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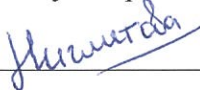
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Hermetova

Date: 28 June 2019

**Exploring the Role of NGOs in Empowering Parents of Children with Disability in
Kazakhstan**

Saida Issakhanova

Submitted in partial fulfillment of the requirements for the degree of

Master of Science

in

Educational Leadership

Nazarbayev University Graduate School of Education

June, 2019

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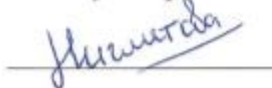
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Signed: Камметова

Date: 28 June 2019

Ethical Approval

Ethics decision Inbox x



GSE Research committee <gse_researchcommittee@nu.edu.kz>

Feb 4, 2019, 2:52 PM



to me ▾

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Thank you very much!

Saida Issakhanova

June 2019

**Exploring the Role of NGOs in Empowering Parents of Children with Disability in
Kazakhstan**

Abstract

Parents play a vital role in the lives of their children. Their role expands when it comes to children with disabilities. This is because parents are an essential element in ensuring that the services and relevant quality education for their children are provided which were mandated by the Law of the Republic of Kazakhstan (Chapter 6, Article 31).¹ The present research study explores the role of NGOs in empowering parents of children with Down Syndrome in Kazakhstan. Parents of children with Down Syndrome in Kazakhstan who participated in parent empowerment programs and NGO representatives were interviewed in relation to six components of parent empowerment model by Kim and Bryan (2017). This research study employed a qualitative approach by interviewing seven respondents of parent organizations (NGOs) about the role of NGOs in empowering parents of children with disabilities and parents' perception of NGO programs. The findings show that NGOs play an essential role in parent empowerment. However, these parent organizations empower parent of CWD only on the personal level but not on the public level of empowerment. Specifically, these NGOs help parents to overcome the barriers like stress, child's diagnosis, self-distrust, discovering yourself from the new side but not from the legislative side.

Key words: NGO, parent empowerment, children with disability, parent organization

¹ http://adilet.zan.kz/eng/docs/Z020000345_

**Изучение роли НПО в расширении прав и возможностей родителей детей с
ограниченными возможностями в Казахстане**

Аннотация

Родители играют жизненно важную роль в жизни их детей, и их роль особенно возрастает, когда речь идет о детях с ограниченными возможностями, поскольку родители являются важным элементом обеспечения предоставления услуг и соответствующего качественного образования для их детей, которые были предусмотрены законом Республики Казахстан (глава 6, статья 31). Данное исследование посвящено изучению роли НПО в расширении прав и возможностей родителей детей с синдромом Дауна в Казахстане. Родители детей с синдромом Дауна, которые участвовали в программах по расширению прав и возможностей, и представители НПО были опрошены в отношении шести компонентов модели расширения прав и возможностей родителей (Ким и Брайан, 2017). В этом исследовании использовался качественный подход путем опроса семи респондентов родительских организаций (НПО) о роли НПО в расширении прав и возможностей родителей детей с ограниченными возможностями и восприятии родителями программ НПО. Результаты показывали, что НПО играют важную роль в расширении прав и возможностей родителей. Однако опрошенные организации расширяют возможности родителей только на их личном уровне, т.е. эти НПО помогают родителям преодолеть такие барьеры, как стресс, диагноз ребенка, неуверенность в себе, раскрытие себя с новой стороны, но не с законодательной стороны.

Ключевые слова: НПО, расширение прав и возможностей родителей, дети с ограниченными возможностями, родительская организация

**Қазақстандағы Үкіметтік емес ұйымдардың (ҮЕҰ) мүмкіндігі шектеулі
балалардың ата-аналарының құқықтары мен мүмкіндіктерін кеңейтудегі рөлін
зерттеу**

Аңдатпасы

Ата-ана баласының өмірінде өмірлік маңызды рөл атқарады. Олардың рөлі, әсіресе, мүмкіндігі шектеулі балалар туралы сөз қозғағанда ерекше артып отырады. Өйткені, ата-ана Қазақстан Республикасы заңында (6-тарау, 31-ші бабында) қарастырылғандай, өз балаларына сапалы тиісті білім және қызметтер көрсетілуін қамтамасыз етуде басты элемент болып табылады. Аталмыш зерттеу жұмысы Қазақстандағы Үкіметтік емес ұйымдардың (ҮЕҰ) Даун синдромымен ауыратын балалардың ата-аналарының құқықтары мен мүмкіндіктерін кеңейтудегі рөлін зерттеуге арналған. Қазақстандағы құқықтары мен мүмкіндіктерін кеңейту бойынша бағдарламаларға қатысқан балалары Даун синдромымен ауыратын ата-аналар мен ҮЕҰ өкілдері ата-аналардың құқықтары мен мүмкіндіктерін кеңейту модельдерінің алты компонентері тұрғысынан сауалдамадан өтті (Ким және Брайан, 2017). Бұл зерттеу жұмысында ҮЕҰ ата-аналар ұйымдарының жеті респондентінен мүгедек балалардың ата-анасының құқықтары мен мүмкіндіктерін кеңейтудегі және ҮЕҰ бағдарламаларын ата-аналар тарапынан қабылдауындағы ҮЕҰ-ның рөлі туралы сауалдама жүргізу арқылы тиімді тәсіл қолданылды. Нәтижелер ҮЕҰ ата-аналар құқықтары мен мүмкіндіктерін кеңейтуде басты рөл атқаратынын көрсетті. Сонымен қатар, осы ата-аналар ұйымдары ата-аналардың мүмкіндіктерін жеке тұрғысында ғана емес, жалпыға қолжетімді деңгейде

кеңейтіп отыр. Атап айтқанда, осы ҮЕҰ ата-аналарға күйзелу, бала диагнозы, өз күшіне сенбеушілік сияқты кедергілерден арылып, өзін заңды тұрғыдан емес, жаңа жағынан ашуда көмектеседі.

Түйінді сөздер: ҮЕҰ, ата-ана мүмкіншіліктері мен құқықтарының кеңеюі, мүгедектігі бар балалар, ата-ана ұйымы

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List of Acronyms

NGO – Non-Governmental Organization
CWD – Children with Disabilities
RK – the Republic of Kazakhstan
ASD - Autism Spectrum Disorder
PO – Parent Organization
DS – Down Syndrome
SES – Socio-Economic Status
PMPC - Psychological Medical Pedagogical Committees

**Exploring the Role of NGOs in Empowering Parents of Children with Disability
in Kazakhstan**

Chapter One: Introduction

1.1. The Role of Parent in a disabled child's life

Parents play a crucial role in the lives of their children, and the importance of their role is different, especially if they have a child with a disability. Thus, parents of children with disabilities have a prior role as caregivers because the first problem that parents face after learning about diagnosis and disability is an issue with their child's health.

When having a child with a disability, parents have constant challenges on the physical, financial, family and social levels. On the physical level, parents equip and accommodate their children with medical care, transportation and facilities. On the financial level, parents may have a crisis in terms of finance. There can be two reasons for that firstly, parents spend much money on medical examinations and medicines for the child, or the parent is not able to work due to caring for the disabled child. On the family level, all family members who live with a disabled child may experience problems in their relationships since the child with a disability needs a special treatment which requires specialized and additional attention (Turnbull et al., 1986, as cited in Itzhaky & Schwartz, 2001, p. 22). Finally, parents' lives change entirely on the social level, when firstly, due to looking after disabled child they do not have free time for socialization, secondly, parents' community might refuse the disabled child because he/she is different, and lastly, the parents fear that embarrassment may affect

their child adversely (McCubbin et al., 1983, as cited in Itzhaky & Schwartz, 2001, p. 22).

Hence, by facing these kinds of challenges after having a child with a disability in the family, parents try to reach a 'normal' life for all family members (Itzhaky & Schwartz, 2001, pp. 21-36; MacDonald & Gibson, 2010, pp. 242-248).

Besides, the parent is the only person who can demand proper service delivery and equal education quality for their disabled children as mandated by the Law of the Republic of Kazakhstan (Chapter 6, Article 31).² Also, parents play a role as an advocate who defends the rights of their CWD in terms of medical, social and academic growth and development. However, sometimes parents take on too active a role in taking care of their disabled children by giving too much attention, not giving them the chance to make a choice or not allowing them to learn from their mistakes (Turnbull & Turnbull, 1988, as cited in Itzhaky & Schwartz, 2001, pp. 22-23; Blacher & Baker, 1992, as cited in Itzhaky & Schwartz, 2001, pp. 22-23; Austin, 2000). Hence, to avoid all this, firstly, the government must support and encourage parents of CWD to attend communities and parent organizations that empower parents on their personal and public levels. Secondly, kindergartens, schools, community and government in total should see parents of CWD as a heterogeneous group of individuals, who have different needs, demands, skills, and preferences (Austin, 2000).

² http://adilet.zan.kz/eng/docs/Z020000345_

1.2. Definition and Parent Empowerment

Scholars have revealed that parent empowerment program is a significant instrument for supporting and helping parents of children with disabilities to gain control over their own and their children's lives, to make their voices heard while advocating for the rights of their children, to make choices, and to make decisions (Kim, Bryan & Fletcher, 2017, p. 1).

In this research study, the term 'empowerment' focuses on a specific population, that is, parents of children with disabilities who were empowered by parent organizations (NGOs). Two definitions directly refer to the key issues of this research study. The first states that it is "an intentional, ongoing process centered in the local community, involving mutual respect, critical reflection, caring, and participation, through which people lacking an equal share of valued resources gain greater access to and control over those resources" (Cornell Empowerment Group, 1989, pp. 1-23). The second definition states that empowerment is a "process that increases personal, interpersonal, or political power so that individuals can take action to improve their situations and the situations of their children with disabilities" (Holcomb-McCoy & Bryan, 2010, p. 262). These two definitions suggest that empowerment is a lasting/ongoing process for parents of disabled children through which parent organizations such as NGOs support and give power to parents of CWDs to develop and improve their lives and those of their children on both the personal and public levels. In most cases, NGOs that are launched by an interested group of people to improve the lives of disabled children are the parents of disabled children themselves. These parent organizations that work with parents and empower them, be it on the personal level or the public level are also recognized as empowering organizations (Zimmerman, 2000).

1.3. The Role of NGOs in parent empowerment on the international level

NGOs like parent organizations play a vital role in providing relevant information and resources for both parents and their disabled children (Dowling, 2012). Precisely, NGOs like parent organizations guide parents of CWD in supporting and helping them to get services that were not provided to them at the time when it was needed. Also, these organizations aim to transform parents of CWD from passive receiver to active advocate who fights for his/her rights as a parent of CWD and the rights of his/her disabled child (Heng-hao, 2009, pp. 35-53).

There are a collection of cases that showed a hard work of parent organizations (NGOs) in empowering parents of children with disabilities. The case in Bosnia and Herzegovina and Croatia showed that parent organizations firstly, provide parents of CWD with information about rights and services for their children (Becirevic, 2010, as cited in Dowling, 2012) as well as increasing their social capital and advocacy skills (Dowling, 2012).

The second case in Taiwan highlights the work of parent organization in empowering Taiwanese women of intellectually disabled children. The key issues that emerged from this specific case were that after participating and finishing parent empowerment program mothers of intellectually disabled children construct new identities by increasing their social status and became an active advocate for their children (Heng-hao, 2009, pp. 34-59).

The third case in Dadaab was also focused on empowering women but specifically refugee mothers of disabled children. The findings of this research study showed that parent organization helped, supported and empowered refugee mothers of CWD by increasing their awareness of importance in involvement in their children's treatment and well-being, as well

as acquiring skills and knowledge in protecting their and their disabled children's rights (Krupar, 2016, pp. 105-121).

In general, these three case studies show how different parent organizations on their goals and focus when empowering parents of children with disability. However, it cannot be denied that all three parent organizations empower parents of CWD not only on the public level but also on the personal level. The following cases describe the work of NGOs (parent organizations) on the national level precisely in Kazakhstani context.

1.4. History of NGOs in Kazakhstan

Since gaining independence in 1991, Kazakhstan has undergone crucial stages in economic, political, educational and social development, including the growth of the NGO sector (Kabdiyeva, 2013, pp. 299-305; Kabdiyeva, 2015, pp. 159-169). The development of the NGO sector was mainly funded by international organizations from Western Europe and the United States (Diachenko, 2008, pp. 44-56; Kabdiyeva, 2013, pp. 299-305; Kabdiyeva, 2015, pp. 159-169; Pierobon, 2016, pp. 203-226).

Since independence until the dates listed below, the development of Kazakhstani NGO sector has gotten through four main stages.

Stage 1 (the late 1980s- 1993) – is marked as the end of the Soviet Union until the Independence of Kazakhstan, where 400 human rights NGOs were created (Makhmutova and Akhmetova, 2011; Nowicki, 2000, as cited in Kabdiyeva, 2015, pp. 161-166).

Stage 2 (1994-1997) – can be distinguished by the support of International NGOs to the local by raising their professional development in administration and management. Thus, the number of registered NGOs reached 1600 (Diachenko, 2008, pp. 44-56; Kabdiyeva, 2013, pp. 299-305; Kabdiyeva & Dixon, 2014, pp. 32-33; Kabdiyeva, 2015, pp. 160-161).

Stage 3 (1998-2002) – marked as firstly, the number of registered NGOs decreased due to political and financial instability in the country (Diachenko, 2008, pp. 44-56; Kabdiyeva, 2013, pp. 299-305; Kabdiyeva, 2015, pp. 160-162). Secondly, in 2002, the President of the Republic of Kazakhstan Nursultan Nazarbayev implemented the “Concept on State Support for NGOs” (ABD, 2007).

Stage 4 (2003 – to the present) – marked as a formal and active partnership of the NGO sector with the government. There were also implemented four main laws related to the improvement and sustainability of the NGO sector. In addition, during this period five “Civic Forums” were held to encourage partnership between the state and the NGO sector and the NGO sector with foreign organizations (Diachenko, 2008, pp. 44-56; Kabdiyeva, 2013, pp. 299-305; Kabdiyeva & Dixon, 2014, pp. 33-34; Kabdiyeva, 2015, pp. 160-162; Pierobon, 2016, pp. 206-215).

1.5. The Role of NGOs in parent empowerment on the national level

With the introduction of inclusive education in Kazakhstan, the ideology of “stigmatization” in society is lightly changing to “normalization”. The ideology of “normalization” has given children with disabilities the opportunity to study with general education students in mainstream schools (Itzhaky & Schwartz, 2001, pp. 21-25; MacDonald

& Gibson, 2010, pp. 242-249). However, “normalization” does not only relate to children with disabilities but also their parents in order to change parents’ view of “stigmatization” to “normalcy”. Thus, today, the government encourages parents to participate in parent organizations which empower parents on their personal and public levels (Austin, 2000). Parents of children with disabilities mostly lead these parent organizations (Mayrowetz & Weinstein, 1999; Hess, Molina, & Kozleski, 2006, as cited in Rollan & Somerton, 2019, pp. 3-5). The main goal of these organizations is to monitor and participate in law configurations and give feedback on decisions of higher authority in favour of disabled children’s rights.

There is not much literature on NGOs that work intensively on empowering parents of children with disability in Kazakhstan since the main number of parent organizations in Kazakhstan specialize more on the development of children with disabilities. Nevertheless, there were found two notable research cases regarding the work of NGOs in keeping track of policies in regards to the rights of CWDs and in empowering parents of CWDs. The first one is the research study by Markova and Sultanalieva (2013) involving the work of parent organization “Ashyk Alem” (“Open World”) on legislation, teachers’ professional development in inclusive education, parents’ awareness of Inclusion and children’s rights (Markova & Sultanalieva, 2013, pp. 51-82). The key issues that emerged from this research study are that NGO representatives advocate for the educational and social Inclusion of children with Autism Spectrum Disorder (hereafter ASD). The second research study by Rollan and Somerton (2019) was related to the role of NGOs from the bottom-up through political, practical, and cultural realms. Thus, the key findings of both research studies revealed that Inclusive education reforms in Kazakhstan are not entirely top-down since NGOs play an active role in monitoring and revising reforms, and ensuring their proper

implementation (Rollan & Somerton, 2019, pp. 1-16; Markova & Sultanalieva, 2013, pp. 51-82). In addition, NGO works on legislative changes but does not empower parents of CWD on the public level (Markova & Sultanalieva, 2013, pp. 51-82).

In comparison with NGOs internationally, where NGOs in different countries empower parents of disabled children not only on the personal level but also empower them on the public level where they parents increase their self-esteem and self-confidence and are able to advocate for the rights of their CWD and advocate for policy formation and policy implementation.

1.6. Problem Statement, Purpose of the Research Study and Research Question

It is a common discourse not only in Kazakhstan but in the whole world that parents of children with disability have a primary and active role in their children's lives. Specifically, this occurs in decision making, in service delivery, in receiving equal rights and equal and appropriate education. Thus, the role of parents of disabled children has grown not only on their personal level of empowerment which means dealing with emotional and social issues that emerged with the child's disability but also on their public level that is being able to defend the rights and speak out on behalf of the child (Itzhaky & Schwartz, 2001, pp. 22-25). However, the difficulties that each parent of a child with disability faces every day and their demands for the rights that were mandated by the Law of the Republic of Kazakhstan pushed parents to launch parent organizations (NGO) to support and empower other parents of children with disabilities who are in need of their help (Itzhaky & Schwartz, 2001, pp. 22-34).

The purpose of this study is to investigate these key issues emerging from the literature and the extent to which it applies within the Kazakhstani context. The researcher intends to look at the role of NGOs in parent empowerment of children with disabilities in two urban cities of Kazakhstan, Nur-Sultan and Almaty. The present research study aims to answer a central research question:

“What is the role of NGOs in empowering parents of children with disability in two urban cities of Kazakhstan, Nur-Sultan and Almaty?”

1.7. Framework of Analyzing the Role of NGOs in empowering parents of children with disability

In order to understand and to assess the role of NGOs in empowering parents of children with disability in Kazakhstan, a conceptual framework provided by Kim and Bryan (2017) was chosen. This framework known as Parent Empowerment Model was developed by Kim and Bryan (2017) as a research-based tool explicitly chosen to analyze the role and impact of NGOs' empowering programs on parents of children with disability in Kazakhstan. This framework has been used in the research study concerning parent empowerment (Itzhaky & Schwartz, 2001, pp. 21-36; Nachshen, 2005, pp. 67-76; Holcomb-McCoy & Bryan, 2010, pp. 259-268; Bloomfield & Kendall, 2012, pp. 364-372). The Parent Empowerment Model (2017) consists of six components, which are consciousness, sense of meaning, self-determination, competence, community participation and community belonging. The first component of 'consciousness' refers to the influence of ethnicity, gender or language on the

parental level of empowerment, and how it affects parents' and their children's lives. The second component of 'sense of meaning' refers to parents' beliefs of meaningful involvement in their disabled children's treatment, education and well-being as well. The third component of 'self-determination' refers to taking control of their own and children's lives and parents' advocacy for the rights of their children. The fourth component of 'competence' refers to parents of CWD who have completed parent empowerment programs and also related to parents' confidence while expressing themselves and advocating for the rights of their children. The fifth component of 'community belonging' refers to parents' sense of belonging to the school or any other community where they can develop and improve their sense of empowerment. Finally, the last component of 'community participation' refers to parents' activities to change or influence decisions of higher authorities in favour of their disabled children's rights (Kim & Bryan, 2017, pp. 168-179).

In order to form a holistic understanding of the role of NGOs and how they empower parents of children with disability in Kazakhstan and to answer the research question, this conceptual framework was applied throughout the research study.

1.8. Significance of the Research Study

Parent involvement implies parent empowerment and parent participation in their children's lives. Touching on the topic of disabled children, the meaning of parent involvement expands. That is when parents are confident enough to make decisions, to protect the rights, to talk on behalf of their disabled children to governing authorities, to change and to force legislation for the well-being of their disabled children. Firstly, this particular research

study is essential to parental organizations to learn about how well their programs empower parents of children with disabilities on six component of parent empowerment model (Kim & Bryan, 2017, pp. 168-179). Secondly, it will shed light on the parents' perceptions of their role of being a parent of a disabled child, parents' perceptions of education for their children in Kazakhstan and parents' perceptions of NGO programs. Thirdly, this research study contributes to enhancing academic knowledge concerning parental organizations in empowering parents of children with disabilities in Kazakhstan. Finally, it will provide insight into how NGOs are currently working in empowering parents in Kazakhstan highlight key challenges that need to be addressed both from an organizational and policy level.

1.9. Outline of the Thesis

The particular thesis consists of five chapters, precisely the literature review, methodology, findings and discussion, and conclusion chapters, and followed by references and appendices.

The first chapter, "Introduction", introduced the background information for the study followed by problem statement, purpose and research question as well as the significance of the research study.

The second chapter, "Literature review" covers the role of a parent in disabled child's life, the history of the NGOs in Kazakhstan, the role of NGOs in Parent Empowerment on the international and national levels, and the Theoretical Framework: Parent Empowerment model.

The third, “Methodology” chapter presents the research design, participants, research sites, data collection procedures and data analysis as well as ethics.

The fourth, “Data findings and Discussion” chapter presents the findings of the study and discussion by connecting research findings with the theoretical framework and reviewed literature. Thus, this chapter will shed light on interviewed NGOs’ background information, the role of two interviewed NGOs in empowering parents of CWD, parents’ reaction to their child’s diagnosis and the themes that emerged and were related to six components of parent empowerment model by Kim and Bryan (2017).

The final chapter, “Recommendations and conclusion”, highlights the key research findings and gives recommendations for a further research study.

Chapter Two: Literature Review

2.1. Introduction

The previous chapter introduced the problem statement, purpose and research question of the current study, including the framework of analyzing the role of NGOs in parent empowerment and the significance of the study. Besides, the brief introduction of parent empowerment, the history of NGOs in Kazakhstan, the role of NGOs in parent empowerment on the national and international levels was given. This chapter discusses a review of the literature relevant to the research topic. The first section covers the establishment of the NGO sector and the role of a parent in a disabled child's life. The second section comprises the role of NGOs in parent empowerment in Kazakhstan and globally. The chapter concludes with the definition of empowerment, what empowerment means according to different sources, followed by six components of parent empowerment model by Bryan and Kim (2017).

Little is impossible for a dedicated parent: nothing is impossible for parents who are united (Markova & Sultanalieva, 2013).

2.2. The Role of Parent in a Disabled Child's life

When parents learn about their child's diagnosis and disability, they also discover that their lives will never be the same as it was before. Firstly, they always feel and think that they

are not fully equipped with information. Secondly, they feel that the responsibilities and daily care for their CWD will always make them overwhelmed (Austin, 2000).

Parents have a central role in their children's lives no matter how old they are (Wikler, Wasow & Hatfield, 1981, as cited in Itzhaky & Schwartz, 2001, p. 22). Especially considering parents of children with disabilities, the magnitude of their roles and responsibilities can be overwhelming at times. The parent is the only person whose principal role is to ensure that his/her disabled child receives proper and equal education and services as mandated by the Law of the Republic of Kazakhstan (Chapter 6, Article 31).³ Unfortunately, not all parents are able or confident enough to advocate for the rights of their CWDs in terms of social, academic and vocational progress.

The role of parents is also crucial in the transition process when parents are mastering a new role as a compromiser with family, services, school, and community. Transitional processes like going to school and then from school to university or adult life is not an easy process for parents and their children. Thus, in this domain, parents make a significant contribution in sharing information about their children to school and community. It is grounded in the belief that parents know best and can provide full information about their children's disability, strengths, weaknesses, needs and preferences, interests and likes (Baer, McMahan, & Flexer, 1999, as cited in Austin, 2000). Parents make a considerable contribution to their disabled children's lives and help them to set goals for their future by ensuring all favourable circumstances to accomplish them (Austin, 2000). Besides, they create favourable conditions for their children to help instill life skills and then assist their children when they

try to take on adult roles, duties and responsibilities. Wehman (1990) suggested that parents firstly, need to teach and enable their disabled children to make choices for themselves and their lives. Secondly, schools and committees need to give an opportunity for disabled children to take part in decision making concerning school society (Wehman, 1990, as cited in Austin, 2000). However, usually, parents take an active role in their disabled children's lives by giving their children too much care, babying them and by not giving them a chance to learn from their mistakes (Turnbull & Turnbull, 1988, as cited in Itzhaky & Schwartz, 2001, p. 22; Blacher & Baker, 1992, as cited in Itzhaky & Schwartz, 2001, p. 22; Austin, 2000). A possible solution could be, firstly, the government needs to support parents by encouraging them to attend committees and parent groups which empower parents as advocates for their children. Secondly, school, community and government authorities should not see parents of children with disabilities as a homogenous group, which means as those who have the same needs, demands, difficulties, preferences, and competences. On the contrary, they must perceive them as a heterogeneous group of individuals (Austin, 2000).

2.3. The Role of NGOs in parent empowerment globally

One of the main stakeholders and one of the most important voices in ensuring the implementation of inclusive education and equal rights of disabled children has always been NGOs (parent organizations). NGOs like parent organizations from all over the world play a leading role in raising an issue about disabled children's rights (Heng-hao, 2009, pp. 34-59).

³ http://adilet.zan.kz/eng/docs/Z020000345_

For instance, the findings of the study in Bosnia and Croatia, firstly, have shown that these parent organizations were viewed as a primary source of information (Dowling, 2012, pp. 1-37). Secondly, all interviewed parents were satisfied with the role of parents' organizations in relation to care and advocacy. Thirdly, the findings also indicated that most parent organizations in Bosnia and Croatia were established by parents of children with disability with the main aim is to enhance parent activism by empowering parents to strengthen their voices to advocate for their children's rights for health, education and social care (Becirevic, 2010, as cited in Dowling, 2012, pp. 2-6).

Moreover, the main goal of interviewed parents while advocating was mainly for the socialization of their children rather than for proper and quality education in mainstream schools. Finally, organizations in Croatia and Bosnia strongly believed that parent organizations need to empower parents of children with disability by raising their awareness and skills on policy formation and legislation, in the way that parents will be able to advocate for the rights of their children (Dowling, 2012). This example suggests that NGOs in Bosnia and Croatia engage in six components of parent empowerment model described by Kim and Bryan (2017): consciousness, sense of meaning, self-determination, competence, community participation and community belonging.

Another case in Dadaab was about parent organization, which was mainly focused on refugee women. Their main aim was to empower women by using trainings where women acquire necessary skills and knowledge and become active agents in protecting their own and their disabled children's rights as well as engaging vulnerable women of Dadaab with their community (Foster, 1995; Dudley-Marling, 2001, as cited in Krupar, 2016, pp. 106-117). By empowering women in Dadaab, the findings revealed women's ability to advocate for the

rights and successful enrollment of their disabled children into mainstream school. This study highlights the work of NGO in Dadaab in engaging women (parents) in consciousness-raising of their children's diagnoses and rights, facilitating these women's competence and advocacy skills development, supporting women as leaders and finally, connecting them to their communities (Kim & Bryan, 2017, pp. 168-179).

The third case in Taiwan demonstrates how participation in parents' organizations empowers parents, especially mothers of disabled children, to engage and participate in their community and to become active agents for their children's disability rights. After completing parent empowerment programs, mothers of intellectually disabled children increased their self-esteem and recognition from family members and as a result started actively participate in advocating the rights of disabled children (Heng-hao, 2009, pp. 34-59).

These three cases have identified an essential element - that NGOs (parent organizations) are one of the main driving force for the implementation of Inclusive education and supporting and empowering parents of children with disability (Dowling, 2012).

2.4. The History of NGO sector in Kazakhstan

Since independence in 1991, Kazakhstan has gotten through momentous steps in political, economic and social development as well as increasing growth in the NGO sector especially in those which engage in service delivery, social improvement and development, health care, education, human rights, environment, and support for people with disabilities (Kabdiyeva, 2015, pp. 159-169). This rapid growth was funded financially primarily at the beginning of the country's development by international organizations and agencies, mostly

from the United States and Western Europe (Diachenko, 2008, pp. 44-56; Kabdiyeva, 2015, pp. 159-169; Pierobon, 2016, pp. 203-226).

2.4.1. Four stages of NGO sector development in Kazakhstan

Stage 1 (late 1980s-1993). This period can be marked as the end of the Soviet Union until the independence of Kazakhstan (Makhmutova and Akhmetova, 2011; Nowicki, 2000, as cited in Kabdiyeva, 2015, pp. 161-166). Within this period, approximately 400 NGOs were created that were engaged in human rights. Thus, one of the first human rights groups which were created and developed in the country were ecological groups.

Stage 2 (1994-1997). This period was marked as an expansion of the NGO sector as a result of new legislation which regulated all the activities of public organizations. During this period of three years, the number of registered NGOs reached 1600 (Diachenko, 2008, pp. 44-56). Also, this period can be distinguished by the support of international NGOs to the local NGOs, by providing grants and conducting training for NGO leaders and representatives in the administration and management of the NGO sector (Diachenko, 2008, pp. 44-56; Kabdiyeva & Dixon, 2014, pp. 32-33; Kabdiyeva, 2015, p. 161). However, there were also unregistered organizations whose activities were prohibited by the government (Kabdiyeva & Dixon, 2014, pp. 27-41).

Stage 3 (1998-2002). Three significant events marked this period. The first was strengthening and consolidation of the NGO sector, just as the Asian Society for Rights of Disabled persons “Zhan” and the Kazakhstan NGOs Confederation (Diachenko, 2008, pp. 44-56; Kabdiyeva, 2015, pp. 161-162). Secondly, due to the political instability and financial

issues in the country, the number of registered NGOs decreased significantly. As a consequence of our country's financial instability and the collapse of NGO involvement and support from international organizations, some poorly established/ low-functioning NGOs were closed. Finally, in 2002 the President of the Republic of Kazakhstan Nursultan Nazarbayev implemented the "Concept on State Support for NGOs" with the aim of stable development and enhancement of NGO's role in solving social problems and delivering public service that state organizations could not do as well as provide support for socially significant projects of NGOs (ADB, 2007).

Stage 4 (2003- until now). The end of the third stage and the beginning of the fourth is marked by the formal and active partnership between the state and NGO sector (Diachenko, 2008, pp. 44-56; Kabdiyeva & Dixon, 2014, pp. 33-34). Thus, starting from 2003 to the present four gradual implementations were concerned with the improvement and sustainability of the NGO sector in Kazakhstan. Firstly, in 2005, the state implemented the Law on "The State Social Order" where government implemented NGO social programs that were related to issues with social security, health, civil laws, education and culture (Kabdiyeva & Dixon, 2014, pp. 27-41). Later, in January 2006 "The Concept of Civil Society Development for 2006-2011" was adopted to guide Kazakhstan to improve relations between the government and NGO sector by enhancing legislative, social, economic, organizational development of civil society organizations (also called the third sector) (Kabdiyeva & Dixon, 2014, pp. 27-41; Kabdiyeva, 2015, p. 162). Since 2007, the government has reduced the registration fee for NGOs. Afterwards, relying on amendments to Kazakhstan's NGO legislation the role and importance of NGOs have increased (Diachenko, 2008, pp. 44-56; Adams & Garbutt, 2008, as cited in Kabdiyeva & Dixon, 2014, pp. 33-34).

The government is still actively involved in the work of NGOs. Therefore, starting from 2003 (stage 4) there were five “Civic Forums” held in order to encourage and foster relations between local NGOs and foreign organizations, and relations between government and NGOs (Kabdiyeva & Dixon, 2014, pp. 34-36; Kabdiyeva, 2015, pp. 165-166; Pierobon, 2016, pp. 208-209).

2.5. The Role of NGOs in Parent Empowerment in Kazakhstan

In the time of the Soviet Union, there was a universally accepted taboo that children with disabilities needed to be kept apart from their general education peers. Moreover, these children were educated in segregation in other words in correctional schools and kindergartens or educated at home by specialists/special educators like ‘language therapist’ and ‘language pathologist’ (Gevorgianiene & Sumskiene, 2017, as cited in Rollan and Somerton, 2019, pp. 1-2). However, with the independence of the country in 1991, one of the leading forces of changing these bases moved to the reins of non-governmental organizations. The leading NGO stakeholders were mostly parents of children with disability (Mayrowetz & Weinstein, 1999; Hess, Molina, & Kozleski, 2006, as cited in Rollan & Somerton, 2019, pp. 3-5). Thus, one of the main goals of parent-driven NGOs was to keep track of policies and laws and monitor the implementation of these laws in favour of disabled children’s rights.

Consequently, NGOs play an essential role in Inclusion, health care, services, and social justice in the lives of children with disabilities and their parents’ lives. Generally, these kinds of NGOs which were established by a group of parents are more sensitive to the needs and are more equipped with knowledge about the needs and rights of CWD. Also, they

participate in the configuration of legislation and laws and give feedbacks on decisions of higher authority.

There is limited academic literature focusing on NGOs that specialize in empowering parents of children with disability in Kazakhstan. However, there were found two remarkable research studies concerning the work of NGOs in advocating specific amendments in legislation in regards to the rights of CWDs and in empowering parents of CWD. The first is the research study by Markova and Sultanalieva (2013) concerning parental organization ‘Ashyk Alem’ (‘Open World’). By collecting the research data, the researchers found out how significantly the organization contributed to Inclusion. Generally, they work on legislative changes, raising teachers’, educators’ and even parents’ awareness of Inclusive education and children’s rights (Markova & Sultanalieva, 2013, pp. 51-82).

The second research study by Rollan and Somerton (2019) examined the role of NGOs from the bottom-up through the political, practical and cultural realms (Rollan & Somerton, 2019, pp. 1-16). According to their research findings, the inclusive education reforms are not entirely state-driven, that is the NGOs in Kazakhstan highlight their significant role in the development of policy, practice and culture. Regarding policy realm, the finding of the studies by Trainor (2010), Scott, Lubienski, and DeBray-Pelot (2009), and by Rollan and Somerton (2019) demonstrated that NGOs led by parents of children with disabilities are viewed as intuitive advocates who do take part in systemic changes such as policy-making, policy formation, policy revision and policy implementation (Rollan & Somerton, 2019, pp. 1-16; Trainor, 2010, pp. 34-47; Scott, Lubienski, & DeBray-Pelot, 2009, as cited in Rollan & Somerton, 2019, pp. 11-12). Thus, in improvements and development of policy in Inclusion, there should be full cooperation between state and NGOs.

Furthermore, in the area of practice, for system change, NGOs use project-based activities. The main goal of project-based activities is to work directly with those stakeholders who are directly related to Inclusion (Rollan & Somerton, 2019, p. 12). For instance, NGOs invite international and local experts to raise awareness and to empower educators and parents of children no matter whether they have disabilities or not. Sometimes, even parents of CWDs hold lectures and seminars with teachers, school staff and school administration to draw their attention to CWDs and train them how to accommodate CWDs' needs (Trainor, 2010, pp.34-47; Rollan & Somerton, 2019, p. 12). Finally, the research finding on cultural context tells how NGOs be they international or local, raise awareness of society about people with disabilities and how they help mainly parents of CWDs. Thus, generally, NGOs raise awareness of society about a marginalized group of people (CWDs also belong to this group) and about their needs and rights through mass media, that is, printing books, TV channels and websites. They also work with parents of children with and without disabilities by informing them about legislation and explaining to them that from the experience of other parents inclusive education is rather beneficial to all children in the classroom (Rollan & Somerton, 2019, p. 13).

To sum up, the findings of the research study by Rollan and Somerton (2019), show that Inclusive education reforms in Kazakhstan are not entirely top-down, they are actually somewhere in the middle because according to the results NGOs are active participants in revising the reforms, ensuring the implementation of these reforms and also in monitoring the outcomes of implemented reforms. NGOs also work closely with state authorities, educators and parents by informing them about needs, problems and rights of CWDs. As a result, they

work very hard for the benefit of improving Inclusive education in Kazakhstan (Rollan & Somerton, 2019, pp. 1-16).

2.6. Parent Empowerment

2.6.1. Multifunctional role of parents of children with disabilities

Parents of children with disabilities have a crucial role in the treatment and education of their children. The role of these parents expands due to their child's disability, which includes different jobs that the parent needs to know; starting from information seeker at the time when a parent learns the diagnosis of his/her child, these jobs increase as a child grows up. These jobs may swell from information seeker to problem solver, committee member, public educator, political activist, spokesperson. The last one is the most important because a parent speaks regarding the needs and rights on behalf of his/her child who might not be able to advocate or communicate to those who have power to effect change due to age and the nature of the disability (Minnes, Nachshen, & Woodford, 2003, as cited in Nachshen, 2005, p. 67). All these jobs/roles encompass the term parent empowerment. Scientists pointed out that empowerment helps and supports parents of CWD to gain control of their own lives and those of their CWDs, to make their voices heard in decision making, and to advocate for the rights of CWDs (Kim, Fletcher, & Bryan, 2017, pp. 1-9). There is much literature that describes what empowerment is, and to which specific population it refers. In this case, it relates to parents of children with disabilities who are empowered by NGOs.

2.6.2. Definitions of parent empowerment

The definition of *empowerment* that directly refers to the key issues of this research study states that it is “an intentional, ongoing process centered in the local community, involving mutual respect, critical reflection, caring, and participation, through which people lacking an equal share of valued resources gain greater access to and control over those resources” (Cornell Empowerment Group, 1989, pp. 1-23). This definition suggests that empowerment is a lifelong process of parents of CWD where NGOs are a source of information that helps and empowers parents to become an information seeker, a confident advocate, policy changer, public educator, community member, and community helper.

The second definition that directly refers to the research study also states that it is a process that “increases personal, interpersonal, or political power so that individuals (parent of CWD), families, and communities can take action to improve their situations and situations of their children with disabilities” (Holcomb-McCoy & Bryan, 2010, pp. 262-263). It implies that it is a process which gives power to parents of CWD to improve their own lives, the life of their community and society by advocating for the rights. Thus, the role of people/consultants who empower parents in Kazakhstan is NGO representatives. Generally, these NGOs are established by a group of parents who have children with disabilities and whose aim is to give power to other parents of CWDs or help parents to build their own power in order to advocate for the rights of their children or influence those who have power (Holcomb McCoy & Bryan, 2010, pp. 259-268; Markova & Sultanalieva, 2013, pp. 51-82). Parents’ role develops not only on the personal level, where they demand services and education but also on the public level

where they take part in decision making and advocate for policy change to enhance the quality of life of their disabled children (Itzhaky & Schwartz, 2001, pp. 21-25).

2.6.3. The processes and outcomes of parent empowerment

Determining how well or poorly parents are empowered by NGOs could be viewed by the processes and outcomes of empowerment. The processes of empowerment incorporate parent empowerment training, programs, or seminars that help to deliver the right vision and perception of empowerment, and outcomes that encompass the achieved level of empowerment (Zimmerman, 2000, pp. 45-47). Precisely, it is important to ascertain how confident parents become after completing programs, how strongly they build their power in order to advocate for their rights, needs, and improved services for their CWD, how knowledgeable they become about the specific disability of their CWD, and how solidly they gain control of their own lives and those of their CWDs (Zimmerman, 1995, pp. 581-599). Therefore, the more active parents are in their decision-making, the higher their level of empowerment (Itzhaky & Schwartz, 2001, pp. 21-36). The results of a research study conducted by Nachshen (2005) demonstrated that after completing parent empowerment programs parents of CWD showed an increased level of knowledge and self-efficacy. Also determined in a research study by Kendal and Bloomfield (2012) about “Parenting self-efficacy, parenting stress and child behavior before and after a parenting program” was that parent training and programs have a positive effect on a parent’s self-efficacy whereby they felt much better and able to understand and cope with their children’s disability (Itzhaky & Schwartz, 2001, pp. 21-36; Bloomfield & Kendall, 2012, pp. 364-372). Civil society

representatives also reported that those parents who finished the training program became active decision makers, confident agents with service and education representatives, tireless advocates who fight to attain the best quality of life for their CWD and themselves as well (Itzhaky & Schwartz, 2001, p. 23).

With the support of the parent organizations (NGOs) parents increase their self-efficacy and reduce their stress which relates to their children and parents' low level of confidence (Bloomfield & Kendall, 2007, as cited in Bloomfield & Kendall, 2012, pp. 365-369; Bloomfield & Kendall, 2010, as cited in Bloomfield & Kendall, 2012, pp. 365-366). Parental self-efficacy and confidence can be heightened through witnessing other parents' success after completing a program and by receiving encouragement and support from parent empowerment program's representatives, namely NGO initiatives (Bloomfield & Kendall, 2012, pp. 364-372).

A high level of parent competence (self-efficacy) and confidence, empowerment cannot be viewed separately from the advocacy. Concerning this study, parent advocacy includes systematized activities when parents of CWD advocate for the issues that were ignored and neglected, for implementation of new laws, and for creating a positive change in people's attitudes towards their CWD (Holcomb McCoy & Bryan, 2010, p. 263). Koren et al. (1992) reported that the level of parental empowerment could be distinguished between those who participated or were a part of advocacy activities for improvement of their own and their CWD lives and those who did not know what advocacy was or those who did not take part in any advocacy activities (Koren et al., 1992, as cited in Nachshen, 2005, pp. 69-73). Notwithstanding Holcomb McCoy et al.'s stance, the results by Jamieson and Nachshen's (2000) study, affirms that advocacy and empowerment can be viewed separately (Jamieson &

Nachshen, 2000, as cited in Nachshen, 2005, p. 73). In any case, empowerment is an essential component for ensuring the improvement of parents' skills (Zimmerman & Perkins, 1995, pp. 569-579).

2.7. The Conceptual and Theoretical Framework: Parent Empowerment Model

2.7.1. The definition of Parent Empowerment Model

The parent empowerment model by Kim and Bryan (2017) has emerged from the study of the parent empowerment literature (Nachshen, 2005, pp. 67-76; Cornell Empowerment Group, 1989, pp. 1-23; Zimmerman, 1995, pp. 581-599; Zimmerman, 2000, pp. 43-63; Zimmerman & Perkins, 1995, pp. 569-579; Itzhaky & Schwartz, 2001, pp. 21-36; Holcomb-McCoy & Bryan, 2010, pp. 259-268; Bloomfield & Kendall, 2007, 2010, 2012, pp. 364-372). Referring to six components of parent empowerment model by Kim and Bryan (2017), four main elements emerged to describe this model:

(a) Engaging parents in consciousness-raising. The process of consciousness-raising occurs when parents are actively involved in consciousness-raising events and activities; in this way they raise their critical awareness and critical reflection of their culture, history, power, barriers that can influence their lives and lives of their disabled children (Kim, Fletcher, & Bryan, 2017, pp. 2-6; Holcomb-McCoy & Bryan, 2010, pp. 263-266).

(b) Facilitating parents' competence and skill development. This refers to parents' confidence, competence and strong beliefs in their capability to help, support and improve their children's lives (Kim & Bryan, 2017, pp. 168-177; Kim, Fletcher, & Bryan, 2017, p. 5).

(c) Connecting parents to their communities through parent and social networks.

Parents belonging to any community (parent groups, school or neighbourhood communities) correlates with parents' sense of empowerment (Neal & Christens, 2014, as cited in Kim, Fletcher, & Bryan, 2017, pp. 5-7). By being a part of any group or community, parents get access to information, resources as well as support from members of a group/community. Moreover, they become able to solve problems and take collective actions for the improvement of their life and their disabled children's lives (Kim, Fletcher, & Bryan, 2017, pp. 1-9).

(d) Facilitating parents as leaders through organizing groups in the school or in the community. Organizing groups play a critical role in raising in parents their leadership skills. By developing leadership skills, parents become able to solve problems, make decisions and advocate for themselves and on behalf of their disabled children (Alameda-Lawson & Lawson, 2016, as cited in Kim, Fletcher, & Bryan, 2017, p. 6).

2.7.2. The significance of Parent Empowerment Model

NGOs that use parent empowerment model know the significance of communicating with and helping parents of children with disabilities. NGOs understand the strength that can be developed as a result of gathering all information about a disability. Precisely, to be involved in their children's lives, to advocate for the rights, to influence the decisions of those who are in power because these representatives of NGOs passed the same way from knowing nothing to becoming empowered or those who have felt all the difficulties of the disability on their skin. Moreover, they know and understand the importance of helping parents of CWD to

firstly, develop their consciousness of how their ethnicity, gender or language can influence the level of parental empowerment, and how this could affect their children's education and service delivery. As illustrated in a research study by Ordonez-Jasis and Jasis (2012) that parents who belong to an ethnic minority, those who are of lower socio-economic status (hereafter SES) and those who are immigrants are less involved or participatory in their children's schooling (Garcia & Jensen, 2009, as cited in Ordonez-Jasis & Jasis, 2012, p. 67-70; Lai & Vadeboncoeur, 2013, pp. 867–892). Secondly, it is essential for a parent to develop their sense of meaning, so their beliefs of meaningful contribution and involvement in their children's treatment, education or well-being in total. Thirdly, knowing and being able to take control of their own, their children's and family members' lives is significant as well as advocating for their rights and expressing themselves in order to reach self-determination. Fourthly, parental competence is necessary in order to accomplish all the tasks that will make their own and their CWD's lives better. Finally, to gather all the information, knowing how to advocate for the rights and needs, how to make other people hear you or reach those who are in power is impossible without the participation of other parents to achieve mutual goals, namely, community participation and community belonging (Bryan & Kim, 2017, pp. 168-179; Holcomb McCoy & Bryan, 2010, pp. 259-268; Zimmerman, 2012).

The conceptual framework of this study is based on the six components of the parent empowerment model by Kim and Bryan (2017). One of the main goals of the parent empowerment model is to encourage and strengthen parents of CWD in the way that they become active advocates (Connor & Cavendish, 2018, as cited in Hsiao, Higgins, & Diamond, 2018, pp. 45-51).

2.7.3. Parent Empowerment Model: six components

As stated by Rappaport (1984), empowerment is a repeated collective process rather than linear. It implies that six components of a particular parent empowerment model are interconnected and do not stand/exist alone (Rappaport, 1984, pp. 1-7). In this section, the six components of Bryan and Kim's parent empowerment model are described and examined more closely (Kim & Bryan, 2017, pp. 168-179).

Consciousness. When parents find out the diagnosis of their child, the most important thing for them is to accept, understand and focus on the reality of their child's situation. This refers to the consciousness or in other words to parents' ecocultural lens (Bernheimer, Gallimore, & Weisner, 1990; Gibson, 1995; Cen & Aytac, 2017; Valle, 2018, as cited in Hsiao et al., 2018, pp. 44-51). This encompasses parents' awareness of their familial beliefs and values, language, culture, ethnicity, relationships, and goals and how that influences their lives and that of their child (Kim & Bryan, 2017, pp. 168-179). Consciousness defines how parents react to their child's disability. Consequently, at this stage, parents might need help and support from professionals. However, in Kazakhstan, this kind of support is carried out by NGOs (parent organizations) (Huang, Kellett, & St. John, 2010, as cited in Hsiao et al., 2018, p. 45).

A sense of meaning incorporates parents' beliefs about worthiness and significance of their contribution to their children's education and lives in total (Spreitzer, 1995, as cited in Kim & Bryan, 2017, pp. 169-170). Parents' sense of meaning concerning their children's lives and future perspectives is connected to parents' strong view of the importance of contributing

to their lives, actively participating in their lives and developing them as individuals, as well as contributing to their education (Kim & Bryan, 2017, pp. 168-179).

Self-determination. Dempsey and Dunst (2004) identified parents who are self-determined as participatory change agents (Dempsey and Dunst, 2004, as cited in Hsiao et al., 2018, pp. 44-51). It refers to parent's self-advocacy, ability to solve problems, make choices, set goals, and express themselves (Prilleltensky, 2008, as cited in Kim & Bryan, 2017, pp. 169-170). It also refers to taking control of all situations which relate to their children's medical, educational, social conditions, and future in total (Hsiao et al., 2018, pp. 43-53).

Competence. In some sources, this component is named differently. For instance, Kieffer (1984) defines this component as participatory competence, Ayers (2016), as engagement in the future and Edwards (2016) as trust and respect (Kieffer, 1984; Ayers, 2016; Edwards, 2016, as cited in Hsiao et al., 2018, pp. 45-47). Firstly, this component refers to parents of CWD who act independently keeping in mind their goals, experiences and economic status while advocating for their children's needs. Secondly, it refers to parents of CWD who have completed all the training on parent empowerment. The level of parents' competence indicates how confidently parents cope with school staff and administration and how confident they are in accommodating their children in the education process (Ball, 2014, as cited in Kim & Bryan, 2017, pp. 168-176).

Community belonging applies to parents' sense of belonging to the school or any other communities (Kim & Bryan, 2017, pp. 170-176). School plays an important role in building school community and in connecting parents to a school community or parent group where they develop their sense of empowerment (Kim & Bryan, 2017, pp. 170-177; Neal & Christens, 2014, as cited in Kim, Fletcher, & Bryan, 2017, pp. 5-7). In these communities',

parents share knowledge and resources with each other, become involved in different activities and movements for educational change.

Community participation. As the child grows up, the skills and experiences of parents develop and mature as well. Dempsey and Dunst (2004) called parents who participate in different communities and committees as advocates over time. They become more knowledgeable and confident to communicate with schools, committee members, society representatives, and government authorities for the rights of their children (Dempsey & Dunst, 2004; Nachshen & Minnes, 2005, as cited in Hsiao, Higgins, & Diamond, 2018, pp. 44-51). This community participation refers to different activities whose main goal and aim are to change or influence decisions about laws and policies and to advocate on behalf of their children. For instance, parents of CWD participate in school communities to change the school system and policy which they find to be a barrier for their children's education (Kim & Bryan, 2017, pp. 168-179).

2.8. Chapter Summary

This chapter presented literature on the role of NGOs in empowering parents of children with disabilities globally and in Kazakhstan, the role of parents in their children's lives and parent empowerment model by Kim and Bryan (2017). This model will be used as a conceptual framework for underpinning the interview questions and for analyzing the collected data, the empowerment work of NGOs in Kazakhstan selected in this study. The next chapter covers the ontological and epistemological beliefs as well as design, participants, ethics, research sites and instrument, data procedures and analysis.

Chapter Three: Methodology

3.1. Introduction

The previous chapter described what is already known in the literature about the role of NGOs (or Parent Organizations) in empowering parents of children with disabilities and revealed a gap in the research literature that there has been little research conducted in empowering parents by NGOs in the Kazakhstani context. This chapter introduces the methodology used to investigate the role of NGOs in empowering parents of children with disabilities in two urban cities of Kazakhstan, Nur-Sultan and Almaty. Precisely, this chapter explains the selection of qualitative research design, participants, research sites, procedures, data collection, and data analysis.

3.2. Ontological and Epistemological Beliefs of the Research Study

According to Guba (1990), a paradigm of the research study is defined by its epistemological and ontological perspectives (Guba, 1990, as cited in Edirisingha, 2012). The chosen methodology of the study is based on the researcher's ontological and epistemological beliefs (Burrell & Morgan, 1989, as cited in Stewart, 2014, p. 148). Ontology identifies and refers to the existence of overall knowledge of the particular phenomenon. Specifically, concerning research study, the ontology seeks to find an answer to the research question (Hudson & Ozanne, 1988, as cited in Edirisingha, 2012, pp. 1-3) whereas epistemology is about researcher's beliefs and how a researcher sees the world. Concerning research study, it

relates to how the researcher is going to reveal the knowledge and learn about reality (Edirisingha, 2012).

The epistemological and ontological belief and position of this research study was based on the social constructivist approach by using phenomenological and interpretive inquiry. Precisely, the collected data was used to construct meaning related to parent empowerment by using a theory of parent empowerment model by Kim and Bryan (2017) as a conceptual and theoretical framework (Kim & Bryan, 2017, pp. 168-179). Thus, the main goal was to understand and interpret the knowledge concerning parent empowerment in Kazakhstan rather than to generalize the existing knowledge (Neuman, 2000; Hudson & Ozanne, 1988, as cited in Edirisingha, 2012, pp. 1-3).

3.3. Design of the Study

This part of the research study points out the research design that was used and explains its choice.

There are three types of research designs: qualitative, quantitative and mixed methods. There is a distinction between qualitative and quantitative research designs, but they should not be seen as the opposite of each other. The qualitative research design focuses more on using and relying on words, while quantitative relies on numbers. Moreover, a qualitative research design uses open-ended questions, whereas a quantitative uses close-ended questions. According to Creswell (2014), a quantitative research method focuses and relies on numbers and statistics whereas a qualitative research method focuses on understanding the problem or issues in-depth (Mills & Birks, 2014; Creswell, 2014). It focuses on understanding and

investigating participant's views and experiences (Mertens, 2014). The mixed method is a combination of quantitative and qualitative research designs (Gorard, 2010, pp. 237-252). Therefore, a qualitative research method best corresponds to the research problem and the purpose of the research study.

The qualitative case study approach was chosen to address the research purpose. This distinct choice of using a case study is that it focuses on the in-depth description and analysis of a case or cases (Creswell, 2014; Stewart, 2014, pp. 145-160). The cases chosen for this research study are two NGOs that are located in two urban cities of Kazakhstan and work on empowering parents of children with disabilities.

This research study is referred to a phenomenological inquiry, as its aim to understand, describe and interpret the participants' life experiences (Bloor & Wood, 2006, pp. 129-130). According to Usher and Jackson (2014), the phenomenology is "the study of the lived experience and that aspect should be prominent in the research question" (Usher & Jackson, 2014, pp. 181-198). This approach guided the researcher to choose interviews for data collection since this method will disclose the understanding of participants' experience and lifeworld on the particular situation (Bloor & Wood, 2006, pp. 129-130). The experience of NGO representatives in empowering parents of CWDs and experience of parents' of CWDs in taking empowerment training/programs is the lived experience explored in this study.

Besides, the research study is also referred to as the interpretive inquiry, where the researcher aims to understand and interpret participants' experiences and lifeworld with the help of collected data (interviews). It will help the researcher to understand the research problem in-depth, i.e. what the role of NGOs in empowering parents in Kazakhstan is and also help to analyze the collected data by categorizing it into main emerging themes (Given, 2008).

3.4. Participants

The purposeful sampling and snowball strategies were applied for selecting the participants and the sites because they can shed light on the research problem (Emmel, 2013, pp. 33-44). The researcher selected two participants (NGO representatives) and chose five participants (parents of CWDs) through the snowball technique. These five participants were suggested and selected by NGO representatives. They are the parents of CWDs who took empowerment program in their NGOs. In this research study, two cases NGO1 in Nur-Sultan and NGO2 in Almaty were selected. The selection of these two NGOs was from two different sources. The researcher found out about NGO1, which is in Nur-sultan city directly from this NGO representative where they met when the representative came to university where the researcher studies. About NGO2 in Almaty, the researcher found out about this NGO from mass media reports. Parents of children with disability initiated these two NGOs. To be exact, the representatives who launched these NGOs based them on their personal experiences and initiatives. The researcher interviewed one representative from each NGO and five parents of children with Down Syndrome who took parent empowerment programs at these NGOs. In total, seven participants were interviewed in this research study.

Purposeful sampling strategy perfectly fitted into this small-scale study and was applied to involve a range of diverse individuals (participants). The criteria for participants to be eligible for this research study was that they: (a) be NGO representative or parents who finished parent empowerment program in the organization; (b) be a parent of a child with

Down Syndrome; (c) have a kindergarten or school-aged child. Also, participants were different in terms of the city, experience and child's age.

In order to find out parents' perception on NGO programs and the role of the NGO in empowering parents of children with disabilities in cities like Nur-Sultan and Almaty, the participants of the research study were split up into two groups. Group one: Parents who are representatives of Almaty NGO. Group two: Parents who are representatives of Nur-Sultan NGO.

3.5. Research site

All seven semi-structured interviews were conducted face-to-face (four Almaty participants and three Nur-Sultan participants) and took place during the scheduled appointment suggested by respondents. All interviews took place at the same locations precisely, on the NGO sites. These NGO sites were the most convenient and trustful places for all interview respondents (Dundon & Ryan, 2009, pp. 1-12).

3.6. Data collection instruments

Data collection was held via semi-structured one-on-one interviews.

3.6.1. Interviews. The theory of the Parent Empowerment Model by Kim and Bryan (2017) was used to underpin the interview questions and also to analyze the collected data (Kim & Bryan, 2017, pp. 168-179). Semi-structured one-on-one interviews were used to get detailed and specific information about the role of NGO in empowering parents of children with

disabilities. The open-ended type of interview enables the researcher to ask and get in-depth information (Creswell, 2014). The advantageous side of using one-on-one interviews is that the interviewee can choose a place for the interview since, when talking about sensitive topics, the interviewee needs to have a trustful atmosphere and safe setting (Dundon & Ryan, 2009, pp. 1-12). Before conducting the one-on-one interview, the participants needed to fill out the consent forms (see Appendices 3 and 4) and return one copy to the researcher. The expected duration of each interview was approximately one hour. However, before conducting an interview, the researcher and the interviewee discussed a suitable date and time. During each interview, all questions and responses were audiotaped and transcribed (Cohen, Manion, & Morrison, 2011, pp. 261-264). Interviews were conducted in English or Russian languages according to what was preferable to the participants. In the event, the interviews were conducted in the Russian language, the researcher at the end of the interviews, translated these interviews into English. Thus, to avoid misinterpretation, the researcher contacted respondents if there was any confusion or misunderstanding.

Also, during this process, the interviewer briefly recorded all notes on the interview protocol form (see Appendices 1 and 2). The protocol form included open-ended questions with free spaces for interviewer's reflections — all open-ended questions related to parent empowerment programs held by NGO.

3.7. Data Collection Procedure

The very first steps before starting a research study, two main procedures were done. First, the researcher got approval by the NUGSE Research Committee. Second, the researcher

took permission from the gatekeepers (NGO representatives) to have access to the sites. After receiving permission, the NGO representatives got their consent forms. The researcher sent this consent form via email for a review. After reviewing the consent form, the NGO representatives chose parents who were empowered by their NGOs and submitted this consent form to them. This kind of procedure saved time for the researcher, especially concerning NGO, which is in Almaty city.

This consent form included information about the research study. After taking consent on participating in the research study which on a voluntary basis, the participants were introduced to the purpose of the research study, procedures, requirements, assurance of confidentiality and anonymity, contact details of the researcher, records of the data and how this data will be used. Then, the participants were informed that they could quit the research any time they want to (Flick, 2007, pp. 68-76). After reading the consent form and asking any questions about the research study and consent form, the researcher asked participants to sign the consent form. After returning the signed consent forms to the researcher, the researcher started the interviews. Seven respondents participated in the data collection. Each respondent was interviewed individually, and all interviews were audio-taped. The interviews were conducted on sites because it was the preferred places for all participants. These interviews were conducted to explore the role of the NGOs in empowering parents of children with disabilities in two urban cities of Kazakhstan, to understand the work of the NGOs with parents of CWD, and to find out the NGOs' parent empowerment programs.

3.8. Data analysis

This part of the research study describes the process of data analysis. The researcher started data analysis when she got all raw materials like one-on-one interviews. In the process of analyzing interviews, the researcher showed the responses to the participants to check that their responses were written correctly (Creswell, 2014). Afterwards, the researcher transcribed the audiotapes from the one-on-one interviews and then translated them into English. While analyzing the received data, the researcher marked and categorized data into several parts. All parts were coded and categorized in relation to the emerging theme (Creswell, 2014). The development of headings was done through the process of starting from coding to the main theme of the collected data.

Table 1.

Representative from Almaty	Rep1Alm
Representative from Nur-Sultan	Rep1Nur
Parent from Almaty 1	Par1Alm
Parent from Almaty 2	Par2Alm
Parent from Almaty 3	Par3Alm
Parent from Nur-Sultan 1	Par1Nur
Parent from Nur-Sultan 2	Par2Nur

3.9. Ethics in Research with Humans

This section is dedicated to research study ethics. Without Ethical approval by the NUGSE Research Committee, the researcher would not have been allowed to start collecting data. After getting approval from the Research Ethics Committee, the researcher sent an official letter to ask permission to conduct a research study. After getting permission, all participants were provided with an informed consent form that highlighted the voluntary nature of participation in the research study and that they may withdraw at any time they want to. Those who agreed to take part in the research study signed two copies of consent forms and after gave one copy to the researcher and retained the second for himself/herself. This process was done before conducting one-on-one interviews.

Thus, the participants were provided with all the information about the research study, explaining the purpose of the study, detailing what might and might not be shared, length of the interview, confidentiality and the researcher's contact details (Flick, 2007, pp. 68-76). Also, the researcher explained the risks and benefits of the research study and described how the identity of participants would be kept confidential and anonymous. All the names of the respondents and the names of NGOs were changed to retain their full anonymity. For instance, NGO in Nur-Sultan – Rep1Nur, Par1Nur, Par2Nur. NGO in Almaty – Rep1Alm, Par1Alm, Par2Alm, and Par3Alm. The participants were also informed that only the researcher and thesis supervisor would have access to the collected data. As soon as the researcher finished analyzing the data, the researcher shared the report with all the participants. Afterwards, the researcher deleted all the recorded data.

3.10. Chapter Summary

The methodology chapter specified an overview and explanation of the ontological and epistemological perspectives of the research study, research design, participants, research sites, data collection instruments, procedures and data analysis that were employed in the present research study. The interview data collection tool investigated how NGOs empower parents of children with disabilities and what NGOs' role is in empowering parents of CWD. By using purposeful sampling and snowball strategies, the researcher recruited seven participants, who shared their stories and experiences about their children's diagnosis, challenges and the work of NGOs in empowering them as parents of children with disability. Their responses were recorded, and in the following chapter, the collected data is presented.

Chapter Four: Data Findings and Discussion

4.1. Introduction

The previous chapter discussed the methodology of the research study, specifically the epistemological and ontological perspectives, research design, participants, research sites, the process of data collection and data analysis. This part of the study focuses on the findings that emerged from the collected data and a comprehensive discussion of the research findings in terms of the role of NGOs in empowering parents of children with disability. The chapter aims to specify the main research question about what the role of NGOs is in empowering parents of children with disabilities in Kazakhstan. The six components from Bryan and Kim's (2017) model of empowerment will be used as a framework for discussing the findings of this study. Additional components emerging from the data will also be discussed.

4.2. Introducing Research Sites (NGOs Background Information)

The two selected NGOs are from large urban cities, Nur-Sultan and Almaty. A shared aspect of these two NGOs is that a group of people launched them with a shared interest, that is mothers of children with Down Syndrome. Though they both share the same specialized field, they differ in terms of length of time they have been operational. The NGO in Almaty has existed for almost four years and in the NGO Nur-Sultan for just one year. They are also different in terms of their goals and focus. The NGO in Almaty focuses more on the development of children with Down Syndrome and then on their parents' empowerment,

whereas the NGO in Nur-Sultan focuses solely on mothers of children with disabilities (mothers of CWD, vulnerable mothers, mothers of many children, and single mothers).

4.2.1. NGO in Nur-Sultan

The NGO in Nur-Sultan is run by three mothers of children with Down Syndrome, and each of them has her responsibilities in the work of this organization. The first co-founder is a representative who participated in this research study who provided all the information about this organization. Thus, the first mother supervises the organizational and educational part. For instance, she is responsible for programs, workshops, approval of a plan with trainers, and controls attendance. The second representative makes contacts with partners who finance their organization and try to find new sponsors. The third representative represents NGO's interests in the media, attends and participates in different conferences and forums. Not so long time ago, two more mothers joined the organization. One of them is responsible for the economic part inside of the organization, whereas the responsibility for the second joined mother is to develop a training manual on how to open NGOs in the regions in Kazakhstan. Consequently, five people in the organization work on a temporary basis and those invited specialists, experts and trainers work on a permanent basis.

However, the existence of this organization would not have been possible without trusteeship and obtaining sponsorship from SOROS Kazakhstan and later US Embassy sponsorship. At the moment, the organization has trained five streams of parents of CWDs where SOROS Kazakhstan sponsored the first three streams whose training program lasted for two months, and the US Embassy sponsored the last two intensive streams that lasted for ten

days. The total number of parents who have already finished NGO's empowerment program is about 120 parents. Therefore, with the increasing popularity of this organization, the number of incoming parents is growing.

This NGO in Nur-Sultan provides an empowerment program only for parents of children with disabilities. Thus, the program includes computer literacy, methods of promotion in social networks, accounting, leadership skills, Sales and Marketing Management, consultations with the NGO's psychologist and lawyer, copywriting, photography, time management, and life-goal orientation.

4.2.2. NGO in Almaty

Similar to the NGO in Nur-Sultan, the NGO in Almaty is also run by three mothers of children with Down Syndrome, but they do not have specific individual responsibilities in the organization in which they specialize as the NGO in Nur-Sultan has. In addition to the founders of the Almaty NGO, the organization also employs specialists permanently such as an exercise therapy specialist, language pathologist, language specialist, teacher who prepares children for school and psychologist who works with teenagers and parents.

The organization was launched in August 2015 and got sponsorship from a volunteer from Azerbaijan. Her name is Kubra Aliyeva, and she has sponsored the organization for three years with her own money. She paid for the work of specialists and utilities. During the opening of the organization, she also helped with the repair and purchase of furniture. Therefore, classes for children are free. There is a symbolic fee of 5,000 tenge for which the organization buys consumables. However, sponsorship ceased a year ago due to personal

problems. Thus, the organization is actively looking for a new sponsor because, in the absence of a sponsor, the organization has financial problems that are covered by donations from parents and outside organizations. To date back, there are approximately 300 parents of children with Down Syndrome who are part of the NGO in Almaty. However, it would be incorrect to say that all 300 parents had attended the training and lectures as it has already been mentioned that the NGO in Almaty focuses on and is directed towards the development of children with Down Syndrome, and then on their parents (Dowling, 2012). According to the representative's responses, they give the most support to mothers who have recently given birth. It is a pity to realize that due to the lack of a sponsor and state support, NGO in Almaty invites and employs specialists at its own expense. Thus, if there is an opportunity to invite experts and specialists who specialize in the development of a child with Down Syndrome, the organization gives lectures and seminars.

4.3. The Role of NGOs in empowering parents

Collecting the data from NGO representatives and parents of children with Down Syndrome about the work of two NGOs in empowering parents of children with disabilities and detailed analysis of respondents' interviews disclosed the NGOs' important role in empowering parents of CWDs. It would be incorrect to claim that the two interviewed NGOs empower parents of children with Down Syndrome at equal levels, which may be because they specialize in different fields and focus on a different audience. As the representative from NGO Almaty responded they focus more on the development of children with Down Syndrome and then on the empowerment of their parents, whereas the NGO in Nur-Sultan

focuses only on parents (mothers of CWDs, vulnerable mothers, women with many children, and single mothers). These two NGOs raise parent empowerment in six main components of parent empowerment model (Kim & Bryan, 2017, pp. 168-179) but on different levels of empowerment.

Thus, from the abovementioned information, it is clear that the two interviewed NGOs have made a considerable contribution to parent empowerment even though they differ in their goals and audience to which they are most directed. Firstly, the center of attraction of NGO in Almaty is the development of children with Down Syndrome, while Nur-Sultan's NGO is the empowerment of parents, especially mothers of children with disabilities. Hence, the NGO in Almaty does not directly engage in empowering parents of CWDs but rather as an extra activity of their general activities with CWDs, while the NGO in Nur-Sultan directly engages in the issue of parent empowerment. Secondly, the NGO in Almaty has been working in its field for almost four years, whereas NGO in Nur-Sultan has been operational for just one year. However, the work experience of this organization did not affect the number of participated parents.

Nevertheless, despite their differences, the two organizations have a common beginning. Firstly, these two interviewed NGOs were created by a group of people with a shared interest, specifically mothers of children with Down Syndrome that corresponds with the reviewed literature of the study (Mayrowetz & Weinstein, 1999; Hess, Molina & Kozleski, 2006, as cited in Rollan & Somerton, 2019, pp. 3-5). Secondly, both NGOs are very active in protecting and changing rights for children with disabilities (Rollan & Somerton, 2019, pp. 1-16). The following sub-section discusses the results concerning each component of the Parent

Empowerment Model (Kim & Bryan, 2017, pp. 168-179) as the conceptual framework for the present research study and additional themes that emerged from the collected data.

4.4. Parents' reaction to the child's diagnosis

All interviewed mothers told their stories about their roles in their children's lives. Firstly, they did not know about their baby's diagnoses during their pregnancy, and all seven mothers claimed that they learned about the diagnosis of their child after birth. Secondly, after giving birth to a child with Down Syndrome, their consciousness was heightened about the society in which they were living. They had thought that the society in which they were living had a role in supporting them and their children. However, instead of getting support, parents realized that they lived in a society where lots of biases exist. As a result of the bias, the treatment at Kazakhstani hospitals was questionable. For example, according to the mother from Almaty, after doctors discovered that the child had Down Syndrome, they immediately transferred the mother and child to a separate ward indicating that our society has biases towards disabled people. Here, doctors showed their bias toward this newborn child reacting as though this child was infectious. Six out of seven parents were in a real depression. One of the mothers was upset about the treatment after delivery. Thus, as the representative from Almaty (Rep1Alm) told:

"I felt the complexity of the situation right in the maternity hospital - after the genetics arrived, my son and I were transferred to a separate room, and no one from the staff came to me in the next two days before discharge. Most of all, in this situation, the attitude towards us is unsettling - if I were lying in the postpartum with all the women, what would happen? Alone during this time, I experienced the whole range of emotions, including thoughts about suicide."

It is clear that there was no support for this mother after discharge, and it led to a feeling of depression and suicide. Another mother from Almaty (Par3Alm) shared similar feelings of depression after the condition of her child was revealed. The doctors were not sure, but they hinted and only after a heart ultrasound, the mother was told that her child had Down Syndrome.

Another mother from Nur-Sultan (Rep1Nur) fell into depression once again after she learned that her child, who already had Down Syndrome, showed autistic traits at the age when the child was already preparing to go to kindergarten.

“When my daughter was diagnosed with autistic traits, everything again turned my world around. It was worse a thousand times than the diagnosis of Down Syndrome. If the Down Syndrome can be socialized at least somehow, then here, my child is a question of everything (kindergarten, school, and so on). Well, I think you can understand my feelings, mental retardation and mental impairment in one child. It is just a bomb. I remember, when I learned about this, I just sat down and began to roar.”

It is evident that this mother again had and felt the entire range of her child’s disability, but this time, it was not only one type of disability but two in one child like Down Syndrome and autism. Only one mother (Par2Alm) out of seven accepted the diagnosis calmly because she had/felt a foreboding that the baby would be born with a disability whereas the other six mothers explained their reaction as something terrible, awful, some of them were in a real depression and angry.

“I accepted it calmly. When I was pregnant, it was my second pregnancy, I was 35 years old, and sometimes I thought that this child might be born with a disability. Maybe because of my age. I do not know I just prepared myself whatever child is born; I will accept him the way he is.”

Parents of children with disability have a constant fight not only with the diagnosis of their children but also with society. As mentioned before, our society has its own biases

towards disability and is not fully aware of people with disabilities, especially the younger generation. Hence, when they notice that someone is different from them, they feel free to show their curiosity and interest. This interest is mainly manifested by pointing to the person with a disability or just staring at him/her. One of the parents from Nur-Sultan (Par1Nur) was not happy and annoyed by the fact that people were pointing or simply staring at her child without embarrassment:

“Well, this is most likely the mentality not only of our Kazakhstan but in general of the entire Post-Soviet sphere. They point with a finger, look at a child, this is the most annoying so far.”

The same situation was described by another parent from Nur-Sultan (Par2Nur), where she had the same problem and the same behavior shown towards her child. Thus, as it was mentioned about the Post-Soviet sphere where people of different disabilities were segregated and studied in special/correctional institutions, this cannot be said for our current times. Today, especially the most interested group of people who are parents of CWDs tries not to hide their children at homes but instead bring them out into society.

4.5. Consciousness

Since the literature review disclosed that parents' ecocultural lens applies to parents' *consciousness* of their child's disability that is a parent's culture, language, gender, place of residence, beliefs and values (Hsiao et al., 2018, pp. 43-53), the data revealed that especially language and place of residence affect the level of CWDs' development and level of parents' empowerment. There were several cases described by respondents, which showed how

language and place of residence affect parents and their children's lives, especially in terms of service delivery and access to education.

4.5.1. Language effect and 4.5.2 Place of residence

According to the results of this research study, language and place of residence currently serve as barriers to service provision, access to education and academic performance of CWDs. For example, all respondents from the NGO in Almaty claimed that language plays a crucial role especially not knowing and not speaking the Kazakh language may affect the provision of certain services and in getting any free quotas. One of the mothers from Almaty (Par1Alm) shared her feelings that not knowing Kazakh could affect her child's life especially in terms of service delivery, but when she applied for disability benefit she was glad that all documentation was provided in two languages:

“Many are now beginning to say that we should speak Kazakh because we live in Kazakhstan. Especially in the southern part of Kazakhstan and I noticed that some Kazakhs are not happy that people speak with them in the Russian language. Thanks to that the documentation now is in two languages (Russian and Kazakh) otherwise I do not know what I would do. Thus, when my son turned four months old, we applied for a disability benefit, stating that my child had a disability by this, we could take free services.”

Another mother from Almaty (Par3Alm) also shared her worries about language effect and mentioned the issue with language that more and more people were insisting on speaking the Kazakh language rather than the Russian with the reason that they live in Kazakhstan and must speak in Kazakh.

However, the NGO in Nur-Sultan denied these statements by claiming that there is no language issue but rather a regional one. All respondents from NGO Nur-Sultan insisted that

in cities like Nur-Sultan and Almaty, there are no language issues, but in rural areas of Kazakhstan, there are some issues with language. It was confirmed by the response of a mother from Nur-Sultan (Rep1Nur):

“It seems that there is no longer a language issue, but living in cities or villages. I see that for example, Nur-Sultan and Almaty are more advanced than other cities. Moreover, if we take villages, for example, they do not know for sure. I think there is no longer a language issue, but a regional one.”

Here, it is evident that this mother did not face any problems which relate to language, especially Kazakh language because it would be incorrect to deny something that you did not actually experience. Not experiencing the issue cannot be said that the problem does not exist. All information as mentioned earlier confirms the research study results by Kim and Bryan (2017) that parents' home language and urbanicity were significantly related to a child's service delivery, access to education and a child's academic performance (Kim & Bryan, 2017, pp. 168-179).

4.5.3. Gender and stigma effect

There were also some cases described by respondents, which showed how stigma and gender affect not only a child's development but also a parent's empowerment growth. One of the mothers from Nur-Sultan (Rep1Nur) raised an issue regarding gender that it influences not only the child's development but also the mother's empowerment and independence (Cankurtaran Öntaş & Tekindal, 2016, pp. 275-289). This mother claimed that men in Kazakhstan get used to having their women stay at home and taking complete responsibility

for looking after the children. Thus, for women, their husbands become a barrier in going and developing themselves and their child as well.

“In the beginning, some of them did not allow their wives to attend these courses. There were even such cases when husbands called and asked what kind of courses they went to, is it true that they should not pay money for it. Basically, we have a huge gender problem in the way that many husbands work, and women stay at home with their children and constantly remain at home.”

These findings correspond with research study findings by Gently (2007) who stated that by empowering women, they are exempt from “economic sexual cycle” which means women can change their traditional roles such as sitting at home and bearing children whereas men are responsible for providing financial support (Gentry, 2007, as cited in Moswete & Lacey, 2015, pp.604-614).

According to another mother’s (Parl Alm) response it is clear that it is not people's physical or mental impairment that becomes a barrier for people with disabilities, but instead, it is society which creates barriers for people with disabilities due to their ignorance, unintelligence, stigma and old views about disability (Shakespeare & Watson, 1998; Cocks, 2000, as cited in MacDonald & Gibson, 2010, p. 242). Our older generation, especially, does not accept disability, or they feel ashamed if they have a child with a disability in their family.

“Many of the older generations still do not understand what Down Syndrome is, that if you do not practice now, you will miss the time. They say, 'Oh, the child will outgrow, do not worry, I also spoke late.' Well, this is because of some illiteracy and ignorance.”

This mother's response corresponds with the statement by Oliver (1993) who claimed that society's attitude and prejudice mostly suppress people with disabilities (Oliver, 1993, as cited in MacDonald & Gibson, 2010, p. 242; Dowling, 2012). This attitude and prejudice from society towards people with disabilities are called stigma (Deatrick et al., 1999; Joachim & Acorn, 2000; Knafl & Deatrick, 2002, as cited in MacDonald & Gibson, 2010, pp. 242-249).

4.6. Self-determination

Parents' *self-determination* is associated not only with their successful completion of parent empowerment programs in these two NGOs but also with their children's health development and academic success (Boehm & Staples, 2004, as cited in Kim & Bryan, 2017, pp. 169-176). Self-determined parents are also associated with self-advocacy. However, according to the research findings, all seven respondents confirmed that NGOs did not assist them in acquiring knowledge of the legislation system of the Republic of Kazakhstan. Nevertheless, not knowing legislation after completing NGO programs parents can still solve problems, make choices, set goals, express themselves, and take control associated with everything related to their children's medical, educational, and social development.

4.6.1. Parent as participatory change agent

When the researcher asked mothers whether they had a chance to defend their children's rights, three out of seven replied that there were no situations in which they could defend their rights. However, if there were, then they would fight for the rights of their children. They have not defended yet, because their children are too small. As two mothers from Almaty (Par1Alm and Par3Alm) recounted if they notice that a teacher in kindergarten or at school does not implement Inclusion into her/his class, then they would demand and ask for changes.

Two mothers out of seven who were from Nur-Sultan (Par1Nur and Par2Nur) said that they had never fought for the rights of their daughters, and they explained that their daughters go to private schools. One of them (Par3Nur) even said that she would never do it by herself. However, both of them suggested that no one is better than a specialist, and it is always better to consult a lawyer or an NGO that specializes in the diagnosis and legislation.

“I think it is always better to consult a specialist. I have never defended, maybe because my child went to private institutions.”

Two more parents who are the representatives of NGOs Almaty and Nur-Sultan (Rep1Nur and Rep1Alm) suggested that the first interested person in protecting the rights of a child is the parent. These two parents are great examples of how parents protect the rights of their children, who also get involved in speaking on behalf of their children, who make the best decisions for the benefit of children and who break and expand boundaries whose personal interests and needs push to open organizations and to help other parents and their children. For instance, the representative from Nur-Sultan shared her experience of how she came to the idea that her daughter deserves much more than she had and launched an organization. Thus, when she got a place at Nazarbayev University in Inclusive Education, she understood that she wants to defend the rights of her daughter.

4.6.2. Parental challenges with children with Down Syndrome

4.6.2.1. Medical support

According to parents' responses, every day, they face different problems. It also depends on the ages of their children. When a mother gives birth, she faces the news of disability. Secondly, she faces the child's health problems. All seven mothers had faced

problems with their children's health. Mostly, the problem is with the heart, and because of this, children need heart surgery. Thirdly, respondents whose children were small said that they had problems with state clinics. One mother from Nur-Sultan (Par2Nur) was disappointed in the Kazakhstani medical system after childbirth, and she found out that there are few qualified specialists in our state clinics.

“First of all, our medical support is not as good as you would expect. I was disappointed in our medical system, especially after childbirth. I understood that we have only a few qualified specialists in Down Syndrome. No one helps you until you ask or do it by yourself.”

Another mother shared the same thought, but this time, it was a mother from Almaty (Par3Alm) who also touched on the topic of medical support and the insufficient number of qualified doctors. This research finding correlates with research findings by Dowling (2012), where parents in Bosnia and Herzegovina were also not satisfied not only with medical support but also with disability assessment (Dowling, 2012). However, only one mother from Nur-Sultan (Par1Nur) was happy with our medical support. According to her point of view, there are no unqualified doctors, but instead, there are incompetent mothers.

“You see here a lot depends on the woman; if a mother knows a lot, then the other person understands what she knows. We have never come across bad doctors. I will say that we do not have bad medical support.”

Three mothers out of seven said that they prefer private clinics because they think that in private clinics, there are more qualified specialists, and they are more equipped to offer personalized care. The other three said that they are happy with our state clinics. Thus, this group of parents did not face any negative situations in state clinics, and they believe that all doctors in our clinics are qualified. Finally, only one mother said that it does not matter for

her to which clinic she goes for her child because this mother believes in her efforts to help her child and doctors are guides in the medical field.

Table 2.

Parents	Clinics they prefer for their children
Representative from Almaty	State and Private
Representative from Nur-Sultan	State
Parent from Almaty 1	Private
Parent from Almaty 2	Private
Parent from Almaty 3	State
Parent from Nur-Sultan 1	State
Parent from Nur-Sultan 2	Private

4.6.2.2. Kindergartens and Schools

Five mothers out of seven said that they had problems with both state and private kindergartens. Two mothers out of seven could not say anything about kindergartens or schools because their children were less than two-years-old.

Table 3.

Parents	Child's age
Representative from Almaty	4,6 years old
Representative from Nur-Sultan	9 years old
Parent from Almaty 1	5 years old
Parent from Almaty 2	1,6 years old
Parent from Almaty 3	3 months old
Parent from Nur-Sultan 1	9 years old
Parent from Nur-Sultan 2	13 years old

Only one mother from Nur-Sultan (Rep1Nur) got a place in a correctional kindergarten for her child, but it took much effort to get her child admitted. This mother has come a long way from the direction of PMPC specialized center to the correctional kindergarten for children with disabilities. She was terrified of everything that she saw in a specialized center and understood that her daughter deserved more than this center. Moreover, she faced additional problems such as big queues and no free places. However, after six months, her daughter finally was admitted to correctional kindergarten. There were some things that this mother did not like in this correctional kindergarten, but they were not significant. For this mother, the most important thing was that her daughter was happy to go to this correctional kindergarten. Now her daughter is nine years old, and she goes to a correctional school which she also loves and is happy to go.

However, not all mothers succeed in getting their children with Down syndrome to correctional kindergartens. For example, another mother from Nur-Sultan (Par1Nur) also tried

to get a place in correctional kindergarten; she tried several times but later just enrolled her daughter in a private kindergarten. She did not consider state kindergartens, and she explained why:

“Our situation was not for the state kindergartens. She got sick with leukaemia (oncology) when she was two years old, and we could not be where there are many people. In general, we could not go to kindergartens, and we still would not have been permitted to go to kindergarten, so we immediately went to a private kindergarten.”

The situation with this child is exceptional due to her illness. The mother did not consider state kindergartens as they are usually crowded, and there was a possibility that the child could quickly catch a cold. Therefore, only private and correctional kindergartens were considered as the number of children in the group is very small compared to public kindergartens.

4.6.3. Parents’ perceptions of education for their children in Kazakhstan

4.6.3.1. Belief in System change and 4.6.3.2. Support in System change

This section describes parents’ beliefs and attitudes about altering the Special Education system in Kazakhstan by parents of children with disabilities and what kind of support is needed to change the system. All seven parents responded that parents of CWDs could change the educational system but in order to do that they need to unite as a group of parents of children with disabilities and take consultation and support from the specialists such as lawyers and NGOs who specialize in their child’s diagnosis and legislation.

A parent from Nur-Sultan (Par2Nur) mentioned about a group of parents and added that before going anywhere to demand rights or system change, they should know what their real goal is:

“I think to change the system we should gather as parents (not only one parent), take consultations from specialists, and we should know exactly what we want to change, I mean for what exactly we are fighting.”

A parent from Almaty (Par1Alm) also supported the idea that parents whose children have a similar diagnosis should work together for the common goal and suggested that the easiest way to inform the government and the whole society about an issue that they would like to change is by contacting a social media:

“Only by seeking to write to the Ministry of Education, through the press, articles, television. To show that our children are not that bad and what needs to be done for them. In my opinion, only with the help of the parents whose children have the same diagnosis, it is possible to change something.”

All parents confirmed that they should rely only on their strength and possibilities. Thus, it is clear that when parents work as a group, they are very powerful, and according to a parent from Nur-Sultan (Par1Nur), it is possible only with the help of legislation specialists and specialized NGOs.

These research findings correspond to the literature review of this study (Hsiao et al., 2018, pp.43-53; Kim & Bryan, 2017, pp. 168-179). The research findings also revealed that parents would never try to change, demand or implement the educational system in Kazakhstan on their own. For example, almost all respondents stated that in order to change the educational system or legislation in Kazakhstan in favour of child protection rights it would be impossible without a group of parents who have a common goal and without the help and support of specialists. Consequently, the role of specialists is played by the NGO representatives and lawyers (Rollan & Somerton, 2019, pp. 1-16; Trainor, 2010, pp. 34-47).

4.7. Community belonging and community participation

Parents' *community belonging* to the NGO community was positively associated with their sense of empowerment (Kim, Bryan & Fletcher, 2017, pp. 1-9). This finding is consistent with qualitative studies, which indicate that parents' sense of belonging only to the NGO community has a positive impact on their and their CWD's lives. Upon completion of the NGO empowerment program, parents become active members of the NGO community from which they get and with which they also share information, as well as resources and give support to newcomer parents of CWDs (Kim, Bryan & Fletcher, 2017, pp. 1-9).

"We have a Whatsapp chat for mothers who have babies and chat for parents whose children are teenagers and adults. In this chat, we share all information, resources and share the achievements of our children. Parents can be a part of our organization as long as they want. Till now, we did not have parents who left our organization."(Rep1Alm)

Here, it is clear that the NGO in Almaty (Rep1Alm) indirectly empowers parents of CWDs by using Whatsapp chat as well as directly when parents come to the organization for seminars and lectures.

Parents' *community participation* was also positively related to parents' sense of empowerment. Parents' participation in different forums, contact with other parents, and participation in parent meetings were all associated with a parent's sense of empowerment. For instance, as it was stated by a parent from the NGO in Nur-Sultan (Par1Nur) some parents took part in "Umai Forum", this Forum was about female entrepreneurship.

"This Forum was about female entrepreneurship. There were various sessions, master classes. On the 'Umai forum', all mothers who participated in the Forum won prizes. There was excellent networking."

These findings are congruent with previous research indicating that parent participation in any communities have positive effects on parents' and their children's lives because they become more knowledgeable and confident to communicate with schools, committee members and other authorities on behalf of their children (Dempsey & Dunst, 2004; Nachshen & Minnes, 2005, as cited in Hsiao, Higgins, & Diamond, 2018, pp. 44-52). By participating in these NGO communities, parents develop their social capital (Auerbach, 2007, as cited in Kim & Bryan, 2017, pp. 170-177).

4.8. Sense of meaning

After completing parent empowerment programs, all respondents confirmed that NGO programs made a positive impact not only on their lives but also on the lives of their CWDs, even having two utterly different parent empowerment programs. Thus, those parents who applied and finished parent empowerment programs understood their principal role in contribution and involvement in their children's treatment, well-being, and increasing their sense of meaning. For example, according to a representative from NGO Almaty (Rep1Alm), most of the parents, after completing parent empowerment programs decided to study in order to retrain to become a qualified speech therapist and a speech pathologist. Furthermore, these parents of CWDs return as trainers/specialists and give lectures at these NGOs.

“For parents, we hold lectures and workshops. We have mothers who finished courses or qualifications as speech pathologists, speech therapists, and neuropsychologists, and then they come as trainers/specialists to our organization for giving lectures.”

These research findings support the literature review finding by Trainor (2010), in which parents of children with disabilities act as disability experts in accommodating the needs of their children (Trainor, 2010, pp. 34-47; Rollan & Somerton, 2019, pp.1-16).

However, parents who completed the NGO empowerment program in Nur-Sultan gather their sense of meaning by listening to different lectures from different well-known specialists who inspire and make parents (mothers) aware of the importance of their personal development and development of their children.

“Different coaches come here, for example, Emin Askerov and Aizhan Kimanova. Those who already have a ‘name and status’. If at first parents were afraid to go to the courses for these coaches simply because they did not know how to declare themselves, then they would begin to relax and say ‘we want more and continue to attend this kind of courses’.”

4.9. Competence

After completing NGO parent empowerment programs, parents increased their competence and self-efficacy. However, according to their responses parents improved their competence on a personal level where they are able to demand services, treatment and proper education but did not enhance their competence on the public level where they were able to advocate for policy formation, policy change or policy implementation (Itzhaky & Schwartz, 2001, pp.21-36). Not having the skill of advocating the rights of the child; nevertheless, through NGO programs, the parents increased their self-efficacy and self-confidence and reduced stress (Bloomfield & Kendall, 2012 pp. 364-372).

4.9.1. Parents' perception of NGO programs

According to all parents' responses upon completion of an NGO program, these programs had a positive impact on their lives. These programs empowered parents in their personal growth but did not assist them to acquire knowledge about the legislation system of the Republic of Kazakhstan for the reason that each NGO has its focus of direction. However, their common goal was to help, motivate and socialize parents of children with disabilities. The NGO representative from Nur-Sultan (Rep1Nur) explained it that the organization is focused on the vulnerable mothers and their empowerment program is aimed to enhance their abilities and develop new skills on the personal level but by no means on the legislative level.

“Our program is for vulnerable mothers. I can say it is an empowering program. Thus, our organization is an empowering organization. That program has little impact on policy, but we provide mothers with different opportunities to develop skills and a sense of control.”

4.9.2. Positive results after completing parent empowerment programs

In the words of the representative from NGO Nur-Sultan (Rep1Nur), parents' competence was positively associated with self-efficacy and self-confidence where some parents after completing NGO parent empowerment programs showed successful results like launching their organizations and businesses or becoming a human rights lawyer.

The NGO representative from Nur-Sultan (Rep1Nur) shared some cases where there were quite significant successes and results after completing the parent empowerment programs.

“One of the representatives from the company sponsored the project that was presented here and this mother who introduced this project has already opened her organization.”

Another mother became a human rights lawyer nine months later when she learned about the diagnosis of her child. Well, a lot of those who merely began to develop their business and many are now in the implementation stage. However, we will probably see real results in two or three years.”

Thus, the representative from Nur-Sultan (Rep1Nur) shared successes of parents, whereas the representative from NGO Almaty (Rep1Alm) shared the most prominent achievements and positive results concerning children with Down Syndrome and their parents. She told about their pilot project, which was a complete success when two children from their organization went to a regular school. As a result, they have more children with Down Syndrome, whose parents decided to send them to regular schools.

“Last year it was a pilot project two children went to a regular school. They were the first to break this path. Now, these two boys are studying in second grade and were accepted pretty well by other children at school. Thus, mothers by seeing the experience of those parents, this year, six children went to a regular school. This year, more of our children went to regular schools rather than to correctional schools.”

This representative (Rep1Alm) also mentioned about parents’ success where after participating in different lectures and seminars that were held in the organization some parents decided to continue with their studies and undertook studies of different courses and at institutions in order to retrain as the qualified specialists to become a language therapist and language pathologist.

“We have many mothers who retrained. For instance, someone was an accountant and went to study to become a speech pathologist. After finishing studies, they became aware that they like the job as a speech pathologist more. I never thought that I would work with children or launch an organization. Now here I am on maternity leave, and I understand when my son grows older, I do not want to return to an advertisement where I have worked for 12 years. It turns out that children have changed our lives.”

4.9.3. Parents' feedback

Both organizations also work to eliminate issues that were raised during the program, and of course, not without the help of the parents who completed their programs. To collect feedback on the completed course, NGO Nur-Sultan representatives (Rep1Nur) distributed a feedback form on which all parent wrote what they would like to change about the course or would like to add to the course.

“After completing the course, mothers fill out a form. Their biggest wish was to add lessons with a psychologist, and in the second extensive program, we included lessons with a psychologist.”

Thus, it is noticeable that the organization in Nur-Sultan pays considerable attention to parental feedback associated with their program. However, the feedback method from parents of the Almaty organization is slightly different. According to the representative of the Almaty organization (Rep1Alm), their feedback is a shared video with other parents on the chat taken after the lecture or master class. In this video, parents share the fact that they apply the theory in practice. These can be techniques and methods for the care and development of the child with Down Syndrome.

“After lectures, parents make and share their videos of how they used the information given at lectures because all these lectures concern the development of children with Down Syndrome.”

These data findings correspond with the research finding in Bosnia and Herzegovina and Croatia, where after completing a program, parents meet and discuss the progress of their children (Dowling, 2012). The findings in this research study suggest that NGOs that use parent empowerment programs play a significant role in empowering parents of children with

disabilities. From all the information that was collected through interviews with parents of children with disabilities and representatives of NGOs, it should be concluded that the two organizations had a positive impact on all parents, especially in terms of increased self-esteem, leadership skills, improving their personal lives and entrepreneurship as well as motivating, socializing and training them. Finally, each organization gave these parents a community. However, none of these organizations equipped parents with the skills to protect the rights of their children. More precisely, these organizations did not teach the legislation of the Republic of Kazakhstan on how to protect the rights of their children. These organizations focused more on the development of the child and the personal development of the parent than on training in the protection of rights of children with disabilities.

4.10. Challenges faced by NGOs in empowering parents

4.10.1. Lack of psychological support in NGO

One of the main challenges that were faced by NGOs' representatives at their initial stages is a lack of psychological support. After establishing the organizations, NGO representatives had to play the role of psychologist. They listened to parents' (mothers') stories about them and their disabled children. However, after some time, they understood and realized that these parents need help from qualified specialists. Thus, with the advent of the psychologists in the organizations, work with parents improved significantly, which facilitated the work of NGO representatives.

4.10.2. Lack of policy and legislation support

The literature and the findings of this research study indicated that NGO parent empowerment programs give strength to parental voices and by empowering them, NGOs connected parents of CWD to educational practices but not to educational policies. To be exact, the interviewed parents (mothers) got access to their community and made new contacts with other parents from NGOs, got more information and resources, and finally acquire new skills for their personal gain and for the benefit of their children's lives and schooling (Kim & Bryan, 2017, pp. 168-179). However, this research study did not demonstrate any connection to educational policy because according to research findings, two interviewed NGOs did not provide any programs on legislation and laws of the Republic of Kazakhstan. Hence, parents were not provided with procedures to protect their children's rights.

4.11. Chapter Summary

It is possible to conclude that NGOs in Kazakhstan work to increase parent empowerment that is to engage parents in consciousness-raising, in developing their skills and competence, connecting them to their communities, and supporting parents as leaders through organizing groups in their children's school and in the community (Kim, Bryan, & Fletcher, 2017, pp. 1-9). In this chapter, the parent empowerment model by Kim and Bryan (2017) was used as a conceptual framework for discussing the data findings of the research study as well as a discussion of new emerged themes.

Chapter Five: Conclusion

5.1. Summary of the Study

It is possible to conclude that NGOs that use parent empowerment programs play a significant role in empowering parents of children with disabilities. To be exact, they enhance parent competence to be in control of their own and CWDs' lives and to be fully equipped to cope with a child's disability. Hence, NGOs in Kazakhstan work to increase parent empowerment that is to engage parents in consciousness-raising, develop their skills and competence, connect them to their communities, and support parents as leaders (Kim, Bryan, & Fletcher, 2017, pp. 1-9).

This research study focuses on the role of NGOs in empowering parents of children with disability in Kazakhstan. The present research study focuses on how NGOs' programs empower parents of CWD in two urban cities of Kazakhstan, Nur-Sultan and Almaty. Focusing on Kazakhstan, this case makes this research study meaningful and very important as it fills a variety of gaps in the literature that relates to the parent empowerment. The findings demonstrate that NGOs in Kazakhstan engage in all six components of parent empowerment model by Kim and Bryan (2017), which are consciousness, sense of meaning, self-determination, competence, community belonging and community participation. The findings of this research study show that NGOs (parent organizations) in Kazakhstan do not fully empower parents of children with disability that is they only empower parents at the personal level but not on the public level as was suggested in the literature review (Itzhaky & Schwartz, 2001, pp. 21-36). Firstly, after completing empowerment programs in these two

interviewed NGOs, parents of CWD can demand services and proper education for their children but are not able to take part in decision making, advocate for the rights of their children or advocate for policy change. Thus, NGOs do not assist them to acquire legislation procedures, and parents are not aware of the laws and policies of the Republic of Kazakhstan. Secondly, after completing the NGO empowerment program, parents started to participate and felt that they belong to the community. However, they only fully participate in the NGO community, not wanting to be involved in other communities. Finally, this research study highlights the implication for legislation governing the role of NGOs in Kazakhstan.

5.2. Limitations

The limitations of the research study are unavoidable due to the study sample. Since only NGOs in the two largest cities of Kazakhstan were involved, much remains unclear about the role that other organizations in other cities in Kazakhstan play in empowering parents of children with disabilities. Nur-Sultan and Almaty do represent more privileged regions, and having respondents just from two NGOs of these two cities is hardly representative of the population. Conducting a large-scale study incorporating qualitative and quantitative methodologies basing on the set of themes developed in this research study would be a logical next step from here, allowing for the generation of more respondent results. More themes might emerge from studying the experience of other regional and, possibly, rural organizations.

5.3. Recommendations

a) For further research study. The current research study revealed that the role of NGOs in empowering parents of children with disabilities supports the recommendation for the need to support such organizations especially financially in order to ensure full and successful implementation of parent empowerment model by Kim and Bryan (2017) in Kazakhstani context (Kim & Bryan, 2017, pp. 168-179). For the further research study, it is advisable firstly, to conduct large-scale sample by using not only qualitative but also quantitative methodologies. Secondly, to study the experience not only of the urban NGOs but also of the regional and, possibly, rural organizations.

b) Legislation in Kazakhstan based on international standards. The present research data findings revealed the need for giving power to NGOs on legislation and policy level to empower parents to fight for the rights of their disabled children.

5.4. Final comment

This study set out to investigate the role of NGOs in Kazakhstan in empowering parents. The study was successful in obtaining information which provided insight into how NGOs in two settings in Kazakhstan work and some of their achievements and challenges. It is without a doubt that this study is significant in highlighting implications for legislation governing the role of NGOs. However, what cannot be easily refuted now is that NGOs that empower parents of CWDs play a significant role on the personal level of empowerment but

not on the public level of empowerment. Consequently, the parent empowerment model by Kim and Bryan (2017) is not fully applicable to the Kazakhstani context, and this is the key finding of the present research study. In other words, it does not fully apply to the third component of self-determination that identifies parents as participatory change agents who can advocate for the rights of their children, solve problems and express themselves in front of a higher authority.

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Appendices

Appendix 1: Interview questions for NGO representatives

INTERVIEW SCHEDULE

Background info: _____

Name: _____

Participant No.: _____

Date: _____

Place of residence: _____

Interview starting time: _____

Phone: _____

- *Note: questions will include details extracted from the documents analyzed and further questions around information will be asked.*

INTERVIEW QUESTIONS

Thank you for agreeing to participate in this research study.

I would like to ask you some questions relating to your role in empowering parents of children with disability and your experience so far.

There are 21 questions. Please feel free to give as much detail as you wish in your answers. If you are unclear about the meaning of any question, please ask for clarification.

1. How many years have you worked for this NGO?
2. What were your roles?
3. What attracted you to work for this NGO?

INVOLVEMENT WITH PARENTS

4. How many parents do you currently work with?
5. Has this number increased or decreased over the past five years? Explain why.
6. What is your key role in working with parents?

EMPOWERMENT

7. How do you define 'empowerment'?
8. Do you think this is important for parents? Why/why not?
9. Does your NGO get involved in empowering parents? If so, how does your NGO get involved in empowering parents?

10. Tell me about your NGO and Empowerment training for parents of CWD?
11. Please give examples of successful results of empowerment program?
12. What have been some of the challenges?
13. Have these challenges related to gender, socio-economic background, ethnicity, language, etc.? If yes, how?
14. What do you think are the benefits of your empowerment program?
15. How do you know this? Did you consult with parents post-training?
16. Give me an example of a parent you have worked with and how your programs have benefitted them?
17. Give me an example of a challenging situation with parents?
18. Is there anything you would change about the program?
19. Do you know about other NGO which gives empowerment training for parents of CWD? If yes, which NGOs?
20. How do their empowerment programs differ from your own?
21. Do you think that parental ethnicity (ethnic trapping) affect their level of empowerment?
 - Does parental ethnicity affect their disabled children's education and service delivery? (CONSCIOUSNESS)
22. After completing your training program, can you say that parents of CWD have a strong belief of the importance of education of their children in mainstream schools rather than specialized schools? (SENSE OF MEANING)
23. After completing your training program, can you say that parents can control their lives as well as their CWD's lives?
 - Can they set goals and express themselves, raise questions about issues that were affecting their CWD's education and their lives in general? (SELF-DETERMINATION)
24. Do you think that after completing your training program parents are confident enough to advocate for their children's education and services, to participate in decision making on school meetings (school community), to make their voices to be heard? (COMPETENCE)
25. Does your training program help or explain parents of CWD of the importance of being a part of the school community or any other communities? (COMMUNITY BELONGING)
26. Do you have any examples of how your training program helped parents of CWD to participate in school meetings where they advocate or work on improving their children's services or education program? Or any other communities that work on changing policies for quality education for their children? (COMMUNITY PARTICIPATION)
27. Are there any questions you'd like to ask me or any further information you'd like to share?

Appendix 2: Interview questions for parents of children with disability

INTERVIEW SCHEDULE

Background info: _____

Name: _____

Participant No.: _____

Gender: _____

Residency (where do they live): _____

Child's age: _____

Disability: _____

When the child was diagnosed? _____

How did you feel? _____

Date: _____

Interview starting time: _____

Phone: _____

INTERVIEW QUESTIONS

Thank you for agreeing to participate in this research study.

I would like to ask you some questions relating to your role as a parent of a child with the disability who was empowered by NGO and your experience so far.

There are 20 questions. Please feel free to give as much detail as you wish in your answers. If you are unclear about the meaning of any question, please ask for clarification.

KNOWLEDGE ABOUT NGO

1. How long have you known (the name of NGO)?
2. How did you come to know about the NGO?
3. What attracted you to communicate with the NGO?
4. Why did you contact the NGO?

EMPOWERMENT

5. What are some of the challenges you face as a parent with a child with disabilities?
6. Have you been involved in speaking on behalf of your child?

7. Have you had to fight for your child's rights? Why?
8. Do you think the NGO helps you in these actions?
9. Were you involved in any programs offered by the NGO?
10. If so, name these programs:
 1. _____
 2. _____
 3. _____
11. Tell me something about this program
 - a. Did you find it useful? Why/why not?
 - b. Did you think it met your needs as a parent? Why/why not?
12. Which parts did you find most beneficial? Why?
13. How did you feel/think before the program and how do you feel/think now after completing empowerment training?
14. If you could change the program, what would you change?
15. Did you find that the program equipped you sufficiently to advocate (explain advocacy) for your child?
16. Do you believe that parents of CWD could change the Special Education system in Kazakhstan?
17. What are the steps?
18. What are the barriers or challenges?
19. What kind of support do you need to change the system?
20. Do you think that your ethnicity can affect or affects your child's education success or service delivery? (CONSCIOUSNESS)
21. What were your thoughts before and after the training program at this NGO about the importance of your child's education? (SENSE OF MEANING)
22. Before taking part in this training program, could you express yourself in front of the school community, advocate for your child's educational rights, or raise questions about issues that affected your child's educations and life in total? (SELF-DETERMINATION)
23. After completing a training program in this NGO do you think that you are self-confident to make decisions and advocate for the educational rights and services of your child? (COMPETENCE)
24. - Can you say that you are a part of your child's school community?
- Are you satisfied and happy with your child's school and school staff? Why? (COMMUNITY BELONGING)
25. - Do you participate in any (school) communities or community projects? Ex: participation in decision making, advocacy)
- Do you participate in any school meetings or projects in order to improve your children's academic success or to improve services for your CWD? (COMMUNITY PARTICIPATION)
26. Are there any questions you'd like to ask me or any further information you'd like to share?

Appendix 3: Informed Consent Form for NGO representatives

INTRODUCTION: You are invited to participate in a research study entitled “Exploring the role of NGOs in empowering parents of children with disability in Kazakhstan”. The focus of this study is to explore the relationship between NGOs and parents and the role of the NGO in empowering parents of children with disabilities. The study will include the NGO you are involved in and parents you are working with.

PROCEDURES: The researcher wishes to interview one representative of the NGO and three parents of children with disability from each NGO, which is why you have been carefully selected. The interview will focus on your role in the NGO and will look at the initiatives you have been involved in terms of empowering parents with children with disabilities. The interview will last no more than 1 hour. You will be required to sign this consent form before the interview, or before the start of the interview if you so choose. The interview will be audio recorded, but your permission will be sought before the start of the interview. The purpose of audio-recording is to record information for reference after the interview. You may choose to decline this if you wish.

RISKS: There is minimal risk in this study. The only potential risk of participating in this study is *translation*. The researcher will conduct interviews in Russian, Kazakh and English languages. In the case when the interviews will be held in Russian or Kazakh, the researcher at the end of the interviews will translate these interviews into English. So, there is a risk of misinterpretation. You will be contacted if there will be any confusion or misunderstanding.

BENEFITS: Firstly, this is the first study in Kazakhstan about parent empowerment by NGOs. Secondly, the information from parents will inform NGOs on possible gaps or areas which require the improvement of the training programs. Hence, any information you provide will be significant and valued.

CONFIDENTIALITY & PRIVACY: Any information that is obtained during this study will be kept confidential to the full extent possible. Your name will be changed to retain your full anonymity. All collected data will be kept on the researcher’s personal computer where the information will be accessed only with the password. Only the researcher and thesis supervisor will have access to the collected data. As soon as the researcher finishes analyzing the data, the researcher will share the report with you as the participant. Afterward, the researcher will delete all the recorded data.

VOLUNTARY NATURE OF THE STUDY: Participation in this study is strictly voluntary, and if you agree to participate, you can withdraw at any time without prejudice.

POINTS OF CONTACT: It is understood that should any questions or comments arise regarding this project, or a research related injury is received, the researcher, Saida Issakhanova, +77786112709, saida.issakhanova@nu.edu.kz should be contacted. Any other questions or concerns may be addressed to the Nazarbayev University Institutional Research Ethics Committee, resethics@nu.edu.kz.

STATEMENT OF CONSENT.

By clicking “I agree” below you are indicating that you are at least 18 years old, have read and understood this consent form and agree to participate in this research study.

- I Agree
- I Disagree

Signature of NGO parent _____
Signature of Investigator _____

Date: _____
Date: _____

Форма информированного согласия для представителей НПО

ВВЕДЕНИЕ: Вам предлагается принять участие в исследовательской работе, на тему «Изучение роли НПО в расширении прав и возможностей родителей детей с ограниченными возможностями в Казахстане». Основное внимание в этом исследовании уделяется изучению взаимосвязи между НПО и родителями и роли НПО в расширении прав и возможностей родителей детей с ограниченными возможностями. В исследование входят представители НПО и родители, с которыми вы работаете.

МЕТОДИКА ПРОВЕДЕНИЯ: Целью исследования является опросить одного представителя НПО и трех родителей у которых есть дети с инвалидностью, в связи с этим вы были тщательно отобраны. В интервью основное внимание будет уделено вашей роли в НПО и инициативы, которые вы принимали в плане расширения прав и возможностей родителей с детьми с ограниченными возможностями. Интервью будет длиться не более 1 часа. Вам необходимо будет подписать эту форму согласия до интервью или если вы этого захотите до начала интервью. Интервью будет записано на аудио, но ваше разрешение будет запрашиваться до начала интервью. Цель аудиозаписи - запись информации для справки после интервью. Вы можете отказаться от этого, если хотите.

РИСКИ: В этом исследовании риск минимален. Единственным потенциальным риском в этом исследовании является перевод. Исследователь проведет интервью на русском, казахском и английском языках. В случае, когда интервью будут проводиться на русском или казахском языках, исследователь в конце интервью переведет эти интервью на английский язык. Таким образом, существует риск неправильного толкования. С вами свяжутся, если будет какая-либо путаница и непонимание.

ПОЛОЖИТЕЛЬНЫЕ СТОРОНЫ: Во-первых, это первое исследование в Казахстане о расширении прав и возможностей родителей со стороны НПО. Во-вторых, информация полученная от родителей проинформирует НПО о возможных пробелах, которые требуют совершенствования или пересмотр учебных программ. Следовательно, любая информация, которую вы предоставите, будет важной.

КОНФИДЕНЦИАЛЬНОСТЬ: Любая информация, полученная в ходе этого исследования, будет конфиденциальной в максимально возможной степени. Ваше имя будет изменено, чтобы сохранить полную анонимность. Все собранные данные будут храниться на персональном компьютере исследователя, где информация будет доступна только с паролем. Только исследователь и научный руководитель будут иметь доступ к собранным данным. Как только анализ данных будет завершен, исследователь поделится с вами отчетом. После этого исследователь удалит все записанные данные.

ДОБРОВОЛЬНОЕ УЧАСТИЕ В ИССЛЕДОВАНИИ: Участие в этом исследовании строго добровольное, и если вы согласны участвовать, вы можете отказаться в любое время без предубеждений.

КОНТАКТНОЕ ЛИЦО: В случае возникновения каких-либо вопросов или комментариев в отношении этого исследования, следует связаться с исследователем, Саидой Исахановой, +77786112709, saida.issakhanova@nu.edu.kz. Любые другие вопросы или проблемы могут быть адресованы Комитету по этике научных исследований Назарбаевского университета, resethics@nu.edu.kz.

ЗАЯВЛЕНИЕ О СОГЛАСИИ.

Отмечая «Я согласен» ниже, вы указываете, что вам не менее 18 лет, прочитали и поняли эту форму согласия и согласились принять участие в этом исследовании.

- Согласен
- Я не согласен

Подпись представителя НПО _____

Дата: _____

Подпись исследователя _____

Дата: _____

Appendix 4: Informed Consent Form for parents of children with disabilities

INTRODUCTION: You are invited to participate in a research study entitled “Exploring the role of NGOs in empowering parents of children with disability in Kazakhstan.” The focus of this study is to explore the relationship between NGOs and parents and the role of the NGO in empowering parents of children with disabilities. The study will include the NGO you are involved with and you as a parent.

PROCEDURES: The researcher wishes to interview one representative of the NGO and three parents of children with disability from each NGO, which is why you have been carefully selected. The interview will focus on your relationship with the NGO and their role in empowering you as a parent of a child with a disability. The interview will last no more than 1 hour. You will be required to sign this consent form before the interview. The interview will be audio recorded, but your permission will be sought before the start of the interview. The purpose of audio-recording is to record information for reference after the interview. You may choose to decline this if you wish.

RISKS: There is minimal risk in this study. The only potential risks of participating in this study are:

1. *Translation.* The researcher will conduct interviews in Russian, Kazakh and English languages. In the case when the interviews will be held in Russian or Kazakh, the researcher at the end of the interviews will translate these interviews into English. So, there is a risk of misinterpretation. You will be contacted should there be any confusion or misunderstanding.

2. *Interview Questions.* Some interview questions may be sensitive, but you will be given the option to answer or not, depending on your level of comfort. These questions which will relate to your child with the disability will be limited, so there is very little chance of discomfort. The researcher will make sure that this is avoided.

BENEFITS: Firstly, this is the first study in Kazakhstan about parent empowerment by NGOs. Secondly, the information from parents will inform NGOs on possible gaps or areas which require the improvement of the training programs. Hence, any information you provide will be significant and valued.

CONFIDENTIALITY & PRIVACY: Any information that is obtained during this study will be kept confidential to the full extent possible. Your name will be changed to retain your full anonymity. All collected data will be kept on the researcher’s personal computer where the information will be accessed only with the password. Only the researcher and thesis supervisor will have access to the collected data. As soon as the researcher finishes analyzing the data, the researcher will share the report with you as the participant. Afterward, the researcher will delete all the recorded data.

VOLUNTARY NATURE OF THE STUDY: Participation in this study is strictly voluntary, and if you agree to participate, you can withdraw at any time without prejudice.

POINTS OF CONTACT: It is understood that should any questions or comments arise regarding this project, or a research related injury is received, the researcher, Saida

Issakhanova, +77786112709, saida.issakhanova@nu.edu.kz should be contacted. Any other questions or concerns may be addressed to the Nazarbayev University Institutional Research Ethics Committee, resethics@nu.edu.kz.

STATEMENT OF CONSENT.

By clicking “I agree” below you are indicating that you are at least 18 years old, have read and understood this consent form and agree to participate in this research study.

- I Agree
- I Disagree

Signature of NGO parent _____
Signature of Investigator _____

Date: _____
Date: _____

Форма информированного согласия для родителей детей с ограниченными возможностями

ВВЕДЕНИЕ: Вам предлагается принять участие в исследовательской работе, на тему «Изучение роли НПО в расширении прав и возможностей родителей детей с ограниченными возможностями в Казахстане». Основное внимание в этом исследовании уделяется изучению взаимоотношений между НПО и родителями и роли НПО в расширении прав и возможностей родителей детей с ограниченными возможностями. В исследовании участвуют представители НПО и вы как родитель.

МЕТОДИКА ПРОВЕДЕНИЯ: Целью исследования является опросить одного представителя НПО и трех родителей у которых есть дети с ограниченными возможностями, в связи с этим вы были тщательно отобраны. В интервью основное внимание будет уделено вашим отношениям с НПО и их роли в расширении прав и возможностей в качестве родителя ребенка с ограниченными возможностями. Интервью будет длиться не более 1 часа. Перед началом интервью вам необходимо будет подписать эту форму согласия. Интервью будет записано на аудио, но ваше разрешение будет запрашиваться до начала интервью. Цель аудиозаписи - запись информации для справки после интервью. Вы можете отказаться от этого, если хотите.

РИСКИ: В этом исследовании риск минимален. Единственными потенциальными рисками участия в этом исследовании являются:

1. Перевод. Исследователь проведет интервью на русском, казахском и английском языках. В случае, когда интервью будут проводиться на русском или казахском языках, исследователь в конце интервью переведет эти интервью на английский язык. Таким образом, существует риск неправильного толкования. С вами свяжутся, если будет какая-либо путаница и непонимание.
2. Вопросы для интервью. Некоторые вопросы интервью могут быть чувствительными, но вам будет предоставлен выбор ответить или нет, в зависимости от вашего уровня комфорта. Вопросы, касающиеся вашего ребенка, будут минимальны.

ПОЛОЖИТЕЛЬНЫЕ СТОРОНЫ: Во-первых, это первое исследование в Казахстане о расширении прав и возможностей родителей со стороны НПО. Во-вторых, информация полученная от родителей проинформирует НПО о возможных пробелах, которые требуют совершенствования или пересмотр учебных программ. Следовательно, любая информация, которую вы предоставите, будет важной.

КОНФИДЕНЦИАЛЬНОСТЬ: Любая информация, полученная в ходе этого исследования, будет конфиденциальной в максимально возможной степени. Ваше имя будет изменено, чтобы сохранить полную анонимность. Все собранные данные будут храниться на персональном компьютере исследователя, где информация будет доступна только с паролем. Только научный сотрудник и научный руководитель будут иметь доступ к собранным данным. Как только исследователь завершит анализ данных, исследователь поделится с вами отчетом. После этого исследователь удалит все записанные данные.

ДОБРОВОЛЬНОЕ УЧАСТИЕ В ИССЛЕДОВАНИИ: Участие в этом исследовании строго добровольное, и если вы в последствии не захотите участвовать, вы можете отказаться в любое время без предубеждений.

КОНТАКТНОЕ ЛИЦО: В случае возникновения каких-либо вопросов или комментариев в отношении этого исследования, следует связаться с исследователем, Саидой Исахановой, +77786112709, saida.issakhanova@nu.edu.kz. Любые другие вопросы или проблемы могут быть адресованы Комитету по этике научных исследований Назарбаевского университета, resethics@nu.edu.kz.

ЗАЯВЛЕНИЕ О СОГЛАСИИ.

Отмечая «Я согласен» ниже, вы указываете, что вам не менее 18 лет, прочитали и поняли эту форму согласия и согласились принять участие в этом исследовании.

- Я согласен
- Я не согласен

Подпись родителя _____

Подпись исследователя _____

Дата: _____

Дата: _____