessive control” (Bernard, 2011:158).

I previously communicated with the staff about the time of my presence. Since I did not have the will to be in direct contact with the children of the organization, I did not get a consent of their parents. Hence, I met all the staff in a separate room from the ones where the children were available. During the interviewing process I was asking the participants questions and getting answers back. Certainly, the participants were informed about the possibility to withdraw from the interview and/or not to provide me with answers if they felt uncomfortable about any question.

Engaging in those small conversations with the staff over a coffee specially before conducting the interviews was an icebreaker. Both the interviewees and I felt more comfortable later, discussing different topics that varied from personal to professional ones in relation to the research. That allowed me to unpack certain ideas, hence, modify the interview questions accordingly. I considered the small conversations as unstructured interviews and “excellent for building initial rapport with people, before moving to more formal interviews” (Bernard, 2011: 158). It facilitated the process and created a friendlier environment that allowed us to mutually exchange information with trust and comfort.

However, the last two interviews that were conducted at the headquarters of the Sesobel organization with the head of the pedagogy department and the head of the physiotherapy

department had a more formal aspect and took place on the same day of one visit. The nature of the interviewing process created an environment that allowed the exchange of insights and information between the interviewees and I in a more effective way. Both meetings with the interviewees took place in their related offices which allowed an authentic and open dialogue.

The secondary data were collected from online sources such as websites, books, and journals.

3.4. Positionality and Ethical Considerations:

Growing up in a poor family with a person with a physical disability (my aunt) allowed me to witness the challenges and opportunities that a person with disabilities might face. On the other hand, I always touched on the lack of awareness as well as the lack of an environment ensuring my aunt's comfortable participation in society. Nothing was encouraging her to be part of Lebanese society without her feeling like a burden every time she decided to engage with 'the outside world'.

Many factors made me realize that the barriers to integrating my aunt into the society were not only limited to structural facts. However, it is also about cultural and societal norms creating a limited and outdated approach to deal with the situation of disability in Lebanon. For instance, the social perception that portrayed my aunt as a struggle that we (her family) must deal with while providing her with assistance. Or, considering our work as heroic by trying to simply treat her equally with other people. Hence, it increased my desire to promote a more inclusive and accessible environment as well as to raise awareness about the necessity of treating PWDs in general, and CWDs specifically, as equal as their peers.

I had this idealistic idea about the work done by the Sesobel organization and kept on comparing it with my personal experience. For me people at Sesobel were the ones doing the heroic work as they are strangers dedicating their work for the assistance of the CWDs. This image was also developed due to the successful stories shared on the social media and the television about different cases of CWDs and how Sesobel contributed to the betterment of their lives.

Furthermore, since the research was conducted in my home country, I felt that my nationality and the fact I come from the same region as the participants gave me the privilege of being an insider. Moreover, being a Lebanese student living abroad in a European country and pursuing a master's degree in an international university was a criterion that gave the participants a kind of reassurance about doing the research.

During the fieldwork, a lot of ethics were taken into consideration. "Ethics is an ongoing responsibility, not a discrete task to be checked off the researcher's "to do" list." (Fujii, 2012:717) It is an important matter because the research includes people hence, their related feelings, dignity, and rights. I approached the participants in an open and transparent manner. I made sure to inform them about the purpose of the study, and that I was only interested in knowing "what they think, and what their observations are" (Bernard, 2011:160). While conducting the interviews, I made sure to ask the participants' permission to take notes while interviewing them as well as to record the interview (Bernard, 2011).

Since the Sesobel organization deals with a vulnerable group of people, it is sometimes used by individuals or other organizations for fundraising purposes. Therefore, I guaranteed that I had no plans to look for funding or any other plans. In addition, I emphasized that any

material/information shared by the participants will be exclusively used for my thesis, with no intention that goes beyond academic purposes. I got a verbal consent from the participants to record the interviews as well as to take notes (their consent was recorded) in addition to a written consent shared with the organization prior the start of my fieldwork as per their request.

3.5. Limitations:

The study focuses mainly on the integration process of CWDs into the society pursued by the Sesobel organization. Yet, it is essential to note that the Sesobel organization also provides support to adults with disabilities, a group that is not included in this study. The generalizability of the findings is limited as the experiences of the adults with disabilities are not fully reflected. Additionally, the constrained timeframe for the fieldwork prevented me from making many in-depth observations according to my preferences. This resulted into preventing me from identifying further behavioral insights, such as spontaneous reactions and interactions of the actor involved in the integration process of CWDs that can't be captured through interviews. The spontaneity element could have helped me better in identifying and analyzing additional potential patterns and practices taking place elaborating more on the specificity of the context of my research.

Furthermore, I encountered other obstacles I had no control over. These included the predetermined selection of participants and timeframe for conducting the interviews by the organization. Hence, I couldn't personally select the participants which resulted in a loss of autonomy in setting inclusion or exclusion criteria (such as, for example, the engagement period of the staff) that aligns with my research objective and interest. I had to adhere to a certain timeframe that impacted the process of data gathering and pushed to compromise the generalizability and the transferability of my research observations. As, I didn't have adequate time to deepen my observations, and had a limited representativeness of a larger population, in my case, the staff of Sesobel.

In the previous chapter, I discussed how I conducted the research by highlighting to the research methodology, the selection of the research area and its characteristics, the selection of the participants and the data collection. I also described the research process, and discussed my positionality, as well as the limitations faced during the research. In the following chapter, more information shall be provided about the Sesobel organization by highlighting an important factor the socioeconomic situation and socioeconomic status impacting the integration process.

Chapter 4: The Sesobel Organization:

4.1. Overview of the Sesobel organization:

As previously introduced the Sesobel organization helps to bring about the integration into society of children and adults with disabilities. It started its mission in 1976 right after the Lebanese civil war, and its mission adopts a global approach covering three angles: (a) the child with a disability, their family, and the society to respect, and acknowledge the dignity of the child with a disability regardless of their disability (Sesobel, n.d.).

A multidisciplinary team of 213 employees with different specialization such as educators, doctors, social workers, and others, work at the headquarters and three other branches of the organization (Sesobel, n.d.).

Different services are provided for more than 1358 children on a yearly basis with the following needs: motor disability, intellectual disability, and autism, in addition to outpatient services in all the Lebanese regions (Sesobel, n.d.).

It is worth mentioning that Sesobel School was rewarded by the CMA CGM Corporate Foundation in 2017 with a reward for its commitment to CWDs and their families (American Journal of Transportation, 2017).

The Sesobel organization funding strategy is based on the collaboration with local and international partners, for instance, embassy of France, USAID, Sesobel Australia, Sesobel France, Sesobel USA, etc. (Sesobel, n.d.). Moreover, their factory and their shops (online and on site), donation campaigns and the donation link on the website, the three-heart lodge that can be booked by clients (Sesobel, n.d.). Additionally, the organization receives subsidies from the Lebanese government as other organizations with the same mission. For instance, the following “Government Is Turning Its Back on the Children of Sesobel” (Kabboul, 2020) was the headline of an article highlighting that the government is falling behind in paying the owed subsidies for the Sesobel organization (Ibid.).

4.2. Finding: Socioeconomic situation and socioeconomic status impacting the integration process:

The Sesobel headquarters encompassed two buildings, where the administrative offices were separate from the areas of medical, educational, and health services. On the left side of the entrance door was the activities’ court where an activity with firefighters was taking place to inform and teach children with various disabilities about their daily life.

In comparison, the Sesobel branch located in Jezzine area, is in the same building as the public school that is part of a collaborative inclusion program between the Sesobel organization and staff and the Ministry of Education. It was an old white building, facing the playground of the school that during summer is used as the school’s bus parking. The ground floor was the floor where the Sesobel branch operates. It was small and divided into two sections: the first section is about two offices for the staff and the second section is about a classroom and playing room.

All the staff of the branch were waiting for me at the reception. They initiated the discussion by apologizing for not being able to turn on the air conditioner as they didn’t have round-clock electricity. Also, they had to reduce the usage of generators to reduce the consumption of fuels due to the limited budget. (In Lebanon usually the generators are used as an alternative to the

public electricity once it is cut off which happens a lot, and following the crises of 2019 generators became the main source of energy for the Lebanese).

During my discussion with one of the participants working at the branch, I was informed that the services provided to the children and their parents are for free. The reason behind it, is that one of the board members of the organization, who is originally from the same region as where the branch operates, decided that the services provided at the branch must be free due to the socioeconomic situation of the region. However, at the headquarter the parents of the CWDs pay for the services provided by the organization as an interview the participant noted. She also mentioned how the difficult life conditions are limiting both the branch and the parents from doing their jobs and how this is affecting the CWDs.

“It was always for free, ever since the branch started operating. As you know the region is poor and went through a lot, and now with this crisis things are getting more difficult for everyone living here, some of the children are not attending in person to the branch because of the high cost of transportation, their parents can’t afford to come on a daily basis, we are trying to assist them online, but it is not the same result for the kids.” (Individual interviews, 2023)

When I asked whether the organization does not provide transportation services for the children attending the branch, an interview respondent replied:

“No, we don’t provide this service. We tried to, but the cost was really high, it is not convenient for us” (Individual interviews, 2023).

Additionally, the branch at Jezzine suffers from the lack of staff but they cannot recruit more due to the budget constraints. This leads to the absence of a proper follow-up with the families of the CWDs at their houses, and to additional workload for the available staff. For instance, another participant mentioned that due to the absence of a social worker in charge of the follow up process with the family, she and the head of the branch oversee doing that. As a result, they cannot always be available at the branch and at the same time they cannot do a proper and frequent follow-up.

I also realized that anyone from Jezzine region is eligible for getting services from the headquarters of the organization if they can afford it. Moreover, the participants also added that since the services at the headquarters are fee -based, they can deal with more severe and advanced cases of disabilities, with more technology involved (if needed), and with a higher number of staff with a diverse background that can provide more diverse and specific services.

When I asked whether the services at the headquarters, are different, an interview participant stated:

“I mean it is the Headquarters, it is different than here, they have more staff, more technology and expenses, and they need more money. Parents pay a lot. The services at the headquarter are different than here.” (Individual Interviews, 2023)

Based on the observations previously mentioned, it is obvious that the difference in the quality of services provided by the Sesobel organization in its two locations is associated with the socioeconomic status of the family seeking the service. In other words, how much a family can afford or have access to provide services that ensure the integration of their children. According

to Bradley & Corwyn (2002), the socioeconomic status of a person is measured by the family's job, income, and education, hence, the equality in accessing to opportunities among families of a child with a disability is related to social position disparities and how much a family is equipped to promote and uphold their children's rights. For instance, a family with higher socioeconomic status and with better financial resources, can have access to better medical services, specialized treatments, and advanced therapies. This can be translated into better outcome when it comes to the process of integration implemented allowing the promotion of the active participation and engagement of their children in the society. Moreover, the socioeconomic statuses of the family impact the quality of education provided for the child and the child's level of integration. This argument is supported by Heward (2009), who considered that, the higher the socioeconomic status of the family, the more awareness about providing better rehabilitation and education services for their children's development, and therefore, the more advantaged opportunities of rehabilitation and education are received.

In conclusion, the socioeconomic situation of where Sesobel is operating along with the socioeconomic status of the families seeking for the integration process determine the quality of the service provided during the process. This fact affects the outcome of the integration process and creates more inequalities among CWDs. The next chapter, more information about additional observations highlighted during the fieldwork, covering the pedagogy, practices, actors involved, and religious influence on the integration process addressed by Sesobel.

Chapter 5: Sesobel addressing its integration process:

In this chapter, I am discussing the findings that answered the main research question addressed earlier in chapter one along with their analysis: Integration of CWDs goes beyond education: Analyzing Individualized Educational Plan as a road map, Family, an integral actor during the integration process, Religious influence on the organization, Spreading awareness at the society level: campaigns and interactions with CWDs.

5.1. Finding 1: Integration of CWDs goes beyond education - Analyzing Individualized Educational Plan as a road map.

The following section elaborates more on the position that providing educational learning for CWDs is not enough and it does not ensure their full integration and participation in the society. Thus, there is a necessity to extending that to teaching children daily life skills that ensure their autonomy and independence according to their specific capabilities, needs and challenges. Hence, the implementation of a holistic approach through the individualized educational plan (IEP) that covers different aspects of the integration process.

The IEP established by the Sesobel organization is the starting point of the integration process for CWDs. During my observations I was informed that this plan is established following an assessment of the child's impairment where two elements are clearly identified: the type of impairment and what capabilities of the child are to be improved, and to what extent their potential could be maximized. Following the assessment, an objective that goes according to the elements of the assessment, is fixed and to be accomplished. Usually, the plan's objective is updated on a yearly basis, taking into consideration the progression of the plan and any upcoming updates with the child. According to an interviewee:

“We assess the child based on their capabilities vs. needs and we work on their potential. We try to maximize their potential and adjust the adaptations in a way that serves this maximization” (Individual Interviews, 2023).

“For this reason, we do analysis to set an individual objective for each child, the medical team meets with the pedagogical team, and we set a common objective together.” (Individual Interviews, 2023).

The previous statements highlight the fact that the collaboration between the medical team and the pedagogical team goes hand in hand according to each child's needs, where the learning program is adjusted to allow the achievement of the individualized objective according to each child's impairment. Therefore, this statement confirms what Rakap (2014:173) said: “Individualized education programs (IEPs) are the road maps for individualizing services for CWDs, specifically through the development of high-quality child goals/objectives”. The importance of these programs stems from the fact that they allow the establishment of a plan that targets the real needs of the child taking into consideration not only their capabilities but also the conditions of the learning process. Rakap (2014) noted that in fact, the plans with objectives that advocate for personalized services that leads to educational and personal growth of the child, allow staff involved in the integration process “to know what to teach, when to teach, and where to teach.” (Rakap, 2014:173).

The participants explained how the IEP is implemented by highlighting to its three aspects. First, the medical aspect based on psychological assistance and physiotherapy, speech therapy, and following up on any chronic diseases (if any). Second, the educational learning and third, skills learning and improvement. To be noted that the last two aspects were the most discussed ones among the three.

The educational learning, is implemented through the curriculum, provided by the Ministry of Education to the Lebanese public schools, however, adjusted according to the impairment and condition of the child. On a yearly basis, prior to its adoption this program is assessed by the organization's medical and pedagogical team and adjusted into functional learning to be taught to children. For instance, teaching the kids to read depending on their visual memory that allows them to read primary words. In the following quotes, the concept of educational learning is pointed out too:

“On a yearly basis, we check the educational program of public schools, because, as a first source of learning we adopt this program. Then we adjust it according to each student's situation and the assessment done by Sesobel, the one I previously mentioned if you remember.” (Individual Interviews, 2023). Another interviewee shared the following:

“I teach them functional reading, for example, I teach them to read functional logos and words. Once they see the logo, they will know what it means. Also, I teach them functional mathematics and the Latin number. My children can read numbers in French and Arabic. They know it and do it very well.” (Individual Interviews, 2023)

Moving to the skills improvement which is about teaching the children life and survival skills that allow them to participate in daily life activities. Moreover, this should allow them to become independent and autonomous according to their potentials. According to all the participants, integration of CWDs into society goes much beyond education, which is elaborated in the following interview quote:

“Our work goes beyond teaching them reading and writing, it is about helping them to survive in society. We teach them how to take care of their hygiene, their appearance, how to play, to buy groceries, to make their own breakfast sometimes” (Individual Interviews, 2023). Moreover, another interviewee share this:

“Sometimes education is not a priority, it depends on every child.” (Individual Interviews, 2023). Once should also consider that:

“We cannot do miracles or force children to do things they can't do. For instance, if a child cannot move their hands (paralyzed), I cannot force them to do so. I can provide them with special tools such as special plate, or spoon to adapt to their disability.” (Individual Interviews, 2023).

The previous statements note that for a better integration process that ensures the participation of CWDs into society, the national educational curriculum on own is not enough. According to Farrell (1997) while the national curriculum allows an easier integration, it is limited for only moderates and mild learning disabilities and excludes the severe disabilities. The integration process must be channeled towards maximizing a child's potentials by taking into considerations their needs and challenges as well. Therefore, teaching them life skills in addition to academic

knowledge would ensure their independence and autonomy and would co-determine a successful integration. This argument is supported by Cross et al., (2004) who considered that successful integration is not only limited to achieving goals, but also to achieve personal growth and development.

Therefore, Sesobel by adopting an integration process that ensures the improvement of the educational and personal life skills of a child with disability acknowledges the fact that the integration process is related to different personal and contextual conditions. Which aligns with the four aspects of integration (physical, functional, social, and public) highlighted by Leliugiene & Kausylinene (2012) and their impact on the quality of life and meeting the needs of a child with a disability within a specific environment.

5.2. Finding 2: Family, an integral actor during the integration process.

In the following section, I am discussing how the Sesobel organization includes the family as a crucial actor in the integration process of their child with a disability. Moreover, I am highlighting how the family accepting their child's disability as well as the reliable exchange of information between the parents and the professionals is very crucial for the success of the integration process.

After having conducted several interviews, the notion that "family is a partner" was very much used and highlighted by the participants. According to them, the family of the child must be fully engaged, and their role is impactful and starts at an early stage of the integration process. As one participant stated:

"The more they are engaged with us, the better for the process to improve." (Individual Interviews, 2023)

This starts from setting the objective in the individualized plan of their child until further implementation steps. As such, the medical and pedagogical teams of the organization share the tentative plan with the child's parents and modify it according to the interests of the parents (if possible) as well. Moreover, the participants highly emphasized the importance of mutually exchanging information between them and the family of the child as it allows reaching the goal set for the child. For instance, parents can share their concerns, and expectations and discuss the effect of the integration process on them as well and the professionals can share updates about the evolution of the process and the developmental stage of the child.

According to one of the interviewee participants:

"We work with the parents, and we inform them about the objectives set, we listen to what they have to say, what scares them, what satisfies them. Anything! And we try to find a common ground between us. (Individual Interviews, 2023)

"They are the first educators, and no one knows their child more than them." (Individual Interviews, 2023)

When I asked the participants about why to include families and the importance of doing so, one of them said:

"Let me start by saying that parents know their child more than anyone else, they see and know things that we don't. I mean they are always around their children, and those small details they

share with us, are helpful more than you can imagine.” (Individual Interviews, 2023). When I then asked a follow-up question about

“what happens if parents have requests that do not match the reintegration plan set by Sesobel?” The participant gave me the following perspective:

“This is why it is important to listen to them, and to inform them about what we can do and what we can’t. Our responsibility is to make things clear for them, so they can manage their expectations. Sometimes the difference in objectives is helpful, it helps us to see what we are missing. It goes both ways, they share with us (information), and we share back.” (Individual Interviews, 2023)

This previous conversation shows the importance of actively engaging the family in the integration process of their children. The interview participants considered this engagement allowing the family to witness the changes occurring, and to compare the different stages of the process and the results. Moreover, it allows the parents to communicate their recommendations, concerns, and thoughts with the organization’s caregivers and team.

The parents’ ability to identify fundamental factors that would affect the process of integration is crucial to its efficiency. This supports the argument of Prezant & Marshak (2006), about the necessity of including the parents’ perspectives in the professional programs to avoid their children’s needs to be missed. Moreover, according to the interviewees, the collaboration between parents and Sesobel translated into the betterment of the IEP and was crucial to reaching the goal of a successful integration process. Which proves that the integration is not an individual task that can be burdened solely by the recipient, Cross et al., (2006) noted, that the collaboration between both actors is crucial for a successful integration experience.

Lastly, the interview findings presented above, highlight the importance of exchanging information mutually between the family of the child with a disability, and the professional team in charge. For instance, according to Cross et al., (2006), parents must share information about the daily routine of their child, and in return, the professionals must share update about the medical situation of the child.

However, the success of this collaboration is conditioned on an important element: the family accepting the situation of their child. This condition was mentioned by almost all the interviewees. Moreover, they emphasized the impact of acceptance on the outcome of the integration process. According to the interview participants, the more the family accepts the disability of their child, the easier the process gets, and the better are the outcomes on the level of the realization of the child’s independence and autonomy. As one of them shared:

“An important element is the family accepting the situation of their child. If they don’t, that means the entire process ‘collapses’ and stops.” (Individual Interviews, 2023)

During my conversations with the participants, they informed me that parents accepting their child’s disability is a key step that contributes to the child’s own acceptance of their disability. For them, despite the fact that they defined acceptance differently, they all agreed on not limiting the disability to its medical definition or consider it as ‘a problematic difference’. Instead, to acknowledge the children’s potential that could be turned into capabilities, and to understand the broader dimensions of the disability in relation to society. This is highlighted as well by the social

model of disability, the model criticizing the medical one. Oliver's (1981) position on the fact that the social model of disability switched the focus from the disability as a limitation within the individual to how from within the social environment there are barriers challenging PWDs from engaging in the society, as highlighted in the following statements by some of my interviewees:

"It is once people stop looking at a child with a disability and feeling sorry about it. Once they look at a child with the disability and the first thing, they see is what a child with a disability can do despite their disability, their potential." (Individual Interviews, 2023). Another participant stated the following:

"Simply, when a child with a disability is considered like everyone else, treated on a humanity basis, and not blaming them for not being able to do, but blaming the 'what did not allow them to do' instead." (Individual Interviews, 2023)

My observations allowed me to understand that according to the Sesobel organization, or at least the participants I interviewed, the importance of family acceptance was linked to the success of the integration process in a holistic view. They all understood that the more the family embraces their child's situation, the more this allows for "fully acknowledging the facts of a situation (disability) and not fixating on how it shouldn't be that way" (The Health News Team | Sharp HealthCare, 2021). However, another important impact has the acceptance of the family on the individual level of the child. According to Dembo et al. (1956), and Wright (1960), accepting a disability is a process that evolves, allowing individuals with disabilities to value their own abilities and strengths rather than looking at their own condition as a limitation compared to others. This is also highlighted in the social model of disability, where the necessity of differentiating between the impairment as individual and private and the disability as structural and public (Shakespeare, 2013).

5.3. Finding 3: Religious influence on the Sesobel organization.

In this section, I analyze how the Sesobel organization incorporates spiritual development in the integration process of CWDs. I am discussing how religion (in this case Christianity) is incorporated in the daily life activities related to CWDs, moreover, how religion is a source of power of the staff involved in the integration process helping them to be motivated to proceed with their work during difficult circumstances.

During my fieldwork, in both the branch and the headquarters of the organization, I noticed that the Christian religious aspects were very much present in the organization. For instance, at the entrance of the headquarters, a big white statue of Lady Mary was centering the reception area, in addition to a painting related to Jesus Christ, the holy family, and others. In one of the branch corners, in addition to small religious paintings, there was a table with a grey and white cover and an old picture of Lady Mary holding Jesus and a lightened candle in front of it. In addition, a big, handcrafted sign with a prayer section that grabbed my attention. When I asked one of my participants about the reason behind this, she told me that, children are taught to pray and to practice their prayers in several ways. In this way the Sesobel organization takes care of the children spiritually as the spiritual development of children is one of its main objectives. The following interview statements illustrate this point:



“Every day, all of us children and staff, we gather together, right here in this small corner, we light up a candle and through our prayers, we say thank you, and get the blessings of the Lady of the House.” (Individual Interviews, 2023)

And,

“we don’t teach our children only life skills and but also, we teach them how to pray. They participate in the masses we

organize especially to celebrate special holy days such Christmas, Easter, and the children’s first communion at the school next door with other students or at the local church.”

(Individual Interviews, 2023) And finally,

“Spiritual development is as important as any other objective set for the children. They go hand in hand.” (Individual

Interviews, 2023)

Figure 2

A picture taken by me, showing the praying section at the Sesobel branch.

These statements, underline the different ways how Sesobel addresses the children’s spiritual development. For instance, daily prayers are used by children to express their gratitude and to get a fresh start of the day. According to the participants, starting the day with a prayer allows the children to adopt a more peaceful attitude which allows the rest of the day to run smoothly. Moreover, according to Hay & Hunt (2002), spirituality is considered as believing in the Higher Power controlling the different life events of an individual. Thus, they considered that by teaching children to pray they are developing this understanding of God’s existence in their daily life routine. Lastly, it was noted that the participants encouraged the participation of CWDs in other collective religious practices such as masses, with the presence of other local families. Usually, Lebanese Christian families (parents and children) go to church as a ritual to celebrate different occasions, for instance, Christmas. The participant described the participation of the children of the Sesobel organization in mainstream events as a chance to foster their feeling of equality to their other peers and to feel valuable. It is important to note that only at the branch located in Jezzine area, the interview participants mentioned that some of their students come from a different religious background (Muslims), and they also participate with the children in praying Al-Fatiha¹. However, nothing was mentioned by the interview participants about their or the children’s participation in other religious mainstream practices beside of the Christian ones.

“Now we learned how to read Al-Fatiha” (Individual Interviews, 2023)

The last form in which faith influenced Sesobel was it being portrayed as a source of resilience provided by a bigger power. Three participants out of five believed that the religious aspect makes the Sesobel organization resilient and protected from any kind of harm. For them, the Sesobel

¹ Al-Fatiha: in English it means ‘the opener’ and it is a prayer recited by Muslims. In the following link, the text of Al-Fatiha and its translation, are available: Khattab, M. (n.d.). Al-Fatihah. Quran.com. Available at: <https://quran.com/en/al-fatiha>

organization is Lady Mary's project, and she is taking care of them and ensuring its continuity. As such, Lady Marry is referred to as the "Lady of the House".

For instance, one of the participants asked me the following:

"Did you see the monument of Lady Marry outside? She is taking care of us. No matter when or where we go, she is always looking for us." (Individual Interviews, 2023)

When I asked her how the project is being protected by the Lady Marry, she added:

"We went through a lot of crises, but we never had the doubts of not surviving them, because she is taking care of us." (...) (Individual Interviews, 2023).

"We were getting paid half salaries, we struggled with lack of fundings, but we always knew it that she will make sure that it is going to be ok." (Individual Interviews, 2023)



And then the participant went to her office and brought me a small piece of paper. She handed it over to me and asked me to read it. It was a prayer that everyone at the Sesobel organization prays when going through hard times. For all the participants, believing in the divine power of God plays an important and positive role and underlies the organization's daily approach. For instance, following the earthquake that hit Turkey and Syria, everyone was invited to say this particular prayer, so the Lady of the House would protect Lebanon from any potential earthquake.

The prayer is presented in the figure 3, and a translation is available at appendix 1.

Figure 3

A picture taken by me, showing the prayer used by the Sesobel community during difficult times.

The narrative of all the participants allowed me to note how religion is positively expressed in the organization, as a source of resilience and motivation within their daily lives' activities. Hence, for this research it is important to understand after Bielefeld & Clevel, (2013), how religion influences the Sesobel organization's work. From my discussions with the Sesobel staff, it is obvious to me that they all looked at the encountered problems and major events in their lives from a religious lens. The staff at the organization have a deep trust in Lady Marry. For the interview participants this trust was a feeling of assurance that no matter what the crisis is, there will always be a greater power saving them. Pargament et al., (2005: 479), also noted that, from a spiritual lens, people look

at their crises differently. For some, it is seen as an opportunity of development, and for others it is seen as loss and a challenge (Ibid). Which aligns with the second category mentioned by Bielefeld & Clevel, (2013:447) in chapter 2 about the expression of religion in “the identity of the organization, religiosity of participants as well as the definition of the outcome measures” and how religion motivates the organization to continue working with CWDs despite the hard times and difficult circumstances.

5.4. Finding 4: Spreading awareness at the society level: campaigns and interactions with CWDs.

This section reveals how the Sesobel organization addresses the integration of CWDs at the level of society by raising activities, including through social media and television campaigns. Sesobel involves the children in some of these activities together with other, non-disabled, children.

The Sesobel organization adopts the global approach for integration of CWDs. Thus, for a successful integration process, the organization’s job is not limited to the children and their families. According to many of my interview participants, working at the level of the society is important too, trying to reduce the barriers that hold children back from being effectively part of the society. As one of them shared:

“Integration goes beyond the child and their family; it is outside of the Sesobel community.” And, “the society is part of our responsibility as well. It is not enough to only focus on individualistic level during the integration process. We need to expand the work to outside of the small circle of Sesobel. If we don’t, our work loses its value and meaning.” (Individual Interviews, 2023).

During my interviews, I asked the participants about the barriers CWDs encounter in society. The most repeated one, in addition to the physical barriers, was the societal attitudes and beliefs regarding the concept of disability. According to one interviewee there is:

“a lot of bullying and teasing. Some people consider CWDs as incapable or a burden, sometimes people ask us what you can even do to the kids?” (Individual Interviews, 2023.) Another interviewee remarked that,

“they usually feel pity and sorry, even if sometimes they don’t say it, but you can read that on their faces.” (Individual Interviews, 2023).

All the participants associated those kinds of attitudes with a lack of awareness within the Lebanese society. They emphasized the big responsibility of the Sesobel organization at this level particularly. For them, it was the area where they have been capable of contributing into making a difference help to eliminate the attitudes that make a child with a disability so often being treated unfairly and socially excluded.

Based on the above, it is obvious for the participants and the Sesobel organization that a successful integration process doesn’t stop at the level of improving the child’s capabilities and maximizing their potential. It must, extend to the level of the society as well, because the society is the place where CWDs with improved skills and capabilities get to apply their earned skills. However, as described by the participants, the society also is a place full of barriers, which can affect the effectiveness of the integration process. For this reason, from the point of view of the participants, increasing awareness about disability is so important. Changing different misconceptions about

CWDs is key. Tackling these aspects is one of the ways to decrease the limitations that the CWDs encounter and that hinder their participation in society. This perception aligns with the rejection of the outdated definition of disability of the medical model that considers disability as a medical problem (Marks, 1995) that needs to be fixed as it is reducing the individual's quality of life and social participation as noted by Trani et al., (2011).

With one of the interviews participants, I had an extensive discussion on the importance of having an inclusive community for CWDs. When I asked her about the mechanisms or tools adopted by the Sesobel organization to raise awareness about disability among the society her answer was the following:

“by spreading the right information and knowledge about disability. By making people listen to real facts and most importantly we make them witness the improvement of the process. We use different platforms such as the social media, the media, our website and other.” (Individual Interviews, 2023).

And later during the conversation she added:

“When people see a person with a disability going to a restaurant, or to any store, any place very frequently and being capable of handling everything their own way, that is when exactly they (people) will understand that PWDs can do it their own way.” (Individual Interviews, 2023).

According to this same interview participant, increasing awareness can take place through several ways. The media, including social media are important tools for the Sesobel organization to share information with the society. The interview participant highlighted different occasions where she or other colleagues participated in TV programs to spread awareness and to highlight how the Sesobel organization is contributing to improving the lives of CWDs. For her, the benefit of spreading awareness has a long-term impact. It ensures the creation of more inclusive community that welcomes everyone no matter what their potential. That supports the argument of Scior (2011:2165), who noted in their paper studying different research on attitudes and beliefs in the UK regarding intellectual disability, that the society's attitude and response to intellectual disability has huge influence on the success of inclusive policies and programs.

Another form of spreading the awareness about disability adopted by the Sesobel organization, is the participation of their children in several daily activities as well as in special national activities. The main purpose this, is to normalize the presence of CWDs in all aspects of life. According to another interview participant, the reason why people have negative attitudes around CWDs is due to their lack of contact with them in daily life:

“The reason why people act awkward around a child with a disability sometimes, because they are not encountering them too often, they are not used to see them in their daily lives.” (Individual Interviews, 2023).

During our conversation, she added that:

“Once they see them at the zoo, the pool, ordering food at a restaurant, working, studying, etc doing the same things as a non-disabled child they (people) will change their perception.” (Individual Interviews, 2023).

The same other interview participant also shared various examples of CWDs participating in different interesting activities. At first, she was sitting at her desk facing me, but at this point then she moved all the way to my side, brought her laptop and started showing me different pictures taken throughout the years of a lot of children who got assisted by the Sesobel organization during their participation in several activities. It was really interesting how she still remembered most of the names of the children in the pictures. For instance, she said:

“Do you see this girl in a white dress holding a camera, her name is XXX and she is our photographer. She is in charge of taking photos for all the organization’s events.” (Individual Interviews, 2023). And,

“this girl here, she participated in a swimming competition outside of Lebanon and she won a medal.” (Individual Interviews, 2023)

Moreover, she told me that on a yearly basis, the Sesobel children compete with other people at the Lebanese marathon. Also, many of them are part of the scout team. Lately, a group of children from the Sesobel organization were visiting several Lebanese schools to explain to other non-disabled students about water management and water importance.

Based on the above, it is noted that the Sesobel organization looks at engagement of CWDs in daily life activities as a powerful message that leads to a positive change. According to the interview participant referred to earlier on this page, it is important to normalize the presence of CWDs in regular context along with other disabled and non-disabled peers. This normalization and witnessing the interaction of CWDs with others makes people more empathetic and understanding better the different capabilities of a child with a disability. Which aligns with the critiques of the social model by Trani et al., (2011) highlighting that during the integration process, it is important to address not only the impairment and the social barriers of the disability, but as well to promote for equal opportunities that allows equal participation of CWDs. She also added, that the more the interaction is realized the more stereotypes are being broken, and thus the higher the possibilities of increasing the awareness of any community. Lastly, she highlighted the importance of a high level of awareness within the community for creating a more welcoming and inclusive environment where CWDs are not segregated from the wider society, thus allowing their better integration. Which is noted by Wolfensberger (1992), who argued that the integration of a segregated part into a wider society will only be meaningful if social interaction and acceptance were involved in the process of social integration.

In conclusion, the integration process for CWDs starts by an individualized educational plan that meets their needs and disability. In addition to the educational learning, CWDs are taught functional skills that allow them to survive, in the place where the integration process takes place: the society.

Moreover, the family’s involvement in the process is key for a successful integration. The information exchange between the family and the professional is an integral part of the process. However, it is important to note that the family accepting the disability of their children is crucial for a better collaboration with the organization and a better outcome of the process.

Additionally, Sesobel being a Christian organization influenced by Christianity values, incorporates religious practices throughout its mission and its daily life practices. Spiritual development is one

of its objectives to be executed while the implementation of the integration process. Additionally, the staff considers the organization as the Lady of the House (as named by the interview participants) project, that is being protected by her ever since the organization was established and during difficult circumstances.

Lastly, Sesobel believes that a successful integration is conditioned with an inclusive environment. Thus, the necessity of social awareness and engagement of CWDs in activities where their potential and capabilities are taken into consideration breaks stereotypes and promotes serves equal life opportunities.

In the last chapter, I will conclude and summarize my findings that answered the main research question addressed earlier.

Chapter 6: Conclusion

In the Lebanese context, and on a public and governmental level, the topic of disability is not prioritized, which is translated into difficulties and challenges hindering the participation of CWDs into the society. As a result, families with a member with a disability in need of services and assistance for integration must look for alternatives.

Many studies were previously done on the barriers and obstacles facing PWDs in Lebanon. However, there are no studies about the private organizations aiding CWDs and how they are functioning, how they are being the alternative and providing integration services. For instance, the Sesobel organization. It is one of the most famous, Christian private organizations providing integration services for CWDs in Lebanon. Therefore, I addressed the following question: *'How does the Sesobel organization address the integration process of CWDs into Lebanese society?'* for the Lebanese families with a child with a disability.

To answer my question, I visited the headquarters of the organization located in Mount Lebanon, as well as in one of the Sesobel branches located in the South of Lebanon, Jezzine area, for data collection. I conducted five interviews with five preselected participants by the organization in addition to observations.

Following the data collection and analysis, the following was identified:

An important detail was highlighted during the research, the difference of provided services by the same organization depending on *the socioeconomic situation and socioeconomic status* of the region where the organization is operating. Even though the branch and the headquarters were managed by the same organization however, the quality of services provided was different. The ones provided at the branch which happened to be free of charges due to the low economic status of the area, weren't from the same quality as the ones provided at the headquarters. The services provided at the headquarters were diverse, and more advanced as parents seeking for assistance there were paying money for the services. It is important to highlight that, Sesobel by adopting the socioeconomic status of the region as a determining criterion can contribute to the creation of inequalities among the CWDs. In fact, during the analysis a link between the inequality of the provided service quality and the socioeconomic status of the family and how this impacts the outcome of the integration process of CWDs was highlighted.

Moreover, *the integration of CWDs goes beyond only educational learning*. It is also about the implementation of the IEP, for each child according to their disability and capabilities. The IEP covers three aspects: the medical aspect, the educational learning which is the educational curriculum adjusted according to each child's disability and thirdly, the skills improvement where the Sesobel team oversees teaching the children daily survival skills, allowing them to effectively participate in the society. According to several participants, educational learning is not always the priority as everything depends on the potential and the disability level of each child. Therefore, during the analysis, the importance of the IEP regarding its individualization of specific services aligning with the needs of each child and its impact on the participation of CWDs in the society, were highlighted.

Additionally, *family as a partner in the integration process*. The role of the family is very crucial and impactful on the implementation and the result of the integration process of their children. Their role starts at a very early stages of the integration process. It starts from the creation of the IEP and setting the objectives as well. During the analysis, it was emphasized the importance of reliable knowledge exchange between the family/parents and the professional caregivers. Additionally, the impact of this exchange on the implementation and outcome of the integration process of the children was discussed. Lastly, the acceptance of the family of their child's disability is a crucial element for the successful implementation of the integration process that affects the individualistic outcomes of the children.

Also, the *influence of religion on the integration process*. The Sesobel organization looks at religion as a form of resilience that motivates the Sesobel community to proceed with their work despite the difficult circumstances. The faith allowed the creation of a trust relationship between the Sesobel community and God's Higher Power. This coping attitude can positively impact the CWDs involved in the integration process, it can be a source of motivation to navigate the different challenges.

Lastly, *spreading awareness at the society level through campaigns and interactions with CWDs*. The Sesobel organization has an important responsibility to increase awareness and to ensure a more inclusive and welcoming environment for the better implementation of the integration process. Spreading awareness in society is crucial as the integration takes place in the society. Thus, the media, social media, and other platforms must be used to promote facts and knowledge about the concept of disability as well as success integration stories and examples of CWDs. Moreover, the involvement of CWDs in daily and national activities to promote the normalization of their presence in the society is key, as the reason why people act weird around a child with a disability is that they don't encounter them a lot which creates stereotypes. Hence, the social engagement of CWDs in different activities is one of the steps that breaks those stereotypes allowing the realization of a more inclusive society.

In conclusion this research was conducted to answer *How does the Sesobel organization address the integration process of CWDs into Lebanese society?* The implementation of an individualized educational plan that meets the needs of each child is key, moreover, the family accepting the child's disability and fully participating in the process from early stages of the process is necessary. It was also noted that the organization's coping attitude influenced by religious beliefs is a source of motivation to navigate the difficult circumstances. Lastly, the integration process isn't limited at the level of the CWDs and within the organization, it aligns with spreading awareness and influencing the society's perception through the awareness campaigns as well as engaging CWDs in different mainstream activities.

Reflection:

It is important to always remember, while reading this research, the specific Lebanese context in which the integration efforts of the organization are being applied. The Sesobel organization's approach might not be seen as the ultimate one and maybe it doesn't align with the standards approved outside of the Lebanese context. Yet, it is crucial to acknowledge the challenges of the country as well as the complexities of its context: what can be applied and what cannot, what is accepted and what is not. Furthermore, this research must be considered as the starting point to

build upon for improvement of the organization's strategies in the future. The feedback/criticism provided should be seen from a constructive standpoint that allows the enhancement of the practices and the betterment of the services provided by the organization. Hopefully, providing an example to be followed by others with the willingness to contributing to a positive change that takes CWDs one step closer towards a more effective participation in society.

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Appendices:

Appendix 1: Interview Guide

Research question:

How does Sesobel Organization is addressing the integration of CWDs into Lebanese society?

To answer this question, I am addressing the following sub-questions:

- 1- What is the policy adopted by Sesobel organization influencing the preparation of CWDs into society?
- 2- How does the pedagogy adopted by Sesobel organization influence the preparation of CWDs for their integration into society, and how is it being updated?
- 3- How does Sesobel organization incentivize its staff involved in the integration of CWDs into society?

Sub-question 1: ***what is the policy adopted by Sesobel organization influencing the preparation of CWDs into society?***

- a- What is the objective of the organization policy adopted regarding the preparation of CWDs to integrate into society?
- b- What are the measures promoted by the organization that guarantees the promotion of inclusive education and equal chances in life for CWDs of the organization in the future?
- c- What are the services adopted by the organization to facilitate the integration of CWDs joining your organization?
- d- Does the organization collaborate with other organizations, ministries, or agencies to enhance the integration and inclusion of CWDs? In case yes, can you tell me how does it happen, and what resources do you rely on?

Sub-question 2: ***how does the pedagogy adopted by Sesobel organization influence the preparation of CWDs for their integration into society, and how is it being updated?***

- a- Regarding the curriculum adopted at your organization, where is it based? Or where does it come from?
- b- Why have you chosen this curriculum specifically? Are there any specific criteria you look for?
- c- In case the curriculum is in a different language than Arabic, what are the mechanisms to make sure that it could be used by Lebanese employees and students? Was the language ever an obstacle during the implementation of the work?
- d- How are the different types and levels of disabilities handled in the organization? Are there any specific approaches adopted to do so?
- e- To what extent do the staff play an important role when it comes to implementing strategies to foster the integration of CWDs into society?
- f- Do the staff in Sesobel organization collaborate with families, support services, and other organizations during the process of integration? If yes, how can/do they do so?
- g- How can technology be used for the betterment of the pedagogical practices dedicated to integrating CWDs?

Sub-question 3: *how does Sesobel organization incentivize its staff involved in the integration of CWDs into society?*

- a- How many people are employed in the institution? And what type of work do they do?
- b- What type of professional development had taken place for the past few years? Does it happen frequently?
- c- Do you feel that you are in a workplace where you are constantly learning?
- d- Do you feel that you are always updated about the latest details and topics regarding your work and CWDs? If yes, how is that happening? If not, what do you think is missing?
- e- Are the development programs clearly communicated to you as a staff of the school?
- f- Are there any incentive programs to the staff? If yes, what is the frequency of the programs? How did they impact you as an employee?
- g- Has your work been ever assessed? Did you ever get feedback relating to your work?
- h- Do you think the institution contributed in any way to enhance/or not your performance at work?
- i- Is the training you get (if any) different than the one of other staff members?
- j- What is it about your work that motivates to come to the organization every day? And does the organization have anything to do with this motivation/demotivation?

Appendix 2: Prayer's translation

The lady of the house prayer:

Dear Virgin Mary, you are our only refuge, and we are in no need to anyone else but you.

We shall feel no fear as you remain with us.

Make us your own family.

Because you can make the impossible,

Because you Son always listens to you,

And because you are our holy mother, we shall fear no difficulties.

Whoever relies upon you shall be not disappointed, thus, we rely on you.

Teach us how to trust you, to do our job, and to leave the rest to your will, the will of the Lady of the house.