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In what ways can children who have a sibling with autism spectrum disorder (ASD) be supported, in partnership with the Rainbow Club Cork Centre for Autism

Emily Kearns

CARL
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RESEARCH LINKS
University College Cork, Ireland

In collaboration with

Rainbow Club Cork Centre for Autism

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CENTRE FOR AUTISM

Name of community and voluntary group:	Rainbow Club Cork Centre for Autism
Community and voluntary group liaison:	Karen O' Mahony, Founder and Manager & Molly Kinane (Manager)
Name of student(s):	Emily Kearns
Name of academic supervisor(s):	Caroline Burke
University course and year:	Masters in social work, year 2
Date completed:	25th of April 2022

Information about CARL

What are Community-Academic Research Links?

Community-Academic Research Links (CARL) is a community engagement initiative provided by University College Cork to support the research needs of the community and voluntary groups/ Civil Society Organisations (CSOs). These groups can be grassroots groups, single-issue temporary groups, but also structured community organisations. Research for the CSO is carried out free of financial cost by student researchers.

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• Provide their services on an affordable basis.

• Promote and support public access to and influence on science and technology.

• Create equitable and supportive partnerships with civil society organisations.

• Enhance understanding among policymakers and education and research institutions of the research and education needs of civil society, and

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Declaration of Originality:

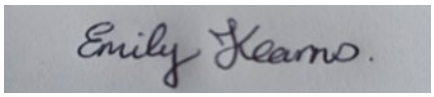
This is to certify that this dissertation: “In what ways can Children who have a sibling with autism spectrum disorder (ASD) be supported, in partnership with Rainbow Club Cork Centre for Autism” is my work and it has not been submitted as part of another degree/ course either in University College Cork or elsewhere.

This research has been submitted to the School of Applied Social Studies, University College Cork as part of the Master of Social Work Programme 2022.

All external references and sources are acknowledged and identified within the contents. I have read and understood the regulations of University College Cork concerning plagiarism. This dissertation has been submitted to Turnitin in advance of the submission deadline and any suggested changes have been addressed.

I have received permission from Rainbow Club Cork Centre for Autism for the use of their logo along with any photographs from their social media used throughout this thesis.

I have received permission from each participant who completed an interview allowing me to use quotes from them for the purpose of this research.



Name: Emily Kearns

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Date: 25th of April 2022

Abstract:

This research was completed in collaboration with Rainbow Club Cork Centre for Autism (RCCCA) as a CARL project. CARL is an initiative by UCC that enables charities and community organisations to work in partnership with students to conduct research. RCCCA was set up by Karen and Jon O'Mahoney when they found out for themselves, how challenging it can be to access services and supports when needed for children with autism (ASD) along with support for their families. RCCCA supports the whole family with their needs, helping them to cope with the challenges they may encounter daily. RCCCA help raise awareness about people who have ASD, and what this looks like for the families involved. RCCCA supports the children with ASD, their siblings, and their parents in communicating effectively. RCCCA addresses how to cope with the diagnosis of ASD and supports the individual and family to develop new skills to navigate the world while providing an inclusive supportive space. RCCCA was set up by people who have a lived experience that they can share with others and understand their service users on a deeper level.

The overarching aim of this research is to understand what ways children who have a sibling with ASD can be supported in partnership with RCCCA. This research is looking to aid RCCCA to move forward with their service and expand in the future to other supports through exploring the experiences of adult siblings with qualitative interviewing.

The epistemological perspective that has been applied to this research is social constructivism which is based on and supported by an interpretive lens. From a social work perspective, it is important to advocate for the voice of the person, therefore interpretivism provides a grounding for the participants voice to be heard.

This primary research was conducted through qualitative interviewing of six participants. The responses were transcribed and analysed for overarching themes. These themes are discussed to show the importance and need for sibling workshops, along with other forms of support in the findings and discussion. The conclusion and recommendations will identify the gaps in research and the importance of taking a holistic approach to exploring the family unit to better support the individuals. Several recommendations include family therapy, further education, awareness in schools, and a support line for siblings.

Acknowledgements

Firstly, I would like to thank my tutor, Ms. Caroline Burke, for all of her support and guidance throughout the process of this research. When feeling unsure if I was on the right path, she offered guidance and support, which kept my confidence and belief strong throughout the process.

I knew from the minute CARL projects were mentioned in first year that it would be a good fit for me. I would like to thank everyone in the Rainbow club, especially Karen, Molly & Tara for co-ordinating and helping me complete this. They were all supportive and available throughout the whole process and made the experience enjoyable. I am particularly grateful to have had the wonderful experience of participating in a sibling group. It was so informative for me and lots of fun.

I would like to acknowledge and thank Anna Kingston for arranging the collaboration and ensuring everything went smoothly, especially in the first few weeks.

To the six participants who kindly volunteered their time and were so honest and forthcoming with their experiences, you all made this piece of research!

Thank you to my classmates, especially my tutorial group, who shared this experience alongside me. It was great to have peers sharing this journey and supporting one another.

To my parents who were always available for proofreading and as sounding boards for different ideas. They helped keep me calm throughout the Masters, I would be lost without them.

Last but not least my partner Simon and my dog Jeffy, the two who put up with the most and remained calm and supportive throughout the entire process, Thank you! Simon always believed in me especially when I did not believe in myself. Encouraging me and learning how to make a cup of tea in the process. While Jeffy was my emotional support, snoozing in his bed in the office alongside my desk, then nudging me when it was time for a break and a walk.

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Table of Contents

Chapter One: Introduction & Background 10

1.1: Research Title: 11

1.2 Introduction and Rationale for the research: 11

1.3 Rainbow club cork centre for Autism (RCCCA) 12

1.4 Research Aims: 12

1.5 Research Objectives: 12

1.6 Research Questions: 12

1.7 Research Chapter Outline: 13

***1.8* Glossary of terms:** 13

Chapter Two: Literature Review 14

2.1 Definition of Autism 15

2.2 Prevalence of Autism 16

2.3 Responsibility of the typically developing sibling (TDS) 16

2.4 Supports available for the TDS 17

2.5 The result of a lack of support for the TDS 17

2.6 Sibling Support Project 18

2.7 The relationship between siblings 18

2.8 The professionals responsibility 19

2.9 Societal Views 19

2.10 Conclusion 20

Chapter Three: Methodology 21

3.1 Introduction 23

3.2 Epistemology 24

3.3 Theoretical Perspective 24

3.4 Community Based Participatory Research 25

3.5 Research Methodology 25

3.6 Research Methods 25

3.7 Recruitment of Participants 26

3.8 Data Analysis 26

3.9 Anonymisation of Data 27

3.10 Ethical considerations 27

3.11 Reflexivity 28

3.12 Challenges and Limitations 29

3.14 Conclusion 29

Chapter Four: Findings and Discussion 30

4.1 Introduction 31
4.2 Themes 31
4.3 Theme one: Feelings evoked as a child 32
4.3.1 Negative feelings: 32
Discussion 32
4.3.2 Positive Feelings: 33
Discussion 33
4.4 Theme two: Available Supports 34
4.4.1 Community/ Family Supports 35
Discussion 35
4.4.2 Professional Supports 36
Discussion 36
4.5 Theme three: Moving forward 36
4.5.1 Suggestions for the future and what participants wanted: 37
Discussion 37
4.6 Theme four: Role clarification within the family unit and path taken by participants in their careers 38
4.6.1 What role did the participant take within their family context and did this affect their career path? 38
Discussion 38
Conclusion 39
Chapter Five: Concluding Remarks and Recommendations 41
5.1 Introduction 42
5.2 Concluding Remarks 42
5.3 Recommendations for the future: 43
Helpline 43
Workshops 43
Counselling/ Therapy/ support services 43
Education 43
Further Research 44
Reflection: 45
Bibliography: 48
Appendices: 56
Appendix One: Participant Information sheet 57
Appendix Two: Participant Consent form 61
Appendix Three: Interview Questions: 63

Appendix Four: Ethics Approval..... 64
Appendix Five: CARL Agreement Summary..... 65
Appendix Six: Communication with RCCCA..... 66

Chapter One: Introduction & Background

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Chapter One: Introduction & Background

In this first chapter, I will introduce the reader to the topic, providing background information and rationale for this piece of research. There will also be a brief introduction to the Rainbow Club Cork Centre for Autism whom I collaborated with for this research. Finally, the aims of the research, along with the objectives, research questions, and chapter outlines will be highlighted.

1.1: Research Title:

In what ways can children who have a sibling with autism spectrum disorder (ASD) be supported during childhood, in partnership with the Rainbow Club Cork Centre for Autism.

1.2 Introduction and Rationale for the research:

I will investigate the experiences of people who have a sibling with ASD to gain a better understanding of what supports they think would help throughout childhood. The literature will show what is available, as well as the background to my topic, to give the reader a greater understanding. I hope this research will aid other organisations and groups throughout Ireland to identify what would be helpful to support children who have a sibling with ASD. This research is in partnership with Rainbow Club Cork centre for Autism (RCCCA) as a CARL project, which is a community initiative supporting organisations. The information gathered in this study will aim to identify what siblings feel they need most, to support other siblings in the future, along with any improvements to what is already available.

When looking into the topic of support available for siblings, before starting my thesis, it became apparent this was an understudied area. In comparison to the topic of support for the child with ASD and the parent or caregiver in partnership with RCCCA, I wanted to highlight the voice of the typically developing sibling (TDS) who has been under-researched. They have not had a voice through research, with regards to their needs during childhood, with a sibling with an ASD diagnosis.

The objective of this piece is to ascertain what supports were available to the interviewees when they were growing up, and what they felt would have helped them further. I believe this dissertation will support my personal development as a practitioner, in developing a greater understanding of the needs of the people who I work with, and support.

1.3 Rainbow club cork centre for Autism (RCCCA)

The Rainbow Club was founded by Karen and Jon O'Mahony, who were able to identify through their own lived experience, the need for holistic support for families within Cork. The aim was to provide support for the family system including the child with ASD, their parents, and their siblings. RCCCA supports the needs of the family in navigating the world and the challenges they may encounter daily. RCCCA offers an ever-expanding array of different supports within its service, including learning new skills, family support, social groups, a teen hub, parenting support, resources for siblings, and a support network. They also provide therapies such as SLT, art therapy, and counselling.

1.4 Research Aims:

This research aims to ascertain what supports are needed for children who have a sibling with ASD. I am looking at this through a partnership with RCCCA and will be interviewing adults who have a sibling with ASD.

1.5 Research Objectives:

1. To explore the life experiences growing up with a sibling with ASD, from an adults perspective.
2. To explore what supports were available to the interviewees, during childhood and what they now feel would have supported them further.
3. To identify what supports are available at present through the Sibling workshops with RCCCA and in the community.
4. To identify if there are gaps and areas for improvement in the supports available currently.

1.6 Research Questions:

1. What supports are currently available for children with a sibling who has ASD and how can these be improved?
2. What do the siblings need to promote a positive relationship with their brother/ sister with ASD?
3. What was the dynamic in the home environment, and the sibling role for this child?

1.7 Research Chapter Outline:

Chapter one: Introduction and Background

This chapter will concentrate on the rationale for the topic along with my interest in the area. There is a summary of what RCCCA's aim is as well as the group it supports and statistics on the prevalence of ASD. This chapter also includes the research aims and objectives and research questions which were agreed upon with RCCCA beforehand.

Chapter two: Literature review

The second chapter examines and reviews current literature available about support for children who have a sibling with ASD. It also highlights the prevalence of ASD within the Irish population. It aims to explore what previous research highlights to support families who have a child with ASD, and any suggestions to support the siblings within the family.

Chapter three: *Methodology*

The third chapter presents a view of the research process and explains the route taken for this piece of research. I look at the epistemology and theoretical perspective chosen, then highlight the research methods used in this piece. I also discuss any ethical considerations along with any challenges and limitations to the piece of research.

Chapter four: Findings and Discussion

This chapter will present the data that has been correlated from the six interviews that took place. I will use thematic analysis to understand the qualitative data which has been collected. The findings of this primary research will then be discussed with reference made to the secondary literature review from chapter two.

Chapter five: *Conclusion and Recommendation*

This is the closing chapter of the research; this will include recommendations based on the research conducted. There will also be observations and remarks on the experience, followed by a reflective piece from myself on my experience of conducting this piece of research.

1.8 Glossary of terms:

Term	Meaning
RCCCA	Rainbow Club Cork Centre for Autism
ASD	Autism spectrum disorder
OT	Occupational Therapist
TDS	Typically developed sibling
SLT	Speech and Language Therapy

Chapter Two: Literature Review

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Chapter Two: Literature Review

2.1 Definition of Autism

"Autism is now understood as a complex, invisible condition which a person is born with. Autism is a developmental condition which means that the way a person communicates, interacts, and understands other people, and the world is different to those who do not have the condition. It can be described as a "spectrum" which means it impacts different people, in

different ways, to differing degrees at different times and in different situations" ("About Autism - AsIAm.ie - Ireland's National Autism Charity", 2022, para.2).

I have conscientiously chosen this less clinical definition instead of the DSM-V of autism as it is less medicalised or disabling, and more accurate when describing a group of people who are all unique.

2.2 Prevalence of Autism

"The European Autism Information System Project highlighted the lack of systematic and reliable data relating to the prevalence of autism spectrum disorders in Europe" (Boilson et al.,2016, para.1).

When investigating the prevalence of autism in Ireland, I found it exceedingly difficult to ascertain a definitive statistic for Cork, Munster, or Ireland.

"*The National Council for Special Education (NCSE) collects data on students with ASD with resource teaching support or in special classes and special schools. Their analysis indicates a prevalence rate of 1.55 per cent and this figure is currently used for planning purposes*" (Department of Health, 2018, p.5).

In relation to this project, the research was specifically focusing on Autism and supporting the siblings of children who have ASD. I struggled to find any up-to-date statistics on the prevalence of autism or specific statistics on autism in children or adults in Ireland, with none specific to the Cork area. However, RCCCA currently supports over 610 children in Cork and has families from other counties enquiring, which indicates a severe shortage of appropriate support and services for this group (Rainbow Club Cork, 2022).

The census carried out in 2017, estimated a prevalence of 1-1.5% of children have ASD in the school-age population (6-11year olds) with this statistic increasing to 52% in special education schools ("Reports on the prevalence of autism in Ireland and a review of the services for people with autism", 2018).

The National Disability survey (2006) breaks down disabilities by category, however, there is no mention of autism within the survey.

2.3 Responsibility of the typically developing sibling (TDS)

From looking at research specific in this area several key issues are prominent, such as the lack of literature that is sibling specific in research. It tends to be aimed at parents and the child with autism (Meyer, 2021).

"The impairments germane to ASD not only affect the diagnosed individual but also his or her caregivers, family, teachers, and community" (Karst & Van Hecke, 2012, p.247). Many children who have a sibling diagnosed with ASD, take on additional responsibilities from an early age. They can also experience a stressful home environment caused by increased incidents of behaviours that challenge, from their sibling.

There appears to be a lack of emphasis on explaining what is happening to the TD child and helping them understand why their sibling is behaving in a particular way (Garrido et al., 2020).

2.4 Supports available for the TDS

From researching what is accessible through different organisations, there is little available to support children who have a sibling with ASD (Services & Supports for People with Disabilities | St Joseph's", 2021) & ("Sibshop Ireland", 2021).

Many services are specifically for the child with the ASD diagnosis and a support group for the parent/ caregiver. There were very few results appearing when I searched sibling support in Ireland. This will be discussed later in chapter four when I ask the interview participants about their experience of accessing support services.

The literature shows that sibling workshops are the best opportunity for siblings to meet with children of similar age in a comparable situation. They can develop a support system, separate and independent of their family network (Baker, 2016).

2.5 The result of a lack of support for the TDS

Many siblings had to gather information and develop an awareness about their sibling with ASD themselves with little information accessible to them as children. Siblings speak about "educating themselves" and having parents who *"did not fully understand the disability themselves*" (Leane et al., 2016, p.99).

"*The impact of having a sibling with a ASD has been subject to even less investigation than that of having a child with autism" (Karst & Van Hecke, 2012, p.253).*

If there was a more holistic and inclusive approach to educating children about different disorders and disabilities this barrier to communication might be easier to overcome for the children with the disability and their TD siblings alike.

2.6 Sibling Support Project

"In 1990, Don created the Sibling Support Project, the first national program in the U.S. dedicated entirely to recognizing and promoting the important roles that siblings play in their families and communities and creating opportunities for brothers and sisters of all ages to receive the information and resources they need to support their families and themselves" (Meyer, 2022, para.2).

Don Meyer highlighted the importance of providing siblings with support and information in a fun environment. He wanted to ensure the siblings had a safe space themselves, he referred to these as Sibshops. Don Meyer explained that siblings of children with additional needs if supported appropriately will be the most important long-standing support to their sibling throughout the lifespan (Meyer, 2022).

Siblings felt excluded and not very well informed of their siblings diagnosis when they were younger or what was involved to support their relationships with their siblings. Most of the siblings in the research conducted by (Leane et al., 2016) had never come across Sibshops. When reviewing sibshops online, they are much more established in America than in Ireland (Meyer, 2022).

Liljekvist & Thorneus (2012) cited in (Leane et al., 2016, p.101) there is a considerable difference between supports available for parents and siblings of children with ASD. Interviewees emphasized that their parents were involved with advocacy and support networks which helped the relationship between them and the child with ASD. However, many siblings noted that they learn from each other, so it is important there is a social aspect for them as the networks do not naturally occur within groups of children. A supportive network needs to be "*cultivated through the organisation of family events or sibling events when siblings are children*" (Leane et al., 2016, p.101).

2.7 The relationship between siblings

There is a specific dynamic between siblings, whether the TDS is younger or older than the sibling with ASD, they tend to take on a caring role and want to keep their sibling protected. In many cases siblings become advocates for their siblings as they know them better than anyone, growing up with them (Leane et al., 2016, p.108).

To support the bond and have a positive relationship between the child and their sibling/siblings with ASD, there needs to be "age-appropriate information" provided along with opportunities for discussions and questions to be asked (Leane et al., 2016, p.108).

"*Siblings are not a homogenous group and their different family configurations; personal circumstances and personality types will influence their perceptions of what supports might be of use to them and their willingness and capacity to engage with same*" (Leane et al., 2016, p.109).

2.8 The professionals responsibility

Professionals and service providers along with parents and other family members may put unknown pressure or expectations on the neurotypical sibling in relation to their brother or sister. "*Siblings described the following nine domains as domains of sibling quality of life: joint activities, mutual understanding, private time, acceptance, forbearance, trust in well-being, exchanging experiences, social support, and dealing with the outside world*" (Moyson & Roeyers, 2011). From this most TD siblings want a level of involvement in their siblings lives; however, they also want their own space and support from the people around them.

In previous research it has been noted that siblings viewed themselves as "co-clients" of the service, the siblings wanted to be treated as clients without the expectations of carers roles (Atkin and Tozer, 2014, p.238). These siblings still had a commitment to their brother/ sister with ASD, but their role expectations may have been of a sibling role and not of a carer.

"Brothers and sisters have a vital role to play in the support and development of siblings who have autism or intellectual disabilities, but that they have had little or no support themselves" (Baker,2016, para.3).

For many of the families who have a child with additional needs, the parent/ parents "struggle to cope with the challenges of having a child with additional needs" (Baker, 2016, para.7).

Many of the organisations and services for children with additional needs offer respite care within residential services and home away from home supports in other people's homes; these options give everyone in the family space and rest (O'Callaghan, 2017).

2.9 Societal Views

Respite opportunities and spaces are in demand and rare for many families who need them ("Respite Care Study - AsIAm.ie - Ireland's National Autism Charity", 2020).

Sibshops are widely recognised as the most popular and effective option for children to meet peers and share experiences in a safe and supportive environment (O'Callaghan, 2017). Leane et al, (2016) found that siblings were rarely consulted by professionals, even though from a person-centered care perspective, (Keenan, 2008) the whole family system should be involved to ensure the best outcome for the person.

In a previous study, Teachers took a test to see if their attitudes toward children with ASD would be as positive as their attitudes to neuro-typical children. *"The results of the study indicated that participants with and without experience of autism produced implicit biases…that indicated greater positivity towards typically developing children relative to children with autism"* (Kelly & Barnes-Holmes, 2013, p.19)

Depending on the age of the child at the time this could have many negative consequences, especially if their neuro-typical sibling is at an age where they can absorb what is occurring but may not fully understand what is happening.

"*For some, this resulted in conflicted emotions about their brother or sister with ID/ASD. On the one hand, they felt embarrassed by their brothers or sisters, and, on the other hand, they felt sorry for them, because of their disabilities*" (Baker, 2016, para.9).

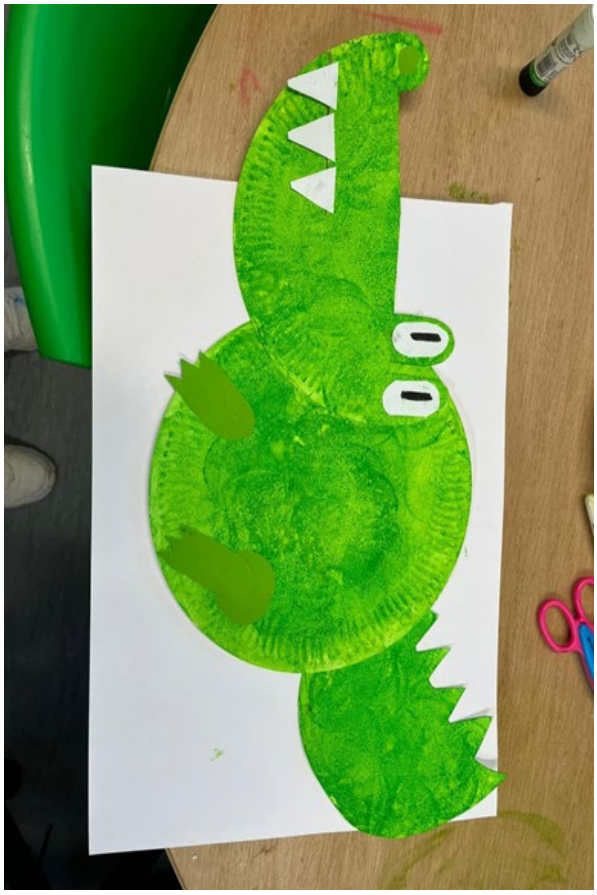
As Dr. Maire Leane et al, (2016) highlight society needs to become more aware of siblings (Leane et al., 2016). There are a lot of different supports and services available and accessible to children with ASD and their families. However, the majority of these are dependent on the government distributing budgets and identifying the need, then appropriately allocating the funds (Department of Health,2019, para.1).

2.10 Conclusion

To conclude my review of the literature, I have found limited studies/ research specific to the children who have siblings with ASD. Most of the research that has been carried out is on parents or specific to the child with ASD, whereas the neurotypical siblings tend to be less researched. I have looked at sustainable supports to ensure the sibling has space and time where they can focus on themselves and share this experience with others in similar situations. The Sibling workshops are a sustainable support where children can access age-appropriate information about ASD while having people who have a shared lived experience

to talk too. The sibling workshop is based in Cork at the moment and supports many families. There is a waitlist and demand for the service from other areas of the county and country.

Chapter Three: Methodology



Chapter Three: Methodology

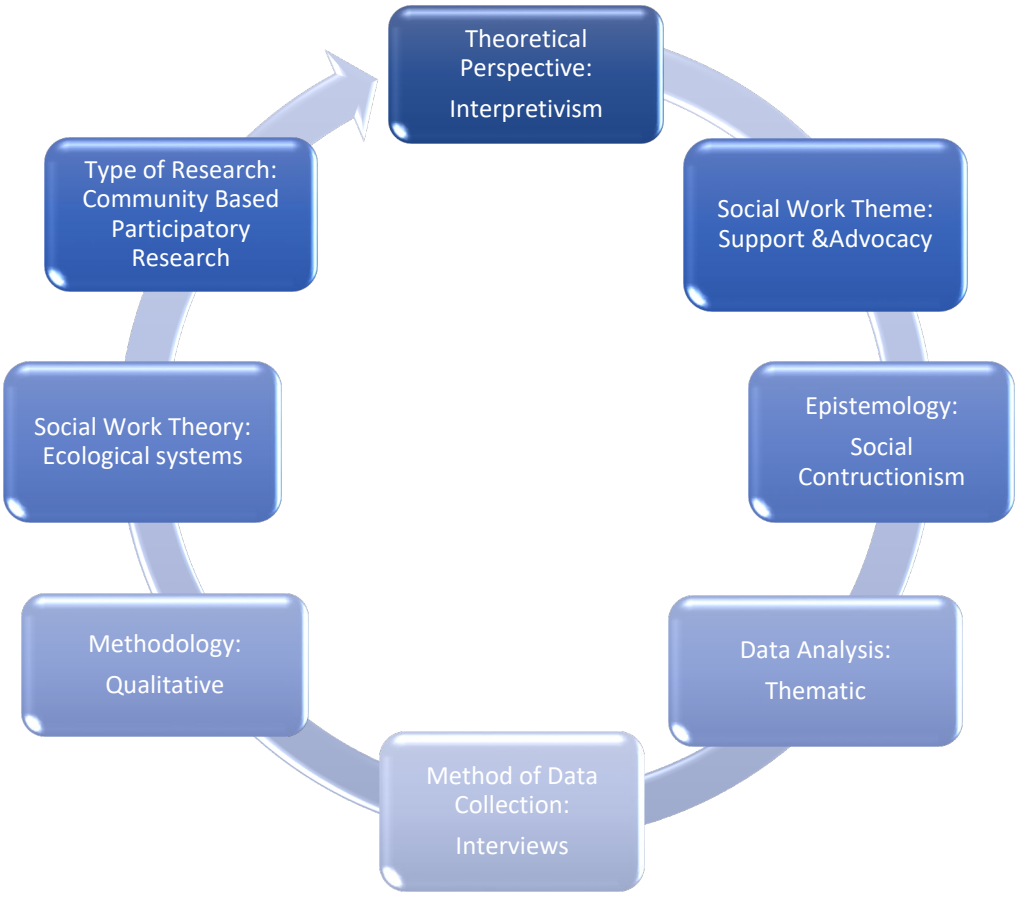


Figure 1: Research Methodology diagram

3.1 Introduction

This chapter will aim to provide an overview of the research process completed for this research. I will discuss and explain the epistemology used and the theoretical perspective chosen for this research. Then I will explore the research using an interpretive lens to look at supporting and advocating for the child who has a sibling with ASD. I will look at this being community-based participatory research, as this research piece is in partnership with RCCCA, as part of the UCC Community-Academic Research Links (CARL) initiative.

In the following section, I will concentrate on the method used in this research in particular qualitative interviews of six participants.

As the researcher, I am aware of my views and biases concerning this subject, so I want to give an insight into my background. I have worked as a Social Care Worker in residential care for adults with an intellectual disability and/or ASD for the past nine years. Therefore, I am conscious of not assuming or asking leading questions of the interviewees. Several ethical considerations will be discussed along with the sensitivity of the topic for the interviewees. To conclude this chapter, I will discuss the challenges and limitations of this research.

3.2 Epistemology

This research is taking the epistemological stance of constructionism also known as collective meaning-making, which works on the idea that reality is through our own experiences and social interactions (Crotty,1998, p.42). Therefore, everyone's interpretation is unique to them along with our assumptions of others. "*Constructionism asserts that social phenomena and their meaning are continually being accomplished by social actors"* (Bryman, 2012, p.710). Social constructivism is well fitted to this research as the siblings being interviewed can give their honest opinions on the questions, supporting greater awareness of their voices and experiences.

3.3 Theoretical Perspective

Ecological systems theory aids my understanding of the Childs position within the family unit when they have a sibling who has a diagnosis of ASD. The child is trying to navigate their world and understand it, with a lack of appropriate support. They are also figuring out the relationship with their sibling who may have communication barriers. Considering the dynamics within the family and how everyone interacts and influences each other, helped to refine my research questions. This theory provides insight into the different dynamics between family members and their relationships with each other as a system. All the members are working together within the one family system, around the individual with ASD. In the family system, there will be barriers that different family members will have to face, such as the eldest child taking on the role of carer to assist their parents.

They may resent the younger sibling with ASD and the attention they require. The youngest child may not receive the same level of attention or independence which may cause them to act out and have an impact on the other children and the activities they can do. Children with additional needs can bring a family closer and/ or put a strain on the relationships. Systems theory provides further insight and exploration of the family unit and my questions for the siblings (Wright & Benigno, 2019). The ecological system is constantly changing, and the relationships are evolving, there are many different contributing factors including their position in the family and their gender as well as their community. We need to consider the community supports available as part of the system also and how this could have an impact on the experiences of the TD sibling.

3.4 Community Based Participatory Research

My research is community-based participatory research, therefore upon completion of the project, I will meet with the Community Partner within one month of the submission of the Dissertation to the University. In this meeting I will discuss the study findings with the community partners, to explore actions/implementation plans arising from the study. We may discuss future public presentations and publications, related to the study as per my CARL agreement (See Appendix five).

3.5 Research Methodology

Ontology	Epistemology	Theoretical perspective	Methodology	Methods	Sources
Interpretivism	Social constructivism	Ecological systems theory	Interviews Literature review	Qualitative interviews	Interviews Peer-reviewed journals Academic books Reports

(Bryman, 2012)

I plan to undertake primary research through the qualitative method of interviews, I feel it would be beneficial to the topic to gain up-to-date real-life experiences from siblings. Through the semi-structured interviews, I want to find out what therapeutic and educational benefits are there for the siblings in engaging with the workshops which RCCCA provides for the families. I will hope to gain an insight into the workshops and if the experiences of the interview participants match the aims of the workshops. I will also be asking the participants what they feel would be beneficial in supporting them and is there anything that they feel would improve the service RCCCA is providing currently (Bryman, 2012).

3.6 Research Methods

To investigate my research, I will be conducting semi-structured interviews with adults who have a sibling with ASD and have experience with RCCCA. The semi-structured interviews will have open-ended questions followed by probing questions if needed. My sample group has been identified for me by RCCCA and I aim to interview six participants in total. These participants all have a sibling/ siblings with ASD and have some connection to RCCCA. I feel this number of participants can offer a varied response to the questions while still ensuring

the quality of data. The data will be collected through MS Teams interviews due to Covid-19 guidelines, where they will be recorded and transcribed. I will also be researching what supports are available through my literature review, exploring what has happened elsewhere and through other research studies.

The data will be collected and analysed; I will be using thematic analysis to determine reoccurring themes throughout the interviews as well as thematic synthesis to compare the literature on previous experiences of support to what is available now.

3.7 Recruitment of Participants

I consulted with the organization to discuss the participant recruitment process, the organisation will reach out to suitable candidates for interviews and forward their details to me if they wish to participate. From discussing the research, both the organisation and I feel it would be best to interview six adult siblings, both male and female who have a sibling with ASD. Permission will be sought from the organisation and interviewees before commencing and each participant will have the opportunity to view the information sheet (Appendix one) and questions (Appendix three) before giving consent (Appendix two) to participate. The process of withdrawing and what their data will be used for will also be explained beforehand.

3.8 Data Analysis

The interview responses received will be analysed using a thematic analysis. The interviews were transcribed using Microsoft teams transcription and then cleaned afterward, with direct quotes extracted. The quotes from the interviewees are presented in chapter as findings and then I will discuss them, making reference to the literature.

I will be using thematic analysis to interpret the interviewees answers and extract quotes to use in the identified themes. The thematic analysis will be conducted using an interpretive lens while looking at the interviews, I chose this as everyone's experiences are different and what people experience depends on them as an individual. Crotty (2008) explains that the theoretical perspective "*is a way of looking at the world and making sense of it*" (Crotty,2009, p.8). In this study, the material from the interviews needed to be interpreted and looked at for reoccurring themes. The themes were then organised into sections to give an overall picture of what presented to the interviewees. Through the discussion, there will then be links to the existing literature. Themes will then be linked back to literature such as support

available, feelings evoked by the siblings, and roles within the family system. Conclusions and recommendations will be composed and presented in chapter five.

3.9 Anonymisation of Data

I have chosen to anonymise the interview participants by numbering them Participants 1-6 to ensure the anonymity of all participants. I chose this method instead of pseudonyms due to having five female participants and one male participant. I was also mindful that this is a CARL project, so many of the participants are known to each other and it is a small community.
I will be recording the interviews through MS teams while logged in using my UCC credentials to guarantee that the data will be stored on MS teams securely after all the interviews are completed. I will be transcribing them myself as soon as possible through the dictate tools in Microsoft word. I will be keeping the transcripts in a file that is encrypted with a password, I will take responsibility for this process.

The raw data will be anonymised at the transcribing stage, I will be providing an information sheet and a consent form to each participant before the interview to explain this. The raw data will not be shared with the community partner or anyone outside the research group. Only the aggregated findings in my dissertation will be shared.

3.10 Ethical considerations

Ethics "refers to rules of good moral conduct, and for the researcher typically relates to sensitive themes" (Carey, 2012, p.26).

An application will be submitted to the ethics committee for the MSW to gain approval for this research. Ethical guidelines of the Irish Association of Social Workers will be always adhered to along with UCC guidelines. I will be following the standards and proficiencies set out by CORU (2019) for social workers to ensure a person centred approach to interviewing. Appropriate authorisation will be sought from the organisations line management, whom I will be working with on the CARL project, in advance of any data collection. I will also keep the line manager informed throughout the study, ensuring they are aware of the research process at each stage. I will ensure a draft of the final dissertation is sent to the RCCCA and feedback is accepted before final submission. I will be conscious of the specific group that I will be interviewing, and any vulnerabilities that may be presented when discussing their first-hand experiences with professionals and their home environment. I will ensure everything is anonymised and confidential for each participant. I will make each participant aware that they

can withdraw their participation at any time during the interview and for set period post interview (Bryman, 2012).

My research may present emotional implications for the participants as it may be the first time, they have spoken about their experiences growing up, and the positive and negative memories they may want to talk about.

Due to the nature of the research, I plan to keep the interview questions open, ensuring the participants only answer with what they are comfortable with. I am very self-aware of the group of participants and how personal the topic could be for them. I will be liaising closely with the organisation to ensure any concerns that come up are dealt with and everyone involved feels comfortable with the plan. I will be providing each participant with a list of support numbers within RCCCA and externally, who will be available to them if they require support.

3.11 Reflexivity

As a researcher, I identify and acknowledge the presence of bias that may occur in this piece of research from myself and the interviewees who are linked with RCCCA.

Reflexivity "means turning of the researcher lens back onto oneself to recognize and take responsibility for one's own situatedness within the research and the effect that it may have on the setting and people being studied, questions being asked, data being collected and its interpretation" (Berger, 2015, p. 220, as cited in Dodgson, 2019, p.221).

I am aware that I enter the research with my value system and background, I chose this topic as it is an area that I feel passionately about.

We need to "*recognise and acknowledge that research cannot be value-free but to ensure that there is no untrammelled incursion of values in the research process and to be self-reflective and so exhibit reflexivity about the part played by such factors"* (Bryman, 2012, p.39).

I have worked in the intellectual disability sector for many years, therefore possessing a rights-based and equality approach to my research. I am conscious of any biases I hold, and I will be engaging with reflective journaling throughout my research process to ensure awareness and reviewing of my work and my thoughts on the stages of research.

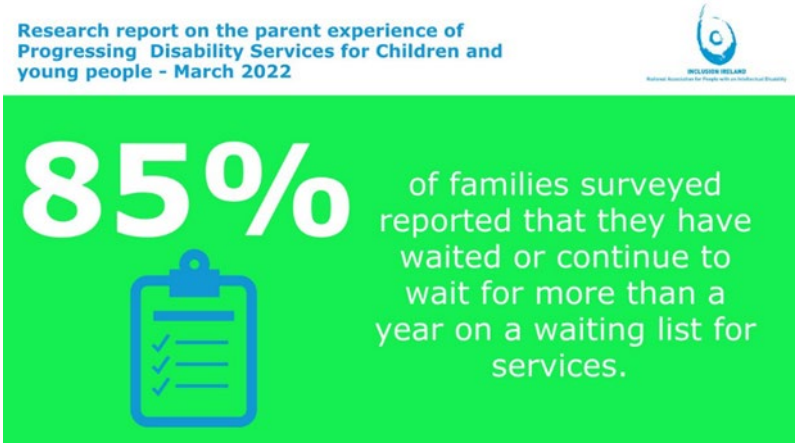
3.12 Challenges and Limitations

I am very aware of how autism, and autistic people, are defined and conceptualised within my piece of research. I do not intend to "problematise" or shame the sibling with ASD, especially as their voice is not being represented in this piece of research, I will be conscious of this and ensure that I remain impartial. This research is not intended to reflect negatively on the relationship between the siblings, however, it is important to highlight any challenges honestly that surface from the interviews. There is an unintentional limitation in this research i.e., all the interviewees who participated were older siblings to their sibling with ASD, which may have contributed to their role within the family unit.

3.14 Conclusion

I have chosen to participate in a CARL project which has been organised between RCCCA and UCC. This is to support community research links between community organisations that need research conducted. Carl connects with students who have an interest in the area of research which is why this piece of research suited my dissertation.

Chapter Four: Findings and Discussion



CARL
COMMUNITY - ACADEMIC
RESEARCH LINKS
University College Cork, Ireland

RAINBOW CLUB CORK
CENTRE FOR AUTISM

Chapter Four: Findings and Discussion

4.1 Introduction

In this chapter, I will present the findings along with a discussion from the six interviews completed for this research. Six participants agreed to be interviewed about their experiences growing up with a sibling who has ASD. I will highlight significant points that were expressed through the interviews along with discussing the findings, making reference to the literature.

During the thematic analysis of the data collected in the interviews, four themes were identified. There are a few sub-themes that emerged from the research questions and the answers received from the interviews, which will be discussed within this chapter.

4.2 Themes

The four themes that will be discussed using quotes from the participants are:

Theme 1	Feelings evoked as a child	• Negative feelings • Positive Feelings
Theme 2	Available supports	• Community/Family supports • Professional supports
Theme 3	Moving forward	• Suggestions for the future • What participants wanted
Theme 4	Role clarification within the family context and whether this contributed to their job/ profession today	• What role did the participant take within the family context? • Did this role affect them in their choices of career/ location?

Figure 1: Thematic Headings

As highlighted in chapter three the epistemology used is constructionism and the theoretical perspective chosen is interpretivism, both have been applied throughout this research. *"Both interpretivism and constructivism explore the construction of knowledge and how it is situated within perspective (Gorski, 2013, as cited in* Botha, 2021, p.5).

The main purpose of both the epistemological perspective of constructionism and the theoretical outlook of interpretivism is to ascertain the persons views of the situation through research exploration. The data that is gathered from the six interviews will give a

representation of the views of adults on their childhood experiences of having a sibling with ASD. Direct quotes from each of the six interviewees have been utilised to ascertain what life was like for them growing up and what could have helped them. At the end of each of the analysis of the four themes, there is a brief discussion that allows a reflection on the quotes from the participants. I will be referring to the literature to gather a sense of the lived experiences of the participants.

4.3 Theme one: Feelings evoked as a child

The first theme that I will discuss centres on "feelings," and this was a result of participants responses to question two. "How was your relationship with your sibling with ASD?": A broad range of feelings emerged, from resentment to jealousy, to love and protection for their sibling. I have divided the answers into two sub-headings to make the results clearer for the reader.

4.3.1 Negative feelings:

- **Participant 3:** *"I was so aware of censoring my feelings as I did not want to upset my mum and dad... I did not want to burden them with more when they had so much going on" "I had a lot of heavy feelings, anger, grief, jealousy, isolation as the attention was on him... it was chaos*"
- **Participant 1:** "*I was very lonely growing up, I had no one to talk to and was very withdrawn… I had a hatred for him, and I felt huge guilt about this" "I loved him, but I couldn't stand him"*
- **Participant 5:** "*I didn't want any interaction with her… she was strange" I did not want her around, which was cruel, but I was a child, and I did not understand... I felt very isolated*" "I was very angry; my sister was getting all the attention and I was craving attention from my parents"
- ***Participant 4:*** *"I was looking at other sibling relationships around me and thinking why don't I have that, it took over my life completely" "I was angry at the situation that I could not control"*

Discussion

From the participants response, there was a lot of anger towards their siblings with ASD, but this was mostly due to the attention that sibling required from their main caregivers. Other contributing factors to this feeling could have been a lack of awareness of ASD

from a psychoeducational perspective. It also depends on how the family unit functioned in terms of their communication styles and how they manage stress, avoid, or address it, etc.

The majority felt isolated and lonely which added to the resentment toward their sibling. *"Disclosure of negative emotions and stress is particularly important because individuals who do not express these emotions are more likely to develop poor adjustment outcomes"* (Zhang, 2017, as cited in Murrin et al., 2020, p.365). Some participants expressed how difficult it was for them and how alone they were growing up, this could have been exacerbated due to only having one sibling who has a diagnosis of ASD.

There was a jealousy present as well as hiding their emotions from the world, some of the interviewees craved their parents attention. One participant spent much of their childhood at their nan's house when all they wanted was their parents attention. Grief and loss also played a role for the siblings who mourned the lifestyle they were accustomed to before their sibling with ASD was diagnosed/ presented behaviours. A few participants spoke further about stopping different activities such as camping or attending parties due to the stress it would cause their sibling with ASD. There appeared to be a lot of sacrifices and accommodations made, which is exceedingly difficult for a child who does not fully understand the rationale behind the decisions.

4.3.2 Positive Feelings:

- **Participant 5:** "*I would have protected her a lot, if someone said something to her, I was the first person over putting on my hard voice*"
- **Participant 6:** "*I was always the communicator for him, we had a connection and I understood him*"
- **Participant 2:** "*When he was diagnosed, it was a big thing, he was different… but he was never different to me he was always just my brother*"
- ***Participant 4:*** *"He is the light of my life and a big motivation for me"*

Discussion

For some of the interviewees, there appeared to be unconditional positive regard when they spoke about their sibling with ASD. Similar to previous research "*The siblings reported having fun with, feeling proud of and even marvelling at the achievements of their brother*

with ASD" (Petalas et al., 2009, p.390). Some interviewees spoke about how proud of their sibling they were for doing their junior cert etc. As challenging as times became for them throughout their childhood years, some spoke very highly of their relationship with their sibling now and how much they cared about them. One participant commented that "*I wouldn't change him for the world"* which illustrated the unconditional love they had for their sibling.

"*A survey of more than 1000 adult TDS found that the majority of TDS report that growing up with their sibling's disability provided opportunities to learn and to understand family dynamics and to develop empathy, compassion, and to become more responsible*" (Hodapp et al. (2010) cited in Nuttall et al.,2018, p.1201). Quite a few of the research participants from my research have gone into the caring professions, which indicates to me from my small research sample, that they developed a passion for caring for others as well as a desire to help and support. This is evident in other research where siblings of children with disabilities and disorders progress into caring professions (Lemoine & Schneider, 2021, p.47).

When considering relationships and supports available to the child with ASD, *"The sibling relationship is commonly the longest many have in their lives"* (Green, 2013, cited in Watson et al.,2021, p.735). Organisations and professionals working with the family need to nurture and support the sibling relationship to benefit all parties involved.

Leedham et al. (2020) as cited in (Watson et al, 2021, p.736) "*described a 'narrative of love, affection, and empathy' with TD (typically developed) siblings having developed increased understanding, empathy, and compassion towards others, due to their experience of having a sibling who has an ASD*" (Watson et al,2021., p.735 & 736).

4.4 Theme two: Available Supports

The second theme, that I will discuss emerged directly from question three which asked, "Did you receive any support or had you, anyone, you could talk to growing up?". The question identified what was available to the interviewees during childhood as well as what resources were not available.

4.4.1 Community/ Family Supports

- **Participant 5:** *"I spent a massive amount of time at my nan's house, I'd even go as far as to say, she probably was my primary caregiver at times when things were particularly difficult"*
- **Participant 1:** *"I could have talked to my mum, but she had her hands completely full"*
- **Participant 2:** *"All my friends understood, so growing up it was different but normal for me… my best friend had a sibling with special needs, so we understood each other"*
- **Participant 3:** *"Mum and dad sat us down, they tried so hard, we watched the Temple Grandin movie" "We went to one sibling activity at a jungle gym but nothing after that"*
- ***Participant 4:*** *"Mums best friend had three children with autism, she knew the signs" "My parents were brilliant, but I never showed them the grey area where I was really struggling" "I didn't have any friends to relate to and felt I couldn't talk to anyone"*

Discussion

There was a varied response to this question with most interviewees having some form of informal support whether that was family or friends. However, most did not want to trouble their support system with their worries or struggles. Several mentioned how their parents were quite isolated with the experience from the diagnosis onwards. This could have resulted in them holding back and not wanting to further burden their parents who were already overwhelmed or stressed.

Many siblings "*keep things to themselves, as they did not want to further burden their parents*" (Watson et al, 2021, p.743). While most of the participants had some form of support, they were aware of the emotional burden and exhaustion already experienced by their families. A few participants had friends who had a shared lived experience, but many did not have anyone their age who understood their situation. Many participants acknowledged that if there were support available such as counselling, which was separate from their family, they would have availed of it. The family unit would have experienced the journey together, however, it would have been a unique experience for each individual which we need to consider.

4.4.2 Professional Supports

- **Participant 5:** *"In terms of support, there was none like my parents did what they could…"*
- **Participant 2:** *"No supports growing up, thrown in the deep end"*
- **Participant 3:** *"My parents did a few courses, initially we had an OT visit the house... as (my brother) got older services seemed to fade away"*
- **Participant 6:** *"No memory of any form of support"*
- **Participant 1:** *"They had nothing for siblings, I attended a workshop for a couple of weeks which was fun but then it ended"*
- ***Participant 4:*** *"I went to the school counsellor, and I was told to go for a walk and drink lots of water"*

Discussion

While it was not a surprise to see the results of the participants experience of professional support, it saddened me to see how little was available. Even when looking for relevant literature to support this, results are absent. This area will guide the recommendations from this piece of research on how we can improve support for siblings of children with ASD in the future. A key piece of learning from my research which is echoed by others is that siblings of children with ASD are under-researched and underrepresented (Meyer, 2021).

"*Ensuring that an individual with ASD lives in an environment that caters for their complex needs requires a large commitment from the family. It is empirically intuitive to assume that quality of life (QoL) is impacted in these families*" (Green,2013, p.2)

From discussions with the interviewees there appeared to be interventions for the sibling with ASD, however not for other children within the household. Even considering the supports that were available to the siblings who had ASD, these were also sparse and dependent on how proactive the family was in advocating for the child.

4.5 Theme three: Moving forward

The third theme focuses on question four "What do you feel would have supported you further as a child?" Each participant produced examples of what they felt would have helped them in managing the situations they encountered growing up.

4.5.1 Suggestions for the future and what participants wanted:

Participant 1	*"Counselling with professionals who understand/work in that field" "The workshops I think would have helped majorly growing up"*
Participant 2:	*"Sibling workshops are a great idea but starting early"* *"A place to get information on how to deal with behaviours, like a support chat line" "Different disabilities taught in school as an optional class or after school"*
Participant 3:	*"Age-appropriate resources and accessible, honest information" "Educating teachers in schools- these children are professionals at hiding their emotions" "sibling workshops"*
Participant 4:	*"Sibling workshops" "Education around autism in general in schools along with society"*
Participant 5:	*"Counselling for my parents individually and as a couple"* *"Education programmes on how to deal with meltdowns" "family support" "Counselling" "respite" "sibling support group so I could realise I wasn't alone"*
Participant 6	*"Autism-friendly social groups" "sibling events"*

Discussion

Many innovative ideas were as a result of discussions with the participants, that they felt would have benefitted them growing up. From looking at other research, *"most of the studies revealed that siblings of children with ASD report, information needs, need for support groups, need to have quality time with parents, managing difficult situation and managing their psychosocial issues*" are what they identify as important for them (Thomas et al,2016, p.101). All these topics were also presented in the discussions with the interviewees for this research. This highlights the need for these supports to be in place for all children who wish to avail of them.

A survey was carried out on a sibling support group setting several years ago to ascertain whether it was beneficial for the children attending.

"This initial investigation of the effects of a community-based support group showed significant improvements in the siblings' adjustment and peer network as well as some

changes in ASD knowledge and sibling–child with ASD interactions" (Kryzak et al.2014, p.170).

4.6 Theme four: Role clarification within the family unit and path taken by participants in their careers

The final theme that was presented through the interviews, was in relation to question five: "Did you take on any particular role with your sibling in the family context?" The theme presented in this was role clarification within the family and looking at the path the person took in life in relation to their career.

4.6.1 What role did the participant take within their family context and did this affect their career path?

Participant one	The older sibling, a parental role for myself	*"I was his sibling, but I had to grow up really fast" "I don't think it did directly but maybe if I got support when I was younger, I would be in a different place now"*
Participant two	The older sibling, babysitter	*"I minded my siblings to give my parents a break it was a necessity, not a choice, I moved away for my health, and I have a good relationship now"*
Participant three	The older sibling, caregiver	*"Yes, I wanted to be a special needs teacher so it did influence that" "I always wanted to be a teacher, but I would have had to move away from home, and I could not leave (my sibling)"*
Participant four	Older sibling	"I always wanted to help people and education was where I was going into initially, I pour my heart into my work now as I don't want people to feel alone"
Participant five	The older sibling, protector	*"I didn't venture too far outside of it for my career, it gave me empathy and skills to deal with people"*
Participant six	The older sibling, babysitter	*"My brother put me on the pathway of social care, but I can't imagine working in disability"*

Discussion

For many interviewees, they felt obliged to take on a caregiving role for their younger siblings. While some parents emphasised this what not an expectation or responsibility for that sibling, the majority still felt obliged due to the necessity of the parents needing to complete household tasks such as grocery shopping/ childminding/ housework, etc.

"*Many TD (typically developed) siblings reported experiencing differential parenting to their sibling with ASD. This included having less access or attention to/from parents and being subject to different expectations than the child with ASD"* (Watson et al,2021, p.743). Some participants highlighted that they needed to "parent themselves" or "grow up quicker," to accommodate the needs of their sibling with ASD. There were sacrifices made throughout their childhood and the older sibling matured into a caregiver role as this was required to support the family dynamic.

For some siblings, they felt closer to their sibling with ASD than their parents and felt they needed to support them with communication as well as protecting the sibling from harm such as bullying. "*Siblings possessed increased knowledge and understanding of their brother's disability this was associated with less embarrassment about the child with a disability and greater acceptance of their circumstances*" (Petalas et al., 2009, p.383)

The sacrifices along with the long-term effects of the interviewees role to their sibling with ASD are not recognised enough. There needs to be a comprehensive approach when caring for a child with ASD and this should involve supporting the other children within the family to develop resilience and coping mechanisms. *"Policy and practice, although increasingly able to recognize their role as 'young carers,' rarely acknowledges the long-term consequences of being a sibling of someone with autism"* (Becker et al. 2001 as cited in Tozer & Atkin, 2015, p.342).

Conclusion

This chapter initially introduced six research participants, who all interacted fully and honestly with the research process, disclosing their own experiences growing up with a sibling with ASD. The interviewees spoke very openly and honestly about the reality of growing up with a sibling with ASD who may present with behaviours that challenge. The participants talk of their experience of needing support as children and how many did not have access to adequate support. Many different forms of support aided the interviewees when growing up such as having a friend to relate to, or extended family to go to for a break. However, many expressed the need for sibling groups and counselling to be available and they feel this would have made things much easier for them and this will help children in the future. I feel from this piece of research that sibling workshops are a necessity and need to be encouraged and supported in other areas also.

Sibling Workshops would support children and alleviate some of the isolation, loneliness, and responsibility that they keep to themselves. All the participants were happy to provide their thoughts and experiences growing up, hoping it would be easier for generations to come while raising awareness for society and organisations.

Chapter Five: Concluding Remarks and Recommendations

Chapter Five: Concluding Remarks and Recommendations

5.1 Introduction

Moving on from the thematic analysis in chapter four, this chapter focuses on the conclusion of the thesis based on the findings from the research. The conclusion of this research has informed the recommendations that will follow in this chapter. The recommendations will be representative of the ideas from the interviewees and myself on what would help moving forward from this research. To conclude this chapter there will be a reflection on the process of completing this research with RCCCA.

5.2 Concluding Remarks

To conclude this thesis, the primary aim of the research was to explore ways we can support children who have a sibling with ASD. Primary research was completed in the form of semi-structured qualitative interviews of six participants who have a sibling with ASD in Cork. Firstly, I completed a literature review to determine what supports are available and what previous research identifies as beneficial to children. From my literature review, I decided to use open-ended questions to ask the interviewees which were agreed upon with RCCCA, to share their experiences and ask what they would find useful.

I then completed the methodology chapter, using social constructionism and an interpretive lens to understand the research from the participants perspectives and ensure their voices were portrayed throughout it. In social work, the person needs to be at the centre of the system to ensure they are heard throughout the process. I ensure the participants voices were present throughout the findings and discussion chapter along with being the basis for the recommendations.

Each of the participants acknowledged that further support would have helped them as a child, as well as school having a greater understanding and knowledge of ASD. They also highlighted that resources in this area were limited and awareness within their communities could be better. Several participants highlighted that their parents never intended for them to take on a caring role with their sibling. However, many felt obliged or wanted to help their parents because they loved their sibling and knew their parents needed support.

This research highlights the need for organisations and professionals working with families to improve their understanding of ASD and what it entails for the family system. It also

shows that siblings need more consideration in relation to research particularly how to support the sibling as they may be lifelong support to their brother/ sister with ASD.

5.3 Recommendations for the future:

Helpline

- Helpline to be developed for enquires relating to ASD as well as a support line for siblings to be able to access advice and support.
- Specific helpline/ chat service for teenagers that is a safe and open space for them to speak to someone and ask questions.

Workshops

- Sibling workshops to continue, but also expand to other areas as they are a safe space to connect with others, develop coping strategies, and access support.
- For children where weekly groups may not suit, there could be school holiday/ summer camps for siblings and children with ASD diagnosis. These would need to be supported by staff and incorporate play and fun activities/positive interactions between siblings etc

Counselling/ Therapy/ support services

- Counselling supports were suggested by the majority of interviewees as something that would have been beneficial for both parents and siblings especially when they receive the diagnosis, then to be followed up and reviewed regularly.
- Family therapy for the family as a whole could be greatly beneficial to ensure good communication and allow members of the family to express how they are feeling to one another.
- Family support to aid the family with necessary tasks such as groceries/ laundry/ Bills/ Adaptive grants/ DCA/ Carers allowance/ respite options etc.

Education

- Support around communication strategies i.e., PECS & LAMH in the home.
- Education around ASD and disabilities in both primary and secondary schools for teachers, students, and parents.
- A booklet to describe ASD in a child-friendly format to give to children who want more information.
- Buddy/mentoring partnerships/projects between students at special education schools and mainstream schools to support inclusion for both.

Further Research

- Further research would be beneficial to hear the voice of younger siblings of children with ASD as I feel it may offer more insight into supports that are needed.
- This piece of research took place when precautions against Covid-19 were still present, therefore all of the interviews were online. I think it would be beneficial to conduct face-to-face interviews with siblings in the future.

Reflection:

"It is not possible to support the child, if the people supporting the child are not supported"

(Interview Participant)

Reflection on this experience:

I always knew I wanted to be a social worker, to support and empower people to advocate for themselves and others. In my undergraduate degree in Social Care, I completed a dissertation on person-centered planning in residential disability services and the level of compliance with HIQA national standards. I have always had an interest in the area of disabilities and Autism, and I have enjoyed working in this sector.

When CARL projects were introduced to us in the first year of the Masters, I knew I wanted to be considered to complete one. To support an organisation with my piece of research was an opportunity I didn't want to miss. When I viewed the available projects last May, the collaboration with Rainbow Club Cork Centre for Autism was my first choice.

Then when I met with Karen and Molly in the café at RCCCA, I could see their passion and drive for the sibling workshops and the positive impact it was making in peoples lives. I was very motivated and excited to support this through my research and emphasize the importance of the services they provide. As mentioned, I had previously completed a piece of primary research in the past, so I knew how enjoyable it is, especially conducting interviews and gathering information from people first-hand.

However, with the excitement, I also felt a level of pressure and expectation I had put on myself as I wanted to do justice to the piece of research. At times I felt overwhelmed and worried that I was not on the right track, but thankfully with perseverance and a great support network the research developed organically.

Although Covid-19 moved the interviews to online and created barriers, such as observing body language and conversations before the interview takes place to ensure everyone is comfortable, there were benefits to online interviewing. It was a great opportunity that the interviewees were able to participate anywhere that they were comfortable as well as no travelling which helped with planning convenient times that suited everyones schedules.

My journey on the masters was a challenging experience, requiring flexibility but one that I thoroughly enjoyed. I feel I have matured as a professional as well as a person and I look forward to my career in social work.

RAINBOW CLUB CORK
CENTRE FOR AUTISM
Sibling Supports
Rainbow Club provides a wide range of supports for siblings of children with Autism through its Support Network & Resources Hub. Siblings will learn about autism through an initial 8-week workshop, they will then go on to weekly sibling groups where they will receive continuous support. We also run various workshops such as art & craft, messy play and more.
What Sibling Supports are available at Rainbow Club?
Siblings will learn about Autism through topics such as sensory needs, communication, social skills, use of gross and fine motor skills & more. Children will learn skills to manage emotions such as anxiety, guilt, jealousy & isolation. Our workshops are delivered through mindfulness exercises, interactive activities, arts & crafts, games & much more.
Why is sibling support important?
Siblings often deal with the same sense of loss, confusion and frustration that parents do. As future advocates and lifelong friends of children with ASD, siblings also require guidance and support along this journey.
What are the benefits?
Allows siblings to explore various strengths and interests through various activities.
Sibling Supports at Rainbow Club help children to learn appropriate skills to self regulate and cope with feelings of anger, sadness & frustration.
Provides siblings with an oppurtunity to build friendships with others in similar situations.
Sibling Supports allow children to build self awareness and self confidence.
Allows siblings to learn about Autism in a fun, interactive and relatable way, which they can put into practice in their home lives.
Sibling Supports provides children with a social outlet outside of the home, which can help with managing stress, anxiety & other common emotions.
To enroll your child, contact us on
086-0805810
molly@rainbowclub.ie

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Appendices:

CARL
COMMUNITY - ACADEMIC
RESEARCH LINKS
University College Cork, Ireland

RAINBOW CLUB CORK
CENTRE FOR AUTISM

Appendix One: Participant Information sheet

University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

College of Art, Celtic Studies, and Social Sciences- Masters of Social Work

PARTICIPANT INFORMATION SHEET

Thank you for considering participating in this research project. The purpose of this document is to explain to you what the work is about and what your participation would involve, to enable you to make an informed choice.

Study title: What way can Children who have a sibling with autism spectrum disorder (ASD) be supported?

Invitation Paragraph:

I am conducting a piece of research in partnership with Cork Rainbow Center for Children with Autism in Cork. This piece of research is a CARL project which is a Community Academic Research Links initiative. The organisation worked with me to suggest a piece of research that they feel would benefit them and I have conducted a literature review and composed interview questions I feel would be of benefit to explore further.

This study has received approval from the Masters in Social Work research committee ethics board, and I will begin conducting research in January 2022.

You are invited to participate in this study which will focus on the experiences and need for support that is sustainable for the children who have a sibling with ASD.

What is the purpose of this research?

My research topic will aim to explore the experiences and needs for sustainable support relating to children who have a sibling with ASD in Cork; I hope that this research will apply to the rest of Ireland.

The objective is to ascertain what supports were available in the past to children who have a sibling with ASD and what supports are available to children in the same situation today. I will encourage the participants to reflect on their own experiences growing up and identify areas where they feel they would have benefited from additional support and what might these supports look like.

The information gathered in this study will be used to complete my dissertation and the findings will hopefully support the Cork rainbow Center for Autism with guidance on what siblings feel they need most to support them sustainably.

Why you have been invited to participate in this study?

You have been invited to participate in this study as you have been identified as an adult sibling of someone with ASD who has been involved with Cork Rainbow Center for Autism.

Do you have to participate?

Participation in this research is completely voluntary and you can withdraw at any time without any need for an explanation. If you chose to participate in this study, you will be given a copy of this participation sheet to keep for yourself. After the interview is completed, you have two weeks from the date of the interview to withdraw if you do not want to participate anymore. The results of the research will be available in June 2022, it will not be possible to withdraw your anonymised data from the research once the two weeks post-interview have passed.

What happens if I choose to participate?

If you choose to participate, I will receive your contact details from Cork Rainbow Center for Autism, I will contact you and provide you with the information sheet and consent form by e-mail. If you are happy to participate you can sign the consent form electronically or scan it to me to proceed.

When the consent form has been returned, I will arrange a suitable date and time with you to conduct the interview. The interview will take between 30-40minutes, and it will be through Microsoft teams. With your permission, the interview will be audio recorded using MS Teams with my UCC Credentials to store the data. The purpose of this recording is to ensure the accuracy of the information to ensure you are not misquoted when I transcribe

the interview. My research is a CARL project which means I am conducting the research in partnership with Cork Rainbow centre for Autism in Cork who will have access to the completed dissertation after submission. The Rainbow Centre may want to publish the findings of the research on their social media platforms or their website to support their sib workshops. They will only have access to the completed dissertation with pseudonyms therefore the data collected will be completely anonymised.

Are there any restrictions for the participants of this research study?

To participate in this study, the interviewees must be over the age of 18 and have a sibling who has been diagnosed with ASD and be linked in with Cork Rainbow Center for Autism. There are no other restrictions on participating in this study.

What are the potential risks of participating in this study?

I do not intend to cause any distress to participants. Some of the questions and topics may be sensitive and personal. Should you wish to stop the interview or not answer a question that is ok. There is a risk of the participants becoming upset or distressed during the interview because of them sharing their own experiences of growing up with a sibling with ASD. I will be making it clear to each participant before the interview that they only need to share what they are comfortable sharing. If at any point during the interview they need to take a break or move on from a question that is ok, and you will be encouraged to do that. The interview can also be stopped at any point, please raise your hand, or inform me, and we will stop it.

What benefits are there in participating in this research?

If you choose to participate in this study, you will be providing personal and in-depth opinions and experiences first-hand as someone who has a sibling with ASD. This will hopefully help towards ensuring there is an awareness and sustainable support developed to help siblings of children with ASD in the future. It will hopefully identify challenges that siblings encounter growing up and focus on their needs.

Is the participation confidential?

Your participation in this research will be always anonymised and kept confidential. I will be using pseudonyms instead of names to ensure no personal details are shared. All consent

forms will be stored on my OneDrive for UCC. All information collected is confidential and will not be available to anyone outside the research team which consists of me, the research team, and my supervisor. I will be following all GDPR guidelines in line with the Data Protection Act (2018).

Recording the interviews:

The interviews will be recorded on MS Teams by myself and stored on a laptop in a password-protected folder, I will then delete all data collected from the folder once the research has been fully completed. The data from this research will be stored by University College Cork in line with the Data Protection Act 2018. During this time, all the data will remain anonymised, and the confidentiality of each participant will be upheld.

What happens to the results of the research?

The raw data from the interviews will not be shared with anyone apart from the research team, the results of the research will not be associated with your name and will be completely anonymised. The results of the interviews will be included as part of the dissertation which will be shared with University College Cork through submission of the research and through a presentation that will be presented at the social work conference next May 2022.

Who organises this piece of research?

The study is being organised by University College Cork, School of Applied Social Studies in collaboration with Cork Rainbow Center for Autism as part of the CARL (Community, Academic Research Links) project.

Who will review this study?

The school of social studies Research Ethics Committee will review this study.

For general information

Researcher name: Emily Kearns 119224415@umail.ucc.ie

Supervisor name: Ms. Caroline Burke caroline.burke@ucc.ie

Thank you for taking the time to participate in this research.

Appendix Two: Participant Consent form

Participant Consent Form

I _____ agree to participate in Emily Kearns' research study. The purpose and nature of this study has been explained to me in writing and if I have had any questions they have been answered.

I am participating voluntarily. I give permission for my interview with Emily Kearns to be recorded.

I give permission for my interview with [**YOUR NAME**] to be [**video/audio]**-recorded.

I understand that I can withdraw from this research, without repercussions, up until two weeks after my interview.

I will explain the role of mandatory reporting before the interviews commence including safeguarding the individual from harm including retrospective disclosures. The participant is welcome to share what they are comfortable sharing; however, I will be discussing that there are boundaries and limitations in the sharing process and the information may be shared elsewhere if there is a concern for a vulnerable person or a Childs safety.

I understand that I can withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted. I understand that anonymity will be ensured in the write-up by disguising my identity.

I understand that disguised extracts from my interview (e.g., my name/location will not be used) may be quoted in presentations and publications (e.g., article, book chapter, student thesis, social media publicity of the study's findings, etc.), if I give permission below (please tick one box):

I agree to participate in this study ☐

I do not agree to participate in this study ☐

I understand that disguised extracts from my interview may be quoted in the research and any subsequent publications if I give permission below:

(Please tick one box)

I agree to quotation/ publication of extracts from my interview. ☐

I do not agree to quotation/ publication of extracts from my interview. ☐

Signed: _____

PRINT NAME: _____

Support Numbers to contact if needed:

- Sharon O'Brien – *Counsellor SharonPCI@rainbowclub.ie*
- Caroline Murphy – *Senior Art Therapist* Caroline@rainbowclub.ie / 0861380444
- Rosarii Ryan IACP Psychotherapist & counsellor for adults and teenagers who have a family member with a diagnosis of Autism 087 1212774 / rosarii.r@gmail.com

Appendix Three: Interview Questions:

There will be six main open-ended questions for the interview followed by several probing questions. I will be combining these to ensure I gain a good understanding of what the participants experience of having a sibling with ASD is like.

1. Can you tell me what was it like for you growing up with a sibling who has ASD?

2. How was your relationship with your sibling with ASD?
   2.1. What supported your relationship with your sibling the most?
   2.2 How has your relationship changed now as you are an adult, or has it changed?

3. Did you receive any support or had you, anyone, you could talk to growing up?
   3.1What supports did you avail of growing up?
   3.2 Is there anything you would change about the supports which were available to you?

4. What do you feel would have supported you further as a child?
   4.1 Can you give me an example of this?

5. Did you take on any particular role with your sibling?
   5.1 Did that impact any other part of your life?

6. Do you feel your experience of growing up with a sibling with ASD has influenced where you are now as an adult?

Is there anything you would like to ask me?

I want to say a huge thank you for taking the time to talk with me and for your honesty throughout the interview. I wish you all the best for your future.
Emily Kearns
Student Number: 119224415

Appendix Four: Ethics Approval

MSW REC Resubmission
MSW Research Ethics Committee

School of Applied Social Studies

Applicant: Emily Kearns, MSW2, 2021/2022

Committee Date: 16th December 2021

Tutor(s): Caroline Burke

Reference: 2021-8

Dear Emily

Thank you for your resubmission to the MSW research ethics committee.

The committee has granted approval for your study. Thank you for making the identified changes.

Final point(s) for you to consider:

1) Please further engage with your tutor and possibly the agency about potential distress participants may experience as a result of participating in your study, and what supports will be put in place for/made available to them.

You do not need to reply to this letter.

We wish you the best of luck with your study. If you have questions, please contact your MSW tutor.

Best wishes,

Dr Kenneth Burns

On behalf of the MSW Research Ethics Committee

Appendix Five: CARL Agreement Summary

We held a meeting on the 3rd of June and the 10th of September with all parties involved to agree on the tasks of RCCCA and me in the research and what the research would entail. The following points were the tasks agreed upon at the meetings:

1. The research topic will focus on experiences and needs for sustainable support relating to siblings of children with autism
2. Emily has undertaken a literature review over the summer looking at models of existing sibling supports: Three main questions emerged from this review and will be explored in the research: What sustainable sibling supports are available in Ireland at present? What do siblings need most to foster a positive relationship with their brothers/sisters? What are siblings' expectations of their relationships with their brothers/sisters (caregivers or just siblings)?
3. Karen will continue to liaise with Emily to provide information about the Pilot Sibling Workshop that the Rainbow Club ran before Christmas and the current model that is now also backed by HSE
4. Karen will recruit participants for face-to-face interviews to take place in early 2022: 4-6 adult siblings with a balance of gender
5. Emily and Caroline will ensure that the criteria for UCC ethical approval of the research are met
6. Questions for interviews will be prepared collaboratively between Emily and Karen before fieldwork
7. Event for dissemination to be discussed closer to the time of submission of thesis

Appendix Six: Communication with RCCCA

3rd of June 2021	Initial meeting with CARL Co-ordinator and RCCCA
21st of September 2021	CARL agreement second meeting to decide what the research would entail.
24th of September 2021	Met with Karen and visited the RCCCA, went through research questions, visited the Café, and enjoyed a lovely coffee.
19th of November 2021	Met with Tara and Molly and spoke about interviews and more about the sibling workshops.
10th of December 2021	Attended sibling workshop to gain an insight into what it involves.
	There have also been consistent communication between Molly and me about interviews, and the use of pictures from RCCCA among other ideas.