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Experiences of Special Sibling Relationships

An Arts-Based Study

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Abstract

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This qualitative and arts-based study explores how adult siblings describe their experiences of their special sibling relationships after arts- and creativity-related activities. The conceptual framework in this study opens up perspectives on (dis)ability and special sibling relationships and approaches the experiences of special sibling relationships through the Sibling Embedded Systems Framework (SESF).

This study included two arts- and creativity-related workshops for legal adults who have or have had a sibling with a (dis)ability. The purpose was that the participants could share their experiences, feelings and thoughts about their special sibling relationship with peers and thereby experience support and understanding. In addition, the purpose was to create such an arts- and creativity-related ground where the participants could achieve affordances to expand their insights beyond analytic thinking. The data in this study was collected through unstructured group interviews and analysed through qualitative content analysis.

The findings of this study are divided into three categories: 1) experiences in childhood, 2) experiences in adolescence and 3) experiences and thoughts about the present and the future. The data analysis showed how the participants processed their family bonds and various systems, which have provided or are providing social support. The key findings are related to the importance of social support when increasing the wellbeing of able-bodied siblings. For future research, it would be beneficial to explore how exo- and macrosystems or factors such as gender, family size, age difference or the type of (dis)ability can influence the experiences of special sibling relationship. The future research could also focus on how arts- and creativity-related activities can be utilised in interaction between the research participants and their environment.

Keywords: Arts-Based Research (ABR), Sibling Embedded Systems Framework (SESF), (dis)ability, special sibling relationship, social support, arts- and creativity-related activities

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1 **Introduction**

”Persons with disabilities have the right to equality, inclusion, self-determination, independent living, non-discrimination and the necessary individual services and support.” (Ministry of Social Affairs and Health, 2025). This quotation is the first thing mentioned considering services and support for people with (dis)abilities[1] on the website of the Ministry of Social Affairs and Health in Finland. I see this quotation reflecting values, which are essential when constructing a meaningful life. Still, such experiences and perceptions emerge that indicate that not all people with (dis)abilities are allowed to live lives based on equality, inclusion, self-determination, independent living or non-discrimination.

For instance, Vehmas and Mietola (2022, p. 84) state in their book related to everyday life and humanity of people with severe intellectual (dis)abilities that (dis)ability services in Finland are mostly constructed on the terms of people with milder rather than severe intellectual (dis)abilities. In other words, (dis)ability services might be more appropriate for people with severe intellectual (dis)abilities than for those with milder ones (Vehmas & Mietola, 2022, p. 84). According to Vehmas and Mietola (2022, pp. 188–189), people with severe intellectual (dis)abilities too often have a meaningless and socially poor life, which takes place mostly in housing units and in day activity centres.

Another example considering situations where equality, inclusion, self-determination, independent living or non-discrimination are not achieved in the lives of people with (dis)abilities is a working life related blog post of Vamlas Foundation. According to this post (Vamlas Foundation, 2025), the employment

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[1] (Dis)ability means loss or limitation of opportunities to participate equally in society (Burchardt, 2010, p. 736). The loss or limitation of opportunities is created by other people through physical structures, institutional norms and social attitudes (Goering, 2015, p. 135).

situation of people with (dis)abilities has not improved significantly over the last two decades. For some people with (dis)abilities it is still hard to keep up with working life which values super efficiency. The blog post calls for critical reflection on working life, as inclusion in working life is also inclusion in society. (Vamlas Foundation, 2025.)

The way of how services and support materialise, is not just a matter for people with (dis)abilities. It is also a matter for their family members. Seeing one's own family member not being enabled to live an individual and meaningful life may easily make the other family members angry, frustrated or sad. Family members may have hard feelings even when the services and support work properly. Namely, to receive the services or support needed, parents of children with (dis)abilities–and of course adult people with (dis)abilities–often need to fight with bureaucracy. For instance, Tawast (Tawast & Leinonen, 2024, pp. 343–344) as a mother of a child with a (dis)ability describes how frustrating it is to fight, not with (dis)ability, but with bureaucracy, which includes for instance a large amount of paperwork and phone calls related to therapy processes and (dis)ability allowance. A family member's (dis)ability, the services and support available and the time and energy spent in the bureaucratic jungle can influence the entire family and its internal interactions.

One unique relationship in a family is a sibling relationship, which can be the longest relationship an individual has in their life. When a sibling has a (dis)ability, it influences both a sibling relationship and the entire network of interaction relationships within a family (Takataya et al., 2019, p. 337; Kramer et al., 2021, p. 258), which creates a special sibling relationship. The topic of special sibling relationship is close to me because I have a special sibling relationship myself. Through my childhood and adolescence my family participated in activities aimed at families with children with (dis)abilities and I met other siblings like me. As an adult I realised that I have no friends with a sibling with a (dis)ability. I wanted to talk with other people who are in the same situation as me, so I tried to find some peer support activities in Northern Ostrobothnia, without success. Instead, I found several peer support groups and information for parents with children with (dis)abilities and for children with (dis)abilities.

People with (dis)abilities unfortunately have a long history of having a marginalised voice in society (Goodley, 2014, p. 5), which can lead people without any certain (dis)ability to invalidate them, their experiences and their identities (Swain & French, 2000, pp. 573–574). Even the social model of (dis)ability, which emerged from the (dis)ability movement itself, cannot meet all the diverse experiences that people with (dis)abilities have. Thus, all the people with (dis)abilities have not been heard or seen even with the help of (dis)ability movement. (Shakespeare, 2004, pp. 13–14.) In addition, some international studies (e.g., Hanvey et al., 2022, p. 937; Takataya et al., 2019, p. 337) have brought up that also the voice of siblings of people with (dis)ability has not been studied enough. It seems that similar thoughts are emerging also in Finland, as can be seen in the need to implement a project called Special Siblinghood in 2015–2019. The aim of this project was to “raise awareness about the wellbeing, risks and strengths of siblings of children with a (dis)ability” (Erityinen sisaruus, 2024).

According to the Special Siblinghood website (2024), a special sibling relationship can both increase and decrease the wellbeing of an able-bodied sibling[2]. On one hand, an individual who have a sibling with a (dis)ability may have learned to take different perspectives and capabilities into consideration, which can make them empathic, patient and adaptable. On the other hand, able-bodied siblings can also become too independent or anxious, or they may lack the attention they would have needed in their families because their sibling with a (dis)ability may have required considerable attention and time from their parents. The challenges that a special sibling relationship can cause and the way the challenges can vary at different stages of life are also well described in

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[2] In this study, an able-bodied sibling means a sibling who does not have any certain loss or limitation of opportunities to participate equally in society (Burchardt, 2010, p. 736).

the Special Siblinghood website. A five-year-old sibling may need concrete information about their sibling’s condition, a teenager may need support in bringing friends home and an adult may be worried about the time after their parents have passed away. (Erityinen sisaruus, 2024.) Thus, especially the availability of social support throughout the life course is important for siblings of people with a (dis)ability, including adult siblings too (Hanvey et al., 2022, p. 938; Kramer et al., 2021, p. 261).

Social support in the form of peer support can promote the wellbeing of an able-bodied sibling because meaningful and supportive peer relations increase the possibilities to be understood, which can decrease experiences of isolation, sadness, anxiety and depression (Hanvey et al., 2022, pp. 937–938). Peer support groups are available for people with (dis)abilities and parents of children with (dis)abilities in Northern Ostrobothnia but it still seems that adult siblings of people with (dis)abilities are lacking peer support activities in the same area. Therefore, I want to create such activities specifically for adult able-bodied siblings through this study.

In addition, I want to utilise arts- and creativity-related activities because of the possibilities that engagement in arts- and creativity-related activities can offer. Engagement in arts- and creativity-related activities can help to create connections both between people and to oneself (Norris et al., 2020, p. 5). Arts- and creativity-related activities also enable multiple ways of interpretation (Leavy, 2020, p. 236) and they can be utilised to evoke emotions, memories and experiences (Leavy, 2020, p. 129, p. 163). In other words, it is possible to process life experiences and construct meaningfulness together with other people in and through arts- and creativity-related activities and with that to promote wellbeing (Huhtinen-Hildén & Isola, 2019, p. 14). All in all, I intend to create peer support activities that lean on arts- and creativity-related activities. In other words, I want to create a ground where adult able-bodied siblings can together achieve affordances to expand their insights considering their special sibling relationship.

2 Conceptual Framework

In this chapter I will introduce my conceptual framework consisting of the Sibling Embedded Systems Framework (Ackoff, 1971; von Bertalanffy, 1968; Kovshoff et al., 2017) and conceptualisations of (dis)ability (i.e. Campbell, 2009; Goodley, 2014; Oliver, 1996; Shakespeare, 2013, 2012, 2004; Vehmas & Shakespeare, 2014; Vehmas & Watson, 2016) and sibling relationship (i.e. Hanvey et al., 2022; Kramer et al., 2021; Milevsky, 2021; Múries-Cantán et al., 2023; Takataya et al., 2019; Tanskanen & Danielsbacka, 2021). In this study I will write the concept (dis)ability with parentheses to highlight the idea that (dis)ability is a continuum on which bodies and minds of all people are placed (Vehmas & Shakespeare, 2014, p. 45). In other words, (dis)ability is diversity of bodies and minds (Waldschmidt, 2018, p. 75), not a label for a certain group of people (Vehmas & Shakespeare, 2014, p. 45) or an individual feature (Waldschmidt, 2018, p. 75). People’s existence is always embodied and embodiment is always influencing the interaction with social and physical environment in a certain societal or cultural context (Vehmas & Watson, 2016, p. 13).

2.1 Sibling Embedded Systems Framework

General system theory (GST) is an umbrella concept for different system theories from various scientific disciplines (von Bertalanffy, 1968, p 37). According to von Bertalanffy (1968, pp. 36–37), who is one of the developers of the general system theory, GST was developed for the need to take larger picture into account when exploring various phenomena. Namely, before the general system theory was developed, science concentrated commonly on exploring the interaction between elementary units in isolation, which is insufficient when exploring for instance problems of organisations. General system theory is broadly applicable to many scientific disciplines, no matter if the object of research is an inanimate or organic thing or a social phenomenon.

The explanation behind this versatile applicability is that GST aimed to develop such principles that are valid in all systems despite of the properties or elements or relations between the elements included in the system. In other words, general system theory aimed to integrate individual scientific disciplines to strengthen the unity of science. (von Bertalanffy, 1968, pp. 37–38.)

According to general system theory, a system consists of at least two elements, which are interrelated. This interrelation is essential because the system does not necessarily work even though all its elements work properly. Hence, focus is always on the system as a whole, not on the separate elements. (Ackoff, 1971, pp. 661–662.)

Systems can be either closed or open. The first means a system, which leans on causality achieving a certain final state depending on the starting point and process. The latter instead, is a system, which can achieve a certain final state from various starting points and through various processes. In addition, an open system interacts with its environment, whereas a closed system instead, exists in isolation. Basically, all living systems are always open systems while closed systems can be considered as theoretically systems. (von Bertalanffy, 1968, pp. 39–41.) When discussing open systems, the environment of a system consists of elements that influence the system but are not included in it. A change in the environment can lead to reaction or response of a system. System’s reaction is instinctive whereas response is deliberate. In addition, an autonomous change, which is not caused by the environment, can also emerge in a system. This is called an act. (Ackoff, 1971, pp. 662–664.)

An open system can, compared to a closed system, avoid and decrease disorders and develop itself towards states of increased order (von Bertalanffy, 1968, p. 41) by interacting with its environment and building up and breaking down its elements (von Bertalanffy, 1968, p. 141). Still, it varies if a system has dynamic and flexible way to interact or if a system has fixed and inflexible arrangements for interaction (von Bertalanffy, 1968, p. 44). Closer to inflexible interaction are reactive and responsive systems. A reactive system behaves in determined way and tries to produce the same outcome every time. A responsive system instead can choose the way to behave but it still tries to produce the same outcome every time. Then there are systems that can choose the way to behave and are capable to produce different outcomes. Still, some of these systems have certain outcomes they have determined beforehand so that the outcomes are not chosen even though they vary. Instead, a system with dynamic and flexible way to interact can act autonomously to both choose proper way to behave and also produce proper outcomes. This kind of system is called purposeful system. (Ackoff, 1971, pp. 664–666.) A purposeful system can picture an ideal goal and it is capable to set reachable goals to get nearer and nearer to the ideal goal. This process requires also capability to learn to become adaptive. A learning and adaptive system can adjust to various changes to increase its effectiveness in achieving its goals. (Ackoff, 1971, pp. 666–669.)

According to Ackoff (1971, pp. 669–670) one example of a purposeful system is an organisation, which is characterised by the concepts of, for instance, wholeness, growth, control or hierarchical order (von Bertalanffy, 1968, p. 47). Basically, an organisation has at least two purposeful elements with a common purpose. To achieve the purpose of the system, purposeful elements have different functional tasks and at least one of them takes control of the function of the system. In addition, purposeful elements can influence each other’s behaviour through observation and communication. (Ackoff, 1971, pp. 669–670.) The idea of an organisation can be applied, when discussing a family and its surrounding environments as embedded systems. Next, I introduce the Sibling Embedded Systems Framework (SESF), which leans on the idea of families and their surrounding environments.

SESF aims to understand experiences and outcomes of able-bodied siblings in families of children with (dis)abilities (Kovshoff et al., 2017, p. 38). According to Kovshoff and others (2017, p. 43), SESF can guide research to explore how able-bodied siblings can be supported during their whole life course and in different contexts. SESF approaches family as a holistic and dynamic system, which is in interaction with other systems. Hence, individual family members are not influencing systems in isolation. Instead, both intra- and interpersonal aspects influence both to an individual family member and a whole family in a bidirectional way that changes over time. SESF is based on theories and empirical research that already exist and it combines elements of family systems theory, the double ABCX model, the diathesis-stress model and bioecological systems model. (Kovshoff et al., 2017, pp. 38–40.)

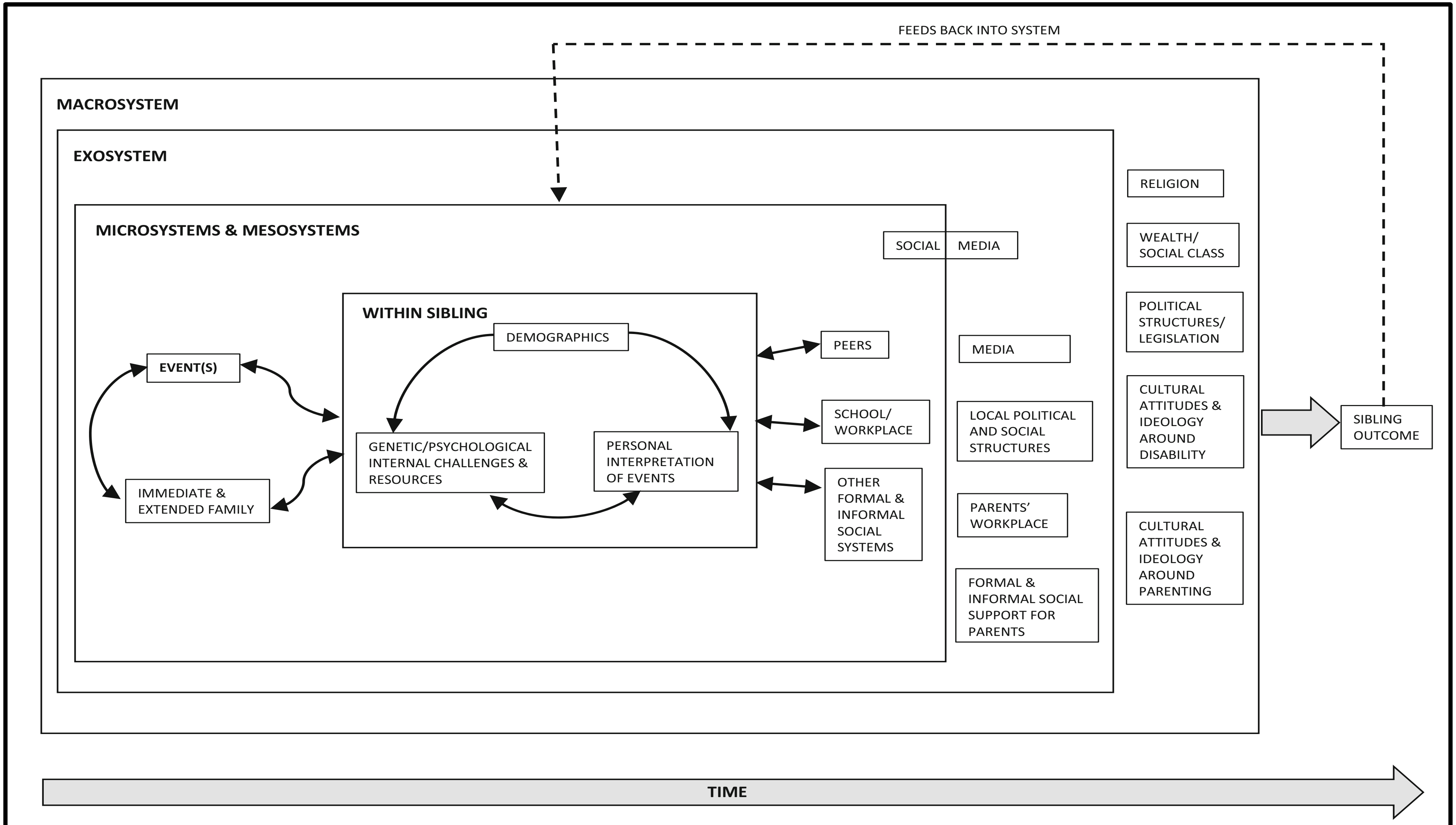

Fig. 1 Sibling Embedded Systems Framework

Figure 1. Sibling Embedded Systems Framework (Kovshoff et al., 2017, p. 39)

Innermost of SESF is a family as a microsystem. It includes three elements, which are shaping an interactive circle. These elements are event(s), a family and an able-bodied sibling. In this context, event(s) can mean for example presence of a child with a (dis)ability in a family, some certain factor of a child with a (dis)ability or some certain moment related to a child with a (dis)ability. Noteworthy is that in SESF a neutral term “event” is consciously chosen to emphasise the positive influence of a child with a (dis)ability in a family and the way how the influencing aspect can vary over time. A family in the context of SESF can mean both an immediate and extended family. Influencing aspects related to a family can be for instance demographic characteristics, parental mental health and parent relationship quality. Event(s) and a family both influence an able-bodied sibling through three different factors. One factor is demographic variables which can mean for instance gender match with a sibling with a (dis)ability or age relative to a sibling with a (dis)ability. Another factor is genetic or psychological internal challenges and resources. Internal challenges are elements that make situations with a sibling with a (dis)ability more difficult to understand, and internal resources are uplifting or helpful elements. Third factor is interpretation of events made by an able-bodied sibling. (Kovshoff et al., 2017, pp. 40–41.)

An able-bodied sibling is not only interacting within the family but they interact also with their peers, school or workplace and other social systems. Systems consisting of people in school, workplace or other social systems can be called microsystems too. When microsystems interact with each other, they create a mesosystem. In addition, an able-bodied sibling and their family interact also with wider systems, which are exo- and macrosystems. Exosystem includes local political and social structures and macrosystem cultural attitudes and ideologies considering people with (dis)abilities and parenting. Finally, SESF includes also a chronosystem, which refers to the system’s development over time. (Kovshoff et al., 2017, pp. 41–42.)

2.2 Conceptualising (Dis)ability

As late as the 18th century, countries were agricultural societies in Europe. Most people at that time lived in small rural communities where people were closely connected to each other. Living with the same rural community throughout life was common, and everyday activities followed the cycle of the year and nature. (Dis)ability was a common and natural phenomenon because many (dis)abilities caused by diseases were common, nutrition was poor and medical knowledge was not so developed. People were living in reality where being dependent on other people was common and natural. (Vehmas, 2005, pp. 53–54.) Such an agricultural society enabled people with (dis)abilities to find their place in their community and find work on a farm or in some family business that took their personal abilities into consideration (Kramer et al., 2021, p. 258; Vehmas, 2005, pp. 53–54).

Industrialisation started to change the structure of western society particularly in 19th century. At the same time, industrialisation changed also the social status of people with (dis)abilities. With industrialisation, work became both a commodity and a central criterion for social appreciation and status. People working in factories were no longer working and living in their rural communities close to each other. Instead, they moved to cities to be able to work in factories. Same requirements were imposed on every worker while working in factories. Requirements were related, for instance, to work efficiency and the length of the working day. The value of the work input was proportional to average productivity: the more productive work input, the more valuable one. Such an industrialised society did not enable people with (dis)abilities to work like agricultural society did. For many people with (dis)abilities, commuting from home to work and meeting the requirements imposed in factories was impossible. So, people with (dis)abilities became a group of people excluded from working life and dependent on society's charity. (Vehmas, 2005, pp. 54–55.)

With industrialisation, the social status of people with (dis)abilities was weakened. This deterioration was explained as being due to their (dis)abilities. This led to (dis)ability being treated in the first instance medically, and thus the medical or individual model of (dis)ability was born. (Vehmas, 2005, p. 56.) This model has two main ideas: (dis)ability is due to impaired functioning and being (Vehmas & Watson, 2016, p. 2) and challenges caused by (dis)ability are individual's own challenges (Oliver, 1996, p. 32). According to the medical or individual model, (dis)ability is such an individual problem, which is considered to be in the need of repair or improvement through various medical interventions (Goodley, 2014, p. 5; Vehmas & Watson, 2016, p. 2). In other words, attempts are made to remove or reduce limitations (Vehmas & Watson, 2016, p. 2). A significant shortcoming of this model is that it approaches (dis)ability strongly ignoring the voice of people with (dis)abilities and the role of a society (Goodley, 2014, p. 5). Lacking the perspective of people with (dis)abilities may draw a tragic picture of (dis)ability created by people who do not have any certain (dis)abilities themselves. If people with (dis)abilities live in such an environment where people without any certain (dis)abilities invalidate them and their experiences and identities, the wellbeing of people with (dis)abilities can really be reduced. (Swain & French, 2000, pp. 573–574.)

In response to the medical and individuality emphasising model, the social model of (dis)ability was born (Goodley, 2014, p. 5). According to this model, (dis)ability is not individual's own challenge but a societal and cultural challenge where experiences of ableism and disablism create disadvantages for people with (dis)abilities (Vehmas & Watson, 2016, p. 2, p. 13). Ableism is structural discrimination against people with (dis)abilities, and it is deeply rooted in society and culture (Campbell, 2009, p. 19). Essential for ableism are beliefs, processes and practices that draw a picture of a natural humanity which defines one's body and mind and therefore make people with (dis)abilities struggle not fitting into normative form (Campbell, 2009, p. 6; Goodley, 2014, p. 22). According to ableism, fitting the form may require for instance impairments, which are seen inherently negative, to be improved or removed when possible

(Campbell, 2009, p. 5), or identity, which is not one's own, to be constructed (Goodley, 2014, p. 22). Disablism instead, is direct discrimination (Campbell, 2009, p. 4).

The social model of (dis)ability makes a clear distinction between the concepts impairment and (dis)ability: impairment means condition of body and mind while (dis)ability means loss or limitation of opportunities to participate equally as others (Burchardt 2010, p. 736). According to Burchardt (2010, p. 736), this means that impairment does not create (dis)ability but the interaction with social, economic and physical environment does. Goering (2015, p. 135) instead describes impairment as something neutral for people with (dis)abilities but (dis)ability as a disadvantage or restriction created by other people through physical structures, institutional norms and social attitudes. In addition, Shakespeare (2013, p. 216) defines impairment as something individual and personal, and (dis)ability as a structural and public issue. Understanding (dis)ability is not unambiguous because (dis)ability is always experienced and defined in a certain societal, cultural and ideological context (Vehmas & Watson, 2016, p. 13). In addition, (dis)ability as a concept does not represent reality. Instead, it represents those meanings and conceptions that people associate with (dis)ability in a certain cultural context. (Waldschmidt, 2018, p. 75.)

Also, disadvantages related to (dis)ability are understood differently in different societal, cultural and ideological contexts. In some contexts, (dis)ability is experienced to create disadvantages whereas in other contexts, (dis)ability is experienced as neutral diversity. In addition, all people experience disadvantages in their life, but not all people experience their life to be strongly restricted. (Vehmas & Shakespeare, 2014, pp. 44–45.) Therefore, it is not always easy to define which disadvantage really makes people struggle, and how these disadvantages should be corrected. One way when reaching out a common understanding about disadvantages is to consider capabilities approach. (Vehmas & Watson, 2014, pp. 643–644.)

The aim of capabilities approach is to promote people's quality-of-life defined by their capabilities. Essential for capabilities approach is to consider what kind of opportunities people have, do people have real freedom to choose from opportunities available and whether any social injustice or inequality prevent some opportunities from being achieved. The concept capability means such opportunities to choose and act that are created together by internal capabilities, meaning for instance personality traits, health condition and intellectual capacities, and political, social and economic environment. In other words, behind the opportunities to choose and act are combined capabilities. Responsibility to develop both internal and combined capabilities is not only individuals' responsibility but also society's. (Nussbaum, 2011, pp. 18–22.)

According to Nussbaum (2011, p. 31), the protection of such capabilities whose removal would make life unworthy of living is one of the essential parts of capability approach. In other words, it is essential to ask what is the bare minimum for a life worth of living (Nussbaum, 2011, pp. 31–32). According to the list of capabilities created by Nussbaum (2011, pp. 33–34), a life with human dignity requires i.e. good health, avoidance of premature death and violence, connection with other people, experiences of being dignified, equal human dignity and a right for joy and meaningful activities. If disadvantages prevent to achieve capabilities described in the previous sentence, disadvantages can be defined to create significant restrictions to life. (Nussbaum, 2011, pp. 31–34.)

Through the social model of (dis)ability it is possible to support people with (dis)abilities to strengthen their self-esteem, construct a positive collective identity together (Shakespeare, 2013, p. 217) and unite to fight against discrimination (Shakespeare, 2004, p. 18). The collective action cannot change everything but it has the power to influence certain societal aspects and thereby to improve society (Oliver, 1996, p. 38; Vehmas & Watson, 2016, p. 22). According to Oliver (1996, p. 37), these societal changes need to be defined by people with (dis)abilities themselves. In other words, the experiences of people with (dis)abilities are essential when considering the social model (Oliver, 1996, p. 31).

Even though the social model of (dis)ability provides progressive approaches to (dis)ability when comparing to the medical model of (dis)ability (Shakespeare, 2013, p. 216), it is not a perfect model either. According to Shakespeare (2004, p. 15), (dis)ability is too complex and diverse phenomenon to be approached through the social model, which provides a generalised and simplified approach to (dis)ability. It is important to take diverse experiences related to (dis)ability into consideration (Vehmas & Watson, 2016, pp. 13–14) but the social model of (dis)ability views personal experiences through a narrow lens (Shakespeare, 2004, p. 13). Therefore, the social model of (dis)ability cannot meet all experiences people with (dis)abilities have. In particular, experiences related to various impairments and identities arising from them are diverse and complex, and therefore difficult to reach through the social model of (dis)ability. (Shakespeare, 2004, pp. 13–14.) For example, Shakespeare (2004, p. 13) states that the social model has not managed to motivate for instance people with mental health issues or challenges related to intelligence issues. As another example, Swain and French (2000, p. 571) remind that some of the impairments can cause pain and suffering even though there would not be any societal restrictions.

Different challenges require different approaches. Therefore, a confrontation of the medical model and the social model of (dis)ability is not useful. Instead, both medical help and environmental changes are needed when considering issues related to (dis)ability. (Shakespeare, 2004, p. 19.) Impairments are never neutral issues (Vehmas & Shakespeare, 2014, p. 46). Sometimes impairments are harmless (Vehmas & Shakespeare, 2014, p. 46), but sometimes they can really reduce one’s wellbeing (Vehmas & Watson, 2016, pp. 13–14) and make people with (dis)abilities to desire medical treatments (Shakespeare, 2004, p. 14). To be able to get proper care and treatment, individual experiences cannot be ignored (Vehmas & Watson, 2016, pp. 13–14). According to Shakespeare

(2012, p. 130), people with (dis)abilities have more needs related to health issues on average comparing to majority of the population. Needs related to diverse health issues must be taken into consideration to prevent the risk of mortality and morbidity from increasing higher than usual (Shakespeare, 2012, p. 130). In addition, as Shakespeare (2012, p. 130) states, without a good state of health nothing is possible. Therefore, promoting rights of people with (dis)abilities is useless if people with (dis)abilities cannot enjoy those rights because of the lack of health (Shakespeare, 2012, p. 130).

When considering identity issues through the social model of (dis)ability, complex issues emerge when discussing (dis)ability and discrimination. Some people have impairments but still they do not identify themselves as people with (dis)abilities. Some people with (dis)abilities have not experienced discrimination but still they identify themselves as people with (dis)abilities. In addition, some people with (dis)abilities have experienced discrimination but not because of their (dis)ability but, for instance, because of their gender or socioeconomic situation. (Shakespeare, 2004, p. 14.) As mentioned earlier, identity is too complex construction to be fully understood through the social model of (dis)ability (Shakespeare, 2004, pp. 13–14).

2.3 Sibling Relationship

One part of family relationships is sibling relationships. A sibling may have various meanings but in this study a sibling means a first-degree sibling who is related to other sibling through genetic relatedness, kinship or co-residence in childhood (Buchanan & Rotkirch, 2021, p. 5). Sibling relationships are often longest and most significance relationships an individual has in their life (Takataya et al., 2019, p. 337). When siblings experience growing up together, they create a companionship, which represents their own way to interact together and love and take care of each other (Chu et al., 2021, p. 796; Diener et al., 2014, p. 1060; Múries-Cantán et al., 2023, p. 193). Because of an ambivalent nature of sibling relationships, they include both altruistic help and emotional closeness but also conflicts and quarrel (Tanskanen & Danielsbacka, 2021, p. 25), and therefore, despite the conflict proneness, sibling relationships can provide important sources of support through the life course (Diener et al., 2014, p. 1060).

It is more common to have rivalry and conflicts between siblings in childhood than in adulthood. Compared to childhood, adulthood provides usually more support and safety nets than conflicts between siblings. (Tanskanen & Danielsbacka, 2021, p. 25.) According to Tanskanen and Danielsbacka (2021, p. 28), the quality of sibling relationships in adulthood has its roots usually in sibling relationships in childhood. Therefore, the issues related to sibling relationships both in childhood and adulthood are processed here hand in hand. Several key factors can explain increased or decreased quality of sibling relationships in adulthood but some of these factors lack support of strong research findings. According to Tanskanen and Danielsbacka (2021, pp. 28–35), factors such as gender, genetic relatedness, childhood co-residence duration, unequal parental treatment and geographical proximity may influence the quality of sibling relationships. Instead, research studies considering factors such as number of siblings, order of birth, age difference or sosio-economical position are still providing contradictory findings (Tanskanen & Danielsbacka, 2021, pp. 30–32).

Considering gender, it seems that sibling relationships between sisters involve more support to each other than relationships between brothers or a sister and a brother. On one hand, relationships between sisters seem also to involve more conflicts than other sibling relationships. (Tanskanen & Danielsbacka, 2021, p. 28.) Considering the genetic relatedness and childhood co-residence duration in turn, it seems that the more siblings have shared genes the more contact and more emotional closeness their relationship probably contains (Tanskanen & Danielsbacka, 2021, pp. 28–29). On the other hand, Tanskanen and Danielsbacka (2021, p. 33) remark that people cannot recognise who have the same genes as they have. Therefore, the factor of genetic relatedness when explaining the quality of sibling relationships can also be explained through phenomenon that co-residence with other people in childhood confirms the sense of being related (Tanskanen & Danielsbacka, 2021, p. 33). In addition, co-residence in childhood can also explain why siblings without genetic relatedness, like adopted siblings, can have a sibling relationship with a good quality.

Regarding unequal parental treatment, it seems that distributing treatment for siblings in unequal way may influence the quality of sibling relationships especially during childhood and adolescence but even in adulthood. This phenomenon is based on sibling's ability to observe relationships between other siblings and their parents and notice unequal treatment by the age of three. The influence of unequal parental treatment can lead, for instance, to challenging behaviour of a sibling, and can, at worst, be remembered even in adulthood. (Tanskanen & Danielsbacka, 2021, pp. 34–35.) Finally considering the geographical proximity especially in adulthood, it seems that the longer distance adult siblings have the less contact they take to each other (Tanskanen & Danielsbacka, 2021, pp. 32–33).

As a bridge between childhood and adulthood is adolescence, which is a more or less tumultuous phase for re-examining and restructuring one's social relationships. Sibling relationships may provide a significant support in the middle of these tumultuous processes. (Milevsky, 2021, pp. 126–127.) According to Milevsky (2021, pp. 133–134), a good quality of sibling relationships can be linked to many psychological benefits such as good self-esteem, academic achievements, getting support under some family distress or, to some extent, compensating for a lack of support of friends or even parents. A cornerstone of adolescence is shaping one's identity, and especially older siblings often have an essential role even in this process. In some cases, siblings are modelling their older siblings, which make them to pursue similarities with them. In other cases, siblings choose a deidentification process to avoid similarities and to create a unique identity compared to their older siblings. (Milevsky, 2021, pp. 126–127.)

During adolescence it is natural that relationships with friends get stronger and closer than relationships with siblings (Milevsky, 2021, p. 128) but still sibling relationships may also remain close. According to Milevsky (2021, pp. 128–132), some factors can predict how the quality of sibling relationships may develop during adolescence. Still, Milevsky (2021, p. 133) reminds that it is complicated and challenging to predict how these individualistic factors influence due, for example, to the fact that these factors also interact with each other. Some predictive factors are age difference, birth order, gender, influence of parents, socio-economic status of a family and cultural differences (Milevsky, 2021, pp. 128–132). The quality of sibling relationships during adolescence may be better when age differences are large and when both siblings are sisters rather than brothers or same gender rather than different. Also, when parents provide a good model of their own relationship, parents are not favouring any of the siblings and parenting style is both demanding and responsive the quality of sibling relationships during adolescence may increase. Finally, when sosio-economic status of a family is good and when a family lives in a culture that values sense of community the quality of sibling relationships may develop to a good direction during adolescence. (Milevsky, 2021, pp. 128–132.)

When a sibling has a (dis)ability, it influences both a sibling relationship and the entire network of interaction relationships within a family in a unique way (Takataya et al., 2019, p. 337; Kramer et al., 2021, p. 258). Among others, the type and level of the (dis)ability (Takataya et al., 2019, p. 337) and the possible role strain of being both a caretaker and an able-bodied sibling (Hanvey et al., 2022, p. 937) influence the relationships in the family. For instance, according to Levante and others (2023, p. 6), an able-bodied sibling who takes care of a sibling with neuropsychiatric or multiple (dis)abilities will more often face difficulties when caretaking compared to an able-bodied sibling whose sibling has some physical (dis)ability. In addition, Levante and others (2023, p. 6) have shown that an intensive role of a caretaker can increase the distress of an able-bodied sibling and decrease the quality of the relationship between an able-bodied sibling and their parents. Both aspects can in turn influence the quality of the sibling relationship negatively (Levante et al., 2023, p. 6).

In addition, people's attitudes towards (dis)ability can influence a sibling with a (dis)ability and other family relationships (Takataya et al., 2019, p. 337). According to Múries-Cantán and others (2023, p. 193), family's experiences about (dis)ability influence the perceptions of the quality of life and family's interactions with surrounded society and communities. However, a family system has a good opportunity to support the wellbeing of both a sibling with a (dis)ability and an able-bodied sibling if siblings encounter negative attitudes considering (dis)ability: a family as a first social environment for siblings can help to promote development, quality of life and identity construction (Múries-Cantán et al., 2023, p. 193).

The availability of good-quality social support such as supportive relationships and communities is significant when considering wellbeing of able-bodied siblings (Kramer et al., 2021, p. 261; Levante et al., 2023, p. 8). For instance, Hanvey and others (2022, pp. 937–938) have claimed that peer support can promote the wellbeing of the able-bodied siblings because meaningful and supportive peer relations increase the possibilities to be understood which can decrease experiences of isolation, sadness, anxiety and depression. According to Buchanan and Rotkirch (2021, p. 6), there are four types of social support: emotional or psychological support provides e.g. empathy, instrumental support e.g. services, informational support e.g. useful information and companionship support such as shared social activities. All these types of social support are needed for able-bodied siblings throughout their life courses.

Considering the social support from childhood to adolescence, it is important for an able-bodied sibling to understand (dis)ability and have possibilities to reflect their emotions. According to Kramer and others (2021, p. 266), an able-bodied sibling must be told about (dis)ability in a way, which takes age into account. Hence, misunderstandings may be more likely avoided when an able-bodied sibling will, for instance, not be afraid that (dis)ability is somehow contagious. In addition, understanding (dis)ability contributes an able-bodied sibling strengthen engagement with their sibling with a (dis)ability (Kramer et al., 2021, p. 266). For instance, (dis)ability can influence development of communicational skills. Thereby, a sibling with a (dis)ability may have a need to use some augmentative or alternative communication method. (Webb et al., 2023 p. 157.) An able-bodied sibling needs information and guidance to utilise the same communication method their sibling with a (dis)ability utilises to be able to communicate and play with their sibling with a (dis)ability. From third point of view, when understanding (dis)ability, an able-bodied sibling may be better prepared to deal with other people (Kramer et al., 2021, p. 267). According to Kramer and others (2021, p. 267), when an able-bodied sibling constructs responses in such situations where other people for instance stare or bully someone because of their (dis)ability an able-bodied sibling benefits from understanding (dis)ability. In addition, an able-bodied sibling may also face mixed feelings and psychological difficulties (Hanvey et al., 2022, p. 937). Sibling can for instance be sad about how the (dis)ability influences their family, embarrassed about the (dis)ability or jealous about the attention their sibling with a (dis)ability receives. These feelings are important to be reflected with someone to avoid for instance longer-term anxious. (Kramer et al., 2021, p. 267.)

Considering the social support from adolescence to adulthood, it is of importance to provide support to an able-bodied sibling especially related to responsibility issues. According to Kramer and others (2021, p. 269), it is common that an adult able-bodied sibling takes a role as a caretaker to provide informal or formal support. Informal support is quite practical such as helping a sibling with a (dis)ability to go shopping or taking a sibling with a (dis)ability to medical appointment. Formal support means that an able-bodied sibling can be for instance an official contact person between a housing unit of the sibling with a (dis)ability and their family or that able-bodied sibling can participate in formal decision making related to the sibling with a (dis)ability. It is also important to note that families are different. For instance, in families with several family members several opportunities emerge to share responsibility issues. In small families, however, one family member may feel pressured to take care of a large amount of responsibilities. (Kramer et al., 2021, p. 269.) Therefore, it is important to have open conversations within a family to make sure that an able-bodied sibling knows what they are expected as caretakers. Also, it is important that an able-bodied sibling has not only emotional and companionship support offered by their family but also an access to instrumental and informational support as well.

A role of a caretaker with some responsibilities is not common only for adult but also for young siblings. According to Kramer and others (2021, p. 266), it is common that able-bodied siblings provide care and support for their sibling with a (dis)ability even in childhood. It is particularly important that a young able-bodied sibling will not take too heavy responsibilities. Too large amount of responsibilities may increase stress and worry, blur the line between being a sibling and a caretaker, lead to premature maturity (Kramer et al., 2021, p. 266) and increase life dissatisfaction (Levante et al., 2023, p. 7). In addition, especially adolescents and young adults may be worried about what happens when parents cannot provide support anymore. Also, they may be worried about not finding a partner who is willing to share responsibilities related to their sibling with a (dis)ability, managing with various responsibilities if they get own children (Kramer et al., 2021, pp. 266–267) and combining working life and the role of a caretaker (Levante et al., 2023, p. 7). Therefore, it is important to support young able-bodied siblings in a way that the possible role of a caretaker will not complicate plans related to their own future.

3 Implementation of the Study

In this chapter I will introduce my research task and question and the underlying methodological starting points. I will also discuss the processes of data collection and analysis and the research ethics in this study.

3.1 Research Task and Question

The research task of this study is to analyse experiences of special sibling relationships based on the Sibling Embedded Systems Framework (SESF). The study includes arts- and creativity-related workshops where participants first memorise their different life stages and then focus on exploring their own experiences of their special sibling relationship during those life stages. The purpose is that participants can share their experiences, feelings and thoughts considering their special sibling relationship with peers and thereby experience support and understanding. In addition, the purpose is to create such an arts- and creativity-related ground where participants can achieve affordances to expand their insights beyond analytic thinking.

My research question is: In what ways do adult siblings describe their experiences of their special sibling relationship after participating in arts- and creativity-related activities?

3.2 Methodological Starting Points

This study is an empirical qualitative and Arts-Based Research (ABR), which leans on verbal data. Qualitative research is an appropriate approach when people’s life experiences are explored because it values people’s subjective experiences, meaning-making processes and depth of understanding (Leavy, 2017, p. 9). Through various art forms, ABR enables the exploration of people’s lives to be expanded from verbal and intellectual ways to emotional, sensory, embodied and imaginative ways. Thereby, ABR enables an access also to those dimensions, which may otherwise remain unnoticed when conducting language-based research. (Blodgett et al., 2013, p. 313.) Applying the combination of qualitative research and ABR enabled me to produce descriptive, rich, authentic and imaginative data to find and understand the deep meanings participants give to their special sibling relationships (Coemans & Hannes, 2017, p. 41; Leavy, 2017, p. 9).

In this study, I applied music- and movement-related activities to evoke participants' memories considering their childhood and adolescence for group interviews. According to Leavy (2020, p. 129, p. 163), both music and movement have capabilities to evoke emotions, memories and experiences. Music and movement are both strongly embodied art forms, and because of the embodied nature of experiences (Leavy, 2020, p. 133, p. 163), engaging in music, both making and listening to it, and movement enables participants to reach out their experiences in a multidimensional way.

I applied also visual arts related activities to reflect participants' feelings and thoughts considering present and future. According to Leavy (2020, p. 236), visual arts enable multiple ways of interpretation. Reflecting one's present and future in and through visual arts and in a group provides opportunities for other participants to reflect on their present and future in and through the visual arts created by other participants.

In addition, I applied arts related activities to create a safer space and relaxed atmosphere before collecting verbal data. For instance, according to UN Association of Finland (2024), a safer space means such a space where people are expected to respect physical and psychological space, experiences and opinions of others, to give space in conversations and not to make assumptions. According to Coemans and Hannes (2017, p. 41), arts related activities are able to provide excellent possibilities to create a safer space for dialogue and self-expression. In addition, Norris and others (2020, p. 5) describe how engagement in arts related activities enables presence in the moment and creates connections between people so that people can see each other and be seen. Engaging arts related activities does not only create connections between other people but it can also create connections to oneself. With these connections it is possible to achieve personal transformation, which can include for instance increased wellbeing (Coemans & Hannes, 2017, p. 41; Norris et al., 2020, p. 5). Hence, I utilised embodied arts related activities to create a ground for participants to express themselves, create connections both with themselves and with the other participants and experience providing and receiving impulses in approving atmosphere.

When participants express themselves or create connections both with themselves and with the other participants, the arts- and creativity-related ground is aimed to provide affordances for participants. Affordances are related to such environmental features that contribute to the interaction between an agent and environment (Greeno, 1994, p. 338). For instance, arts- and creativity-related activities can provide opportunities to process life experiences. However, the interaction between an agent and environment needs not only affordances but also such abilities of the agent that contribute to the interaction between the agent and environment (Greeno, 1994, p. 338). In other words, affordances and abilities are fundamentally related to each other: without abilities there is only an opportunity to action, but no actual action. Essential when considering abilities are motivation to engage in some certain activity and ability to achieve perceptions. (Greeno, 1994, pp. 338–340.) For instance, arts- and creativity-related activities can provide opportunities to process life experiences but the agent is required to be motivated to engage in arts- and creativity-related activities and abled to achieve perceptions related to these activities to achieve provided affordances. Finally, it is important to notice that affordances are not only physical features of environment but they can also be social features (Windsor & de Bézenac, 2012, pp. 110–111). In other words, engaging in arts- and creativity-related activities together as a group enables participants to provide affordances to other participants (Windsor & de Bézenac, 2012, pp. 110–111).

3.3 Data Collection

To collect data I organised two workshops for participants who are adults and who have or have had a sibling with a (dis)ability. These workshops included both arts- and creativity-related activities and unstructured group interviews with a light plan and a conversational style. I chose group interview as a data collection method because group interview enables participants to be stimulated by others, which can help them to recall memories. Hence, group interview processes probably lead to richer data than individual interview processes. (Flick, 2009, p. 196.) I decided to conduct group interviews as unstructured interviews with a few open-ended questions decided beforehand. Hence, I was able to follow those experiences, feelings and thoughts participants reach in, through and after arts- and creativity-related activities considering their own special sibling relationship. An open plan and a conversational style increase participants' role in deciding what experiences they want to share and reduce the effect of my potential pre-assumptions on the data (Blodgett et al., 2013, pp. 319–320). All interviews were audio-recorded by Zoom H2n Portable WAV/MP3 Recorder to collect verbal data.

These workshops were arranged in co-operation with two local associations who work both with people with (dis)abilities and families with a family member with a (dis)abilities. Both associations shared invitation letter by e-mail to their own members and some letters were shared at the offices of the associations. The associations also made social media publications of the invitation letter and these publications ware shared in Instagram and Facebook by the associations, by myself and by some private persons. Registration time was initially from the beginning of March to the end of April, but due to a lack of participants, the registration time was extended to the beginning of May. At the end, four participants signed up, which was enough to collect a data for the purpose of this study. In addition, another of the associations also offered a space for the workshops for free.

The first workshop was in May 2024 and it lasted nearly two hours. Before this workshop, the participants had received an information sheet considering this study in advance by e-mail. In the beginning of this workshop, I introduced myself and explained where the idea of this study came from. Then we went through the information sheet and the participants signed the consent forms.

The participants did not know each other beforehand so we utilised an exercise related to visual arts to get to know each other. I had spread some postcards with various visual images on the table and the participants chose one card that somehow described them. According to Leavy (2020, p. 236), visual arts can evoke multiple meanings depending on a viewer and a context. In addition, visual arts can evoke such emotional and visceral responses that arise from subconscious or far away from conscious control (Leavy, 2020, p. 236). Thus, postcards with various visual images provided both a freedom and intuitive impulses to the participants to choose what do they want to share about themselves. Probably this activity also provided the participants some help to detach themselves from analytic thinking and possibility to get surprised. After introducing ourselves, we talked about safer space guidelines and the participants were free to tell what made them feel safe in situation where people are sharing personal experiences.

According to Tanskanen and Danielsbacka (2021, p. 26), sibling relationships in adulthood have usually several roots in sibling relationships in childhood. Therefore, after postcards we started to approach our experiences in childhood as a main topic for the first workshop. We utilised a three-phase activity related to movement, sound and game. In the first phase, we listened to womb sounds while we were standing in the space. The participants were allowed to close their eyes if they wanted and they were instructed to concentrate on their own body and mind. I facilitated this phase by asking questions like “What is in your mind?”, “What are you feeling right know?” or “Is your body still or moving?”. After concentrating on inner feelings and thoughts we started to walk freely in the space and thus started to step towards the second phase. We turned the focus from ourselves to the physical space and others. I gave the participants playful instructions like “Move near the walls.”, “Move near the chairs.”, “Take eyes contact with others.”, “Move in the same pulse as someone else.”, “Pass people behind them.” or “Walk between two people.”. Finally, we started the last phase, which was a playful name rhythm game. We were imitating our names, playing with sounds and experiencing a common pulse. The aim of this three-phase activity was to further familiarise the participants with each other and the space. In addition, because experiences are living in our bodies and therefore they can be reached out by engaging in embodied activity, such as making music and movement (Leavy, 2020, p. 133, p.163), the aim was to return to childhood, the beginning of the life, through rhythm as a primitive embodied element and playfulness as an essential embodied part of childhood. After this activity we had our first group interview considering participants’ experiences of their special sibling relationship during their childhood. After finishing the first workshop, I wrote some notes in my research diary. Notes were mostly related to the conducted activities to help me to remember what did we finally do.

Second workshop was in June 2024 and it lasted nearly two and a half hours. In this workshop we had three focus points: adolescence, which is equally important life stage with childhood when processing sibling relationships in adulthood (Tanskanen & Danielsbacka, 2021, p. 36), present and future. After asking how everyone is doing and describing what we are going to do this time, we started an activity related strongly to music but also to movement. I called this activity “Teen Radio” and it was created based on a phenomenon according to which music has a significant role in adolescence (MacDonald & Saarikallio, 2022, p. 732). In adolescence, music can be a ground for shaping identity through, for instance, exploring, negotiating and expressing social status, values or sexual identity. In addition, it is a space for both interpersonal processes, such as making friendships and group bonding, and internal processes, such as emotional self-regulation in the middle of personal experiences. (MacDonald & Saarikallio, 2022, p. 732.) Based on this meaningful role music commonly has in adolescence, I asked the participants before this workshop to share two songs which had been important for them in their adolescence. I had taken a sample of one minute from all of these songs and built a music collage of eleven minutes. In this activity, we listened through the collage by standing in a circle with a small instruction for movement. The participants had a task to choose one body part, which they could move through listening the music. They were allowed to change the body part while listening, take impulses from the movement by others, spread the movement to other body parts and decide the movement they wanted to do. The instruction was very loose because the aim was to give impulses for free movement. The aim of this activity was to recall memories from adolescent years through favourite songs and embodied music listening. After "Teen Radio" we had a second group interview concentrating on participants' experiences of their special sibling relationship during their adolescence.

Finally, we returned to the postcards the participants had chosen in previous workshop. I applied a metaphoric approach to enable the participants to reflect their present and future focusing on their special sibling relationship. In metaphoric reflection, feelings and thoughts can be processed through metaphors to evoke creativity and imagination, and this process can be augmented by creative self-expression (Schwind et al., 2019, p. 471). In the workshop, a metaphor of life being a flowing river was applied, and all the participants drew their own rivers to the backside of their cards with coloured pencils. I instructed them to start their rivers from present and draw them forward to the future. I also gave some small metaphoric impulses for starting the drawings but after all the participants had a full freedom to create their own interpretation of the task.

After drawing, we had our third group interview where the participants had a chance to share their thoughts and feelings by giving meanings to their visual rivers. According to Shcwind and others (2019, p. 471), a metaphoric reflection augmented by arts- and creativity-related activity can elicit richer dialogue with the creative representation and with the other people involved in the same process. At the end of the group interview we closed the circle by returning to the pictures of the postcards. In the beginning of the first workshop, the participants had introduced themselves through the cards. Now at the end of the second workshop, the participants reflected together through the same cards how their experiences of their special sibling relationship have influenced them through the childhood and adolescence to the present. After finishing the second workshop, I wrote again some notes in my research diary.

3.4 Data Analysis

The data consisted of 2 hours and 41 minutes of recordings and a research diary. I stored and organised my data after both workshops (Leavy, 2017, p. 150). For collected data I created two folders with a password in my own computer, which is not used by anyone else. One folder was for the audio recording made during the first workshop and other for two audio recordings made during the second workshop. In addition to the recordings, I had a research diary as a paper notebook, which included my own notes considering the workshops. The password protected folders including audio recordings were also backed up to my own hard drive which was only in my own use.

All the audio recordings were transcribed with Word to prepare the data for analysis (Leavy, 2017, p. 150). After completed the transcriptions that resulted of 53 pages of transcribed data the original audio recordings were destroyed both from the computer and from the hard drive. Then, the raw transcriptions were pseudonymised and finally destroyed both from the computer and from the hard drive. Both the raw and pseudonymised transcriptions were stored in the same folders as audio recordings. Before starting content analysis, I went through the pseudonymised transcriptions and my research diary and made some free notes to see my initial thoughts and feelings considering the data (Leavy, 2017, p. 150).

I chose qualitative content analysis as my analysis method. The aim of my analysis was to process subjective experiences collected through workshops so that the phenomenon can be described compactly and on a general level. In addition, I needed a method by which a text can be analysed systematically and objectively. Content analysis as a method fits these purposes well (Tuomi & Sarajärvi, 2018, p. 117). I started the content analysis by reading the pseudonymised transcriptions again and searching all the passages that were related to the experiences the participants had shared considering their special sibling relationship. I wanted to see all the coded passages and becoming categories at one glance so I wrote the coded passages on pieces of paper and spread them on the floor. In other words, I reduced my data, which is the first step when conducting a content analysis (Tuomi & Sarajärvi, 2018, pp. 122–124).

In the next phase of the content analysis I started to search similarities and differences between the codes with which I could start grouping the codes into larger and larger categories (Tuomi & Sarajärvi, 2018, p. 124). Finally, I named the categories, wrote the names on pieces of colourful papers and put the pieces of papers above the groups of codes and categories. Through the whole analysis process I found it easy to add, remove or rename the passages, codes and categories with the help of the physical pieces of papers.

Categories were divided into three larger categories: experiences in childhood, experiences in adolescence and experiences and thoughts about the present and the future. The first category was divided into five smaller categories: play during childhood, discussing sibling’s (dis)ability, roles of an able-bodied sibling, social networks of a family and other people’s attitudes towards a sibling with a (dis)ability. The second category was divided into two smaller categories: relations in adolescence and moving away from home. The last category was divided into five smaller categories: relations in adulthood, concerns considering the future, resources considering the future, wishes considering the future and influences of having a sibling with a (dis)ability.

3.5 Research Ethics

I committed to the basic principles of research ethics and integrity, which means taking reliability, honesty, respect and accountability into consideration throughout the whole research process (Finnish National Board on Research Integrity [TENK], 2023, p. 12). In the beginning of designing the study, two main ethical issues emerged: one considers the research topic and the other the participants (Leavy, 2017, p. 31). The topic of this study, exploring the experiences of adult siblings considering their special sibling relationship, emerged strongly from my own life as an adult able-bodied sibling having a sibling with a (dis)ability. Through my own experience, I could see the significance of this topic for people who have a sibling with a (dis)ability, who are parents of both siblings with (dis)abilities and able-bodied siblings and who are working with families with children with (dis)abilities and able-bodied siblings. My position made me a peer with the participants of this study, which may have helped the participants to share their experiences because I did not approach this topic as an outsider with pre-assumptions. On the other hand, I needed to understand that peers do not necessarily have the same experiences, which meant that I needed to be careful not to approach the shared experiences only through my personal lens.

The other ethical issue was to take the wellbeing and rights of the participants into consideration (Leavy, 2017, p. 31). When designing the implementation of this study, I processed carefully with my supervisor how to avoid potential harm, risks and negative effects when conducting the study with the participants. One important aspect was to admit that I am not a professional of the social and health care field, which meant that it was not ethical to conduct the workshops with participants who would have a very vulnerable life situation. Therefore, I mentioned in the invitation letter that the workshops are aimed at legal adults, they offer peer support and they are not suitable for dealing with an acute crisis situation or for therapy purposes.

In addition to considering the wellbeing and rights of the participants, I leaned on TENK (2019, p. 10) and sent information of the content, the implementation, the data collection and the data preserving of this study to the participants in advance by email. They were informed what it actually meant to participate in this study and how the study is conducted in practice. Potential harm, risks, benefits and effects of participating in this study were also introduced to the participants. (TENK, 2019, p. 10.) Considering the data preserving they were guaranteed that their personal data would be stored confidentially in accordance with current data protection legislation (TENK, 2023, p. 14). The participants received all the above information in writing in Finnish, which was a language the participants understood. The information was sent so well in advance that they had time to familiarise themselves with the information, ask questions if they wanted and consider whether they will participate or not. Participants' consent to participate in this study was documented in writing. The consent forms were digitised and stored in their own folder with a password in my computer. The original consent forms were destroyed safely. The password protected folders including the audio recordings and the consent forms were also backed up to my own hard drive, which was only in my own use. No ethics permission was needed, and co-operation partners were not requiring any ethics permission. (TENK, 2019, p. 10.)

The participants had also a right to participate voluntarily. This meant, they had a right to refuse to participate in this study and discontinue the participation whenever they wanted without any explanations or suffering any consequences. (TENK, 2019, p. 9.) In addition, it was important to be clear during the data collection that the participants had a right to participate in arts-and creativity-related activities in their own way or step aside if needed. It is always possible that people engaging in arts- and creativity-related activities may feel the engagement challenging (Blodgett et al., 2013, p. 327; Coemans & Hannes, 2017, p. 41). Therefore, a researcher needs sensitivity to find the best way for the participants to participate. As a professional educator from culture and arts field I was capable to be sensitive enough to support engagement in arts- and creativity-related activities.

When analysing the data and constructing findings and conclusions, it was important to take my position into consideration because I needed to acknowledge my own biases, values and attitudes to achieve as strong objectivity as possible (Leavy, 2017, p. 38). In addition, to construct reliable findings and conclusions I utilised especially pre-reviewed research articles, academic books and edited books that offered current knowledge.

4 Findings

This study included arts- and creativity-related workshops where participants first memorised their different life stages and then focused on exploring their own experiences of their special sibling relationship during those life stages. The purpose was that the participants could share their experiences, feelings and thoughts considering their special sibling relationship with peers and thereby experience support and understanding. In addition, the purpose was to create such an arts- and creativity-related ground where the participants can achieve affordances to expand their insights beyond analytic thinking. In this chapter I present how the data analysis answers to my research question, which is: In what ways do adult siblings describe their experiences of their special sibling relationship after participating in arts- and creativity-related activities?

I divided the categories generated through the data analysis into three large categories: 1) experiences in childhood, 2) experiences in adolescence and 3) experiences and thoughts about the present and the future. The first category is divided into five smaller categories: 1) play during childhood, 2) discussing sibling's (dis)ability, 3) roles of an able-bodied sibling, 4) social networks of a family and 5) other people's attitudes towards a sibling with a (dis)ability. The second category is divided into two smaller categories: 1) relations in adolescence and 2) moving away from home. The third and last category is divided into five smaller categories: 1) relations in adulthood, 2) concerns considering the future, 3) resources considering the future, 4) wishes considering the future and 5) influences of having a sibling with a (dis)ability. I approach these categories from the perspective of the Sibling Embedded Systems Framework (SESF), which is aimed to understand siblings' experiences and outcomes in families with children with (dis)abilities (Kovshoff et al., 2017, p. 38).

4.1 Experiences in Childhood

According to the SESF, the most central system for a child is a family as a microsystem among all the surrounding systems. In this microsystem three components–event(s), a family and an able-bodied sibling–are interacting together. (Kovshoff et al., 2017, pp. 40–41.) The participants described their relation with their sibling with a (dis)ability during childhood. According to the data analysis, they have had common ways to play with their siblings with (dis)abilities. The participants have for instance played with baby dolls and soft toys, games and card games and they have done some outdoor activities like skiing or skating. Some participants mentioned also that they have squabbled with their sibling with a (dis)ability like any siblings would do. All in all, the participants described that playing with their sibling with a (dis)ability was fun and natural, and they did not need any help from their parents to be able to play together.

The participants also discussed that they had not only common but also very unique experiences considering the ways they spared free time together with their sibling with a (dis)ability. In the context of SESF, event(s) as one component of a family as a microsystem can mean for example some certain factor of a sibling with a (dis)ability (Kovshoff et al., 2017, pp. 40–41). Data analysis shows two examples of factors that contributed to the unique experiences that emerged. One factor is that some siblings with (dis)abilities had assistive devices for moving. These devices were utilised in a creative way when playing, and thereby, the siblings with (dis)abilities were enabled to participate in the play. Another factor is a physical (dis)ability which meant that one sibling with a (dis)ability did para sports and the able-bodied sibling had a chance to participate too. These experiences were still memorised with joy:

> Of course, I wanted to enable experiences for my sibling (with a (dis)ability). So, my sibling had a wheelchair and sometimes we went out

> to run a rally. I can still remember how my sibling giggled when we did tight twist and turns with the wheelchair. (*Participant 4*)

According to the data analysis, the (dis)ability of the sibling also had a restrictive effect on playing. Data analysis shows that if the sibling had a physical (dis)ability, siblings could not play physical plays and games together. Instead, they for instance played card or board games which enabled the sibling with a (dis)ability to join too. Sometimes the able-bodied sibling felt sorry because they could not play with their sibling with a (dis)ability in the same way they could with their friends. If the sibling with a (dis)ability had a cognitive (dis)ability, siblings were playing together especially when their cognitive capabilities were at the same level.

Some participants described how their parents told them about sibling's (dis)ability and thus supported their sibling relationship. According to SESF, three factors within an able-bodied sibling may influence their experiences: demographics, genetic or psychological internal challenges and recourses and personal interpretation of event(s) (Kovshoff et al., 2017, pp. 40–41). When approaching participants' experiences of joint play during childhood through the factor of personal interpretation of event(s), it is important that their parents have discussed sibling's (dis)ability with them. According to Kramer and others (2021, pp. 266–267), discussing (dis)ability so that age is taken into account will more likely reduce misunderstandings and uncertainty. The data analysis shows how discussions supported the able-bodied sibling to understand why the sibling with a (dis)ability was, for instance, behaving in a certain way, unable to participate in certain plays, visiting hospital or stared at a street. Understanding in turn could support the able-bodied sibling to interpret various events and thus increase the wellbeing of the able-bodied sibling:

> When I was a child, I remember my parent saying that my sibling (with a (dis)ability) is kind of special but still the sibling must be treated equally when playing. And when discussing the (dis)ability I was told what it

> means so that I could understand why my sibling visits for instance hospital. (*Participant 2*)

In a way, discussing (dis)ability can also support engagement with a sibling with a (dis)ability (Kramer et al., 2021, p. 266) and therefore increase the quality of the sibling relationship through increasing the possibilities to create such a companionship which represents siblings own way to interact together and love and take care of each other (Chu et al., 2021, p. 796; Diener et al., 2014, p. 1060; Múries-Cantán et al., 2023, p. 193). On the other hand, data analysis shows that all the parents did not discuss sibling's (dis)ability. The participants felt that childhood experiences were partly hard to remember which means that discussions about (dis)ability may have happened but the adult able-bodied siblings cannot remember it, or then discussions were embedded in everyday lives of their families in a way that the participants have not even noticed it.

According to the data analysis, the participants described three different roles they took in their family: a helper, a caretaker and an over-independent child. As clearly in line with Kramer and others (2021, p. 266), the participants described how they took their roles as a helper and a caretaker naturally. The participants did not experience that they had been forced by their parents to take any role. Instead, the participants themselves experienced that they wanted to help and take care. Still, the data analysis shows that parents were influencing the role to some extent, which is, according to Kramer and others (2021, p. 266), also natural. For instance, if siblings were playing with other children, the able-bodied sibling was in some cases instructed by their parents to take care that playing is not making any harm for the sibling with a (dis)ability. The data analysis shows that the third role, an over-independent child, included an idea that the able-bodied sibling did not want to worry their parents because the sibling with a (dis)ability required considerable attention from their parents:

> When I was young, I thought that I am persistent and I can manage by myself. I did not want to worry my parents. My sibling (with a (dis)ability)

> required so much attention from our parents so I did not want to ask attention to myself. (*Participant 3*)

According to Kramer and others (2021, p. 266), this role was probably developed when the able-bodied sibling was drifted to take too much responsibility for themselves.

According to the SESF, when approaching the roles of able-bodied siblings through the factor of genetic or psychological challenges and resources within an able-bodied sibling, both potential challenges and resources can be recognised. Learning to help and take care of people strengthens empathy skills, which present a significant psychological resource. On the other hand, when learning empathy skills, it is also important to learn to set healthy boundaries so that one’s own wellbeing is being ensured (Raatikainen et al., 2022, p. 411). A lack of healthy boundaries may get an able-bodied sibling, for instance, to overestimate the challenges their parents may face which in turn may hide the needs of an able-bodied sibling from their parents.

Still, family is not the only microsystem where a child is interacting (Kovshoff et al., 2017, pp. 41–42). The participants discussed also their friends, neighbourhood, relatives, cousins, other families who have been friends with their childhood family and associations related to people with (dis)abilities. According to SESF, the above-mentioned social systems are also microsystems where an able-bodied sibling interacts, and these microsystems create the mesosystem around an able-bodied sibling (Kovshoff et al., 2017, pp. 41–42). These microsystems are also a significant source of social support that an able-bodied sibling needs throughout their life course (Buchanan & Rotkirch, 2021, p. 6).

The data analysis shows that friends were important for the able-bodied siblings. According to data analysis, the participants’ friendships were supported by their parents, friends’ parents and teacher. Some participants had explained for their friends about the (dis)ability of their sibling but not all. Those who had not explained about the (dis)ability experienced that friends had also grown with the fact that their friend had the sibling with a (dis)ability and they were used to this situation. The participants were open-minded when telling their friends about their sibling’s (dis)ability. In some cases, both parents of the able-bodied sibling and parents of their friends did talk about the (dis)ability and how it may affect for the friends. In one case, the teacher in school told to the whole class about the sibling’s (dis)ability. It seems that especially parents have an important role when supporting both agency of an able-bodied sibling within different microsystems and interaction between a family of an able-bodied sibling and other microsystems. In addition, when referring parents discussing the (dis)ability with an able-bodied sibling discussed earlier in this chapter, parents can also support agency of an able-bodied sibling through discussion about (dis)ability. As Kramer and others (2021, p. 267) also state, a vocabulary and explanation appropriate for certain age gives an able-bodied sibling useable ways to explain (dis)ability independently for instance to their friends.

In addition, neighbourhood, relatives, cousins, other families and associations were described by the participants when discussed people who were part of their life in their childhood families and who provided social support for the whole family. According to the data analysis, neighbourhood, cousins and other relatives were supporting the family especially when the parents of the participants were discussing the (dis)ability open-mindedly with other people, if neighbours and relatives had grown with the sibling with a (dis)ability and if the sibling with a (dis)ability did not seem to be different. Still in some cases, neighbourhood, cousins and other relatives were not supporting the family. The sibling with a (dis)ability may have had behavioural challenges which has been difficult for other people to understand. Some people seemed to have problems to react to the behaviour of the sibling with a (dis)ability and they probably chose not to take contact at all. In other words, it seems to be easier to families to interact in the mesosystem when the microsystems around families discuss (dis)ability and are familiar with it or when a sibling with a (dis)ability has quite easy behaviour.

One group of microsystems, which deserves special attention, is organisations. By organisation it is referred to associations providing activities for families with a family member with a (dis)ability. According to the data analysis, some childhood families participated actively in activities organised by associations and thereby the able-bodied siblings had possibilities to experience for instance spa, skiing competitions or camping. Some participants had even worked in associations when they were older. Such organisations have a significant potential when providing social support both for a whole family with a family member with a (dis)ability and some certain family member: “There was all kind of events for all of us and probably there was something related to the certain (dis)ability for the adults. Quite much doing things together and supporting each other.” (*Participant 1*) A particular aspect that distinguishes these organisations from other microsystems is that they enable meeting peers more likely than the other microsystems. According to Hanvey and others (2022, pp. 937–938), peer support can promote the wellbeing of able-bodied siblings through the increased possibilities to be understood which in turn can decrease for instance experiences of isolation sadness, anxiety and depression. Due to this, all families with a family member with a (dis)ability should have opportunities to participate in activities of organisations of people with (dis)abilities.

4.2 Experiences in Adolescence

According to the data analysis, experiences in adolescence have a strong emphasis on relations within the family. The participants discussed especially their relation with themselves and with their sibling with a (dis)ability but also with their parents. According to Milevsky (2021, p. 126), this is natural because adolescence is a time for shaping one’s identity and re-examining and reconstructing one’s social relationships–including family relations. During adolescence it is also common to take distance to parents and sometimes to siblings too (Milevsky, 2021, p. 126, p. 128). The participants described how they took distance to the whole childhood family. For some participants taking distance was unconscious and they only realised the distance taking in adulthood. Some participants described that they wanted to have time and space for themselves. Therefore, they liked to spent time by their own or do less things together with their sibling with a (dis)ability. The sibling with a (dis)ability may have been very talkative and may have tried to get into the room of the able-bodied sibling all the time which bothered the able-bodied sibling. In other words, the needs of both an able-bodied sibling and a sibling with a (dis)ability may be hard to combine. According to the SESF, being unable to get own space in the middle of the independent process may have been such a psychological challenge for the able-bodied sibling that may have brought challenges to the sibling relationship.

When discussing the relation between the sibling with a (dis)ability and the able-bodied sibling, the participants described both aspects which supported the relation and aspects which weakened the relation. When approaching these aspects or events through SESF, it seems that cognitive, communicational and behavioural factors are central events when assessing the quality of the special sibling relationship. According to the data analysis, if the sibling with a (dis)ability did not have cognitive, communicational or behavioural challenges, the able-bodied sibling experienced that the relation with the sibling with a (dis)ability was good. If the sibling with a (dis)ability had cognitive or communicational challenges but no behavioural challenges, the able-bodied sibling experienced too that the relation with the sibling with a (dis)ability was good. Then, if the sibling with a (dis)ability had behavioural challenges, the able-bodied sibling experienced that these challenges weakened their relation. The able-bodied sibling may have been embarrassed because of the behaviour of the sibling with a (dis)ability. Therefore, the able-bodied sibling did not want to tell their friends about their sibling with a (dis)ability and be with the sibling with a (dis)ability in public space. The data analysis shows that events related to behavioural challenges can influence the feelings of an able-bodied sibling and the quality of their sibling relationship. This statement is supported by, among others, Chu and others (2023, pp. 795–796).

Even though the participants understood that they needed space and distance, they may have felt confused when thinking about the relation with their sibling with a (dis)ability: “I felt sorry (about taking distance to the sibling with a (dis)ability) but still I could recognise why I needed my own time so much.” (*Participant 2*) The able-bodied sibling may have felt guilty or sorry when taking distance with their sibling with a (dis)ability because the able-bodied sibling may have been a very important social support for the sibling with a (dis)ability. According to the SESF, the able-bodied sibling may have interpreted the sibling with a (dis)ability lacking social support because of the selfish act made by the able-bodied sibling when taking distance and own space. For instance, one participant described how their sibling with a (dis)ability did not have own friends or leisure activities to participate in. Therefore, the able-bodied sibling was socially an important person for the sibling with a (dis)ability. Actually, this experience shows how important it is to support also a sibling with a (dis)ability within their own friendships and leisure activities. It may not help only a sibling with a (dis)ability but also an able-bodied sibling when an able-bodied sibling do not need to feel to be the only one in the life of their sibling with a (dis)ability.

The data analysis shows that the able-bodied sibling may have felt sorry about the embarrassment experienced in adolescence even in adulthood. According to Kramer and others (2021, pp. 266–267), it is important that an able-bodied sibling has a possibility to discuss their difficult thoughts and emotions with someone when those thoughts and emotions emerge. According to the SESF, all the reliable relationships within the central microsystems of an able-bodied sibling are potential when trying to find someone with whom an able-bodied sibling can reflect their thoughts and emotions. However, parents as a part of the most central microsystem of an able-bodied sibling have a crucial role when discussing thoughts and emotions with an able-bodied sibling. Therefore, parents in turn may need support to have these discussions and, from this point of view, various organisations working with parents with children with (dis)abilities have an essential role to support the parents.

In addition, parents getting supported by organisations working with parents with children with (dis)abilities may also get beneficial information and advice how to support, not only the sibling relationship or wellbeing of individual siblings, but also the relationship between parents and able-bodied siblings. For instance, when discussed processes of moving away from home, the data analysis shows that if a sibling with a (dis)ability moves away from home before an able-bodied sibling does, the relation between an able-bodied sibling and their parents may change. One participant described how they got more time and attention from their parents when the sibling with a (dis)ability moved away from home and was not anymore requiring time and attention. This change was described as nice and luxurious.

In addition to the mesosystems, families are living also within wilder systems: exo- and macrosystems. Exosystem includes for instance local political and social structures and macrosystem cultural attitudes and ideologies considering (dis)abilities. (Kovshoff et al., 2017, pp. 41–42.) In other words, for instance quality and accessibility of societal services and ableist attitudes towards (dis)ability may also influence the interpretations of events made by an able-bodied sibling. According to Múries-Cantán and others (2023, p. 193), ableism influences a whole family by affecting both their perceptions of the quality of life and their interactions with a surrounded society and communities. As an example, data analysis shows that during adolescence one participant started to understand better what did the (dis)ability of the sibling mean. This participant thought that because of the (dis)ability their sibling had a difficult life situation. This made the able-bodied sibling value health and wellbeing and feel happiness not to have any (dis)abilities themselves. Such thoughts caused guilty feelings to the able-bodied sibling:

> I do not know if it is wrong to say but I felt happy not to be in the same kind of situation (as the sibling with a (dis)ability). Sometimes I even had a bit guilty conscience when thinking this way. (*Participant 4*)

It may be that treatment and care were not the best for the sibling with a (dis)ability or then physical structures, institutional norms and social attitudes restricted the life of the sibling with a (dis)ability and therefore the able-bodied sibling had mixed feelings.

Some participants discussed also their relation to their friends and peers who also had siblings with (dis)abilities. Some participants had peer support during adolescence and some not. According to the data analysis, having peers was experienced as an awesome thing. Most important was to share the same situation with someone else that understood the situation: “It was an awesome feeling. I was excited that someone understands me and therefore I could tell about everything.” (*Participant 3*) This experience is supported by Hanvey and others (2022, pp. 937–938) who have argued that peer support can promote the wellbeing of an able-bodied sibling because meaningful and supportive peer relations increase the possibilities of being understood.

4.3 Experiences and Thoughts about the Present and the Future

By adulthood, sibling relationships provide usually more support than conflicts (Tanskanen & Danielsbacka, 2021, p. 25), which can also be shown in the data analysis. The participants described experiencing their relationship with their sibling with a (dis)ability good now in adulthood. Some participants described how the relationship with their sibling with a (dis)ability is close again after the distance they took in adolescence. They also described that now when both siblings are adults and they are living their own lives it varies how much they keep in touch.

In adulthood, siblings may become part of a new microsystem, also called a family. In this family siblings are adults and possibly parents themselves. According to the data analysis, the able-bodied siblings experienced that the interaction between these microsystems–their own family, their childhood family and the family of the sibling with a (dis)ability–appears as life events (for instance birthdays, weddings or funeral), visiting each other, sending messages, phone calls and meeting each other in their childhood home and thus strengthens their special sibling relationship.

The participants discussed their concerns and resources considering their family relationships. Three main topics emerged according to the data analysis: an able-bodied sibling having a baby, responsibility issues and services and information. These findings are clearly in line with Kramer and others (2021, pp. 266–267), who state that it is common that an able-bodied sibling can be worried about having a baby or taking responsibilities related to a sibling with a (dis)ability. When approaching these topics from the perspective of an able-bodied sibling doing personal interpretation of events, the data analysis shows that the scope and intensity of sibling's (dis)ability influence the interpretation. This finding is in line with Takataya and others (2019, p. 337), who state that the type and level of (dis)ability influence family relationships. In the context of an able-bodied sibling having a baby, some participants were worried about having an own baby. They were wondering how their sibling with a (dis)ability would react to the baby, how the relationship with their sibling with a (dis)ability could change and how to tell to their sibling with a (dis)ability that there is a baby on the way, especially if the sibling has cognitive challenges. A sibling with a (dis)ability may also have a strong preconception about their sibling having a baby which may also strengthen able-bodied sibling's concern. It seems, the more a sibling with a (dis)ability has cognitive and communicational challenges the more an able-bodied sibling may be concerned how their sibling with a (dis)ability finally relates to the baby:

> It is not sure if my sibling (with a (dis)ability) could understand what I am saying (about having a baby). And then, I could not be sure what my sibling answers because the sibling is not familiar with the words related to this topic. (*Participant 1*)

In the context of responsibility issues, the data analysis shows how the able-bodied sibling interpreted that the more independent the sibling with a (dis)ability was the less the able-bodied sibling thought they need to take responsibilities. Still, data analysis also shows that the able-bodied sibling is in any cases aware of the possibility that they may need to take some responsibilities related to their sibling with a (dis)ability. In addition, if the approach to these responsibility issues is changed from interpretation aspect to the aspect of other people being part of the microsystems of the families, other sibling(s) and partner are mentioned according to the data analysis. The data analysis shows that if a childhood family includes other sibling(s), an able-bodied sibling is less concerned about taking responsibilities because it is possible to share the responsibilities. Instead, if a childhood family does not include other sibling(s), an able-bodied sibling may be concerned whether they are capable to carry responsibilities related to a sibling with (dis)ability. Kramer and others (2021, p. 270) highlight the importance of peer support when considering some direct support for adult able-bodied siblings. Perhaps other sibling(s) could be somehow interpreted as peer support. Anyway, other sibling(s) can provide a significant support related to responsibility issues for each other.

According to Kramer and others (2021, pp. 266–267), it is common that an able-bodied sibling is worried about finding a partner who will value a sibling with a (dis)ability and is willing to share responsibilities related to a sibling with a (dis)ability. Related to this, a partner can be considered one of the potential individuals who can provide social support to an able-bodied sibling. The data analysis shows, that if an able-bodied sibling has a partner, they may not be so concerned because their partner is supporting the able-bodied sibling. In other words, an able-bodied sibling may have a chance to share such concerns with their partner which are not possible to share with a sibling with a (dis)ability. For instance, one participant felt sad because it was not possible to share the ageing of their parents with their sibling with a (dis)ability. Instead, the participant was sharing the ageing issue with their partner who supported the participant. In addition, the data analysis shows that if a sibling with a (dis)ability had a partner, an able-bodied sibling may not be so concerned about responsibility issues in future because the partner of the sibling with a (dis)ability is taking the responsibility.

Finally, in the context of services and information offered by society, the data analysis shows that the more a sibling with a (dis)ability needs services and assistance the more an able-bodied sibling is critical of available services and assistance. According to the data analysis, some participants were concerned but some pleased about the quality of the services organised by society. They also felt that information needed considering different services is well available. Still, a noteworthy point when approaching concerns and resources from the perspective of available services and information is that, according to the data analysis, the participants did not discuss systems included in exo- and macrosystems when discussing experiences in childhood or adolescence. According to the SESF, exosystem includes for instance local political and social structures such services and macrosystem includes cultural attitudes and ideologies related to (dis)abilities (Kovshoff et al., 2017, pp. 41–42). The data analysis shows that an able-bodied sibling is interested in factors of exo- and macrosystem particularly in adulthood. One probable explanatory aspect is that an able-bodied sibling is aware of the possibility that they may need to take responsibilities related to their sibling with a (dis)ability after their parents. In other words, they have not had to think about responsibility issues of this scale in childhood or in adolescence.

According to the SESF, one of the factors within an able-bodied sibling that influence a special sibling relationship is genetic or psychological internal challenges and resources of an able-bodied sibling (Kovshoff et al., 2017, pp. 40–41). The data analysis shows that uncertainty considering the future was one aspect when the participants described their concerns. For instance, some participants were concerned about the life expectancy of their sibling with a (dis)ability if the life expectancy is shorter than usual or unsure. An able-bodied sibling may wonder with uncertainty who dies first and what happens if it is a parent, a sibling with a (dis)ability or themselves who die first. Still, the data analysis shows also how resilience and trustfulness as supporting resources help coping with the concerns. Regarding to this, the participants for instance described that it is important to be open-minded and willing to experiment when for instance looking for a good housing arrangement for their sibling with a (dis)ability. This attitude helps to accept if some experiments do not go well. As another example from the context of having own baby, the data analysis shows that an able-bodied sibling feels getting supported with their concerns when remembering for instance that their sibling with a (dis)ability has been with babies at some stage of their life and that their sibling with a (dis)ability is good with babies. All in all, according to one of the participants: “There is no point in worrying twice: first beforehand and then when something is current.”

The participants discuss their wishes too. According to the data analysis, the participants hope that the relation with their sibling with a (dis)ability will last for the whole life even though they were both living their own lives. They wish that housing arrangements and services would remain good. In addition, the participants hope that their sibling with a (dis)ability could live healthy and meaningful life.

Finally, the participants reflected how their special sibling relationship has probably influenced them as a person. (Dis)ability has influenced the whole family. According to the data analysis, if the childhood family had not included a sibling with a (dis)ability, the whole growth environment would have been totally different and therefore the participants may have had different personality. The participants described also how their special sibling relationship has probably strengthened their resilience and given them new perspectives to life. In addition, special sibling relationship may also influence professional career, and therefore, an able-bodied sibling may finally work with people with (dis)abilities. Special sibling relationship can really support an able-bodied sibling despite all the struggles it may also bring with. Through the experiences of special sibling relationship an able-bodied sibling may also get beneficial perspectives which may help an able-bodied sibling to influence attitudes towards (dis)ability at many levels: “I have learned to explore this world in a certain way or from a certain perspective. So, without it (the sibling with a (dis)ability), there would not be this perspective either.”

4.4 Summary of the Findings

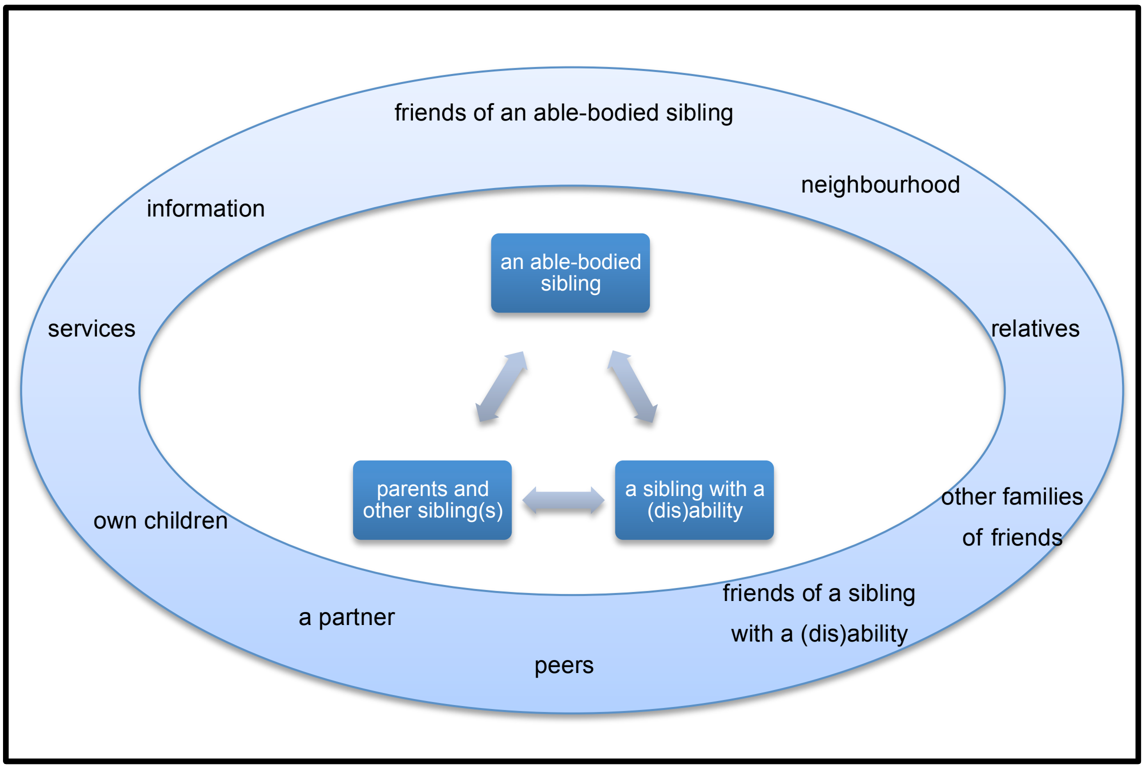

Figure 2. The summary of the findings. A family of an able-bodied sibling is in the centre, and the systems as providers of the social support are around them.

The data analysis shows how the participants process their family bonds when they discuss experiences, thoughts and feelings of their special sibling relationship in childhood, adolescence, present and future. In addition to the family bonds, they also discuss various systems, which have provided or are providing social support.

5 Conclusions

The research task of this study was to analyse experiences of special sibling relationships based on the Sibling Embedded Systems Framework (SESF). The study included arts- and creativity-related workshops where participants first memorised their different life stages and then focused on exploring their own experiences of their special sibling relationship during those life stages. The purpose was that participants could share their experiences, feelings and thoughts considering their special sibling relationship with peers and thereby experience support and understanding. In addition, the purpose was to create such an arts- and creativity-related ground where participants could achieve affordances to expand their insights beyond analytic thinking. My research question was: In what ways do adult siblings describe their experiences of their special sibling relationship after participating in arts- and creativity-related activities?

5.1 Key Findings

Key findings are related to the importance of social support when aiming at increasing the wellbeing of an able-bodied sibling through supporting the quality of special sibling relationship, providing ways to reflect one's mixed feelings related to the (dis)ability, helping the able-bodied sibling to have their own space in adolescence, supporting the able-bodied sibling to take responsibilities in a manageable way and helping the able-bodied sibling to plan the future. According to Buchanan and Rotkirch (2021, p. 6), there are four types of social support: emotional or psychological, instrumental, informational and companionship support. All these types of social support are needed for an able-bodied sibling throughout their life course. The findings explicate that in childhood the most important source of social support is provided by the parents of the able-bodied sibling. Support provided by the parents is significant during adolescence too, but the role of friends strengthens as an able-bodied sibling re-examines and reconstructs their relationships and takes probably distance to their parents. In addition, the findings explicate that organisations providing activities for families with a family member with a (dis)ability are also an important source of social support in childhood and adolescence especially because they can support an able-bodied sibling through supporting parents with their parenting and through enabling the able-bodied sibling to meet peers. However, in adulthood the findings explicate that important sources of social support are provided by the partner of both an able-bodied sibling and a sibling with a (dis)ability, other sibling(s) and (dis)ability services.

Based on the findings, the perspective of an able-bodied sibling needs to be taken into consideration throughout the life course. According to Levante and others (2023, p. 8), if an able-bodied sibling can process the positive aspects of having a sibling with a (dis)ability, the wellbeing of the able-bodied sibling will probably increase. Levante and others (2023, p. 8) also comment how increasing the awareness considering the social support provided to an able-bodied sibling by their family and health services can also increase their wellbeing. Hence when meeting a family with a child with a (dis)ability in social and health services, it would be beneficial to extend the focus from the sibling with a (dis)ability, parents and the relation between the sibling with a (dis)ability and their parents to the able-bodied sibling, the relation between the siblings and the relation between the able-bodied sibling and their parents.

When considering the perspective of an adult able-bodied sibling, the findings explicate that an able-bodied sibling needs to be involved when planning the future of their sibling with a (dis)ability. Sibling’s role when discussing specific duties related to their family is culturally bound. For instance, Buchanan and Rotkirch (2021, p. 10) remark that in non-industrialised societies it is more common that a sibling has duties related to their siblings compared to industrialised societies. For example, the oldest sibling takes care of their younger siblings in everyday life or makes marriage arrangements for their siblings. However, in industrialised western societies siblings are living more independently. (Buchanan & Rotkirch, 2021, p. 10.) In addition, when discussing sibling’s responsibilities related to a sibling with a (dis)ability, there are no legal duties according to the Finnish law (Finlex, 2023). Nevertheless, according to the findings, an able-bodied sibling seems to take it almost for granted that they or their other able-bodied sibling(s) take care of their sibling with a (dis)ability to some extent. Because family situations can vary, it is recommendable to have open negotiations between an able-bodied sibling, other sibling(s) and their parents to clarify responsibilities related to a sibling with a (dis)ability to avoid possible conflicting assumptions. As Buchanan and Rotkirch (2021, p. 14) also state, duties related to family members, and in this context especially to siblings, are not only moral norms but also negotiated commitments.

When negotiating with parents and other sibling(s) and taking responsibilities related to a sibling with a (dis)ability, an able-bodied sibling needs information about available (dis)ability services. One important source of information is organisations from the field of social and health care. According to Finnish Federation for Social Affairs and Health (SOSTE, 2020), these organisations support people by providing help, information and possibilities to participate in activities. In practice, these organisations organise, for instance, leisure activities and advisory services (SOSTE, 2020). The importance of organisations is also evident in the study findings, which explicate that activities provided by associations enable social support for all family members. In addition, associations are well placed to provide peer activities (SOSTE, 2020). Hanvey and others (2022, pp. 937–938) claim that peer support can promote the wellbeing of an able-bodied siblings, because meaningful and supportive peer relations increase the possibilities to be understood, which can decrease experiences of isolation, sadness, anxiety and depression. In addition, Levante and others (2023, p. 8) state that in peer relations an able-bodied sibling can learn beneficial strategies to manage the responsibilities related to their sibling with (dis)ability. Therefore, it is important for organisations working especially with people with (dis)abilities to consider various ways to provide peer support also for able-bodied siblings in their different life stages.

What are the possibilities when combining social support with arts- and creativity-related activities? At its best, engagement in arts- and creativity-related activities enable an able-bodied sibling to achieve affordances to create connections to their emotions and memories and to reach out to their experiences in multidimensional way (Leavy, 2020, p. 129, p. 163; Norris et al., 2020, p. 5). By reflecting and organising the personal meanings of such arts- and creativity-related experiences and processing the reflected and organised meanings in relation to one's own life narrative, an able-bodied sibling can achieve personal transformation. Through this achievement, it is possible to promote the agency and wellbeing of an able-bodied sibling. (Huhtinen-Hildén & Isola, 2019, p. 15.)

Agency needs to be taken into consideration when promoting the wellbeing of an able-bodied sibling through social support. When supporting an able-bodied sibling, for instance, to process their feelings related to (dis)ability, their thoughts related to their own future or their capabilities to take responsibilities related to their sibling with a (dis)ability, an able-bodied sibling benefits from active agency. Without agency, an able-bodied sibling would not lead their own life (Huhtinen-Hildén & Isola, 2019, p. 15). Thus, with agency, an able-bodied sibling is able to create a meaningful and good life for themselves. In addition, agency is important not only for an able-bodied sibling, but also for a sibling with a (dis)ability. The more the sibling with a (dis)ability is able to promote their active agency, the more they will have their own voice heard. In addition, the more the sibling with a (dis)ability is heard and seen in society, the more their family members can live a satisfying life with their family member with (dis)ability and be optimistic about the future.

5.2 Discussion

As discussed in the introduction chapter, experiences of siblings of people with (dis)abilities are not studied enough. This statement is supported by some international studies such as Hanvey and others (2022, p. 937) and Takataya and others (2019, p. 337), and a Finnish project called Special Siblinghood, which was implemented in 2015–2019 (Erityinen sisaruus, 2024). Still, research studies bringing up certain risks and resources when having a special sibling relationship do already exist (e.g. Chu et al., 2021, pp. 795–796; Hanvey et al., 2022, pp. 937–938; Múries-Cantán et al., 2023, p. 193) and the findings in these studies are in line with previous research findings. It is crucial to recognise these potential risks and resources in order to be able to provide appropriate social support for coping with emerging challenges and for understanding the benefits of having a sibling with a (dis)ability. Therefore, as discussed already in the introduction chapter, versatile social support provided to an able-bodied sibling in different life stages needs to be available. This statement is supported both by previous literature (e.g. Hanvey et al., 2022, pp. 937–938; Kramer et al., 2021; Levante et al., 2023, p. 1) and the findings constructed in this study.

This study concentrated on exploring the able-bodied siblings’ experiences related to their special sibling relationship. This study was conducted as qualitative research because people’s subjective experiences, meaning-making processes and depth of understanding beyond the experiences needed to be valued, and qualitative research design is appropriate for such process (Leavy, 2017, p. 9). In addition, ABR design was also utilised when conducting this study to expand the exploration of the experiences from verbal and intellectual ways to emotional, sensory, embodied and imaginative ways, and thereby to access also those dimensions, which may otherwise remain unnoticed when conducting language-based research (Blodgett et al., 2013, p. 313). To be able to evaluate the findings constructed in this study, the reader needs to be aware of the role of the researcher and how the study was conducted step by step (Leavy, 2017, p. 154).

The topic of this study strongly emerged from my own life as an adult able-bodied sibling of a sibling with a (dis)ability. This position clearly has two sides. On one hand, I approached the experiences the participants shared as their peer instead of an outsider. Because of this, I probably managed to reach the spectrum of experiences of the participants quite well. On the other hand, I needed to be careful not to approach the shared experiences only through my personal lens. It was important to recognise that people are living in different circumstances and therefore the experiences of the same phenomenon may vary. To avoid any harmful influence of my own personal experiences on the research process, I did not discuss my experiences when conducting the group interviews. In addition, I leaned strongly on the collected data when constructing the analysis and the findings.

This study was carried out logically, to appropriately serve the research task, from the conceptual framework to the findings. Central for the conceptual framework was the Sibling Embedded Systems Framework (SESF), which aims to understand the experiences of able-bodied siblings and the potential outcomes in families with children with (dis)abilities (Kovshoff et al., 2017, p. 38). In addition, SESF guided me to explore how able-bodied siblings can be supported during their entire life courses and in different contexts (Kovshoff et al., 2017, p. 43). In addition to the SESF, the conceptual framework conceptualised (dis)ability and sibling relationship to add depth in the exploration of the experiences.

The recorded verbal data was collected through group interviews and transcribed afterwards. Group interviews enabled the participants to be stimulated by other interviewees and therefore helped me to collect probably richer data compared to individual interviews (Flick, 2009, p. 196). I had designed some open-ended interview questions beforehand but more important was to listen to the participants and let follow-up questions and new topics emerge, not only from my thoughts processed beforehand, but also from the participants. In addition, through recordings and transcriptions I could return to the atmosphere of the interviews and the experiences shared through them without missing any essential information.

The sample of four participants was the minimum to conduct the group interviews. With a smaller sample it would have been challenging to benefit from the group setting, but on the other hand, the sample could not have been too numerous either. In a larger group of people, it would have been challenging to distribute all the participants enough time to speak. Because of the small sample, the phenomenon could not be described exhaustively from all points of views. On the other hand, the most important aspect of a qualitative research is to focus on exploring and describing people's subjective experiences and the depth of meanings of their experiences (Leavy, 2017, p. 124). Having said this, this study could not capture an extensive description of the experiences of the able-bodied siblings but, instead, a deep and meaningful description.

Still, even though the data could not include all possible experiences of special sibling relationships, it was still possible to construct findings, which explicate general and transferable knowledge. For such findings, appropriate data analysis methods and interpretation are needed. I utilised content analysis as an analysis method to keep the verbal data close to the analysis, to analyse the data systematically and objectively and to achieve knowledge on a general level (Tuomi & Sarajärvi, 2018, p. 117). Through interpretation, I could find essential categories and process them using a theoretical lens and, consequently, achieve valid and transferable findings, which demonstrate valuable and significant knowledge related to the experiences of the able-bodied siblings considering their special sibling relationship.

However, when it comes to the transferability and generalisation of the findings, it is important to recognise the socio-cultural context in which this study was conducted. According to the cultural model of (dis)ability, (dis)ability as a concept represents those meanings and conceptions that people associate with (dis)ability in a certain cultural context (Waldschmidt, 2018, p. 75). In other words, (dis)ability as a concept does not have a uniform definition that would be understood similarly in every society around the world. Another essential aspect related to socio-cultural context is the emphasis on individuality, which is common in industrialised western societies (Buchanan & Rotkirch, 2021, p. 10). Especially in non-industrialised societies it is more typical that people receive strong social support from their family members and other relatives throughout their life courses, compared to, for instance, Finland, where (dis)ability services and support provided by various societal institutions may be necessary at all stages of life. All in all, experiences related to special sibling relationship may vary in different socio-cultural contexts.

5.3 Suggestions for Future Research

After conducting this study, three main suggestions for future research emerged. According to SESF, an able-bodied sibling is surrounded by different bioecological systems (Kovshoff et al., 2017, pp. 41–42). The findings explicate that while micro- and mesosystems are distinctly discussed, the exosystem, which includes for instance local political and social structures (Kovshoff et al., 2017, pp. 41–42), and the macrosystem, which includes for instance cultural attitudes and ideologies considering people with (dis)abilities and parenting (Kovshoff et al., 2017, pp. 41–42), are not discussed in particular. So, in future research it would be beneficial to explore how an able-bodied sibling experiences especially the influence of exo- and macrosystems.

This study involved four participants, which is a very small sample. Guaranteeing anonymity was essential, which meant that factors such as gender, family size, age difference or the type of (dis)ability were not taken into consideration. Still, for instance Tanskanen and Danielsbacka (2021, pp. 28–35), Milevsky (2021, pp. 128–132) and Takataya and others (2019, p. 337) state that these factors may have an influence on the quality of the sibling relationship. Therefore, in future research, it would be interesting to have a larger sample of participants so that those factors could be taken into consideration. Hence, more specific research findings could be constructed, which in turn could contribute to providing more specific social support for able-bodied siblings.

Finally, this study was not only qualitative research, but also an arts-based research. From a methodological point of view, the participants engaged in arts- and creativity-related activities within a peer support group. In future research, it would be fascinating to create such a piece of art with the participants that could be performed or shown to people outside the group of research participants to evoke, provoke or unsettle, for which, according to Leavy (2017, p. 191), ABR provides suitable opportunities. For instance, when considering the first suggestion for future research mentioned before, exploring the experiences of able-bodied siblings related to the influence of exo- and macrosystems could benefit from such a methodological starting point where art is utilised to evoke, provoke or unsettle. Namely, these systems are strongly related to ableism, which is rooted deep in society and culture (Campbell, 2009, p. 19), and through ABR able-bodied siblings could process their experiences combined with (dis)ability advocacy.

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Appendices

Appendix 1: Consent Form

TUTKITTAVAN SUOSTUMUS

Tutkimuksen nimi: Erityinen sisaruus – aikuisten kokemuksia heidän erityisestä sisaruussuhteestaan

Tutkimuksen toteuttaja:

Tutkija / opinnäytetyötekijä
Korkeakoulu: Metropolia Ammattikorkeakoulu
Nimi: Erja Mesimäki
Puh. xxxx
Sähköposti: xxxx

Tutkimuksesta vastaa / opinnäytetyön ohjaaja
Titteli: Opettaja ja tutkijatohtori
Nimi: Margarida Baltazar
Korkeakoulu / yksikkö: Metropolia Ammattikorkeakoulu ja Musiikin, mielen, kehon ja aivojen huippututkimusyksikkö (MMBB), Musiikin, taiteen ja kulttuurin tutkimuksen laitos Jyväskylän yliopisto
Sähköposti: xxxx

Minua (nimi) ____ on pyydetty osallistumaan yllämainittuun tutkimukseen, jonka tarkoituksena on selvittää aikuisten kokemuksia heidän erityisestä sisaruussuhteestaan ja kehittää taidepohjaisten menetelmien hyödyntämistä vertaistukiryhmätoiminnassa.

Olen saanut tiedotteen tutkimuksesta ja ymmärtänyt sen. Tiedotteesta olen saanut riittävän selvityksen tutkimuksesta, sen tarkoituksesta ja toteutuksesta, oikeuksistani sekä tutkimuksen mahdollisesti liittyvistä hyödyistä ja riskeistä. Minulla on ollut mahdollisuus esittää kysymyksiä ja olen saanut riittävän vastauksen kaikkiin tutkimusta koskeviin kysymyksiini.

Olen saanut tiedot tutkimukseen mahdollisesti liittyvästä henkilötietojen keräämisestä, käsittelystä ja luovuttamisesta ja minun on ollut mahdollista tutustua tutkimuksen tietosuojaselosteeseen. Olen saanut myös tiedon haastatteluiden äänittämisestä.

Osallistun tutkimukseen vapaaehtoisesti. Minua ei ole painostettu eikä houkuteltu osallistumaan tutkimukseen.

Minulla on ollut riittävästi aikaa harkita osallistumistani tutkimukseen.

Ymmärrän, että osallistumiseni on vapaaehtoista ja että voin peruuttaa tämän suostumukseni koska tahansa syytä ilmoittamatta. Olen tietoinen siitä, että mikäli keskeytän tutkimuksen tai peruutan suostumuksen, minusta keskeyttämiseen ja suostumuksen peruuttamiseen mennessä kerättyjä tietoja ja näytteitä voidaan käyttää osana tutkimusaineistoa.

Allekirjoituksellani vahvistan osallistumiseni tähän tutkimukseen.

______________, _____ . _____. ________

Allekirjoitus: ____

Nimenselvennys: ____

Alkuperäinen allekirjoitettu tutkittavan suostumus sekä kopio tutkimustiedotteesta liitteineen jäävät tutkijan arkistoon. Tutkimustiedote liitteineen ja kopio allekirjoitetusta suostumuksesta annetaan tutkittavalle.

Appendix 2: Participant Information Sheet

TUTKITTAVAN INFORMOINTILOMAKE

TIEDOTE TUTKIMUKSESTA

Erityinen sisaruus – aikuisten kokemuksia heidän erityisestä sisaruussuhteestaan

Pyyntö osallistua tutkimukseen

Teitä pyydetään mukaan tutkimukseen, jossa tutkitaan aikuisten kokemuksia heidän erityisestä sisaruussuhteestaan. Olemme arvioineet, että sovellutte tutkimukseen, koska olette täysi-ikäinen ja suomenkielentaitoinen, teillä on tai on ollut erityinen sisarus ja haluatte jakaa kokemuksianne vertaisten kanssa. Tämä tiedote kuvaa tutkimusta ja teidän osuuttanne siinä. Perehdyttyänne tähän tiedotteeseen teille järjestetään mahdollisuus esittää kysymyksiä tutkimuksesta, jonka jälkeen teiltä pyydetään suostumus tutkimukseen osallistumisesta.

Vapaaehtoisuus

Tutkimukseen osallistuminen on täysin vapaaehtoista ja siitä saa kieltäytyä. Tutkimukseen osallistumisen saa keskeyttää milloin tahansa. Myös aiemmin annetun suostumuksen tutkimukseen osallistumisesta saa peruuttaa milloin tahansa. Kieltäytymiselle, keskeyttämiselle ja peruuttamiselle ei tarvitse ilmaista erityistä syytä eivätkä ne aiheuta kielteisiä seurauksia teille tai tulevaisuuden osallistumisellenne tutkimuksen yhteistyökumppaneiden toimintaan.

Tutkimuksen tarkoitus

Tämän tutkimuksen tarkoituksena on selvittää aikuisten kokemuksia heidän erityisestä sisaruussuhteestaan ja sen myötä ymmärtää paremmin, millaista tukea sisarukset mahdollisesti tarvitsevat erilaisissa elämänkulun vaiheissa. Lisäksi tämän tutkimuksen tarkoituksena on kehittää taidepohjaisten menetelmien hyödyntämistä vertaistukiryhmätoiminnassa.

Tutkimuksen toteuttajat

Tutkimuksen toteuttaa Metropolia Ammattikorkeakoulun opiskelija Erja Mesimäki. Tutkimuksen yhteistyökumppaneita ovat kaksi paikallista yhdistystä. Tutkija ei ole sidoksissa kumpaankaan yhteistyökumppaniin. Tutkimusta ei rahoiteta.

Tutkimusmenetelmät ja toimenpiteet

Teiltä odotetaan osallistumista kahteen Erityinen sisaruus –työpajaan osoitteessa xxxx Työpajat järjestetään sunnuntai-iltaisin 12.5. ja 19.5.2024. Yhden työpajan kesto on arviolta 1,5 tuntia. Tutkimus toteutetaan siten, että kaikki työpajat sisältävät taidepohjaista toimintaa yhdessä työpajaan osallistuvien kanssa sekä äänitettävän ryhmähaastattelun.

Tutkimuksen mahdolliset hyödyt

Tutkimukseen osallistuessanne saatte mahdollisuuden jakaa kokemuksianne vertaisten kanssa.

Tutkimuksesta mahdollisesti seuraavat haitat ja epämukavuudet

Teille ei koidu haittaa tutkimukseen osallistumisesta. On kuitenkin mahdollista, että aiempiin kokemuksiin ja perhesuhteisiin liittyvät epämiellyttävät tunteet ja muistot voivat nousta pintaan.

Kustannukset ja niiden korvaaminen

Tutkimukseen osallistuminen ei maksa teille mitään. Osallistumisesta ei myöskään makseta erillistä korvausta tai matkakustannuksia.

Tutkittavien vakuutusturva

Teillä ei ole tutkimuksen puolesta vakuutusturvaa.

Tutkimustuloksista tiedottaminen

Tutkimus on opinnäytetyö, joka julkaistaan avoimesti Theseus-tietokannassa. Opinnäytetyön valmistuttua tutkimuksen tulokset voidaan myös esitellä lukukauden päätöstilaisuudessa opettajien ja opiskelijoiden kesken sekä yhteistyökumppaneiden tilaisuudessa yhdistysten työntekijöiden kesken. Teille lähetetään myös lyhyt raportti tutkimustuloksista tutkimuksen valmistuttua.

Tutkimuksen päättyminen

Myös tutkimuksen suorittaja voi keskeyttää tutkimuksen. Mahdollisia syitä keskeyttämiselle ovat sellaiset lääketieteelliset ja henkilökohtaiset syyt, jotka estävät tutkijaa jatkamasta tutkimusta, muutokset tutkimukseen käytettävän tilan saatavuudessa tai ulkoiset odottamattomat tapahtumat. Näissä tilanteissa teille ilmoitetaan keskeyttämisestä viipymättä ja kerrotaan, mitä kerätylle aineistolle tehdään.

Lisätiedot

Pyydämme teitä tarvittaessa esittämään tutkimukseen liittyviä kysymyksiä tutkijalle/tutkimuksesta vastaavalle henkilölle.

Tutkijoiden yhteystiedot

Tutkija / opinnäytetyötekijä
Nimi: Erja Mesimäki
Puh. xxxx
Sähköposti: xxxx

Tutkimuksesta vastaa / opinnäytetyön ohjaaja
Titteli: Opettaja ja tutkijatohtori

Nimi: Margarida Baltazar

Korkeakoulu / yksikkö: Metropolia Ammattikorkeakoulu ja Musiikin, mielen, kehon ja aivojen huippututkimusyksikkö (MMBB), Musiikin, taiteen ja kulttuurin tutkimuksen laitos Jyväskylän yliopisto
Sähköposti: xxxx

Tutkimuksen tietosuojaseloste: Henkilötietojen käsittely tutkimuksessa

Tässä tutkimuksessa käsitellään teitä koskevia henkilötietoja voimassa olevan tietosuojalainsäädännön (EU:n yleinen tietosuoja-astus, 679/2016, ja voimassa oleva kansallinen lainsäädäntö) mukaisesti. Seuraavassa kuvataan henkilötietojen käsittelyyn liittyvät asiat.

Tutkimuksen rekisterinpitäjä

Rekisterinpitäjällä tarkoitetaan tahoa, joka yksin tai yhdessä toisten kanssa määrittelee henkilötietojen käsittelyn tarkoitukset ja keinot.

Tässä tutkimuksessa henkilötietojen rekisterinpitäjä on Metropolia Ammattikorkeakoulu ja Erja Mesimäki.

Voitte kysyä lisätietoja henkilötietojenne käsittelystä rekisteripitäjän yhteyshenkilöltä

Rekisterinpitäjän yhteyshenkilön nimi: Erja Mesimäki
Organisaatio: Metropolia Ammattikorkeakoulu
Puh. xxxx
Sähköposti: xxxx

Tutkimuksessa teistä kerätään seuraavia henkilötietoja

Henkilötietojen käsittely on oikeutettua ainoastaan silloin, kun se on tutkimukselle välttämätöntä. Kerättävät henkilötiedot on minimoitava, niitä ei saa kerätä tarpeettomasti tai varmuuden vuoksi.

Sähköpostiosoitteet kerätään yhteydenottoja varten.
Nimi ja allekirjoitus kerätään tutkimuksen suostumuksen antamisen yhteydessä.
Ääntä kerätään, koska työpajojen haastattelut äänitetään.
Henkilökohtaisia tarinoita ja pohdintoja kerätään työpajojen haastatteluiden yhteydessä.

Teillä ei ole sopimukseen tai lakisääteiseen tehtävään perustuvaa velvollisuutta toimittaa henkilötietojanne vaan osallistuminen on täysin vapaaehtoista.

Tutkimuksessa kerätään henkilötietojanne myös seuraavista lähteistä

Tutkimuksessa ei kerätä henkilötietojanne muista lähteistä.

Henkilötietojenne suojausperiaatteet

Tutkimuksessa noudatetaan tarkasti henkilötietojen suojausperiaatteita, jotta teiltä kerätyt henkilötiedot säilyvät luottamuksellisesti turvassa. Alla näette henkilötietojen keräämiseen ja käsittelemiseen käytettävät menetelmät ja järjestelmät sekä toteutettavat suojatoimenpiteet.

Henkilötietojen kerääminen:

Sähköpostiosoitteenne kerätään ilmoittautuessanne työpajoihin. Niitä ei välitetä eteenpäin.
Nimenne ja allekirjoituksenne tulee olemaan suostumuslomakkeessa.
Ääntänne äänitetään työpajojen haastatteluiden aikana äänentallennuslaitteella. Tutkimuksen aikana äänentallennuslaitetta käyttää vain tutkija Erja Mesimäki eikä tallennettu tieto ole kenenkään muun saavutettavissa.

Tiedon säilyttäminen:

Sähköpostiosoitteenne säilyy alkuperäisissä sähköpostiviesteissä eikä sähköpostiosoitteita säilytetä erikseen. Tutkimuksen päättymisen jälkeen nämä sähköpostiviestit poistetaan.
Tutkimussuostumuslomakkeet, jotka sisältävät nimenne ja allekirjoituksenne, digitalisoidaan ja säilytetään Metropolia Ammattikorkeakoulun hallinnoimalla suojatulla palvelimella (Z verkkoasema). Paperiset kopiot silputaan ja hävitetään turvallisesti. Digitaaliset kopiot säilytetään kolme vuotta ja poistetaan pysyvästi sen jälkeen.
Äänitallenteet siirretään tutkijan henkilökohtaiselle tietokoneelle jokaisen työpajan jälkeen niin pian kuin mahdollista. Äänitallenteet varmuuskopioidaan Z verkkoasemalle. Äänitallenteet litteroidaan Word-dokumentiksi, tallennetaan tutkijan henkilökohtaiselle tietokoneelle ja varmuuskopioidaan Z verkkoasemalle. Kun litteroinnit on saatu valmiiksi, äänitallenteet tuhotaan lopullisesti sekä tietokoneelta että Z verkkoasemalta.

Tietosuojatoimenpiteet:

Salasanasuojaus: Tutkijan henkilökohtaisella tietokoneella säilytettävät tiedostot suojataan salasanalla. Tämä toimenpide estää luvattoman pääsyn tietoihin.

Rajoitettu pääsy: Pääsy Z verkkoasemalle on rajoitettu ja vain tutkijalla on sinne pääsy. Äänentallennuslaite säilytetään tilassa, jonne on myös rajoitettu pääsy. Näin varmistetaan, että tietoja käsittelevät vain sellaiset henkilöt, jotka liittyvät suoraan tutkimukseen, ja jotka ymmärtävät tietojen luottamuksellisuuden merkityksen.

Tiedon jakaminen: Kerättyjä tietoja ei jaeta kenellekään. Erja Mesimäki kontrolloi tarkasti pääsyä tietoihin suojellakseen tutkimukseen osallistuvien yksityisyyttä.

Henkilötietojenne käsittelyn tarkoitus
Sähköpostiosoitteidenne käsittely liittyy vain tutkimukseen liittyvään kommunikointiin, kuten työpajoihin ilmoittautumiseen sekä mahdolliseen tiedotukseen liittyen työpajojen aikaan, paikkaan tai muutoksiin. Teille lähetetään myös lyhyt raportti tutkimustuloksista tutkimuksen valmistuttua.
Nimenne ja allekirjoituksenne kerätään, jotta voitte antaa suostumuksenne tutkimukseen.

Henkilökohtaisten tarinoiden ja pohdintojen äänittämisellä ja käsittelemisellä tavoitellaan sellaista tutkimustietoa, jota analysoimalla voidaan löytää vastauksia tutkimuskysymykseen.

Henkilötietojenne käsittelyperuste
Henkilötietojenne käsittelyperuste on suostumus.

Tutkimuksen kestoaika (henkilötietojenne käsittelyaika)
Tutkimus kestää 31.12.2024 asti.

Mitä henkilötiedoillenne tapahtuu tutkimuksen päätyttyä?
Kaikki kerätyt henkilötiedot tuhotaan lopullisesti 14 päivää opinnäytetyön julkaisemisen jälkeen. Ainoana poikkeuksena on allekirjoitetut suostumuslomakkeet, jotka säilytetään kolmen vuoden ajan laillisiin tarkoituksiin.

Tietojen luovuttaminen tutkimusrekisteristä
Henkilötietojanne ei luovuteta tutkimusrekisteristä.

Henkilötietojenne mahdollinen siirto EU:n tai ETA-alueen ulkopuolelle
Tietojanne ei siirretä EU:n tai ETA-alueen ulkopuolelle.

Rekisteröitynä teillä on oikeus
Koska henkilötietojanne käsitellään tässä tutkimuksessa, niin olette rekisteröity tutkimuksen aikana muodostuvassa henkilörekisterissä. Rekisteröitynä teillä on oikeus:

- saada informaatiota henkilötietojen käsittelystä
- tarkastaa itseänne koskevat tiedot
- oikaista tietojanne
- poistaa tietonne (esim. jos peruutatte antamanne suostumuksen)
- peruuttaa antamanne henkilötietojen käsittelyä koskeva suostumus
- rajoittaa tietojenne käsittelyä
- rekisterinpitäjän ilmoitusvelvollisuus henkilötietojen oikaisusta, poistosta tai käsittelyn rajoittamisesta
- siirtää tietonne järjestelmästä toiseen
- sallia automaattinen päätöksenteko nimenomaisella suostumuksellanne
- tehdä valitus tietosuojavaltuutetun toimistoon, jos katsotte, että henkilötietojanne on käsitelty tietosuojalainsäädännön vastaisesti

Jos henkilötietojen käsittely tutkimuksessa ei edellytä rekisteröidyn tunnistamista ilman lisätietoja eikä rekisterinpitäjä pysty tunnistamaan rekisteröityä, niin oikeutta tietojen tarkastamiseen, oikaisuun, poistoon, käsittelyn rajoittamiseen, ilmoitusvelvollisuuteen ja siirtämiseen ei sovelleta.

Voitte käyttää oikeuksianne ottamalla yhteyttä rekisterinpitäjään.

Tutkimuksessa kerättyjä henkilötietoja ei käytetä profilointiin tai automaattiseen päätöksentekoon

Henkilötietojen käsittely aineistoa analysoitaessa ja tutkimuksen tuloksia raportoitaessa
Teistä kerättyä tietoa ja tutkimusaineistoa käsitellään luottamuksellisesti lainsäädännön edellyttämällä tavalla. Nimiä ja yhteystietoja ei säilytetä samassa paikassa tutkimusaineiston kanssa. Äänitallenteet poistetaan heti, kun litteroinnit ovat valmiit. Litteroitu aineisto anonymisoidaan poistamalla huolellisesti kaikki mahdolliset tunnisteet. Aineisto analysoidaan koodattuna ja tulokset raportoidaan ryhmätasolla, jolloin yksittäinen henkilö ei ole tunnistettavissa. Lopulliset tutkimustulokset raportoidaan ryhmätasolla eikä yksittäisten tutkittavien tunnistaminen ole mahdollista.

Tutkimusaineistoa ja tutkimuksen yhteydessä kerättyjä näytteitä säilytetään tutkijan henkilökohtaisella tietokoneella ja Z verkkoasemalla 14 vuorokauden ajan opinnäytetyön julkaisemisen jälkeen, jonka jälkeen ne hävitetään lopullisesti poistamalla kaikki digitaaliset tiedostot.

Kerättyjä tietoja ei käytetä myöhempiin tutkimuksiin.

Appendix 3: Codes and Categories of the Data Analysis

Codes and categories considering the experiences in childhood:

Skating, cycling, dancing, swimming, skiing and outdoor activities. Playing with sandbox, baby dolls, soft toys, play house, wheelchair and tricycle. Playing games and roleplays.	Playing together with the sibling with a (dis)ability.	PLAY DURING CHILDHOOD
Physical (dis)ability restricted opportunities to play. When cognitive capabilities were at the same level, siblings played more together.	The influence of (dis)ability when playing together.	
Playing with sibling with a (dis)ability was fun and natural. Able-bodied sibling may have felt sadness, if the opportunities to play were restricted.	Feelings considering joint play.	
Able-bodied sibling has taken care that playing has not been too boisterous. Able-bodied sibling has explained to other children how to consider sibling with a (dis)ability when playing.	The responsibility of the able-bodied sibling when playing together.	
Participating in activities organised by associations and para sports.	New experiences for able-bodied sibling.	

Discussing with able-bodied sibling considering his/her age. No actual discussion with able-bodied sibling. Discussing with able-bodied sibling so that he/she understands, why sibling with a (dis)ability may e.g. visit hospital. Discussing other people's reactions with able-bodied sibling.	Discussing with able-bodied sibling.	DISCUSSING SIBLING'S (DIS)ABILITY
No actual discussion with the friends of the able-bodied sibling. The friends had grown with the sibling with a (dis)ability so discussion was not needed. Discussing with the friends in advance.	Discussing with the friends of the able-bodied sibling.	
Parents discussed with the friends of the able-bodied sibling. Parents of the friends of the able-bodied sibling discussed with their children.	Parents (both of the friends of the able-bodied sibling and of the able-bodied sibling) discussing.	
Able-bodied sibling discussed sibling's (dis)ability open mindedly and directly. Able-bodied sibling felt important to discuss with his/her good friends.	Able-bodied sibling discussing.	
Teacher of the able-bodied sibling discussed with the class and took care that no one bullied the able-bodied sibling.	Teacher of the able-bodied sibling discussing.	

Role of a helper formed naturally. Able-bodied sibling wanted to help sibling with a (dis)ability and hence make things better for sibling. Role of a helper formed especially during adolescence, because sibling with a (dis)ability needed physical help and able-bodied sibling was strong enough to help.	Helper.	ROLES OF THE ABLE-BODIED SIBLING
Role of a care taker was formed already during childhood and it did not disappear even though able-bodied sibling needed to take distance to the family during adolescence. Role of a care taker felt natural and did not disturb. Able-bodied sibling experienced that he/she had a responsibility to take care of the sibling with a (dis)ability in everyday life. In a small family, it was natural for able-bodied sibling to take responsibility for the sibling with a (dis)ability.	Care taker.	
Sibling with a (dis)ability required so much attention from their parents that able-bodied sibling did not want to worry their parents.	An over-independent child	

Sibling with a (dis)ability played with other children in the neighborhood.	Neighborhood.	SOCIAL NETWORKS OF THE FAMILY
Families sharing the same life situation considering (dis)ability spent time with them.	Other families as friends.	
The whole family participated in activities organised by associations.	Associations.	
Some friends of the able-bodied sibling were also playing with the sibling with a (dis)ability.	Friends of able-bodied sibling.	
Some relatives and especially cousins have spent time with the family.	Relatives and cousins.	

An active parent has influenced positive attitudes e.g. in the neighborhood. Friends of the able-bodied sibling had grown together with the sibling with a (dis)ability and therefore they were used to the (dis)ability. The (dis)ability was not so visible. Sibling with a (dis)ability did not have challenging behaviour.	Positive attitudes.	OTHER PEOPLE'S ATTITUDES TOWARDS THE SIBLING WITH A (DIS)ABILITY
Sibling with a (dis)ability had challenging behaviour, which made other people to be afraid of the sibling or to bully the sibling. People were staring the sibling with a (dis)ability at the public places. People did not know how to contact the sibling with a (dis)ability so they did not contact the sibling.	Negative attitudes.	

Codes and categories considering the experiences in adolescence:

Sibling's impairment did not restrict communication and therefore able-bodied sibling found it fun to spend time with sibling with (dis)ability. Sibling with a (dis)ability had challenging behaviour which made able-bodied sibling to be embarrassed and take distance to the family in public places. Sibling with a (dis)ability evoked challenging emotions in the able-bodied sibling. Able-bodied sibling did not want to talk about the sibling with a (dis)ability.	Relation with sibling with a (dis)ability: supporting and weakening aspects.	RELATIONS IN ADOLESCENCE
Able-bodied sibling took distance to the sibling and whole family. Taking distance to the family seemed to be unconscious when reflecting the situation afterwards. Able-bodied sibling enjoyed being by him/herself and wanted time for him/herself. Sibling with a (dis)ability talked a lot and tried to enter sibling's room even though able-bodied sibling did not want.	Relation with self.	
Taking distance to sibling with a (dis)ability made able-bodied sibling feel bad and guilty, because able-bodied sibling was a significant social support for sibling with a (dis)ability. Able-bodied sibling understood that sibling with a (dis)ability had a challenging situation because of the (dis)ability, which made able-bodied sibling feel lucky not to be in the same situation, which in turn made able-bodied sibling feel guilty. It has been hard to talk about the embarrassment considering own sibling even as an adult, which have made able-bodied sibling feel ashamed at their thoughts and feelings during adolescence.	Contradiction considering relations between siblings and between able-bodied sibling and self.	
Parent have encouraged to find peers during adolescence, but able-bodied sibling have felt no need for the peers. Peer support during adolescence has varied a lot. Having peers in adolescence was awesome, because someone shared the same situation and understood.	Relation with peers.	

Moving away from home caused taking distance to the family, which felt natural.	Able-bodied sibling moved first.	MOVING AWAY FROM HOME
Sibling with a (dis)ability had moved away from home, when able-bodied sibling was quite young, so there was no actual influence during adolescence. Sibling with a (dis)ability had required lots of attention from their parents and when he/she moved away from home, able-bodied sibling got more attention from their parents. Able-bodied sibling felt like they were having nice quality time with their parent after sibling with a (dis)ability moved away from home first.	Sibling with a (dis)ability moved first.	

Codes and categories considering experiences and thoughts about the present and the future:

Sibling with a (dis)ability liked little children, but at the same time he/she had a preconception that able-bodied sibling cannot get a child, because this potential situation was so hard to understand. It feels uncertain, what happens to the sibling relationship if able-bodied sibling gets children. It is challenging to talk about getting children with sibling with a (dis)ability because of communicational/cognitive challenges. Sibling with a (dis)ability is not used to little children.	Influence of able-bodied sibling having a child.	CONCERNS CONSIDERING THE FUTURE
If sibling with a (dis)ability would be living alone, it would make able-bodied sibling to think, who takes the responsibility of the sibling in future. Able-bodied sibling thinks that in the future he/she is going to take the responsibility of both sibling with a (dis)ability and parents. Able-bodied sibling has talked with parents about responsibility. Able-bodied sibling feels uncertain that what would be his/her responsibility, when he/she need to be ready to take the responsibility and if he/she is capable to take the responsibility. Able-bodied sibling is concerned if he/she needs to take the responsibility alone.	Taking responsibility for a sibling with a (dis)ability.	
When life expectancy of sibling with a (dis)ability is shorter than usual, able-bodied sibling may be concerned, if sibling with a (dis)ability dies before other family members.	Life expectancy of the sibling with a (dis)ability.	
All the services are not functioning properly. There have been challenges considering living arrangement of sibling with a (dis)ability, which makes able-bodied sibling to worry about possible changes in living arrangements in the future.	Functionality of the services aimed to people with (dis)abilities.	
There are no other siblings sharing their parents aging. It is hard to share parents aging with sibling with a (dis)ability.	No other siblings sharing their parents aging.	
It is hard to say, what life will bring.	Uncertainty.	

Sibling with a (dis)ability likes little children. Able-bodied sibling is concerned and trustful at the same time, when thinking about getting a child. A child of able-bodied sibling and sibling with a (dis)ability like to spend time together. Able-bodied sibling thinks that his/her child and sibling with a (dis)ability support each other's growth.	Able-bodied sibling having a child.	RESOURCES CONSIDERING THE FUTURE
Sibling with a (dis)ability is quite independent and there may be no need for able-bodied sibling to take the responsibility in the future. There are other siblings in the family so one sibling do not need to take the whole responsibility. Sibling with a (dis)ability has a partner, who is taking the responsibility.	Sharing responsibility for a sibling with a (dis)ability.	
Partner can support able-bodied sibling, when siblings' parents are aging. Partner can support sibling with a (dis)ability in everyday life.	Partner of both sibling with a (dis)ability and able-bodied sibling.	
There are lots of opportunities considering for instance living arrangements so it is important to be open-minded for testing several opportunities. Able-bodied sibling knows and accepts that it is not possible to know everything in advance.	Open mind.	
There are enough information about services. Services are functioning well.	Accessibility of information and services considering people with (dis)ability.	
Because one cannot know, what life will bring, it is best to face challenges as they emerge, not beforehand. Do not worry twice: beforehand and now.	Trustful life attitude.	

Able-bodied sibling wishes that even though siblings have their own lives they would still keep in touch.	Sibling with a (dis)ability part of life.	WISHES CONSIDERING THE FUTURE
Able-bodied sibling wishes that living arrangements of sibling with a (dis)ability and other services for people with (dis)ability would remain good.	Living arrangement and other sercives.	
Able-bodied sibling wishes that sibling with a (dis)ability could have a chance to life a meaningful life.	A meaningful life.	
Able-bodied sibling wishes that sibling could be as healthy as possible. Able-bodied sibling wishes that all the family members would live a long life.	Health.	

Able-bodied sibling assesses that the sibling relationship is closer in adulthood than during adolescence. It brings joy, when siblings have found each other again as adults even though they are living in separate apartments. When visiting childhood home, siblings spend time with their parents quite separate and it feels good for everyone. Able-bodied sibling finds the quality of the relationship with sibling with a (dis)ability good, when they are not meeting so often. Siblings have their own lives, but they keep in touch every no and then. After moving away from home, both siblings need to reflect, how they can keep in touch at the same time when constructing their own independent life.	Living together and separately.	RELATIONS IN ADULTHOOD
Life happenings like wedding, funeral and birthdays unite siblings. Everyday contact like sending messages and visiting each other strengthens the relationship. Sibling with a (dis)ability phones almost every day. Able-bodied sibling meets with sibling with a (dis)ability several times in months when they visit their childhood home together. Sibling with a (dis)ability is proud of being an uncle/aunt, which strengthen the sibling relationship.	Aspects that make sibling relationship closer.	
Because of COVID-19 sibling with a (dis)ability had no permission to visit childhood home or receive visitors in living unit, which increased distance.	Aspects that make sibling relationship distant.	

Without a sibling with a (dis)ability the growth environment would have been so different that it probably would have influenced to the whole personality. Having a sibling with a (dis)ability have supported able-bodied sibling to become a caring person. Without a sibling with a (dis)ability, the role of the care taker would probably be not so strong.	Development of personality.	INFLUENCES OF HAVING THE SIBLING WITH A (DIS)ABILITY
Living with a sibling with a (dis)ability has strengthened the acceptance that people cannot affect everything. “Let’s not worry about things beforehand” mentality has strengthen thanks to the sibling with (dis)ability. Able-bodied sibling understands to enjoy the moment, because he/she also understands that things can always change worse.	Resilience.	
Living with a sibling with a (dis)ability has taught new perspectives to view the world. There are things considering sibling with a (dis)ability, which are natural for able-bodied sibling, but not for everyone. Able-bodied sibling has learned to respect health.	Perspectives to life.	
Able-bodied sibling is working with people with (dis)abilities and it feels cosy.	Professional career.	

Appendix 4: Research Diary

Erityinen sisarus -työpaja I: lapsuus

1. Esittele itsesi kuvan keinoin

2. Kuuntele itseäsi, herättele kehoa

3. Kävele vapaasti tilassa
   ~ kävele kaukana kaikista - lähellä kaikkia
   ~ seuraa jonkun kävelyrytmiä
   ~ ota katsekontaktia
   ~ mene kahden ihmisen välistä

minä < kontakti muut

kehdun äänet

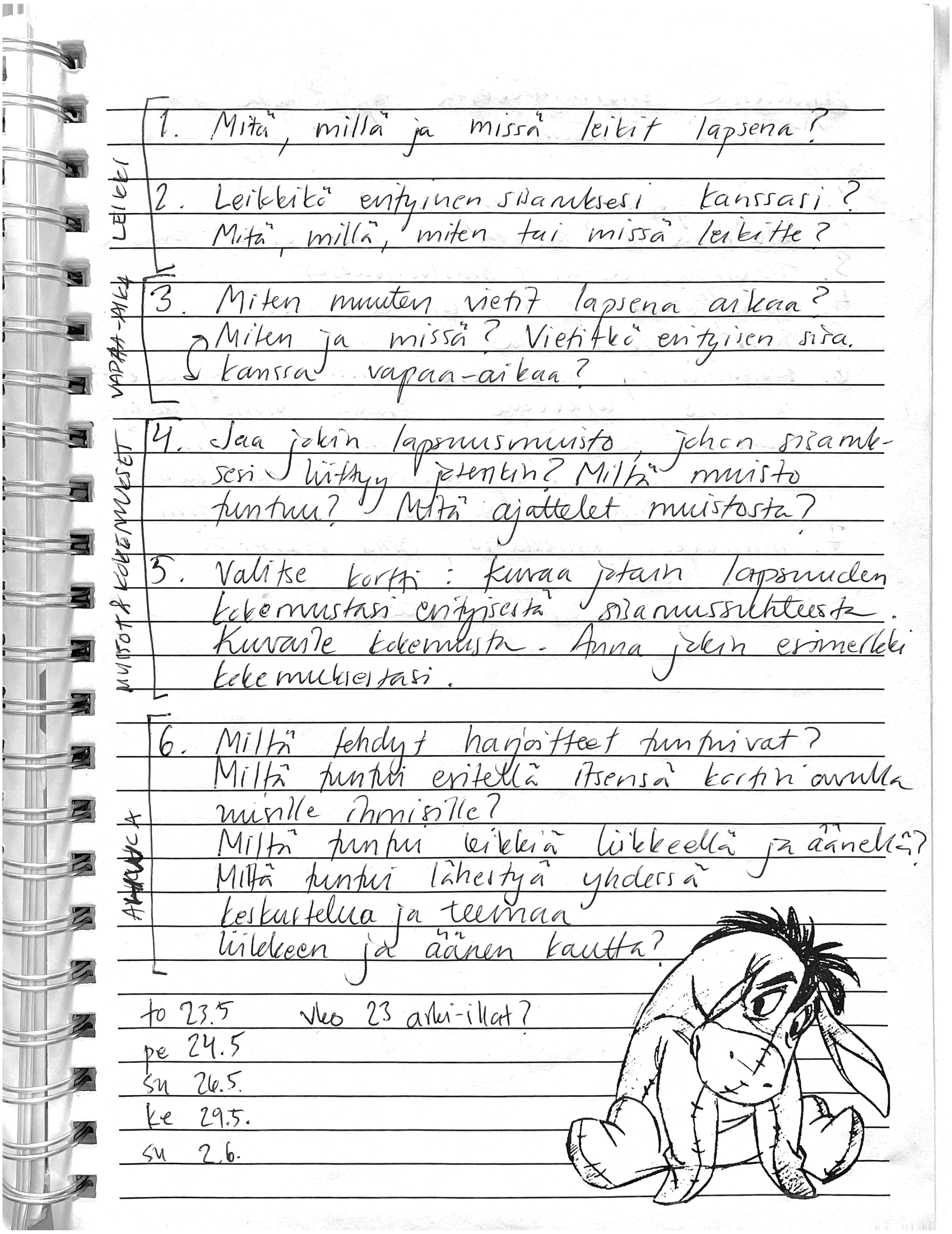
4. Nimileikki N-Y-T NYT!

5. Haastattelu

Mitä leikit lapsena? Leikitkö yhdessä sisaruksesi kanssa? Millaisia leikkejä leikitte? Millaista hänen kanssaan oli leikkiä? Mikä oli parasta? Ärsyttikö joku? Oliko sisaruksella muita leikkikavereita?

Erityinen sisarus -kortit
→ valitse kortti, joka muistuttaa lapsuudesta / kuvailee lapsuusajan ajatuksiasi

Kerro jokin mieleen tuleva tilanne, tapahtuma, tarina, joka valottaa korttia.



LEIKKI

1. Mitä, millä ja missä leikit lapsena?

2. Leikkikö erityinen sisaruksesi kanssasi?
Mitä, millä, miten tai missä leikitte?

~~VAPAA~~-AIKA

3. Miten muuten vietit lapsena aikaa?
Miten ja missä? Vietitkö erityisen sisa.
kanssa vapaa-aikaa?

MUISTOT & KOKEMUKSET

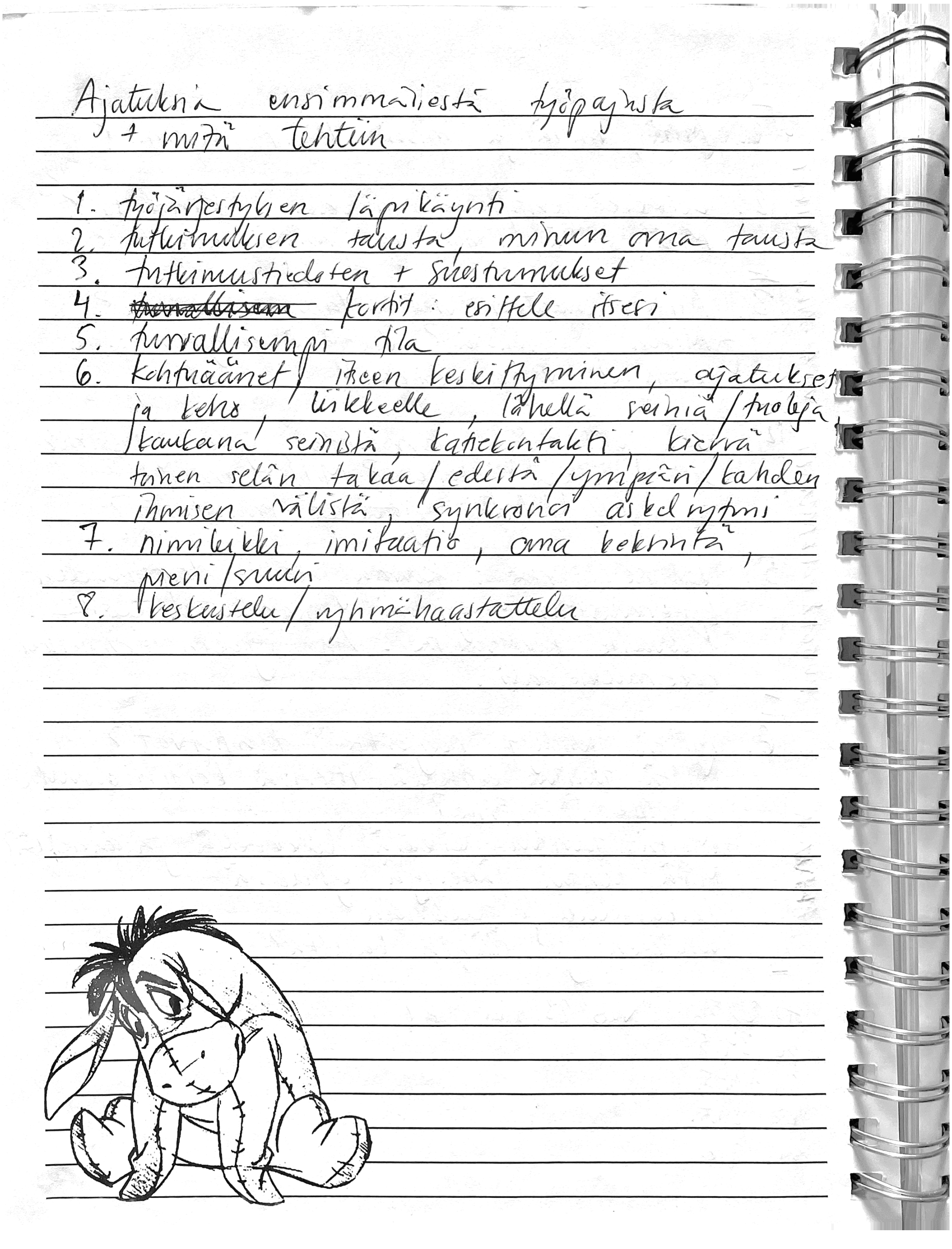
4. Jaa jokin lapsuusmuisto, johon sisaruksesi
liittyy jotenkin? Miltä muisto
tuntuu? Mitä ajattelet muistosta?

5. Valitse kortti: kuvaa jotain lapsuuden
kokemustasi erityisestä sisaruussuhteesta.
Kuvaile kokemusta. Anna jokin esimerkki
kokemuksistasi.

[illegible]

6. Miltä tehdyt harjoitteet tuntuivat?
Miltä tuntui esitellä itsensä kortin avulla
muille ihmisille?
Miltä tuntui leikkiä liikkeellä ja äänellä?
Miltä tuntui lähestyä yhdessä
keskustelua ja teemaa
liikkeen ja äänen kautta?

to 23.5 vko 23 arki-illat?
pe 24.5
su 26.5.
ke 29.5.
su 2.6.



Ajatuksia ensimmäisestä työpajasta
+ mitä tehtiin

1. työjärjestyksen läpikäynti
2. tutkimuksen tausta, minun oma tausta
3. tutkimustiedoten + suostumukset
4. ~~turvallisen~~ kortit: esittele itsesi
5. turvallisempi tila
6. kohtuäänet / itseen keskittyminen, ajatukset ja keho, liikkeelle, lähellä seiniä / tuoleja, / kaukana seinistä, katsekontakti, kierrä toinen selän takaa / edestä / ympäri / kahden ihmisen välistä, synkronoi askelrytmi
7. nimileikki, imitaatio, oma keksintä, pieni / suuri
8. keskustelu / ryhmähaastattelu

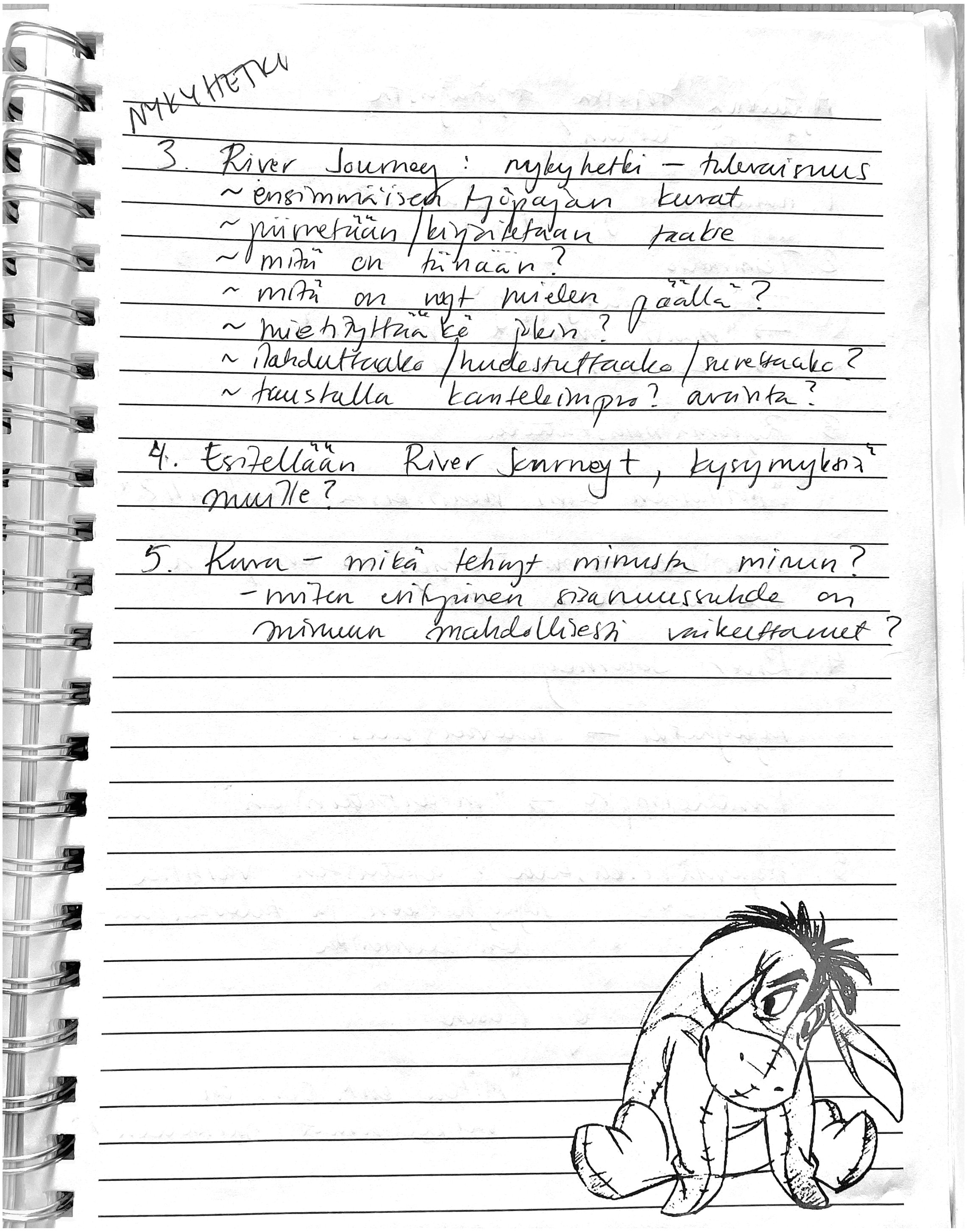
Erityinen sisaruus -työpaja II: nuoruus & nykyhetki

NUORUUS

1. Teiniradio
   - ~valitse kehonosa, jolla "kuuntelet"
   - ~liike saa levitä
   - ~impulssit muulta sallittuja
   - ~Maan pinnassa

2. Keskustelu/haastattelu

Millainen teini olit? (Mitä itse muistat, mitä sinulle kerrottiin, yms.)
Mitä ajattelit erityisestä sisarestasi?
Miten suhtauduit sisarussuhteeseesi?
Teiniaika, itsenäistymisen aikaa
→ mitä ajattelit omasta / sisaruksesi itsenäistymisestä?
Teineille tyypillistä tarve olla samanlaisia
→ koitko erilaisuutta sisaruksesi vuoksi?
⇒ Onko erityinen sisarussuhteesi vaikuttanut itsenäistymiseesi? Herättikö ajatuksia, tunteita?

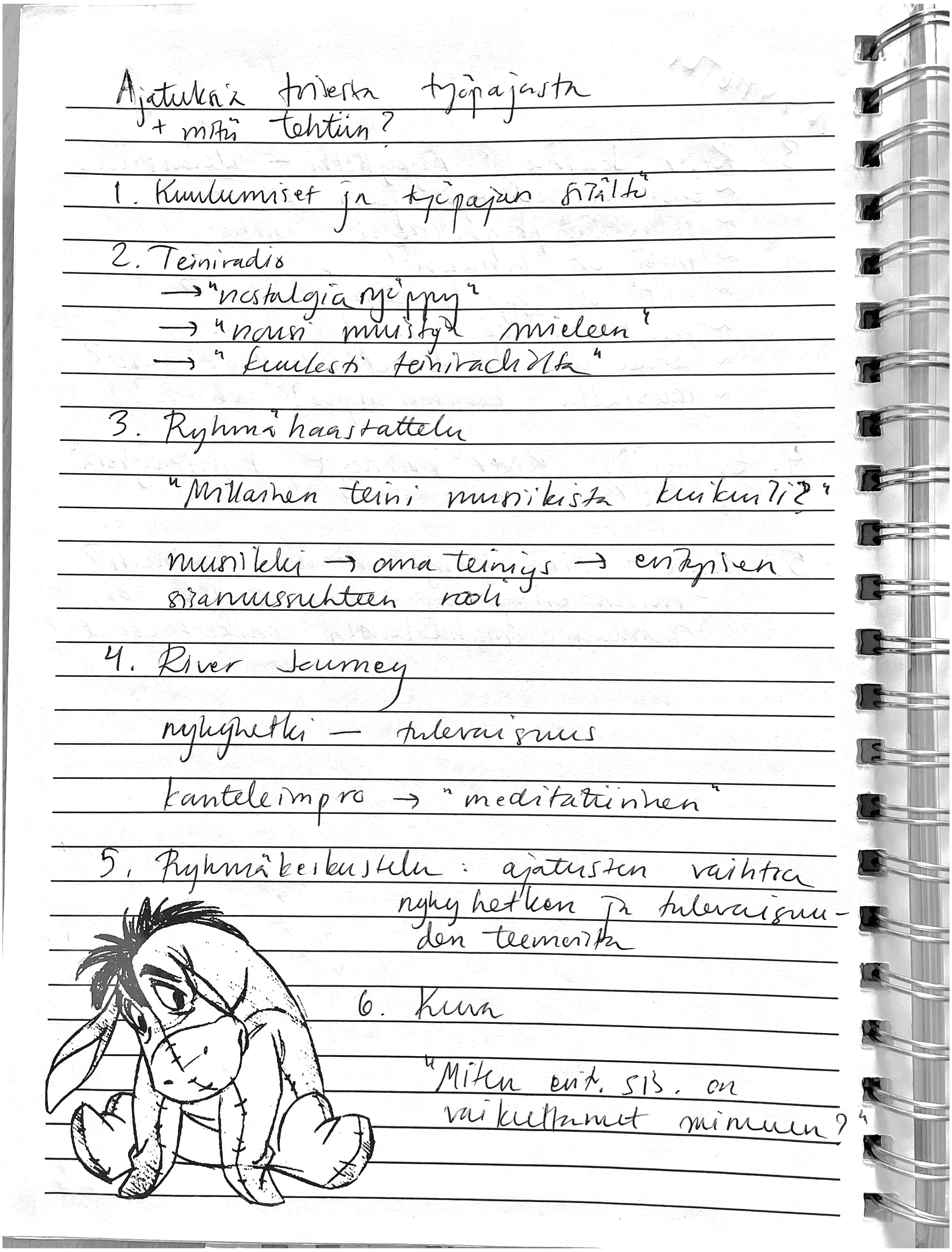


NYKYHETKI

3. River Journey: nykyhetki – tulevaisuus
~ ensimmäisen työpajan kuvat
~ piirretään/kirjoitetaan taakse
~ mitä on tänään?
~ mitä on nyt mielen päällä?
~ mietityttääkö jokin?
~ ilahduttaako/huolestuttaako/surettaako?
~ taustalla kanteleimpro? avointa?

4. Esitellään River Journeyt, kysymyksiä muille?

5. Kuva – mikä tehnyt minusta minun?
– miten erityinen sisarussuhde on minuun mahdollisesti vaikuttanut?



Ajatuksia toisesta työpajasta
+ mitä tehtiin?

1. Kuulumiset ja työpajan sisältö

2. Teiniradio
→ "nostalgiaryöppy"
→ "nousi muistoja mieleen"
→ "kuulosti teiniradiolta"

3. Ryhmähaastattelu

"Millainen teini musiikista kuului?"

musiikki → oma teinius → erityisen sisarussuhteen rooli

4. River Journey

nykyhetki — tulevaisuus

kanteleimpro → "meditatiivinen"

5. Ryhmäkeskustelu: ajatusten vaihtoa nykyhetken ja tulevaisuuden teemoista

6. Kuva

"Miten erit. sis. on vaikuttanut minuun?"