Bacheloroppgave

VPL05 Vernepleie

How can Social educator's help immigrant families with children with intellectual developmental disabilities?

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Forord

"... Og så måtte jeg finne ut hvor han skal få hjelp, hvilket sted, hva går, hva går ikke, sånne ting som jeg har gjort for meg selv, ingen andre hadde fortalt meg. Fikk ikke denne informasjonen som jeg burde ha fått." (Früh et al., 2016:278).

Summary

The current qualitative literature study seeks to explore how the competencies of the social educator can be used to address different challenges of immigrant families who have children with intellectual developmental disabilities in order to provide a better quality within health and social services. Both Norwegian and international literature are used in this study. The findings show different challenges faced by the immigrant families in terms of language, belief, culture and understanding of the intellectual developmental disability which affect the quality of services they get from the welfare system. The findings will be discussed in relation to how the competencies of social educators can help immigrant families with children with developmental disability through the use of VERA, the social educator's core roles, communication skills, and the social educator's expertise in environmental healthcare work. The conclusion of the study presents how the competencies of the social educator can play a vital role to help immigrant families who have children with intellectual developmental disability to achieve better quality welfare services.

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1.0 Introduction

Moving to and settling in a new country could be challenging for immigrants in terms of language, politics, culture, and beliefs as stated by Berg. Berit Berg is a senior researcher who has focused much of her work on refugee related concerns. Her expertise includes different areas: immigration and refugees, social work and disability, working life, organization and work marginalization, and social policy (samforsk: 2016). In her book entitled "Innvandring og funksjonshemming" (2012) she discussed that many immigrants in Oslo, have both limited Norwegian language knowledge and lack of understanding of the Norwegian welfare system. Challenges include interaction with the Norwegian society in general and the service system in the country. These challenges can be particularly difficult for families who must also cope with the demands of daily life while caring for a child with special needs. Indeed, these immigrant families have greater needs for close engagement with the healthcare system, rehabilitation system, and training at various levels (Berg: 2012).

In Aftenposten (2011), Olga Stokke wrote about how a parent from Pakistan who has two children with severe intellectual disabilities experienced prejudices. Lisbeth Mhyre cited in this article (2011) describes how language barriers prevent most immigrants from asking for help or support. Most of them struggle to explain their situation which either causes misunderstandings, or they give up. This can cause them to have much more difficulty than other parents in the same situations. In addition, according to Nabila Zulfqar, a Norwegian -Pakistani mother, she felt that it was difficult when someone in the Pakistani society and others talked about them having two children that are not the same as other regular children (Aftenposten 2011).

"Skamfølelse. Ensomhet. Dårlig samvittighet. Ukjent med rettigheter og muligheter. Språkproblemer. Mangel på kunnskaper. Motstand mot avlastning. Mangel på informasjon. – Det var vanskelig å be om hjelp. Jeg var redd for at andre skulle tenke at jeg ikke er en bra mor, sier Zulfqar." (Aftenposten, 2011).

2.0 Statement of the problem

The current study will focus on immigrant families with children with intellectual developmental disabilities and what challenges and problems they may encounter in dealing with social and health services. Moreover, this study will discuss the different competencies of the social educator profession and how these competencies can be used to address the challenges of immigrant families whose children have special needs. Social educators might come into contact with these families through work in refugee services, kindergartens, schools, NAV, collaborations with general doctors, healthcare nurses etc. Based on this, we have chosen the following problem statement:

How can the competencies of social educators be used to help immigrant families with children with intellectual developmental disabilities?

2.1 Scope and limitation of the study

The study is not only focusing on immigrant families in Norway but also foreigners in other countries who have children with intellectual developmental disabilities. Furthermore, the scope of the study will only tackle how language, culture and beliefs affect the provision of social and health services and the quality of intervention for those immigrant groups living in a foreign country. Families with children with intellectual developmental disabilities are the main focus of this study due to the available literature that the authors could gather. For example, children with neurological conditions: cerebral palsy, epilepsy, and cognitive delay (Sørheim, 2000).

2.2 Preconception

As immigrants, we have personally experienced some of the challenges involved in getting proper information to access different services that the country can offer due to language barriers. For example, one of the authors experienced that it was hard to describe the changes that happened during her pregnancy, because she could not find any English translation to describe it correctly. At that time, she had lived in Norway for a few months. In this situation, she realized how important language was for her to receive necessary information during her pregnancy period. In addition, culture and beliefs might play a big role in how immigrants are able to adapt to society and seek help from the system. To illustrate this issue, the other author's experience was that in her culture they do not seek a doctor every time someone in the family is sick. Rather, they tend to use home remedies to heal themselves due to the belief that using home remedies is better than to depend on medicines that are prescribed by the doctor.

From the author's personal point of view, being an immigrant can be challenging in general, but it might be more challenging for families with children with developmental disability. We had an understanding that language can be a big challenge for these groups, as it might lead to misunderstandings or misinterpretations related to the necessary services they need for their children.

In working with this thesis, our own preconceptions were supported after reading different studies, which presented different challenges faced by immigrant families with children with intellectual developmental disability. It showed how language, culture and belief affects how they seek help from different services. In this way it affects our own preconceptions with these challenges mentioned above. Our understanding is that the system/service provider might also need to have a necessary competency in terms of understanding other cultures, beliefs, skills and knowledge in foreign languages and also willingness to help others. In this way it might improve services to address the difficulties of immigrants in Norway and especially those families who have children with intellectual developmental disability.

2.3 Definitions of Terms

2.3.1 Competency:

Skau (2017) claims that professional competency requires theoretical knowledge, professional and personal skills to provide the greatest possible working environment for the user. The theoretical knowledge involves knowledge based on facts and research. For example, knowledge about communication and how it affects the interaction between service provider and service user. Other examples can be knowledge that you've learned in school about other cultures and beliefs to understand other perspectives and point of view.

The next one is professional skills which includes the practical skills which pertain to the techniques and procedures learned, for example training from internship and school that are necessary to certain professions and that will be implemented in work. Skau (2017) also wrote that personal skill is also needed to be professionally competent. The personal skills are about who we are as individuals, both towards ourselves and in our dealings with others. Moreover, she pointed out that these three aspects to be professionally competent are closely related, affect each other and are interdependent to one another (Skau 2017).

2.3.2 Social educator:

The curriculum for Bachelor of Social educator (2020) emphasized that social educator is a profession with double competence in both health and social sciences. They work with children, young people, adults, and elderly who have, or may develop functional, mental, and social disabilities. Their task is not limited to specific groups, but people with developmental disabilities are the main target of this profession. A social educator can come into contact with immigrant children with special needs through home, school, kindergarten, work and community institutions according to Vitenskapelig, Internasjonal og Diakonal (VID) vitenskapelig høgskole AS (Vid n.d.).

The social educator performs different tasks from environmental work, habilitation, and rehabilitation to help people with physical, mental, and social disabilities. They assist service users in gaining more independence and improve their quality of life. In addition, they seek to encourage an individual's self-determination, engagement, and mastery of daily life through focused stimulation and training. The role of the social educator might also include preventing functional challenges. That is why collaborative skills are necessary both in education and in professional activity (Fagplan 2016-2017).

2.3.3 Immigrant:

In this study the term immigrant is pertaining to those people or groups of people who moved and live in another country. Immigrants named in this study are those people who moved from their country due to civil war, wishing for a better life and safety, or to find better paid work to name a few.

2.3.4 Intellectual disability / intellectual developmental disability:

The international statistical classification of diseases and related health problems (ICD-10) by the World Health Organization (WHO) cited in NAKU (2021a) defines developmental disability as a medical diagnosis for those who have an intelligence quotient (IQ) level below 70. It is also characterized by delays in different developmental areas such as motor skills, social competence, and the ability to cope with everyday activities before the person reaches the age of 18. People diagnosed with developmental disability are vulnerable or at risk of developing illness and disorders such as epilepsy, sight and hearing problems. This means that those who have been diagnosed with developmental disability have very different individual challenges (NAKU 2021a). Similarly, an ICD working group cited in Carulla et. al (2011: 175) defines intellectual developmental disability as "a group of developmental conditions characterized by significant impairment of cognitive functions, which are associated with limitations of learning, adaptive behavior and skills".

3.0 Background

3.1 Level, causes and manifestation of Intellectual developmental disability

The knowledge about the different levels, causes and manifestations of intellectual developmental disability can be very relevant for social educators for them to give the necessary intervention based on the person's needs and interests to master their everyday life.

Helt sentralt i vernepleiefaglig kompetanse er et helhetssyn på mennesker som vektlegger kunnskap om ulike sosiale og samfunnsmessige utfordringer, og hvor sosiale funksjonsvansker har samme fokus som fysiske og psykiske funksjonsvansker (Norlund, Thronsen & Linde 2015: 19).

According to NAKU (2021a), developmental disability has four levels. These are mild, moderate, severe and deep. Having a mental age of 9-12 years old with IQ level estimated

to be between 69-50 falls under the mild developmental disability. The person can master many of the daily living activities, other practical skills, can carry a normal discussion but might encounter difficulties in academic aspects and their language skills vary greatly, both in terms of understanding and expressions. Second is the moderate degree, with a mental age between 6 and 9 years and IQ between 49 and 35. The person has delayed language development, which includes both the ability to express and understand language. The ability to self-care and motor skills is reduced and some will require lifetime supervision and support in most daily tasks. The third level includes a mental age range from three-six years with IQ between 34 and 20. It resembles mild mental retardation in appearance, but the competence level is lower. The majority of people with this diagnosis have drastically impaired motor skills, as well as other disorders caused by poor development or damage to the central nervous system. The last level is deep developmental disability, with mental age less than three years and IQ is less than 20. There is severe impairment on a person's ability to speak and interpret verbal. Some can grasp simple nonverbal communication techniques. People with deep developmental disabilities frequently have severe mobility limitations and little or no capacity to care for themselves, necessitating constant aid and support. Epilepsy, autism, decreased vision, and hearing loss are all common complications (NAKU 2021a).

The most prevalent cause of developmental disability is organic brain injury according to NAKU (2021a). Moreover Holden (2016) explained that there are biopathological causes which include hereditary conditions and chromosomal anomalies, as well as traumas before, during, and after birth. The most prevalent cause of developmental disability is thus genetic factors that impact brain development early in pregnancy. Other factors that might cause brain injury in the newborn include the mother's usage of medicine, alcohol and narcotics during pregnancy (NAKU 2021a). Perinatal causes are another cause of developmental disability due to oxygen deficiency before, during, and shortly after delivery. Postnatal Infections such as meningitis and encephalitis are the most prevalent causes of developmental problems after delivery. Other reasons include head injuries, such as a fall (NAKU 2021a).

Developmental disabilities are manifested by varying degrees of cognitive issues that result in varying degrees of obstacles in many aspects of everyday living. The environment can be unpredictably chaotic for many individuals with developmental difficulties. They may also have a limited ability to alter their surroundings since they do not grasp the relationship or why things happen. Many people with developmental disabilities may struggle to communicate and convey their needs and goals through verbal communication. Mentally disabled people may find it difficult to deal with complex forms of communication such as irony, facial expressions, and symbolic language (NAKU 2021a)

In general, the cognitive issues of people with intellectual developmental disability mean that they have weak tactics for learning and recalling what they have learnt. Planning and starting an activity or performance can also be difficult for them. Emotion regulation refers to the ability to control emotions such as joy, rage, jealousy, and so on. People with developmental impairments face more cognitive difficulties, which increases the chance of missing or distorting emotion control development (NAKU 2021a). As stated by Holden (2016) Children with developmental difficulties are more likely to engage in problematic behaviors.

3.2 Immigrants and intellectual disabilities in Norway:

In the 1980s, the majority of immigrants came to Norway from western countries, but today, non-western immigrants make up 73% of the immigrant population. Non-Western descent means people from Eastern Europe, Asia, Africa, South and Central America and Turkey. The term "immigrant" refers to persons who have come to Norway for a variety of reasons. Many of the early immigrants arrived as immigrant workers, while others arrived as refugees or asylum seekers, and yet more arrived as a result of family reunification with people who had already settled in Norway. Norway now has residents from over 200 different nations. However, immigrants are frequently referred to as "minorities." Wherein Norwegian generational societies also contain minorities such as Sami and Kvens, which made the phrase deceptive (NAKU 2021b).

According to Steinkellner & Gulbrandsen (2021) there were 800,000 immigrants in Norway at the beginning of 2021 which is about 10,000 more than the year before. Immigrants from Poland, Lithuania, Sweden, Syria, and Somalia were the five largest groups in Norway. Immigrants with Polish country background have an estimated number of 102,000. Furthermore, in the beginning of 2021 there were 197,900 Norwegian-born to immigrant parents in Norway which is 9,100 more than in the beginning of 2020. Moreover, the statistics bank showed that the five largest countries with both immigrants and Norwegian-born with immigrant Parents belong from Poland, Lithuania, Somalia, Pakistan, and Sweden (Steinkellner & Gulbrandsen 2021).

According to NAKU (2021b) immigration to Norway has risen steadily over the last 25 years. As of now, Norway already has residents from more than 200 countries, where children and adults with developmental disorders or other disabilities are included in the immigrant population. However, there are few national studies on immigrant families and developmental disorders. Søndenaa et.al (2010), states that Norway has an estimated 0.44 per 100 inhabitants who have intellectual disability with higher prevalence found in the north region. However, it was not specified in this study how many of those had an immigrant background.

4.0 Theoretical Framework

In this chapter, we present two theoretical models that will be used to guide the discussion of the current problem statement. Firstly, the social educator core roles model by Brask, Østby and Ødegård (2016) will be described to highlight the social educator's competence, values, and approaches. Secondly, the social educator's working model "VerA" is presented. This is a tool of systematic representation of different stages of social educator professional work. Wherein, experience, professional understanding and concepts, ethics, law, and professional practice principles and characteristics, as well as the user's needs and goals, are combined to achieve the user's wishes, goals, and progress. In the entire process, the aim of using the work model "VerA" is for the person to be an active participant (F0: 2017).

4.1 Social educator core roles - A model of reflection

In the book of Brask, Østby and Ødegård (2016) "Vernepleierens kjerneroller: en refleksjonsmodell" explain about a model which contain four roles of social educator both in individual and system level: (partner role) partnerrolle, (responsibility role) ansvarrolle, (bridge builder role) brobyggerolle and (drivers' role) pådriverrolle. They stated that roles help to maintain order and predictability in the environment as actors of their own profession. Furthermore, to reflect critically and apply their own competency in a flexible and integrated manner it is necessary to be aware of one's own professional function.

Partner role (partnerrolle) is about the interaction between social educators and service users on an individual level where approach in partnership and dialogue are adaptable and adjustable in accordance with service user. The main keyword in this role is service users' ability to make their own choice and be involved in making decisions concerning their own life. In some situations, selv decisions can be very challenging where a person with disability can have difficulties to realize what's best for them. Therefore, partner competency related to communications skills, active listening, respect, empathy are vital for social educator roles (Brask, Østby and Ødegård 2016).

The second role is about responsibility (ansvarsrolle). It is about making decisions on behalf of the person if the person is not able to make safe and healthy decisions alone. It concerns how the social educator demonstrates the capacity to act on difficult issues connected to the patient's ability to perceive their own best. Where the own desires and interests of the service user are considered (Asheim, 2014, quoted in Brask, Østby & Ødegård 2016). In this role coercion and power (Tvang og makt) in accordance with §9 helse og omsorgstjenesteloven are one of well-known examples (Brask, Østby and Ødegård 2016). It is the responsibility of social educators to implement their power in a professional, ethical, and lawful way to avoid injury from the service user itself and also in a situation where service users can potentially harm others. For example, social educator competence to assess the emergency and make necessary decisions and action to prevent a person with cognitive disability from being injured. This occurs when the service user has no full understanding of the consequences of her/his own actions.

The third role is being a "bridge builder" (brobyggrollen); here, the social educator is working at the system-level where they need to interact and communicate with families, environmental workers and other professions. It is a role of the social educator to provide the best possible service to users. In this role it is essential to have interprofessional teamwork with diverse specialists. Active listening, building trust, being open to others' ideas, and working for shared solutions are vital qualities in the position of social worker in working with an interdisciplinary team (Brask, Østby & Ødegård 2016).

The last role of social educator as "drivers" (pådriverrolle) is when the dialogue and bridge builder role (brobygerolle) are not enough on an individual level. Social educators can take over some of the responsibilities from the user when the user viewpoint and self-determination are lacking, and the engaging method produces negative consequences. In this situation a driver role is required. This role focuses more on facilitating framework conditions and health and social policy actions on the user's behalf (Brask, Østby & Ødegård 2016).

4.2 Problem-solving model (VerA):

"Vera" is a problem-solving model used by social educators as a tool that provides an overview of systematic work. It is divided into six categories: Charting (Kartlegging), analyzing and discussion (analyze og drøfte), goal selection process (målvalg process), measures with implementation plan (tiltak med gjennomføringsplan), method, and evaluation and reevaluation of the set measures (Nordlund, Thronsen & Linde: 2015). Since the six processes have influence on one another it requires skills and knowledge from the social educator in working with this problem-solving model. The first phase is charting, where social educators collect data and gather information through their own observation, reports, interviews with the service user, families, friends, healthcare provider and anyone who knows or works with the user. In this process of gathering information, the competencies of the social educator in terms of using systematic observation and registration methods are important (Nordlund, Thronsen og Linde: 2015). At this stage, the observer should not interpret the action but instead one should describe what is happening. It is important to take into consideration that the service users or the closed family give consent before gathering the information jfr. §4-1 (Pasient og brukerrettighetsloven 1999).

Moreover, confidentiality of all the gathered information will serve as to protect the identity of the service user. "Taushetsplikten er begrunnet i forhold som personvern, nødvendigheten av et tillitsforhold mellom fagperson og klienter og behovet for å sikre mot maktmisbruk" (Røkenes & Hanssen 2012: 260).

The second stage is to analyze the data from all the gathered information. In this analysis process the social educator will discuss certain areas of the service user challenges based on the charting and explain it with the use of the theory. The outcome of the discussion can lead to conclusions which will be the basis to come up with concrete goals which is the third stage of the problem-solving model. When working with goals, the service user should be involved in the whole process, where service users wish should be prioritized. Furthermore, when the goal(s) is set, social educators need to work with the measures and implementation plan in collaboration with the service user, family and people working around the user. It is important to note that the measures should always be in writing and must be concrete and specific with instructions that all concerned individuals understand. After the plan is implemented, the social educator needs to evaluate and re-evaluate the outcome of the measure(s) (Nordlund, Thronsen & Linde: 2015).

According to Norlund og Linde (2006) problem-solving models are work tools adapted in environmental work (miljøarbeid). In the social educator profession, environmental work holds a very important role. This is a systematic facilitation of physical and mental aspects in the environment to achieve a higher quality of life and personal growth both at an individual and system level (FO, 2008 quoted in Brask et al., 2016). Collaboration is important in environmental work when working with users. In addition, being aware of the risk factors and vulnerabilities of specific users while also providing safety factors is part of the environmental work (Viken 2018). Environmental workers (miljøarbeider) should take into consideration that service users can contribute, decide and share their own perspectives about their own life.

5.0 Method

In answering the problem statement of the current assignment, literature study was used as the method. Method refers to the procedures for conducting the study. This is a method, procedure, or tool for obtaining answers to inquiries and learning new information in an area. The approach refers to how we gather, organize, and interpret data (Larsen 2017).

Due to time limitations, lack of resources like first-hand information, and as a bachelor requirement not to gather information from specific respondents, a literature study was used. Literature study is a systematic approach through gathering literature, reviewing it critically, and synthesizing information from textual sources. The goal is to provide the reader with an up-to-date and thorough comprehension of the knowledge in the field, as an explanation of how one came to this information (Thidemann 2019).

Prior to literature search, we used the PICO format which stands for Population, Intervention, Comparison and Outcome to have a systematized literature search. The purpose of using PICO is to identify keywords and terms which are useful in searching for relevant literature that will be used in this study (Thindemann 2019) (see table 1 appendix 1). In working with this PICO format, we got in touch first with the librarian to have knowledge how this method works. After learning how it works, we were able to do it by ourselves by searching words related to our problem statement.

We used two search engines were used: Oria and Google support. Additionally, we searched through textbooks for relevant chapters. By using google support we found relevant information through using websites like nationale kompetanse (Naku), SSB, Fellesorganisasjon (FO), VID.no and lovdata. In this study, both Norwegian and English keywords were used to search for different related literatures and articles: Children, intellectual disability, minority in norway, help, developmental, refugee, culture, experiences, family, understanding, needs, learning disability, community, knowledge, parent, shock, immigrant, intellectual disabilities in Norway, funksjonshemming, innvandrere, barn, tjeneste apparat, kompetanse and minoritetsbakgrunn are some of

examples. See Table 2 in Appendix 2 for an overview of the search strategy and search words and see Table 3 in Appendix 3 for a list of all included literature.

Det finnes anerkjente vitenskapelige metode regler og kunnskapskrav. Metoden må være oppfylt. Validitet står for relevans og gyldighet, Det som måles, må ha relevans og være gyldig for det problemet som undersøke. Reliabilitet betyr pålitelighet, og handler om at målinger må utføres korrekt, og at eventuelle feilmarginer angis (Dalland 20017:48).

In choosing literature we excluded student assignments like bachelor thesis and master dissertations, as these cannot be considered reliable sources. We also reviewed the validity of the included literature in the current thesis and think that all included articles and chapters are relevant to our problem statement. The choice of book chapters and articles are assessed based on the author's academic background, peer review on authors articles, and approved websites that were relevant and useful to answer the topic of the problem statement. In searching relevant literature in our problem statement, we divided the task where each of us had to find articles that were related to our study and wrote the findings individually and put it on one summarized study.

Most literature used in this study was from Norway, but we also included studies from Sweden and Turkey. There might be differences when it comes to economics, and social and health care services of these countries. Turkey is a country that cannot be compared to Norway, due to the different system of living. Norway can be considered to have a well-established welfare system to support the refugee families. Yet, a living condition survey conducted by Bufdir (2022), revealed that there was a lower percentage of adult immigrants that experienced their own health as excellent compared to the overall population.

In relation to the relevance of using literature from Sweden and Turkey, the present study is focusing on how language barriers that exists between the workers and the refugee families can lead to not getting the support that is needed, due to not being fluently understand the language can build misunderstanding, not getting full information and therefore, or not

knowing the full rights and help one can receive in the host country. This study does not focus on the economic factors and kind of social welfare systems in delivering services to these immigrant families.

In general, in working with this thesis, both of us tried as much as possible to have an equal division of the task, especially in working with the different literature. We were always both present to meet our thesis adviser to have proper guidance in working with this assignment. We helped each other when it came to grammar checking and formulating sentences when we found it difficult. In working with all the chapters of this study we did it together by exchanging different ideas and perspectives about our topic. To work with this study effectively and efficiently, there were instances where we worked independently in the assigned topic. Afterwards we went through the texts together to check if the content was relevant and needed further improvements. In working with the entire process of the assignment we've always made sure that both of us were present during bachelor supervision. We both agreed that it was best that only one of us could send a message to our thesis adviser to avoid confusion. We've always discussed first and talked with regards to the inquiry before we sent it to our thesis adviser, and everyone got a copy to make sure that all were well informed.

6.0 Results

6.1 Challenges/ problems encountered by immigrants' children/families with intellectual disability:

In the following sections, we will present and discuss different relevant chapters and articles that were found to support the current study about immigrant families whose children have intellectual developmental disabilities. The articles and chapters explain and discuss the different challenges facing by immigrant families in receiving health care services from healthcare professionals and how these problems become barriers in receiving quality service in terms of language, beliefs, culture and ethnicity. In the article "Psychosocial and Cultural Needs of Children with Intellectual Disability and Their Families among the Syrian Refugee Population in Turkey" (Oner et.al., 2020). It is stated that the general health of Syrian refugee children is not currently being taken into account when it comes to their general health after moving to Turkey. The refugee parents in this article have moved from a country with civil war for a better life. What this study highlights are that these refugees must adapt to new culture, identity, and different laws (system of living) etc. Additionally, they have a child with an intellectual disability, but because of language barriers they are not able to ask for help and support. Refugees do not get the same accessibility to services that citizens do. As a result, those with disabilities suffer the most with lack of medical attention and with no access to vital equipment and not being a fluent speaker in the new country of residence led to difficulties adjusting to the culture, understanding the rules and procedures and contacting medical professions (Oner et.al., 2020).

The study included one hundred forty-two children with the age average of 90.5 months. To evaluate, screen cognitive abilities, motor and language development and medical concern and behavioral difficulties in children, items from the Developmental Disabilities Profile-2 were used. Developmental Disabilities Profile-2 is a tool that provides an accurate and detailed description of the characteristics of persons with developmental disabilities that are connected to their service needs. Data was collected through a family's needs survey with open-ended and close- ended questions as an aim to map their needs. As a result of the openended questions, it was confirmed that there was a negative effect on families related to language barriers and translation problems. Furthermore, access to professional services like special education services was identified as another important factor, which in this service was unreachable for these families (Oner et.al., 2020). The results of this study implied that providing high- quality and consistent translation service and increasing Turkish competence is essential. Moreover, financial needs and information on services must be met with priority for families, where information must be adapted based on the child's individual needs and development level. Special education and physical therapy should also be more widely available and of higher quality (Oner et.al., 2020).

In the article "Experiences of immigrant parents in Sweden participating in a community assessment and intervention program for preschool children with autism" (Nilses et.,at., 2019), information was derived from immigrant parents of 11 preschool children with autism through a multidisciplinary team in Sweden (Nilses et.,at., 2019). The methods that were used in this study were semi-structured interviews. The study explains that there are barriers that can affect immigrant parents from getting the support they need with their autistic children. This is because the immigrant parents of those with autistic children tend to delay asking for help when they need it. Immigrant parents of those who are with autistic can find raising their children extremely challenging because knowledge about their child is difficult for them to comprehend, especially with language barriers and not having knowledge of accessible support (Nilses et.,at., 2019).

It was also mentioned in this study about some concerns raised by the parents. The first one was about several emotions and reactions expressed after learning of their child's diagnosis. For some of the parents it was difficult to accept that their child is diagnosed with autism, because they never heard about the word autism before, it was completely new for them. The news of the child's diagnosis provoked strong emotions that were difficult to control. Parents expressed shock and anxiety in their responses: Sadness is another widely mentioned emotional experience. The second one was about the various facets about parents' experiences participating in their child's intervention program. On the other hand with regards to cooperating with the team, parents expressed that they were very satisfied with the intervention team, such as being able to contact them easily, dealing with the same specialists throughout the assessment and interventions, and being fully heard (Nilses et.,at., 2019).

"Innvandring og funksjonshemming" by Berit Berg (2012) focuses on immigrants and the problem they face, as they try to understand a child's problem with disability and at the same time getting help equal like everyone else. This study was built upon thorough interviews with forty-seven families of a total fifty children with different disabilities. A majority of the families included in this study are from Pakistan, and the rest are from Middle Eastern and Africa origin. The immigrant parents' experiences reveals that there is still a gap between the public ideal of equal healthcare services and the reality of the everyday lives of immigrant families of children with disabilities.

Immigrants come from various countries and cultures and might have different ways of dealing with disabled children or loved ones. The study showed that most immigrant families encounter both negative and positive experiences, but many families are having trouble dealing with shame and guilt (Berg 2012). In this article it was mentioned that a study conducted by Sørheim (2000) showed that there were many religious models and punishments for sin that were seen as explanations for developmental disabilities by the Pakistani families in Norway. Moreover, communication between service providers and immigrants was also found to be a problem in the study (Berg 2012). Berg further states that there are misunderstandings or a problem regarding labels on disability. One example is about those young children growing up being told they are *sick* and then as they grow up, they are labeled as disabled. By exploring immigrant parents' experiences, this study highlights the importance of mobilization at both the individual and systemic levels to fill the current gap and provide tailored and accessible services to the entire population (Berg 2012).

The article "Innvandrerfamilier med barn med spesielle behov – mødres tilknytning til arbeidslivet" by Frü et.al (2016) tackled how mothers with immigrant backgrounds who have children with special needs, reflected over their own expectations and possibilities to be employed. This was a qualitative study with an exploratory design. The data material was gathered through semi structured interviews of 27 parents with children with special needs. There were 18 mothers and nine fathers, a total of 21 families with 23 children with special needs. In addition, the study also undertook three focus group interviews with parents from Poland, Pakistan and Vietnam. This was to discuss the similarities and differences regarding immigrant phases and traditions for women occupational participation. The study separated those new immigrants from Poland who had recently moved to Norway and those who were more established immigrant groups from Pakistan and Vietnam (Frü et.al (2016).

According to Frü et.al (2016), immigrant children with special needs and their parents experience many difficulties associated with language and communication. Furthermore, these families may also have minimal understanding of the kind of assistance measures and governmental social support which can be important to be employed (Berg 2014, Kittelsaa 2012a cited in Frü et.al 2016). It is also shown in the study that parents with refugee backgrounds might have some challenges connected to social networks. Some of the reasons could be culture, religion, and language. It is extra challenging for people with minority backgrounds that have children with intellectual disability due to follow up needs and great care, and for that reason they have been seen as double vulnerable (Früh et. al 2016).

In the study, it is written about Radha who is a young immigrant who did not understand much about her child's development. Radha came to Norway through family reunification. She was not familiar with the system in Norway nor the language, which led to difficulties in writing a good application to apply for support from the welfare service. It took time before she found the right agencies and offers for her child. Through a brochure, Radha found random information regarding follow-up offers in the habilitation service, but no agencies referred her child (Früh et. al 2016). It was also said that there was a short page of information about rights in the habilitation service. The information Radha received either came late or she was informed by friends or from parents in the same situation as hers. It is concluded that Radha and people with similar problems are in need of better information from the case officer in the district, NAV, and the first-line service, to get better help and support (Früh et. al 2016).

The book "Innvandrere med funksjonshemmede barn i møte med tjenesteapparatet" by Sørheim (2000) was based on research on Pakistani families with disabled children and explains and documents the experience of these immigrant families with regards to having a disabled child. The study explored the meeting of families with the Norwegian service provider's availability, relevance and usefulness, and public services and measures for disabled. The research involved 30 Pakistani families in Oslo with 35 kids with disabilities. But only six out of 30 families said yes to be part of the deeper study which took two years. This includes three families with children who were boys and three families with children who were girls with disabilities. In this research the children had different neurological

conditions: cerebral palsy, epilepsy, known and less known diseases and with mental retardation. Children were at age of 0-12 when this research was completed (Sørheim, 2000).

One of the general problems that was raised in this study was the problem in communication, between the patient and healthcare worker. One explanation that was mentioned was that maybe healthcare workers do not have good enough communication skills and good enough methods of interaction. There are also special issues in meeting with immigrant families such as language problems, culture differences, and stereotypes that act as barriers for good communication. When healthcare workers considered culture difference as impossible to overcome and interpreting general problems in interaction as cultural problems. Therefore, this was considered as one of the biggest barriers for good communication (Sørheim 2000).

The article "Innvandrere og barn av innvandrere med utviklingshemming og deres familier: En kunnskapsoppsummering" (Sajjad 2012) is composed of fourteen different studies done by different authors in relations to the challenges of immigrant families with disabled children. The topics of the studies talked about the language, culture and not getting enough information from the services provider.

One of the chosen topics of this study was the cultural and linguistic challenges related to the diagnosis and concept of developmental disabilities and how it was understood. A main feature of the studies at (Sørheim & Sajjad cited from Sajjad, 2012) is that the parents largely explained the children's conditions either as a gift from God or a punishment. The gift is easier to carry than the punishment for e.g., taboo violations (use of alcohol, opposing a marriage, etc.). The gift is about God seeing that they are good caregivers and further wanting to get a confirmation of this regarding life after death. Both the gift and the punishment are about the same thing; the ordeal, which they wanted to pass to the best of their ability. This is not specifically related to Islam and Muslims, but also recognizable in many religions. The women expressed that their relationship with God became stronger after they had "sick" children, and that this relationship was important for their mastery. Due to these beliefs, children of these families ask and get late diagnosis and intervention from the services provider (Sajjad 2012).

Sajjad's (2012) studies reveal that gaining access to information regarding rights, benefits, and services, as well as trying them in practice, is a major difficulty for families. Most service providers did their best to help immigrant families even though there was doubt as shown in the study. As claimed by Berg (2012) quoted in Sajjad (2012), access to information should be understood in terms of "institutional racism/discrimination". It conveyed that discrimination occurs when better access to information is not provided which is shown in some of the studies. Sørheim (2004b) quoted in Sajjad (2012) also showed in her study that service providers do not have enough knowledge or experience in their own profession to provide the necessary guidance and help for immigrant families. In this article it was mentioned that when service providers meet some families who have economic problems and other issues who seek access to services, these families are asked to seek support elsewhere (støttekontakt) by themselves (Sajjad 2012).

Furthermore, it was discussed in the article that language and communication challenges were an additional burden and barriers for families with developmental disability children and adults who have immigrant background (Sajjad 2012). Service providers need interpreters in situations where there are challenges to communicate with the immigrant families in order to understand each other. As it was shown in this study interpreters were used too little. One example that was highlighted in the article was that more than half of Nav offices rarely or never hire an interpreter, even when one is required. Most of the time the service user gets help from his/her children (Sajjad 2012). In order to be professional, ethical and in accordance with law, it is important for service providers to have interpreters to be able to deliver good service (Sajjad 2012).

7.0 Discussion

7.1 How can social educators help with their competencies?

According to Fellesorganisasjon (FO) (2017), social educators are certified health professionals and the only profession where health and social competence are combined. To provide the best quality wellness to service users, social educators must have knowledge in

health sciences, legislation, social sciences, pedagogy, and psychology. Having these knowledge, social educators can work mainly in the health and social care area. It could be in municipal homecare, daycare, or a specialty health care facility, in substance abuse treatment facility, mental health treatment, geriatric care, schools and kindergartens, or NAV and some can also work in the private sector as well (Utdanning 2021).

A social educator working in refugee services or in NAV can help immigrant families to educate and provide necessary information about their rights and privileges having children with special needs. In this situation social educators can take part in the partner role, bridge builder role and driver role in the case of Radha who was named in the previous literature (Früh et. al.2016). Radha has no full understanding about her child's development and due to unfamiliarity with the system in Norway, it took time before she found the right agencies and offers for her child. In this case a social educator being in a partner role can help Radha by educating and providing necessary information about the laws and what privileges she is entitled to address the needs of her child with special needs.

A social educator's function as a bridge builder and driver role is to collaborate with families, environmental workers, municipal agencies and many others. They work at a system level, where having communication skills are important for example to solve problems that arise or work with immigrant families who need help. Social educator in bridge builder role can help Radha to connect her with different agencies which are beneficial to her child's rehabilitation. For example, social educators can collaborate with other agencies like specialist health service (spesialisthelsetjenesten) who might have expertise in assessing a child's diagnosis. This can help Radha understand her child's development and how she can facilitate the necessary needs of her child. Being in a driver role, social educators can help Radha to fight for her rights regarding all the necessary support she needs for her child from the system. As stated by Helsedirektoratet (2021), having a child with a disability can be very difficult when the child is living at home. Physical strain, heavy lifting, lack of sleep at night and anxieties are common among parents of children in need of assistance. Parents/relatives also find it hard to stay in contact with their loved ones because of their busy daily life. Competencies of social educators being in partner roles and bridge builder roles will help Radha to have a meaningful life by facilitating proper guidance and relief for

having full responsibility for her child and at the same time to be employed in a job in accordance with her interest and ability.

According to Flastad og Berg quoted from in Sajjad (2012), being new in Norway, involved challenges in different areas such as having knowledge of the Norwegian society, network, language etc. Moreover, they also have additional problems for having refugee backgrounds due to war and exile which increased the burden of immigrant families.

As it was mentioned in the result chapter of the study about Pakistani families with disabled children it was found out that communication was the general problem such as lack of communication skills and good methods of interaction among healthcare workers. Language problems, culture differences and beliefs were the mentioned barriers for establishing a good communication among Pakistani immigrants (Sørheim 2000). To deal with this challenges experience by these immigrant families can social educator apply their competency on using problem solving model (VerA) & partner role by gathering necessary information through conversation like asking about their biggest challenges, how they are doing after moving to the new country, experience in war, how these families culture, language affect their daily life and also how's their collaboration with healthcare worker is.

The competency of social educators in systematic observation and registration methods, it might be possible to capture the contributing factors which affect good communication with the healthcare worker. Moreover, with the use of this method social educators can identify how culture and beliefs can hinder communication. The professional knowledge of social educators will help to analyze all the gathered data with the support of relevant theory which can explain the findings. After charting, analyzing stage social educators can set a specific goal that is attainable and based on the service users' interest and needs (Nordlund, Thronsen & Linde: 2015). For example, a goal of families "to have better communication with the healthcare workers". Justification behind this was for families to acquire more clear and understandable information from the healthcare worker. To attain this goal social educators can set a necessary measure like for example using a competent interpreter or alternative

supplement communication (ASK) (Næss 2015). It is part of the VerA process to assess if these measures attained the service user goals to have better communication among healthcare workers. In using this model, social educator competencies in working directly with these families as a partner role where confidentiality, self-decision and user participation was given priority in the different phases of problem -solving model (VerA).

In general, immigrant families with intellectual disability children have experienced different challenges in terms of beliefs, culture, and language. These findings were found in most of the articles used in this study. Some did not get enough information about where to seek medical help for their children (Sajjad 2012). A social educator in a bridge-builder role (brobyggerollen) plays a vital role in working with these families and other interdisciplinary agencies to help the families to receive the necessary information of where to seek medical help for their children with special needs. It is also a responsibility of social educators being in a partner role (partnerrolle) to redirect these families to the right agencies who can help their children. The knowledge about disability, and how the system and laws regulate it might be a big help for these families to be educated about their children's condition and rights for necessary services.

Due to their culture and beliefs, some families avoided seeking help from professionals due to the belief that having a child with disabilities is a punishment or gift from God and no deep understanding of what intellectual disability is (Sajjad 2012). In this situation, as social educators are in responsibility roles (Brask, Østby & Ødegård 2016). For example, if parents refused to get necessary help for their child due to religious beliefs, and this was harming the child and potentially breaching Norwegian laws, then the social educator could take on a responsibility role and set in place the necessary actions to protect the child like contacting child protective services etc.

Social educators can discuss with parents how best to support children with complex disabilities. Using a partner role (partnerrolle) a social educator can make appointments with the parent and discuss or have conversation about the child's disability, explain the science behind the disease, what is happening in the cells, and other medical explanations in general.

Helping them to understand can be a big help for the child to get all the support needed and for the parents to have someone to lean on.

In the article about "Psychosocial and Cultural Needs of Children with Intellectual Disability and Their Families among the Syrian Refugee Population in Turkey" (Oner et.al., 2020) it was mentioned that the refugees who moved to Turkey had lots of challenges due to language barriers. They had difficulties asking for help or support because of communication problems. Those with disabilities suffered the most from lack of medical attention, as well as issues adjusting to the culture, understanding the rules and contacting medical professionals in their new country of residency. Social educators being in a driver role (pådriverrollen) can stand/defend the rights of these families to acquire the necessary medical attention that due to their culture and language problems these families are not strong enough to speak and stand for their own rights (Brask, Østby and Ødegård 2016).

The competency of social educators in using problem-solving models could be an important tool to provide necessary intervention for the child's condition. Knowledge about the different observation and registration methods applied by social educators can be a big aid to chart the family's situation and child's behavior for further work with the VerA process (problem-solving model) and possible intervention. Indeed, social educator competencies in utilizing the problem-solving method (Vernepleierens arbeidsmodell) plays a key role when analyzing and facilitating different measures and interventions that are modified to the needs and interest of the service users (Nordlund, Thronsen og Linde: 2015). Through these models, social educators can identify the needs of the users by using the systematic observation and registering methods and other charting methods that will be beneficial to come up with goals, measures, and intervention to be implemented.

Moreover, according to Skau's (2017) competence triangle is important, where one profession should possess the following three competencies. Theoretical knowledge, personal competence and professional skills, these professional competencies help the social educator to be secure and qualified in giving services to these mentioned groups. As social educators being in partner roles, they are expected to have empathy, acknowledgement of

the services users and needs, and have good verbal and nonverbal skills. Furthermore, it is also necessary that social educators have good interpersonal relationships working with the service user, families, and interdisciplinary team where building trust plays an important role. Collaborating with the different professionals and agencies, such as school, social services, national insurance office, and different public health-care units was shown in the study of "Experiences of immigrant parents in Sweden participating in a community assessment and intervention program for preschool children with autism" (Nilses et.,at., 2019). Parents expressed their positive feedback in working with the interdisciplinary team where they were completely heard, got easy contact and had consistently meeting with the same specialist in terms of personal experience in their child diagnosis through the whole assessment and intervention (Nilses et.,at., 2019).

Furthermore, language plays a big role in how these immigrant families can acquire information on how they can ask for help for their children with special needs. All literature and articles revealed that language can be very challenging for how these families can express their struggles having a child with special needs. It can depend on how good they are at communicating using the acquired language of the foreign country (Früh et. al 2016). For example, immigrants here in Norway vary on how long they have lived in the country and how well they can speak the Norwegian language. There might be those families who can speak very well in Norwegian and can express themselves and communicate well with the different social health agencies (Berg 2014). Those might get better and higher quality services compared to those families who can't speak the language well. The use of competent interpreters can be a good medium to help these families with poor Norwegian language skills, but there might also be a challenge with how competent the interpreter is (Sajjad 2012). As a social educator it is important to avoid using the family's children to interpret. It is the interpreter's duty to establish communication between the two parties who do not understand the same language. Children cannot bear all the responsibilities for this. In addition, due to the child's knowledge, not all information may be exchanged. It might be recommended that a competent translator is present to support and to resolve the language barriers.

Social educators are expected to be effective communicators with strong interpersonal skills in collaboration with interdisciplinary partners and communities. They also have competencies in leadership and organizing services which require them to solve the difficulties in the health and social sectors where interdisciplinary and interprofessional teamwork play a vital role (Ålmås et.al. 2018). Social educator skills in good communication can also be used to address the challenges in language of these immigrant families. Knowledge about verbal and nonverbal communication and use of other forms of communication will be a helping tool to minimize the language barriers (Eide og Eide 2017). This competency is required to effectively interact with service users, families, and other occupational groups.

According to Lorentzen (2013) numerous children with neurological impairment, genetic syndromes, and disabilities find it hard to learn and understand verbal language. It is critical to establish effective communication, and possibly even more critical in the case of children with disabilities to discover techniques to communicate, not only with their parents, but also with social educators and other health care providers. In this regard, competencies of the social educator can play a very important role, for example in providing training in the use of alternative supplementary communication tools. Social educators also have specialized knowledge in environmental work (miljøarbeid), which is necessary as a professional approach to altering both environmental factors and individual requirements in order to improve the user's capacity to cope with their everyday circumstances (Fagplan 2016-2017).

8.0 Conclusion

The present thesis aimed to answer the problem statement: How can the competencies of social educators be used to help immigrant families with children with intellectual developmental disabilities?

Social educators meet people from various backgrounds, with different languages and cultures. As a result, it's critical that social educators have broad knowledge and awareness of these people. Acknowledgement, understanding, acceptance and respect are important for establishing a connection between a social educator and immigrant families. A social educator is expected to have competencies in healthcare (FO, 2017). This implies that being

a social educator, one should have a deeper knowledge and understanding about the term intellectual disabilities, levels, diagnosis and what kind of intervention can be provided. Knowing the challenges experienced by these immigrant families in accessing the healthcare service for their children with intellectual needs, the social educator competencies on four core roles- model of reflection and problem-solving model (VerA) plays a big role to help these immigrant families to address the identified challenges in this study. To have a set of core values and competency in career roles are also essential when making a good decision in a complex working situation (Brask, Østby and Ødegård 2016). Being a social educator, meeting different types of service users such people with physical and cognitive disability, elderly people with dementia and children with challenging behavior just to name a few of it. Here social educators wear different masks based on their roles as partner, responsibility, bridge builder and drivers, where they can be competent and flexible enough to move between these roles and make decisions based on the situation they are dealing with (Brask, Østby and Ødegård 2016).

According to Eide og Eide (2017) communication means to do something in common where exchanging of verbal and nonverbal cues and signals between two or more individuals occur. Having good communication skills is essential for quality and the safety of the patient. Effective communication skills allow us to understand the patient as a person, to give better care and support and also to make the right choice together. Active listening and clear communication are essential for avoiding making poor decisions and receiving wrong treatment (Eide og Eide 2017). In working with people with different cultural backgrounds and other languages, communication might be extra challenging for social educators. Therefore, social educator competency on communication plays a vital role in providing necessary help for immigrant families with intellectual developmental disability children. It is necessary that social educators have an understanding or knowledge of certain issues related to how these families understand the child's disability out of their culture and beliefs. This could be done through preparing beforehand, for example reading about the immigrant's culture, providing an interpreter if required to have a better understanding of the situation of these families.

From the perspective of the study, it's important to recruit employees from diverse ethnic backgrounds who have a better understanding of immigrant families. Furthermore, social educators should engage parents in a discussion as to which values are necessary in child upbringing in Norway, as well as which values may be carried from the culture and traditions of the homeland. Knowledge about different judicial laws is also expected of a social educator. It is said that the social educator profession should have a competence in delivering services that are professionally, ethically and law bound (Nordlund, Thronsen & Linde 2015). Indeed, according to Viken (2018), it is essential that social educators can facilitate that target groups can participate and to be included in the society to promote the sense of belongingness. As a social educator, knowledge about legislations and laws is important. By being knowledgeable about the law, wherein they can fight for the rights of users who are unable to do it themselves (Viken 2018).

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Appendix 1

Table 1: PICO FORMAT

P: Population/patient/problem	Immigrant families with children with Intellectual developmental disabilities
I: Intervention	competencies of social educators
C: Comparison	Not related
O: Outcome	Aid /help

Appendix 2

Table 2: SEARCH ENGINE FORMAT

Search	Search strategy	Hit	Potential relevant	Included
Oria				
	Innvandr*AND Funksjonshem*	165	9	
	Innvandr*AND Funksjonshem*AND barn	109	7	
	Innvandr*AND Funksjonshem*AND barn AND tjenesteappa*	10	5	3

Search	Search strategy	Hit	Potential relevant	Included
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Oria				
	Children* OR disability* OG minority* OR refugee*	338 146	(Not assess due to high number of hits)	
	Children* OR disability* OG minority* OR refugee* OG intellectual* AND needs* AND cultur*	956	(Not assess due to high number of hits)	
	Children* OR disability* OG minority* OR refugee* OG intellectual* AND needs* AND cultur* OG developmental	453	6	
	Children* OR disability* OG minority* OR refugee* OG intellectual* AND needs* AND cultur* OG developmental AND famili*	232	4	1

Search	Search strategy	Hit	Potential relevant	Included
Oria				

Immigrant* AND intellectual disability OG experiences	9262	(Not assess due to high number of hits)	
Immigrant* AND intellectual disability OG experiences OG family* AND children*	3149	(Not assess due to high number of hits)	
Immigrant* AND intellectual disability OG experiences OG family* AND children* OG participating* AND community* AND knowledge*	716	(Not assess due to high number of hits)	
Immigrant* AND intellectual disability OG experiences OG family* AND children* OG participating* AND community* AND knowledge* OG culture AND parent AND shock	49	6	1

Appendix 3

Table 3: List of all included literature

References used in the "Result" chapter 6:	Method of
	discovery

Articles	Nilses, Jingrot, M., Linnsand, P., Gillberg, C., & Nygren, G. (2019). Experiences Of Immigrant Parents In Sweden Participating In A Community Assessment And Intervention Program For Preschool Children With Autism. Neuropsychiatric Disease and Treatment, 15, 3397–3410	Search in Oria
	Oner, O., A. K Kahilogullari, B. Acarlar, A. Malaj, and E. Alatas. "Psychosocial and Cultural Needs of Children with Intellectual Disability and Their Families among the Syrian Refugee Population in Turkey." Journal of Intellectual Disability Research 64, no. 8 (2020): 644-56.	Search in Oria
	Früh,Elena Albertini Hilde <u>Lidén</u> , Ragnhild Gardsjord, Petra Aden, & Lisabeth Gravdal Kvarme. <i>"Innvandrerfamilier med</i> <i>barn med spesielle behov-mødres tilknytning til arbeidslivet"</i> Published: 22.september 2016	Search in Oria
Book	Berg, Berit. Innvandring Og Funksjonshemming: Minoritetsfamilier I Møte Med Tjenesteapparatet. Oslo: Universitetsforlag, 2012.	Search in Oria
	Sørheim, Torunn Arntsen. 2000. Innvandrere med funksjonshemmede barn i møte med tjenesteapparatet. Gyldendal Norsk Forlag AS.	Search in Oria
Article	Sajjad, Torunn Arntsen. 2012. "Innvandrere og barn av innvandrere med utviklingshemning og deres familier. En kunnskapsoppsummering". 8. November, 2012.	Search in Google