

# A Social Inclusion Analysis for Individuals with Autism, from the perspectives of young adults, parents, and staff at the Rainbow Club Cork Centre for Autism

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**CARL Research Project**

in collaboration with

**The Rainbow Club Cork Centre for Autism**



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## **What is 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 community and voluntary groups/ Civil Society Organisations (CSOs). These groups can be grassroots groups, single-issue temporary groups, but also structured community and voluntary organisations. Research for the CSO is carried out free of financial cost by student researchers.

CARL seeks to:

- provide civil society with knowledge and skills through research and education;
- 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
- enhance the transferrable skills and knowledge of students, community representatives and researchers ([Living Knowledge Network](#)).

## **What is a CSO?**

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## **Why is this report on the UCC website?**

The research agreement between the CSO, student and CARL/University states that the results of the study must be made public through the publication of the final research report on the CARL (UCC) website. CARL is committed to open access, and the free and public dissemination of research results.

## **How do I reference this report?**

Author (year) *Dissertation/Project Title*, [online], Community-Academic Research Links/University College Cork, Ireland, Available from: <https://www.ucc.ie/en/scishop/rr/> [Accessed: date].

### **How can I find out more about the Community-Academic Research Links and the Living Knowledge Network?**

The UCC CARL website has further information on the background and operation of Community-Academic Research Links at University College Cork, Ireland, <http://carl.ucc.ie>. You can follow CARL on Twitter at [@UCC\\_CARL](https://twitter.com/UCC_CARL). All of our research reports are accessible free [online here](#).

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### **Are you a member of a community project and have an idea for a research project?**

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- *Alex Mulcahy*

## Abstract:

This research project was conducted in collaboration with the Rainbow Club Cork Centre for Autism and the CARL project initiative. The purpose of this research is to provide a social inclusion inquiry into how the social requirements of young people with autism are satisfied or not met from an inclusionary stance. This study is ethically approved by the school of Applied Social Studies, University College Cork.

Primary research was conducted and included interviews with seven participants, who represented a variety of viewpoints, including young adults with autism, parents of children with autism, and Rainbow Club staff members who provide services. The interpretations of this study were viewed through a social constructivist lens in order to analyse the effects of societal assumptions when understanding the lived experience of autism. The findings are presented using a thematic analysis, in which five themes emerged; social needs, social enablers, social barriers, autism social inclusion and services provided by the RCCCA that fulfil the needs of persons with autism.

The study's findings illustrated that although society has made some efforts to include persons with autism into society, there is still a long way to go before social cohesion is achieved. The social needs of young people with autism were found to be unmet in a variety of social contexts. Participants were, however, able to identify social enablers in society that enhance participation, for example inclusive social environments, parents, and the support of the RCCCA. The complete integration of people with autism into society, however, was severely hampered by discrimination, a lack of understanding, and the absence of environments that were universally acceptable. Participants indicated that acceptance of autism, as well as universal access to all supports and services, were among their top priorities for achieving social inclusion. The RCCCA's services were also investigated, with the Teen Hub, the Mentorship Programme, social groups, summer camps, and adapted sports among the most beneficial, boosting a sense of independence and social skills. Participants also indicated prospective future services that the RCCCA could provide in the future.

In conclusion, this social inclusionary study discovered that society does not fully address the social needs of persons with autism, with participants' lived experiences highlighting how restricting society can be. The RCCCA, on the other hand, was known as a safe, judgment-free environment that encouraged and allowed every person with autism and their family to meet their social needs and be socially engaged. Prospective suggestions were offered, as well as recommendations for future autism research.

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# Chapter 1

## Introduction and Background:

### **1.1 – Introduction:**

In the first chapter of this study, the researcher will present the reader to the project's research title as well as provide an introduction and rationale for the study. The researcher will introduce the work of the Rainbow Club Cork Centre for autism, as well as how the importance of conducting this study arose. The aims, objectives, and questions of the study are discussed, and an outline of each chapter is provided to give more details on what will be covered in each section. A glossary of terms and closing comments are provided at the end of this chapter.

### **1.2 Research Title:**

“A Social inclusion analysis for individuals with autism from the perspectives of young adults, parents, and staff at the Rainbow Club Cork Centre for Autism”.

### **1.3 – Introduction and Rationale for the Research:**

This study seeks to identify the ways in which, from the perspective of social inclusion, the social needs of children, adolescents, and young adults are fulfilled and not fulfilled. In order to develop a realistic perspective of inclusivity, the research will examine the lived experiences of young adults with autism, parents of children with autism, and staff members who provide services within the Rainbow Club Cork Centre for Autism. This is in the hope of shaping service provision and creating ways in which our communities can potentially do better when it comes to autism social inclusion, both locally and nationally, to reduce marginalisation. Conducting this study in collaboration with the Rainbow Club Cork Centre for Autism as a Community-Academic Research Links (CARL) project will enable the Rainbow Club to utilise the results to enhance their services.

From a professional standpoint, I was inspired to work on a CARL project as I was interested in completing a project that would benefit the local community and potentially bring about a shift for the better in society. However, when investigating this subject and reading the



existing literature, I observed a scarcity of information about the extent to which the requirements of children and young people with ASD were/were not satisfied, as well as a lack of up-to-date perspectives of parents and young adults with ASD from an Irish context. This therefore served as the impetus for the study's examination into the real-life experiences of autism in assessing the factors that facilitate and inhibit social inclusion.

## **1.4 –Introduction to the Rainbow Club Cork Centre for Autism**

### **(RCCCA):**

Due to a paucity of autism resources for their two sons, CEO Karen O’Mahony and her husband Jon, launched the Rainbow Club Cork Centre for Autism in 2015 (RCCCA, 2020, P1). The Rainbow Club now offers a range of supports and therapeutic services to over 610 children, teenagers, and young adults with autism, aiming to “intervene early and continue to build skills to overcome the challenges of ASD that lead to educational disadvantage” (RCCCA, 2020, P1). The Rainbow Club, from an Irish perspective, is the only establishment in the nation to provide a range of therapies and services for young people with autism, their parents, and relatives under "one roof" (RCCCA, 2020, P1). There are many resources available, such as social groups, adaptive sports, teen hubs, mentoring in life skills, family support groups, and much more (RCCCA, 2020, P1). The RCCCA also supports parents of children and young adults with ASD through the provision of family support groups aiming to support the family unit as a whole, adopting person-centred and strength-based approaches to practice (RCCCA, 2020, P1).

The Rainbow Club's overarching goal is to spread its multidisciplinary approach throughout Ireland, so that no child suffers educational and/or social disadvantage owing to a lack of service provision (RCCCA, 2020, P1). The extensive array of services and supports given demonstrates that the RCCCA is a vital resource for children and young people with ASD, as well as their siblings and families, in order to help them achieve their developmental needs. According to the Rainbow Club, creating a centre that provides the resources and supports that children with autism require, allows for the development of “inclusivity, education, and career opportunities [which lead to] a fulfilled lifestyle and participation in all aspects of society” (RCCCA, 2020, P1).

## **1.5 –Research Aims:**

The purpose of this research is to offer a social inclusion analysis of how young people with autism’s social needs are met/not met from an inclusionary standpoint. By performing primary research in the form of semi-structured face-to-face interviews, this study will delve into the experiences of children and adolescents with autism, parents of such children and teenagers, and RCCCA employees. This is to achieve the goal of addressing the RCCCA’s and individuals’ inclusionary prospects and challenges in the context of greater society and social policy.

## **1.6 –Research Objectives:**

1. To critically assess how the social needs of children and young people with autism are met or not met within the Rainbow Club Cork Centre for Autism.
2. To determine how young adults with autism, parents of children with autism, and the Rainbow Club’s staff perceive the social needs of individuals with autism, with respect to how they may differ from those of the general population.
3. To gain insight into the views of young people, staff, and parents of children who participate in Rainbow Club programmes in order to establish how autism-inclusive society is.
4. To evaluate any potential gaps in service provision within the RCCCA, local and national services, and to obtain respondents viewpoints on the development of future services.

## **1.7 –Research Questions:**

1. What are the social needs of children, adolescents, and young adults with autism?
2. What are the current barriers and enablers affecting children, adolescents, and young adults with autism in Ireland as they strive to meet their social needs and be included into society?
3. In what ways do services provided by the RCCCA and other enablers in society help fulfil social inclusion of children, teenagers, and young adults with autism?

## 1.8– Chapter Outline:

- **Chapter 1: Introduction and Background:** The first chapter will focus on the study rationale and the researchers' interest in this subject, as well as the aims, objectives, and research questions. A description of the Rainbow Club Cork Centre for Autism is provided, along with information on its objectives and services.
- **Chapter 2: Literature Review:** The second chapter includes a review of existing literature, investigating how society supports and/or limits social involvement for young people with autism. Aspects including education, work, and inclusive social environments are discussed along with the prevalence of autism.
- **Chapter 3: Methodology:** The study's approach is thoroughly outlined in the third chapter. This chapter also examines the selection, data anonymisation, and data analysis procedures as well as the study's epistemological, theoretical, and reflexive stances. The study's challenges and limitations, as well as ethical considerations, are furthermore discussed.
- **Chapter 4: Findings and Discussions:** The fourth chapter outlines the study's research findings in the form of five themes; social needs, social enablers, social barriers, autism social inclusion and the supports provided by the Rainbow Club. Discussions are offered for each theme, based on the responses provided by participants, with references to existing literature.
- **Chapter 5: Conclusions and Recommendations:** The final chapter offers concluding remarks and recommendations, based on the research findings. Post research reflections are also provided for.

## 1.9– Glossary of Terms:

<b>RCCCA</b>	Rainbow Club Cork Centre for Autism
<b>ASD</b>	Autism Spectrum Disorder
<b>CARL</b>	Community-Academic Research Links
<b>SEN's</b>	Special Education Needs
<b>SNA's</b>	Special Needs Assistant
<b>UNCRPD</b>	United Nations Committee on the Rights of Persons with Disabilities

# Chapter 2

## Literature Review:

### **2.1 – Definition for Autism:**

Autism, or autism spectrum disorder (ASD) can be defined as “a broad range of conditions characterised by challenges with social skills, repetitive behaviours, speech and nonverbal communication” (Autism Speaks, 2023, P1).

Autism spectrum disorder is today recognised upon a continuum based on social communication and sensory motor behaviours, with symptoms varying from very mild to severe across individuals (Lord et al., 2018, P508). According to the medical DSM-5 diagnostic criteria, the individual must exhibit evidence of “persistent difficulties in social communication and social engagement in the past or present, as well as evidence of confined, repetitive sensory motor behaviours from a young age” (APA, 2013, cited in Lord et al., 2018, P509). Poorly integrated verbal and nonverbal communication such as facial expressions, eye contact, and so on, trouble creating, sustaining, and comprehending relationships, and difficulties expressing or sharing one's feelings are all examples of social communication and social engagement deficiencies, according to medical interpretations (APA, 2013, cited in Lord et al., 2018, P509). Confined, repetitive sensory motor behaviours-deficit examples under the DSM-5 diagnostic include but are not limited to; children having rigid thought patterns, intense attachment to or fascination with uncommon items, hyperreactivity or hyperreactivity to sensory components of the environment and strict adherence to routines and reluctance to change of routine (APA, 2013, cited in Lord et al., 2018, p509).

However, socially inclusive views on neurodiversity, “shift away from this deficit-based medicalised strategy and place more emphasis on neurological differences” (Middletown Centre for Autism, 2021, P4). In this way, a study on community inclusion conducted by (Middletown Centre for Autism, 2021,P4), state that “ in the neurodiversity model, the strengths associated with autism are recognised, and disability is viewed as resulting from environmental failures to accommodate the needs of the autistic person”. In order to evaluate autism for the purposes of this research project, the researcher will employ the

social model of disability as opposed to the medical model, where both terms will be discussed in more depth later in this chapter.

## **2.2 – Prevalence of Autism in Ireland:**

The National Council for Special Needs research in 2018 suggests that 1 in 65 school-age children (1.5% and 14,000 individuals) receive extra support at school as a result of their autism diagnosis, however there is no other reliable estimate of the current prevalence rates of autism in Ireland (NCSN, 2016, P3). The Irish Society of Autism, on the other hand, claims that because many individuals self-identify as having autism without receiving a formal diagnosis, this prevalence figure may not be entirely accurate (ISA, 2022, P1). The 2016 Irish Census found that “66,611 people or 1.4% of the population suffered from an intellectual disability, 8,902 higher than in 2011, representing 15.4% increase” (CSO, 2016, cited in NCSN, 2016, P14). However, these figures do not give a breakdown of “ASD prevalence as no nested study has been undertaken to date” (NCSN, 2016, P14). As a result of a dearth of monitoring, Ireland's up-to-date autism prevalence statistics remain unclear. Furthermore, there is no source of geographic statistics on autism in Ireland (Neilson, 2016, P1).

## **2.3 – Autism Assessments in Ireland:**

Children with autism can be examined and diagnosed in Ireland through either the public or private systems (Asiam, 2022, P1). Assessment is free in the public system and can be done through early intervention and school age teams, or by applying for "assessment of need" examination (Asiam, 2022, P1). However, the public system of assessment is heavily criticised due to extremely long waiting lists, which impede children with autisms access to clinical diagnosis and therapeutic supports (Jensen-Burke, 2021, P1). The Disability Act 2005 establishes legal requirements on the HSE in terms of need assessments and services for all people with disabilities and on the autistic spectrum (Department of Health, 2018, P13). According to (Department of Health, 2018, P13) “the terms of the Act indicate that an assessment of need should commence within three months”. However, more than 3,500 children were placed on waiting lists for disability evaluations, including autism diagnosis, in 2021, with 83% of this cohort waiting longer than the three-month threshold for over four years (Jensen-Burke, 2021, P1)(Mulcahy,2022,p6).

Although the private system involves a shorter waiting time for assessment, such system is also criticised for being “heavily oversubscribed” and costly, representing “a gross and unjustifiable inequity in healthcare and education provision, where children whose parents cannot afford to pay privately, take legal action or who live in areas with long waiting lists, are at a significant disadvantage in accessing the supports which they need and deserve” (O’Byrne, 2022, P1, cited in Baker, 2022, P1)(Houses of the Oireachtas, 2022, P1). Between 2018 and 2020, 212 legal complaints were filed against the state owing to excessive wait periods for autism assessments, costing the state approximately €700,000 in legal fees (Houses of the Oireachtas, 2022, P1). Furthermore, in 2021 “18,303 children [were] on occupational therapy waiting lists, 9,531 children [were] on psychology waiting lists and 8,167 children [were] on speech and language therapy waiting lists” (Houses of the Oireachtas, 2022, P1). Access to necessary treatments in Ireland is thus hampered by excessively long waiting lists as well as the cost of private examinations and therapeutic assistance (Mulcahy,2022,P6).

A study conducted by (Roddy & O’Neill, 2018, P1106) found that the average family spends €28,464.89 per year on private services and care, whereas the state spends €14,192 per child a year. According to the study's findings, Irish families with autistic children are more financially responsible for meeting their autistic children's needs, and that “... policy implications... suggest that significant investment and commitment is needed to address the needs of individuals living with autism spectrum disorder and their families” (Roddy & O’Neill, 2018, P1106) (Mulcahy,2022,P6).

## **2.4 – Education and Autism in Ireland:**

The Education Act 1998 provides provisions for the education of every child in the State, including all children with special educational requirements (Government of Ireland, 1998 cited in The Irish Society of Autism, 2022, P1). The Education for Persons with Special Educational Needs Act 2004 makes specific reference to children with disabilities and asserts a commitment to provide inclusive educational environments, under section 2, “with children who do not have such needs unless the nature or degree of those needs of the child is such that to do so would be inconsistent” (Government of Ireland, 2004). The Education (Admission to Schools) Act of 2018 is another advantageous legislative change that

streamlines the admissions procedure for children, particularly those with additional needs (Government of Ireland, 2018). In accordance with the provisions of the Act, if a child is having difficulty securing a school placement, "the National Council for Special Education or the Child and Family Agency may designate a school or centre for education which a child is to attend" (Government of Ireland, 2018).

In 2016, 113,888 children (63%) with special educational needs (SEN's) attended mainstream school, where accommodations such as Special Needs Assistances were provided (Ombudsman for Children, 2022, P7). However, an Oireachtas debate in 2019 highlighted that "4,000 children were awaiting diagnostic assessment in order to get a school place, and that more than 850 children with SEN were receiving Home Tuition because a place could not be found for them in proximate schools" (Dáil Debate, 2019, cited in Ombudsman for Children, 2022, P17). Furthermore, concerns are expressed in the Plans for Places Report 2022 by the Ombudsman for Children, regarding the lack of school spaces in local areas for children with SEN. From 2020 to 2021, it was reported that the School Transport Schemes costs increased from €63,579 per day to €72,704, "due to children having to travel further distances out of their local area in order to be able to reach their schoolplacement" (Ombudsman for Children, 2022, P17). As stated in Article 24(2) of the CRPD, which defines inclusive education as a "fundamental human right for all learners", the research concludes that Ireland's provision of educational opportunities for children with autism does not meet this definition (UNCRPD, 2006, cited in Ombudsman for Children, 2022, P57). To ensure Ireland adopts an inclusive approach to education, the report provides recommendations including personalised educational plans for autistic children, specialised training for teachers and SNAs, and a whole-systems approach to school placement allocations (Ombudsman for Children, 2022, P57).

With the publishing of the Autism Good Practice Guidance for Schools in Supporting Children and Young Adults in 2022, the government has demonstrated a change in its commitment to inclusive education (Government of Ireland, 2022). The 250-page document outlines guidance for teachers, SNAs, and staff in the education system, providing "information and support across eight key areas of practice, [such as] learning environments, [ways to support] social, emotion, academic and behavioural development" etc (Government of Ireland, 2022, P39). Furthermore, the introduction of the new third-level National Access plan for people

with autism will make the transition to higher education more inclusive than ever, demonstrating the government's commitment "to ensuring that every student has the opportunity to succeed and achieve to [their] fullest potential" (Government of Ireland, 2022, P3)(Government of Ireland, 2022, P1). Assessing the execution of both of these social inclusion developments in practice will truly reveal how inclusive Irish education is when it comes to meeting the needs of individuals with autism.

## **2.5 – Employment and Autism in Ireland:**

According to the 2016 Census, just one-third of persons with disabilities were employed in Ireland, compared to two-thirds of those without disabilities (CSO, 2016, cited in, Kelly & Maitre, 2021, Pxi). Furthermore, those with intellectual disabilities made up one of the smallest proportions of the workforce, accounting for 14.6% (CSO, 2016, cited in, Kelly & Maitre, 2021, Pxi). Again, the census did not include precise data for those with autism; nonetheless, Ireland was reported to have the fourth lowest EU employment rates for individuals with disabilities (CSO, 2016, cited in, Kelly & Maitre, 2021, Pxi).

According to a recent study undertaken by As I Am in partnership with Irish Jobs, 461 participants with autism experienced several obstacles in the workplace, including a lack of accommodations and assistance, as well as prejudice and discrimination (As I Am, 2023, P8). 84% of participants stated that their fellow colleagues did not know enough about autism to adequately help them and their needs (As I Am, 2023, P5). Furthermore, 96% of participants believe it would be harder for them to find employment opportunities than those without autism, illustrating the disparities in working experiences (As I Am, 2023, P8). The government has undertaken attempts to enhance job prospects and conditions, such as grant programmes and disability information services like Employers for Change and the Employer Disability Information Service, all of which strive to foster workplace equality (Irish Society of Autism, 2021, P1). To maintain inclusive work settings, (As I Am, 2023, P9) advises adopting new modes of working that encourage accommodation improvements for persons with autism, such as calm surroundings, regular breaks, and continual education training for staff (As I Am, 2023, P9).



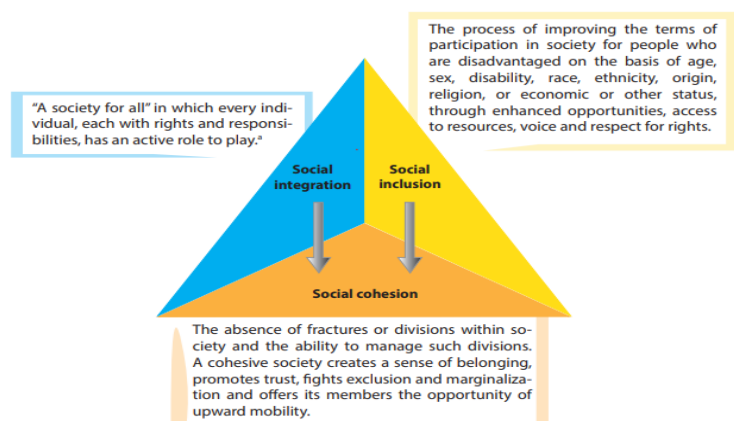
## 2.6 – Autism and Sensory Needs:

According to Howe and Stagg (2016), differences in sensory processing is a distinct characteristic for those who have autism, having a profound effect on the individual's life. Sensory processing differences can lead to hypersensitivity and hyposensitivity, which is the over responsiveness or under responsiveness to a wide range of stimuli (Autism Speaks, 2023, P1). Howe and Stagg's (2016) study on how sensory experiences affect teenagers in mainstream classrooms discovered that overstimulating the senses interfered with their ability to learn and concentrate, causing physical pain and anxiety. Kapp et al (2019, P1782) observed that self-stimulatory behaviours such as stimming helped to "calm or soothe overwhelming sensations or emotions". For persons with autism, it's crucial to make accommodations that meet their needs, including their sensory requirements.

## 2.7 –Social Inclusion and Autism:

The United Nations defines social inclusion as “the process of improving the terms of participation in society, particularly for people who are disadvantaged, through enhancing opportunities, access to resources, voice, and respect for rights” (UN, 2016, P20). Social integration is the process by which “unity, inclusion and participation” is achieved at all levels of society (Amparo Cruz-Saco, 2008, P1). Social cohesion, or the ability of society to operate as a single unit and eliminate differences at all levels of civilisation, happens when social inclusion and integration are achieved (UN, 2016, P21). According to the literature reviewed above, there are variations in how persons with autism engage in society in terms of access to services, education, and employment, some of which may constitute breaches of the UNCRPD.

### Social inclusion, integration and cohesion



(UN, 2016, P21)

The UNCRPD is a global human rights agreement that "promotes, protects, and ensures the full and equal enjoyment of all human rights and fundamental freedoms by all disabled persons" (NDA, 2023, P1). Article 5 of the UNCRPD addresses the rights of individuals with disabilities in terms of equality and non-discrimination, declaring that disability discrimination is prohibited within member states (UN, 2006, P1). Article 24 of the treaty concerns the rights of people with disabilities to an education, as does Article 27 of the convention, which addresses employment rights (Government of Ireland, 2021, P38-47). Despite not ratifying the convention until 2018, Ireland's signing of it in 2007 marked a significant turning point in the effort to advance the rights of those with disabilities in Ireland (Government of Ireland, 2021, P4).

Since Ireland has committed to safeguarding the rights of individuals with disabilities in accordance with the UNCRPD, it is important to note how Ireland has prepared the Autism Bill 2022. This Bill is a national autism policy that will establish legal commitments to people with autism, guaranteeing that their needs and "access to education, other public services, employment, and social inclusion can be met by public service providers" (Government of Ireland, 2022, P4). Despite the fact that the Bill has not yet been passed, when it does, it will acknowledge the disproportionate disparities for those with autism and, one hopes, serving as a cross-sectional barrier against prejudice and exclusion.

It should additionally be noted that autism-inclusive settings are becoming more common in Ireland in recent years. Clonakilty in County Cork is Ireland's first autism friendly town, with over 80 businesses and organisations pledging to be inclusive of the needs of people with autism (Clonakilty, 2023, P1). The municipality has demonstrated its dedication to creating inclusive settings by being service dog friendly, giving autism-friendly training to staff, creating quiet zones, and being sensory aware (Clonakilty, 2023, P1). Adam Harris, the founder of the autism organisation As I Am, stated that "the town of Clonakilty has rejected isolation, stigma, and loss of potential in favour of autism inclusion, acceptance, and cooperation. The small changes which the organisations in the town have committed to, will make a tangible difference in the life of autistic people locally but will also have a much wider impact - challenging businesses, organisations, and communities across Ireland to think what they can do to become more autism-friendly" (Harris, 2018, cited in Gittens, 2018, P1).

## **2.8 –Disablism as a Social Construct:**

Anti-discriminatory practice, which "seeks to diminish, undermine, or abolish prejudice and injustice," is a common focus for social workers (Thompson, 2006, p34). Disablism, according to (Thompson, 2006, P115) is the "combination of social forces, cultural values, and personal prejudices which marginalises disabled people, portrays them in a negative light and thus oppresses them, denying disabled people full participation in mainstream social life". The social model of disability therefore "underpins the concept of disablism", having the view that "disability is constructed by the way society is shaped, rather than it being an inherent physical state" (Thompson, 2006, P115) (Wilson et al, 2011, P566). The social model of disability looks beyond the views of the medical model and disagrees with the beliefs that in order to have a "high quality of life, defects must be cured, fixed, or completely eliminated" (ODPC, 2018, P1). Rather than blaming the individual for their impairment, the social model of disability criticises society's ideas and behaviours, as well as the environment in which we live, for constructing barriers to "obtaining full citizenship rights" (Wilson et al, 2011, P566). Lack of access to education, work, health, the physical environment, housing, services and supports and so on, are all barriers to full participation in society.

Looking at disablism as a social construct, this critical disability theory, as well as a review of current research, has helped me understand how the needs of children and young people with ASD may or may not be met. If society adopts a medical view towards autism, it ignores the need for societal transformation and instead lays the burden of change on the individual. Alternatively, if society adopts a social model of disability towards autism, it acknowledges that society has a part to play in ensuring the rights of children and young adults with ASD are met. When undertaking this study, the researcher acknowledges the importance of considering the theoretical concepts which may underpin the lived experience of autism (Mulcahy,2022,p6).

## **2.9 –Conclusion:**

In conclusion, despite Ireland's modest progress towards assuring social inclusion, integration, and coherence, praise must be given to Ireland's recent attempts to achieve autism social inclusiveness, through legislation improvements and advancements towards inclusive environments. However, this literature review has highlighted the ways in which

society continues to hinder full participation for persons with autism. These barriers include a lack of supporting employment, education, and diagnostic procedures, as well as adverse attitudes towards neurodiversity. Furthermore, in reviewing the available literature, I discovered a dearth of current perspectives on the lived experience of autism and social inclusiveness, particularly from an Irish context, that predated two years or more. Therefore, the purpose of this study is to present an up-to-date stance on the lived experience of autism from a socially inclusive perspective.



# Chapter 3

## Methodology:

### **3.1 – Introduction:**

For the purpose of this chapter, the researcher will present the study's epistemological and theoretical stance, as well as social work theories that influence the research. Additionally, the research's methodology, sampling, data anonymisation and analysis will be explored. The researcher's reflexive viewpoint and ethical considerations will be assessed. An assessment of the study's challenges and limitations will be made at the chapter's conclusion, along with some concluding remarks.

### **3.2- Epistemology and Theoretical Perspective:**

According to Brown (2015), “epistemology is the theory of knowledge and deals with how knowledge is gathered and from which sources”. Social Constructivism is a form of epistemology that “emphasises the importance of culture and context in understanding what occurs in society and constructing knowledge based on this understanding (Derry, 1999, cited in Orey, 2001, P1).

I have chosen to adopt the epistemological position of Social Constructivism in order to interpret the ways in which the social needs of people with autism are met or not met, from an organisational and societal level. Such approach sees “a one-sided adherence to either a biological or a social explanation [which] leads to a moral dilemma, for autistics and for those living with them” (Bervoets & Hens, 2020, P1). Hues & Jones (2015, P1) argue that “autism is a socially constructed discourse rather than an objective phenomenon... [as] it is shaped by the social meanings that individuals and societies attach to it”. For the purpose of this study, using a social constructivist perspective will assist the researcher in understanding the medical and societal perspectives of autism, as well as how leaning on either approach may impact supports available. As a result, the concept of social constructivism is appropriate for comprehending the lived experience of autism and how social needs are met or not met.

This study will adopt an interpretivist philosophical stance, obtaining its knowledge from the conviction that “humans construct knowledge as they interpret their experiences of and in

the world” (Constantino, 2008, cited in Hiller, 2016, P103). In contrast to positivism, which is “based purely on facts and considers the world to be external and objective”, interpretivism was selected as it is more suitable for interpreting subjective life experiences such as autism (Dudovskiy, 2018).

As per CORU proficiency 5.2 – Professional Knowledge and Skills, social workers must “demonstrate a critical understanding of social work theory, methods and skills, social policy and social research, including consideration in a global context” (Coru, 2019, P11). To provide a theoretical perspective, a variety of social work theories, including Bronfenbrenner's System theory, Maslow's hierarchy of needs and the concept of disablism, are investigated throughout the research.

### **3.3- Social Work Theory:**

#### **- Bronfenbrenner's Ecological System Theory:**

To completely perform a social inclusion analysis of individuals with Autism, it is necessary to comprehend ASD from an ecological viewpoint, where autism is contextualised in the individual's social environments (Predescu et al., 2018, P32). The Microsystem, Mesosystem, Exosystem, and Macrosystem are the four environmental levels that Bronfenbrenner identified as having an impact on an individual's growth and sense of societal connection (Alam, 2023). From the viewpoint of social inclusion, the macrosystem is undoubtedly influential because it is here that societal standards, values, duties, and rules are developed, which in turn influence every level of an individual's ecological system.

### Bronfenbrenner's Bioecological Model of Human Development

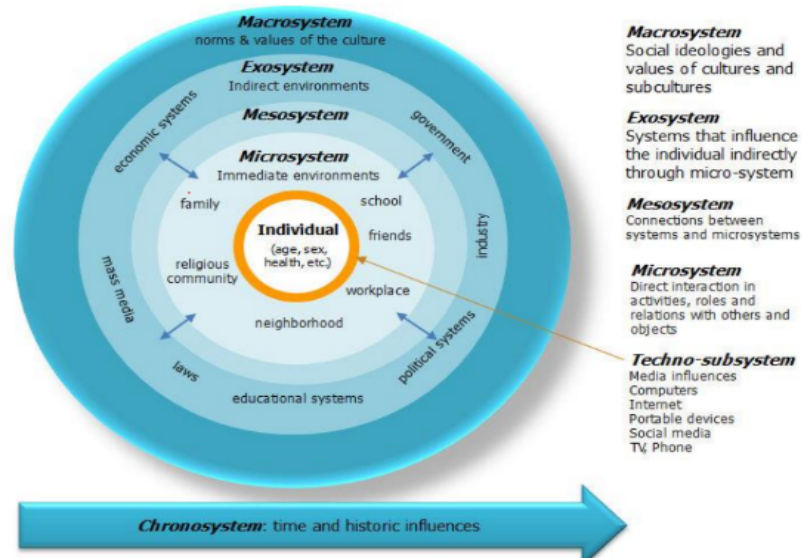
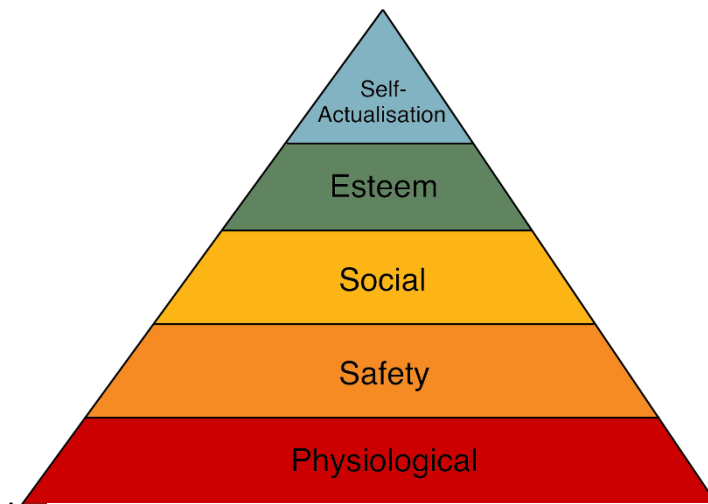


Figure: (Bronfenbrenner, 1979 cited in Predescu et al., 2018, P33).

Therefore, it can be said that one's ecological system can "influence children's development constructively or deconstructively... [influencing] how they act and interact, their physical maturity, personal characteristics, health and growth, behaviour, leadership skills, and others" (Alam, 2023). Each environment will have varying effects on each research participant. The researcher will see to it that the results are evaluated from each participant's viewpoint on social integration. In order to determine whether society retains an ableist or disablist view on autism and how this will affect the individual's social needs in turn, the researcher will benefit from using Bronfenbrenner's Ecological Systems Theory.

### Maslow's Hierarchy of Needs:

In 1943, Maslow created a hierarchy of needs that "must be met in order for a person to reach self-actualisation" (Sharp, 2016, P1). Maslow's third stage in attaining "self-actualisation" alludes to the necessity of satisfying one's social needs of belonging and inclusion within one's immediate environment (McLeod, 2018, P4). Feeling accepted, being a part of a social group, or having meaningful relationships can all help one meet their social requirements (McLeod, 2018, P4)



(Maslow, 1943, cited in Careers in Theory, 2023).

The purpose of this research is to identify how the social needs of children, teenagers, and young people with autism are presently fulfilled or not met within society, as well as how society enables or disables complete participation. According to Sparks, meeting the requirements of underrepresented groups in society requires a systematic approach if equality and diversity are to be improved (Sparks, 2016, P1). Therefore, in order to evaluate the effects of societal need fulfilment, I will use Maslow's Hierarchy of needs to inform my analysis.

### **3.4 – Methodology:**

As this research project is part of the Community-Academic Research Links Initiative (CARL), community-based participation with the Rainbow Club Cork Centre for Autism is essential. Duke (2020, P1) defines community-based participatory practice as “a methodological and epistemological approach to applied community projects in which researchers and community members collaborate as equals in the research process”. As a result, I will collaborate closely with all organisation members and pertinent parties associated with the CARL project.

As a qualitative data collection technique, I have chosen to conduct primary research using face-to-face interviews. Semi-structured face-to-face interviews will enable more precise study results, that capture the views, emotions, and feelings of the study's participants. By using this method of data collection, I hope to learn what exact social needs for individuals with autism are being met or missed. This in turn will help to accomplish the objective of



addressing the inclusionary prospects and challenges of the RCCCA and individuals with autism. As I tend to be extroverted by nature, I felt I would enjoy this personal and interactive element of the study. I believed that this method of data collection would furthermore give a real-world sense of validity to my findings.

### **3.5 – Sampling:**

It was agreed that the recruitment process of potential candidates would occur internally, with the RCCCA recruiting eligible candidates for the study. Both the researcher and the organisation agreed that a total of 8-10 participants would be optimum, allowing for a varied spectrum of opinions among participants. It was agreed that 2/3 young adults with autism, 3 parents of children/teenagers with autism and 2 staff members from the RCCCA would be recruited. Inclusion criteria for the study included adults over the age of 18 years of age, young adults with autism or parents of children/teenagers with autism who directly or indirectly avail of services or a RCCCA staff member. A consent form and information document (attached in the appendix) were given to each prospective participant after the organisation identified a sample that satisfied the inclusion requirements for the research. Only applicants who gave written consent via the consent form supplied were to be permitted to participate.

### **3.6 – Data Analysis:**

I will analyse the data using a thematic analysis, which is described as “a method for identifying, analysing and reporting patterns/themes within data” (Braun and Clarke, 2006 cited in Lochmiller, 2021, P2029). Each interview will be audio recorded and transcribed with UCC credentials using Microsoft Word's transcription feature. Each interview will be evaluated in light of the research questions for the study, and commonalities between the data will be colour-coded to help the researcher identify recurring themes.

### **3.7 – Anonymisation of Data:**

To ensure anonymity, each participant received an identification code during the interview process. This is to ensure anonymity is maintained if direct quotations from the audio recording were used. Only the researcher will be aware of each participant's special identification code, and whom it relates to. Participant-identifying information and identification codes will be password protected on a word document and uploaded to

OneDrive, a Microsoft storage service, using the researcher's UCC Credentials. The researcher will also transcribe the interviews, where the audio will be erased, leaving only the anonymised password protected transcription.

### **3.8 – Ethical Consideration:**

As a student researcher within the social work discipline, I will adhere to CORU's code of professional conduct and ethics for social workers when undertaking this research study, maintaining a high standard of professional "conduct, performance and ethics" (CORU, 2019, P6). One of the most significant duties of a student researcher is to "...act within the limits of your knowledge, skills, competence, and experience" (CORU, 2019, P6), which is a duty that the researcher will take very seriously (Mulcahy, 2022, P13).

On the 3<sup>rd</sup> of November 2022, the researcher applied for ethical clearance. On the 7<sup>th</sup> of February 2023, the MSW Research Ethics Committee approved the undertaking of the study.

It was agreed that no one under the age of 18 would be included in the study due to ethical implications and consent. The study and interview questions may highlight sensitive topics related to the lived experience of autism, which may have an emotional impact on interview applicants. It is therefore important to consider and plan for such anticipated issue (Mulcahy, 2022, P7). Throughout the project, I will collaborate closely with the CEO, Karen O'Mahony and RCCCA staff to ensure that participants receive any necessary supports. The RCCCA offers free counselling sessions to those over the age of 18. The RCCCA also offers parent support groups, which provide emotional support to parents of children and teenagers with autism. The researcher will make sure the participants are informed of such resources and will assist them in making use of them if necessary (Mulcahy, 2022, P7-12).

All questions will be asked in plain English, and if a candidate has any queries, the researcher will make every effort to make sure they are clear. I will make it apparent to each participant that they should only answer questions if they feel comfortable in doing so. If participants do become emotional at any point of the interview, the interview will be paused or adjourned, until the participant is comfortable to continue. I will ensure to inform participants that all of the information provided will be kept confidential and anonymous. Each candidate will be informed that involvement is voluntary. I will outline that after the interview, each participant will have the option to withdraw at any point throughout the subsequent two weeks. After

this point, withdrawing will not be possible. I will explain that withdrawing from the research will not be possible once the thesis is submitted to the School of Applied Social Science in University College Cork (Mulcahy, 2022, P9).

### **3.9 – Reflexivity as the Researcher:**

Reflexivity in social research can be defined as “a process of looking outward to the social and cultural artifacts and forms of thought which saturate our practices and inward to challenge the processes by which we make sense of the world (White, 2001, p102, cited in D’Cruz et al., 2007, p78). As the researcher, I believe it is important to examine my own value base and beliefs in order to establish how such may influence the course of the research study. This CARL project with the RCCCA piqued my attention because I have always been interested in accessible community resources to improve one’s outcomes. As someone who has dyslexia, I understand the value of social resources and supports, which is why I was drawn to the RCCCA’s work and how they assist people with autism and their families. (Leung et al., 2011,p72) state that “the understanding of the self is very important in the social work profession, both in micro and macro practice, because the self is the tool that brings forth positive changes in the well-being of service-users”. As a result, I will make sure that, throughout the research, my interpretations of the findings are accurate and impartial with respect to each participant's accounts. Throughout the process, I have regularly used journaling as a form of self-reflection to assess my own ideas, feelings, and emotions. Additionally, having my tutor's support has enabled me to have conversations about my reflexive stance throughout the course of the project.

### **3.10 – Challenges and Limitations:**

One of the main limitations of this research, I believe, is the study’s sample size. To guarantee a range of viewpoints on the study topic, the researcher and the RCCCA initially intended to question 8–10 people. Despite the difficulty of finding volunteers, a total of 7 candidates took part in the study. As it would have been challenging to assemble an adequate sample of only young people with autism, parents and staff members were also included in the study sample. However, I believe the study's sample provides for a wide range of perspectives from all pertinent parties, including support providers and family members. Furthermore, due to ethical considerations, young children and teenagers could not be included in the study,

which prevented such cohort from contributing additional perspectives on autism and social integration.

As previously mentioned, Interview candidates may have felt emotionally impacted by the research and interview questions as they may have brought up sensitive subjects pertaining to the lived experience of autism. Due to the need for accurate transcriptions for the research, the audio recording of each discussion may have placed pressure on participants when answering each interview question. However, if the interviews had not been recorded, they may have been answered more openly. It is important to consider such limitations when interpreting the study's findings.

### **3.11 – Interview Questions:**

For reference, the interview questions are attached in the appendix.

### **3.12 – Chapter Conclusion:**

The study's epistemological stance, social constructivism, was explored in this chapter. The study-related social work theories of Maslow's hierarchy of needs and Bronfenbrenner's ecological systems theory were also investigated. The methods, sampling, data anonymisation, and analysis of the study were also investigated, as was the process of performing semi-structured face-to-face interviews. The challenges and constraints of the study were examined, along with ethical concerns and the researcher's reflexive perspective.



# Chapter 4

## Findings and Discussions:

### 4.1 – Introduction:

The seven interviews with study participants were conducted with the aim of presenting the findings in this chapter. In order to have a variety of viewpoints when examining how inclusive society is when addressing the needs of people with autism, interviews with two adults with autism, three parents of children or teenagers with autism, and two Rainbow Club staff members were conducted. The findings will be presented using a thematic analysis, in which five themes will be investigated and literature on each theme will be provided. Sub-headings within themes will also be discussed. A discussion will be provided at the end of each theme. To guarantee anonymity when directly citing participants, each shall be identified as follows;

<b>Participant identified as:</b>	<b>Participant description:</b>
Participant 1	Young Adult with Autism
Participant 2	Young Adult with Autism
Participant 3	Parent of a child with Autism
Participant 4	Parent of a child with Autism
Participant 5	Parent of a teenager with Autism
Participant 6	Staff member
Participant 7	Staff member / Parent of teenagers with Autism

### 4.2 – Identified Themes:

The results of the study's thematic analysis are shown below. Themes 1 and 2 will address the first research question of the study, which is: in what ways are the social inclusion needs of children, teenagers, and young adults with autism being met? Themes 2, 3 and 4 will answer the second research question, which will identify the current barriers and enablers affecting young individuals with autism as they strive to meet their social needs and be included in society. The last research question will be addressed in the final theme, which will examine

the services offered by the RCCCA and how they help meet the social needs of young people with autism. It will also analyse any potential gaps in service delivery and gather feedback from respondents on the potential need for additional services in the future.

<b>Themes:</b>	<b>Sub-headings:</b>
Theme 1: Social Needs	<ul style="list-style-type: none"> <li>- Sensory Needs.</li> <li>- Supportive Social Environments.</li> <li>- Structure and Routine.</li> </ul>
Theme 2: Social Enablers	<ul style="list-style-type: none"> <li>- Autism Awareness and Inclusive Environments.</li> <li>- Parents.</li> <li>- RCCCA.</li> </ul>
Theme 3: Social Barriers	<ul style="list-style-type: none"> <li>-Judgment and lack of Understanding.</li> <li>-Lack of Universally Supportive Environments.</li> </ul>
Theme 4: Autism Social Inclusion	<ul style="list-style-type: none"> <li>- What does "Autism Social Inclusion" mean to participants?</li> </ul>
Theme 5: RCCCA Services and Supports	<ul style="list-style-type: none"> <li>-Services that fulfil Social Needs.</li> </ul>

### 4.3 – Theme 1: Social Needs:

In response to question 2 (see appendix), participants identified that individuals with autism have different sensory needs, require supportive social environments, and need structure and routine.

#### 4.3.1 – Sensory Needs:

**Participant 1:** *"Where the lights are like dimmer, and the music isn't as loud and there's not that much rush helps in shopping a lot. It's like the small touches that gets me to overstimulate so quickly and I'm not myself".*

**Participant 3:** *"Lights turned down, no flashing lights".*

**Participant 7:** *" With autism and stimming ... It looks awkward. It looks different. I have a child that stems. So, if he did that socially outside, like in the supermarket, people do look and stare and go God, what's wrong with him? He's talking to himself or whatever, but it's what they need to do".*

### Discussion:

Overstimulation of the senses, as previously emphasised by Howe and Stagg (2016), can have a significant effect on the daily interactions experienced by people with autism. According to Kojovic et al (2019), sensory processing is critical for developing trustworthy perceptions of the environment, where overstimulation can impair daily living skills and social interaction. (Palmer et al, 2021) states that there is a lack of understanding when it comes to society and the sensory needs of people with autism, stating that people with autism have "difficulties tolerating a range of stimuli such as bright environments, artificial lighting, unpredictable movements, visual distractions, and particular colours". Many participants characterised "stemming" as a method of self-regulation when overstimulated. Both jumping up and down and flapping of the hands were provided as examples. In order to better meet the social requirements of people with autism, participants voiced a need for society to understand their sensory requirements.

#### 4.3.2 – Supportive Social Environments:

**Participant 2:** *“Definitely like doing new things would be difficult, like new activities or like joining clubs and stuff. Like that would be very difficult. It's like going to a place that you've never been in before. You know nobody there and stuff like that would be very difficult.*

**Participant 3:** *“Things would have to be slowed down and be calmer. I can never understand how fridges in shops have to make so much noise. You know, checkouts having loud noises, those kinds of things. And just if somewhere is very fussy, if there's an awful lot going on, then she's just not able to deal with that”.*

### Discussion:

Participants indicated a need for social spaces that are friendly and attentive to the needs of individuals with autism. Calm and inclusive environments were identified as a social requirement for young persons with autism, who might be triggered by unfamiliar, noisy, and overstimulated surroundings. A study conducted by (Krieger et al, 2018), found that "social environments can support or hinder participation [where] security and connection represent meaningful, subjectively relevant, and feasible aspects of the environment”.

### 4.3.3 – Structure and Routine:

**Participant 3:** *“If you're supposed to go one direction and she knows we go that direction and for some reason you go a different way. You know, they're the kind of things that would not impact a person who wasn't autistic, but they have huge impact on her and therefore, our whole family”.*

**Participant 4:** *“It's better to have a plan for him. So, if he has to play or anything like that socially, that there's a start, middle and end that he knows that and what's expected of him”.*

#### **Discussion:**

Young people with autism need structure and a sense of routine in their social interactions, according to the participants. Aspire Ireland (2022) claim that regularity and structure create a feeling of predictability, which can be "very soothing" for those with autism. Routine and structure, according to (Zauderer, 2023, P1), create a sense of independence and control while minimising the likelihood of sensory overload. Smith et al (2021) conducted a study with 16 families with children / adolescents with autism, and found that “overt behaviours, self-regulation, and social communication needs were the greatest autism influence that caused families to centralise decisions, choices and routines around their child with autism”, which is consistent with participant 3's assertion that structure and routine needs have a significant impact on the entire family unit.

## **4.4 – Theme 2: Social Enablers:**

In response to question 4 (see appendix), Participants acknowledged that through supportive environments, autism recognition, the parents, and the RCCCA, people with autism are socially enabled to participate in society and have their social needs met.

### 4.4.1 – Autism Awareness and Inclusive Environments:

**Participant 7:** *“I think socially and inclusively, there's a lot more sports clubs getting involved, there's a lot more people in general that are starting to view special needs very differently, which absolutely needed to happen in this country”.*



**Participant 6:** *“The panto had an inclusive performance for all children with disabilities and there was also a circus we went to... I think people are getting on board and I think that's what we need more of is that you know there are loads of different types of people in the world and just because you have autism, or any other disability doesn't stop you from being any less important”.*

**Participant 5:** *“the sunflower lanyard... if you wear that, automatically all over Europe, it brings awareness that there's a disability and if you wear it in like an airport, people will automatically come to you rather than you seeking out the help, which is absolutely brilliant”.*

**Participant 1:** *“Cork Airport were very kind and understanding and as I had my hidden disability lanyard on, they immediately asked like, “hey, do you want someone to go with you? Do you want someone to help you with your bag? Or if you want to go early to be one of the first on the plane that you can easily. It was amazing”.*

#### **Discussion:**

It was encouraging to find that participants were able to identify inclusive social settings that supported and acknowledged people with autism. The sunflower lanyard was one of the most positive enablers mentioned by participants, allowing them to receive assistance without having to ask. According to the Hidden Disabilities Initiative (2023), the sunflower lanyards “raise awareness of the wide range of non-visible disabilities, building an index of disabilities that have few or no outwards visible signs”. The lanyard was identified as being most helpful in airports, where (Youd, 2022, P1) describes how airports can be an “extremely daunting and challenging experience [where] busy lines of people, loud announcements and uncertainty caused by flight delays can act as a sensory overload”. The existence of inclusive sports teams and social entertainment activities like pantomimes, circuses, and autism-inclusive movie showings were all valued by participants and seen as a means of allowing young people with autism to actively participate in society.

#### **4.4.2 – Parents:**

**Participant 4:** *“There is an awful lot of push for a parent to make sure constantly that their needs are catered for. So as parents, we need to push through and realise would there be these questions for someone without autism?”.*

**Participant 6:** *“It's down to their parents all the time so I think they're the biggest enablers around”.*

**Participant 3:** *“There is definitely a big gap in understanding, so I would definitely find that its parent supporting parents who are in the same situation also”.*

### **Discussion:**

Participants also stressed the important role that parents play in enabling their children to be included in society. A study performed by (Papadopoulos, 2021) which interviewed nine mothers of children with autism discovered that as a consequence of their children facing "autism stigma", mothers had to "overcome social barriers and discrimination" for their children. A significant drawback of the social autism services offered, according to the study, is that the majority of mothers must "actively search" for programs for their children (Papadopoulos, 2021). In many instances, parents become advocates for their children's welfare, as shown in the work of Ryan & Cole (2008, P49), who refer to these parents as "social model mothers [who] set up provisions to fill a gap that they felt their children needed”. This shares many similarities with Karen O'Mahoney, CEO of the RCCCA, who founded the club in response to the dearth of resources available to her autistic children. In many ways, the parent participants in this research also shared this perspective, believing that they needed to "push" for their children's social needs to be met.

### **4.4.3 – The RCCCA:**

**Participant 7:** *“My son had his very first ever one to one conversation, sitting at a table doing Lego with another child. I left the room in tears, because that's something my son never did before. It's something that I didn't think he was capable of, and that's what the Rainbow Club did for him, you know. It really improves their ability to socialise”.*

**Participant 2:** *“The Rainbow Club, it definitely has helped a lot. Like I've only just last week joined a group of other young people with autism. It's a lot easier to be kind of more open and social because you're not overthinking everything”.*

**Participant 3:** *“The Rainbow Club helps in that it’s an outlet where everyone is the same. Here there’s no differences. It’s a space where she could come and just be herself and nobody judges her”.*

### **Discussion:**

The RCCCA was identified by several participants as a supporter of their own / their child's social needs. It was described as a safe, judgment-free setting that met each child's needs at their own level. Participants stated that the support they or their children receive enables them to grow their social abilities and allows them to be their authentic selves. According to participant 7, the RCCCA's services enabled their son to play proactively with another child, which was a skill that had a profound impact on their son's life. Participant 5 described the RCCCA as an all-encompassing, comprehensive service, saying that "everything is under one umbrella" and that this allowed their child's social requirements to be met. When conducting the interviews, it became clear how grateful each participant was for the RCCCA's services and how, in many ways, these programmes have enabled every member—whether they are directly or indirectly affected by autism—to be supported in a welcoming social environment.

## **4.5 – Theme 3: Social Barriers:**

In response to question 5 and 7 (see appendix), Participants stated that judgements and a lack of understanding, as well as a lack of Universal Environments and Supports hinders their / their child’s ability to participate in society and have their social needs met.

### **4.5.1 – Judgment and Lack of Understanding:**

**Participant 1:** *“I’ve worked before. I wasn’t able to continue. It was just way too much. The reason why I quit was because they gave me hours as a student from like 6pm until like 2-3am like four times a week. I was just like I’m a student, I’m unable to do those hours, and their response was like there are multiple different students here and they don’t get anything*

*special. There was a lack of understanding and kind of just looking like, oh, we need this, and it doesn't matter what your kind of going through. It was heart-breaking”.*

**Participant 7:** *“If you've got an autistic 3- or 4-year-old that's lying on the floor screaming in the supermarket, they're not doing it because they've been bold. They're doing it because there's a whole load of stuff going on around them that they're not able to process. There's too much going on, the lighting could be too much. The noise is too much, and people need to view that differently because you get a lot of looks and it feels very uncomfortable. But if everyone else gets on about their business and just lets that parent deal with the child as best they can without any judgement, they just need to take judgement out of it”*

**Participant 6:** *“I think that we just need to understand them more and understand their ways and needs, and how they are different to what we call a neurotypical child. I think that they need a lot more support, but just a lot more understanding for their needs too”.*

#### **Discussion:**

One of the most significant hurdles to full involvement in society among participants was judgement and a lack of understanding. School, employment, and social contexts such as grocery shopping were all been identified as triggering environments that prevent full inclusion and participation. Participants' perspectives are consistent with the findings reported in The Same Chance Report (As I Am, 2022, P5), in which 32% of 3,970 people with autism also indicated that judgement and a lack of understanding were the most significant social barriers. Participant 1's employment experience parallels prior research, in which 461 other people with autism reported a lack of accommodations, support, prejudice, and discrimination (As I Am, 2023, P8). Participants also indicated a lack of awareness of people with autism's social requirements, emphasising the importance of society adopting a holistic approach to meeting the needs of people with disabilities throughout society.

#### **4.5.2 –Lack of Universal Environments and Supports:**

**Participant 3:** *“She was knocked out of the early intervention services that the HSE offered because she was of school going age? She was to be transferred over to school age team and*

*she technically was transferred onto a list somewhere in X, but there were no services, there was nothing. There are no services other than in the private system that has such a long waiting list. So, I mean, that's ridiculous. It's infuriating".*

**Participant 4:** *"You don't have a holistic plan for your child. It's all bits go to speech therapy, occupational therapist. Go to wherever. You have little bits. And as parents you to put the puzzle together to come up with the plan for the teacher, for your child. You don't actually get the holistic approach or a holistic plan of how to move forward".*

**Participant 1:** *"School can really make you feel like you're either stupid or just not worthy as a person. It will really bring you down because you spend the majority of your day there. It really affects you and it has made me depressed and stopped me from trying to socialise. So, if education were like properly put in something in place so that autistic children or just neurodiverse children will have a place to feel comfortable, or even just have an adult that they can talk to for 10 minutes a day so that they don't feel that judged it would help a lot"*

**Participant 7:** *"When we went to apply for secondary school for X. There were four ASD places in Cork, and I think about 150 kids".*

**Participant 6:** *"There's not enough support there to make sure that these kids are getting everything that they deserve, and I think it just comes down to our government".*

#### **Discussion:**

Participants once again emphasised the lack of a comprehensive strategy to achieve universal environments and services. Waiting lists, as well as a lack of resources and financing, were recognised as hurdles to obtaining autism supports within the public and private healthcare systems. Parents once again felt compelled to "put the puzzle together" for their children in order for them to receive the assistance they required. School was also identified as a social barrier to full participation in society, as Participants 1 and 2 stated that their school experiences were hampered because school environments were not inclusive of their needs and the supports provided were not directly related to their autism diagnosis. If adopted, autism safe zones in mainstream schools were identified as aiding their participation, by providing a safe location for them to regulate their overstimulation. Parent participants also expressed concerns about a lack of "proper training" among school staff, as well as a shortage

of overall school placements, which generated anxiety and stress for parents. Despite being a step in the right direction towards inclusiveness, the publication of the Autism Good Practise advice for Schools in Supporting Children and Young Adults in 2022 merely provides guidance and does not address the training requirements of staff members, which is a concern raised by participants (Government of Ireland, 2022).

## 4.6 – Theme 4: Autism Social Inclusion:

When participants were asked to describe what "Autism Social Inclusion" meant to them, as per question 6 (see appendix), individuals with autism should be given the same chances and degree of acceptance as young people who are neurotypical, and there should be increased awareness about autism in society, according to participants.

### 4.6.1 –Autism Social Inclusion:

**Participant 1:** *“Having more social supports in society would give like a lot more freedom and it would make me definitely happy. Happier that I'm able to do something alone. I'm able to do this independently and I can feel confident in it”.*

**Participant 7:** *“Society as a whole needs to understand that our kids are people with disabilities, they they're not capable of change. It's society that needs to change. Society needs to accept that we're not all robots. We're not all the same”.*

**Participant 3:** *“It would be being able to access everything that our typical child can access and that the modifications and accommodations are automatically there, without having to ask”.*

**Participant 4:** *“Acceptance that not everyone is the same. That we accept people at their own level as opposed to making them fit in”.*

**Participant 6:** *“As mother of three kids with no disability, I've never had to face any of that. Their entitlements were there. They went to school, they got their education, they got everything. It was like a normal progression... I get so cross at what these parents have to go through to give their kids the same life that I was able to give mine but they're fighting tooth and nail”.*

## Discussion:

As previously indicated while evaluating existing literature, Ireland has made efforts towards achieving autism social inclusion through legislative advancements and progress toward inclusive environments. However, participants stated that despite developments, society is still “nowhere near where it needs to be”. An adult participant with autism highlighted how they would have more independence if society supported their social needs. Article 19 of the UNCRPD establishes the concept of independent living, with subsections B and C stating that persons with disabilities must be supported by community services and facilities on an equal basis as persons without disabilities, and that society as a whole must "prevent isolation or segregation from the community" (UN, 2006). Participants' experiences in society, however, greatly diverge from the human rights principles provided by the UNCRPD and demonstrates how society has not yet adopted the social model of disability. Participants expressed their desire for autism acceptance, as well as their frustration that persons with autism did not have access to the same opportunities as those without. The participants' responses are consistent with the findings of The Same Chance Report (As I Am, 2022, P5), which found that 89% of 3,970 autistic people interviewed believe that the Irish population is underinformed about autism, with 81% agreeing that Ireland should adopt a National Autism Strategy to better support the autism community.

## 4.7 – Theme 5: The RCCCA’s Services and Supports:

When asked about the RCCCA's services and how they help to meet the social needs of people with autism, corresponding to question 8 (see appendix), participants named the Teen Hub, Adaptive Sports sessions, the Wellness and Life Mentorship programme, and others as social enablers.

### 4.7.1–RCCCA Services that fulfil Social Needs:

**Participant 1:** *“(Teen Hub) The only place that I'm able to socialise, I really don't go anywhere, I'm just too scared to. So, this is the only place where I talk with people. I don't really have friends. So, this place really helps to kind of give that boost for the next week and it's been so*

*extremely nice because I haven't had that boost for years and now having it, it just brings me up.*

**Participant 2:** *“(Teen Hub) People are very similar to you and very likeminded and you don't have to, like be apprehensive of everything that's happening, it's a lot more relaxing for you”.*

**Participant 2:** *“(Wellness and Life Mentorship Program) Like even for me, I love music, so we do a lot of stuff to do with music in that session, which helps me become a lot less like anxious”.*

**Participant 1:** *“(Wellness and Life Mentorship Program) My appeal has been declined multiple times (for Disability Allowance) and I am getting ready to write another one, but the Rainbow Club, they've helped so much. I would be absolutely lost without them, and I don't think they get enough credit for the work they do”.*

**Participant 3:** *“The adopted sports is brilliant because the lads end up playing games with the kids without them necessarily realising that there are in an exercise class. X did play therapy and loved it, and art therapy. X goes to the social clubs and the summer camps each year. Everything is just really good here. There are so many benefits... there's a huge sense community here. Just as important as services for the kids, it is as important to have outlets for parents”.*

### **Discussion:**

Many services provided by the RCCCA were identified as fulfilling the social needs of children, teenagers, and young adults with autism. The Teen Hub and Wellness and Life Mentorship Programme, in particular, were recognised as the most beneficial services provided for adults with autism, boosting their independence and socialisation abilities with others.

For one member in particular, the teen hub is their sole social outlet, demonstrating how crucial such support is. A recent study conducted by (Umagami et al, 2022, P2315) found how adults with autism are more likely to experience higher levels of loneliness and “long for connection and belonging in the same way that non-autistic people do”. It is therefore a vital social outlet for teenagers and young adults with autism to establish friendships and develop their social skills. The mentorship program was also seen as a vital support, especially for participant 2 who stated that such support aided their anxiety levels. A 2018 (Van Steensel et



al) research of 2,121 young adults indicated that 39.6% of young adults with ASD experience anxiety, with 16.6% reporting everyday social anxiety. Such service has also aided young people in completing crucial documentation, such as social welfare applications and appeals, which was recognised as an essential social and emotional support.

For younger children, social clubs, social summer camps, and adaptive sports sessions were just a few of the many resources identified as satisfying social and inclusionary requirements. A few of the beneficial effects experienced since joining the RCCCA were improvements in children's self-esteem, social skills, and capacity to develop and maintain friendships. Parents also emphasised the importance of having their social needs met as primary carers, through parent support groups and counselling sessions. Overall, the RCCCA has a variety of social supports that are inclusive of individuals with autism, and their families, being encompassing of “the whole family unit”.



# Chapter 5

## Conclusion and Recommendations:

### 5.1– Introduction:

This chapter will outline the research's conclusions, offer recommendations, and identify areas that require additional research. Recommendations are based on the concerns raised by participants as well as those that I, the researcher, thought were crucial as a result of this study.

### 5.2 – Conclusion:

The primary goal of this study was to provide a social inclusion analysis of how young people with autism's social needs are met or not met from an inclusionary stance. In order to obtain a range of viewpoints on lived experiences, semi-structured face-to-face interviews with a total of 7 participants—2 adults with ASD, 3 parents of children or teenagers with ASD, and 2 RCCCA staff members—were facilitated. To assess the findings of the research, a social constructivist perspective was adopted, and the findings were presented using a thematic analysis. Five themes in total were examined: social needs, social enablers, social barriers, autism social inclusion, and how the RCCCA meets the social requirements of young people with ASD.

Although Ireland has made strides towards achieving social inclusion for people with ASD, the general culture still prevents full involvement, according to the study's literature analysis. This study's findings also underscored how society is "nowhere near where it needs to be", in terms of achieving complete social inclusion for persons with autism.

The first theme identified how young people with ASD require social environments that are supportive and sensitive to their sensory demands, as well as structure and consistency to meet their social needs. This study showed how, in many instances, these demands are unmet in a variety of social contexts, such as shopping centres, schools, workplaces, etc.

The second theme of the study showed how autism inclusion and awareness, along with parental and RCCCA's support, function as social enhancers for children, teenagers, and

young adults with autism. However, parents of children with disabilities feel that in order to meet their children's needs and get beyond prejudice and societal barriers, they must "push" more than parents of children without disabilities.

The third theme focused on the barriers that prevent people with autism from participating fully in society, including prejudice, a lack of understanding, and a lack of environments that are universally accepting. Waiting lists, as well as a lack of resources and funding were some of the factors contributing to the increased marginalisation of those with autism.

When asked what autism social inclusion meant to them, participants indicated that acceptance of autism, as well as universal access to all supports and services, were among their top priorities for achieving social inclusion. Participants' social experiences, however, showed how society has not yet embraced the social model of disability and how they significantly deviated from the human rights principles established by the UNCRPD.

The last theme examined how RCCCA supports improved the independence and socialisation skills of adults and young children with autism, as well as helping them cope with anxiety and loneliness. For some participants, it served as their only social outlet. The Teen Hub, the Mentorship Programme, social groups, summer camps, and adaptive sports were some of the most helpful services identified. Participants indicated prospective future services that the RCCCA could provide, which are addressed below.

In conclusion, this social inclusionary study found that society does not completely meet the social requirements of people with autism, and participants lived experiences revealed how inhibiting societal impacts can often be detrimental to their involvement and inclusion in it. The RCCCA, on the other hand, was recognised as a secure, judgment-free environment that supported and enabled every person with autism and their families to fulfil their social requirements and be socially involved. Being one of the only services of its kind in the country, it was recognised by many as a crucial component of their/their child's social development and served as a service that changes lives in many ways.

## 5.3 – Recommendations:

### 1. RCCCA SUPPORTS:

- The necessity for additional "teenager sports sessions" were noted by participants. Examples provided were teenage football and basketball sessions.
- Adult participants identified a need for "evening social spaces" for adults aged 20-24 years. Adult participants also expressed a desire for additional "community integration outings" to improve their social skills and abilities to interact in socially appropriate settings.
- Adult participants expressed a need for interview skills sessions to aid in the development of their interpersonal skills when applying for employment or college placements.
- Participants also identified a potential service for grandparents, who were in many ways identified as the "secondary primary carers" for young people with autism. Supports to better inform grandparents about autism was seen as beneficial support for future implementation.

### 2. SOCIAL NEEDS:

- Participants expressed a desire for society to understand their sensory and social needs. The implementation of a national action plan is needed immediately to improve autism awareness and reduce social isolation and discrimination.
- Autism-friendly surroundings need to be implemented in all businesses and social venues nationwide.
- Participants cited the necessity for ongoing conversation about autism in society, not just around April (autism acceptance month). To raise autism awareness throughout the year, mass media and educational campaigns are required.

### 3. EDUCATION:

- Participants stated that school environments were not inclusive of their needs and the supports provided were not directly related to their autism diagnosis. Individualised educational plans are needed for persons with autism in order for them to excel in their school environments.

- Increased supports and sensory-appropriate environments in schools, such as autism safe zones, are required to improve educational attainment and help regulate overstimulation.
- The absence of "proper training" for school staff and the scarcity of overall school placements were cited as serious problems. The government ought to prioritise training for employees and increasing the number of school placements for autistic kids.

#### **4.EMPLOYMENT:**

- The ability to participate in the workforce has been severely hampered by a lack of autism-friendly accommodations and understanding. Legislation should be enacted to make it a legal obligation for people with autism to be properly supported, as well as workplaces to ensure they are carrying out regular training on the needs of various disabilities in order to foster diversity in the workforce.
- Interview accommodations should be made for persons with autism to ensure their sensory needs are fulfilled.

#### **5. SUPPORTIVE SOCIAL ENVIRONMENTS:**

- Autism-friendly environments are needed nationwide, and other towns in Ireland should look to towns like Clonakilty as a model for promoting autism friendly environments locally.
- Participants could only pinpoint airports as the best setting for using sunflower lanyards. To raise awareness about hidden disabilities, a nationwide educational campaign should be launched to encourage the use of these lanyards in all social contexts.

#### **6. AUTISM SOCIAL SUPPORTS:**

- Participants expressed concern for other families that do not have access to resources such as the RCCCA. As the RCCCA is Ireland's sole autism support service of its sort, participants urged for the government to support autism services countrywide, ensuring that "every hometown in Ireland has something like the RCCCA".
- Parent and staff participants expressed a desire to expand Teen Hubs across the country. According to participants, this cohort is "really let down both locally and

nationally," as their social requirements would not be met if not for the RCCCA's teen hub.

- In both the public and private healthcare sectors, more government funding was determined to be necessary in order to reduce waiting lists and develop comprehensive supports and programmes for people with autism.
- Ireland's adherence to the UNCRPD and its duty to provide autism assistance needs to be reviewed by the government.

#### 5.4 – Recommendations for Future Research:

- Young children or teenagers could not be interviewed due to ethical considerations. In order to take their perspectives into consideration, future research should explore this cohort's viewpoints on autism and social integration.
- Future studies should, to the extent possible, look at the perspectives of adults of all ages to determine how society promotes or discourages full engagement at various periods of life.



***“They're not doing it for every child locally or nationwide to make sure that every child of every age group whether or not they have autism or any other disability ... they're not all treated the same and that's the biggest problem I think that we face is that there is such a divide between what we call our normal child and our child with a disability, and I think that's what's got to change” – Participant 6***

## Post Study Reflection:

**Looking Back:** Looking back on this research experience, I am very grateful for the opportunity to conduct a CARL project in collaboration with the Rainbow Club. This has been an invaluable experience for which I am both personally and professionally grateful, as I have learned so much about the importance of collaborating with key service providers and service users, as well as how powerful their voices and lived experiences are when investigating how society can enable or restrict full participation. I have, from the start of this endeavour, been indebted for the positive support and encouragement of Karen, Molly, Sara, and Anna, in endorsing the validity of undertaking this research and for offering their knowledge and encouragement when and where needed. I am also very grateful to all of the study participants who shared their genuine feelings about social inclusion and autism. I cannot thank them enough for their contributions to this study's rich results and for assisting me in my investigation of autism-related lived experiences.

**Looking In:** Looking into my own value base, I knew I always wanted to assist others improve their life outcomes. I didn't know exactly how I would be able to achieve this, and in reflection it did not become apparent to me until my third year BSc Public Health placement, where I was situated within Headway, a rehabilitation centre for clients with acquired brain injuries. This experience piqued my interest in the subject of social work and opened my eyes to the manner in which the social care and social work professionals serve clients using a variety of everyday practical supports and skills. It furthermore demonstrated to me how vital services are within the community to better support clients with disabilities, and how such supports can be lifechanging to clients and their families. As a consequence, I was drawn to the RCCCA's work right away, and when the idea of completing a CARL project was brought to me, I knew I would be so lucky to collaborate with the RCCCA. As this was my first time performing primary research, I felt I placed pressure on myself to do credit to each and every participant, as well as the RCCCA. This accentuated my inner critic and caused me to doubt myself and my abilities at times. However, the continuous encouragement and reinforcement I received kept me on track and helped me to realise my potential when finishing such a valuable piece.

**Looking Out:** Conducting this research piece has genuinely opened my eyes to how each member in society has unique differences, and how, in many ways, a lack of knowledge and perspective exacerbates injustice, marginalisation, and a lack of social cohesiveness. It has demonstrated to me how different daily experiences, such as employment and schooling, may exist for young people with autism, and how, in many respects, individuals in society can take daily amenities for granted when their requirements are met. To guarantee that everyone is fully supported and included in society, society as a whole, in my opinion, must assume responsibility.

**Looking Forward:** This experience has made clear to me the value of research in guiding practice and the significance of translating theory into action. Conducting this project has shown me how social work, as a profession, needs to be mindful of the micro, meso, exo, and macro systems, and how clients' social environments can positively and/or negatively affect their social participation. This research has shown me how to best serve clients with autism, considering their social requirements and environments, as well as how to best support the family unit as a whole. In addition, it is underlined that clients are the experts in their own lives, and I will, in accordance with CORU proficiency 5.6, "demonstrate a critical understanding of cultural competence; and work towards social inclusion" as a future social worker in practice (CORU, 2019, P11).

***"We're not all the same".***





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# Appendices:

## Appendix A- Ethical Approval:

### MSW REC

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MSW Research Ethics Committee  
School of Applied Social Studies

Applicant:  
Alexandra Rose Mulcahy, 2022/23  
Committee Date:  
7th February 2023  
Tutor(s):  
Sara Kelleher  
Reference:  
2022-5

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

Your application is approved.

The committee recommend that you continue to work on the title and the interview questions with your tutor. You do not need to send any further submissions to the MSW REC.

We wish you all the best with your research project. If you have questions, please contact your MSW tutor.

Best wishes,

Dr Kenneth Burns  
On behalf of the MSW Research Ethics Committee



**Kenneth Burns**

[k.burns@ucc.ie](mailto:k.burns@ucc.ie)



## Appendix B- Information Sheets for Participants:



### Information Sheet for Participants

Thank you for considering participating in this research project. The purpose of this document is to explain the rationale of the project and what your participation would involve, to enable you to make an informed choice. Alex Mulcahy, a final year master's student in Social Work at University College Cork, will conduct this research, in collaboration with the Rainbow Club Cork Centre for Autism, as part of the Community Academic Research Link Initiative (CARL).

**Research title:** "A Social inclusion analysis for individuals with autism from the perspectives of young adults, parents, and staff at the Rainbow Club Cork Centre for Autism".

**The purpose of this study** is to provide a critical analysis of how children, teenagers, and young adults' social needs are fulfilled and/or not met from an inclusionary viewpoint. This research will delve into the experiences of young people with autism, parents with children / teenagers with autism and RCCCA staff. This is to achieve the goal of addressing the RCCCA's and individuals' inclusionary prospects and challenges in the context of greater society and social policy.

**The objective of this research** is to acquire insight into the lived experience of young people with autism, parents with autistic children or teenagers and RCCCA staff. This study aims to establish the ways in which the social needs of autistic individuals are satisfied and/or not addressed from an inclusionary standpoint. Participants will be asked to reflect on their experiences with service provision, accessibility, and inclusivity in society, in order to determine if the requirements of autistic persons are met in an enabling or disabling manner.

The findings of the study will be utilised to compose the researcher's dissertation and/or conference presentation, as well as to inform inclusive behaviours and practices that fulfil the social needs of persons with autism. The Rainbow Club Cork Centre for Autism and the CARL Initiative can publish the study findings on their social media platforms, however, all information provided by you will be anonymised upon the studies completion.

**Why Participate?** You have been selected to consider your participation in this study because you are either a young adult with autism, a RCCCA staff member, or a parent of an autistic child or teenager, and so meet the inclusion criteria for this study.

Should you choose to participate, you will be asked to take part in a one-to-one interview with the researcher, Alex Mulcahy. This interview will be audio recorded and will take approximately 20-30 minutes to complete. The purpose of audio recording the interview is to verify that your information is obtained accurately, reducing the possibility of misquotation.

The HSE and government regulations regarding Covid-19 must be adhered to during one-on-one interviews. We politely request candidates not show up for the interview if they exhibit symptoms or think they might have Covid-19. The researcher will reschedule the interview upon request.

The project is expected to begin in February/March 2023. Participation in this study is completely voluntary. There is no obligation to participate, and should you choose to do so, you can refuse to answer specific questions. After the interview, you have the option to withdraw at any point throughout the subsequent two weeks from date of interview. After this point, withdrawing will not be possible. Withdrawing from the research will not be possible once the thesis is submitted to the School of Applied Social Science in University College Cork.

**What happens if you choose to participate?**

If you agree to participate, the RCCCA will provide the researcher with your contact information, which I will use to contact you and offer you this information sheet and consent form to complete. The research consent form must be signed and returned to the researcher.

All of the information you provide will be kept confidential and anonymous and will be available only to the researcher and the researcher's tutor Mrs Sara Kelleher. The only exception is where information is disclosed which indicates that there is a serious risk to you and/or to others. As a mandated person, if there are disclosures that concern the protection of vulnerable persons and/or the safety of children, such concerns will be communicated to appropriate statutory agencies under the Children's First Act 2015.

Once the interview is completed, the audio recording will immediately be transferred to UCC's approved Microsoft products, using the researchers UCC credentials. The interview will then be transcribed by the researcher, and all identifying information will be removed. Once this is done, the recording will also be deleted and only the anonymised transcript will remain. This will be stored on a

University College Cork supported Microsoft storage platform. The data will be stored for minimum of thirteen months.

We do not anticipate any negative outcomes from participating in this study. The interview questions may raise sensitive issues related to the lived experience of autism. As a result, an introduction to the interview process as well as a post-interview debrief will be facilitated. I will discuss with you how you found the experience and how you are feeling. I will make it clear to you that you may only answer questions if they feel comfortable in doing so. If you do become emotional at any point of the interview, the interview will be paused or adjourned, until you are comfortable to continue. Throughout the project, I will collaborate closely with Karen O'Mahony and RCCCA staff to ensure that you receive supports such as counselling services and/or access to parent support groups if you need.

This study has obtained ethical approval from the UCC Social Research Ethics Committee.

If you have any queries about this research, you can contact the researcher and/or the researcher's tutor:

- Alex Mulcahy [116341951@umail.ucc.ie](mailto:116341951@umail.ucc.ie)
- Sara Kelleher [sarakelleher@ucc.ie](mailto:sarakelleher@ucc.ie)

If you agree to take part in this study, please sign the consent form overleaf.

## Appendix C-Consent Forms:



### Research Consent Form

I.....agree to participate in Alex Mulcahy's research study.

The purpose and nature of the study has been explained to me in writing.

I am participating voluntarily. I give permission for my interview with Alex Mulcahy's to be audio recorded. I understand that anonymity will be ensured in the write-up by disguising my identity.

I understand that I can withdraw from the study, without repercussions, whether before the study starts or while I am participating. I understand that I have the option to withdraw at any point throughout the subsequent two weeks from date of interview. After this point, withdrawing will not be possible. Withdrawing from the research will not be possible once the thesis is submitted to the School of Applied Social Science in University College Cork.

I understand that the information I provide will be kept confidential and anonymous. The only exception is where information I disclosed indicates that there is a serious risk to myself and/or to others. I understand that if there are disclosures that concern the protection of vulnerable persons and/or the safety of children, such concerns will be communicated to appropriate statutory agencies under the Children's First Act 2015.

I understand that the Rainbow Club Cork Centre for Autism and the CARL Initiative can publish the study findings on their social media platforms, however, all of my information will be anonymised upon the studies completion.

I am aware that during one-on-one interviews, Covid-19 regulations set forth by the HSE and the government must be followed. I understand that if I exhibit symptoms or think I might have Covid-19, I will not attend the one-to-one interview. I am aware that the researcher will reschedule my interview in this situation.

I understand that disguised extracts from my interview (e.g., my name / location won't be used) may be quoted in presentations and publications (e.g., 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

Signed: .....

Date:

PRINT NAME: .....

## Appendix D -Interview Questions:

### Data Collection Instrument: Interview Guide

An introduction will occur before the interview process begins. The researcher will introduce herself and provide an overview of the information sheet in order to give a synopsis of the study's purpose. It will be confirmed and double checked that consent forms have been signed before the interview begins.

Participants will be given a general overview of the research project and its objectives and will be encouraged to ask questions if they are unsure about any specifics. The researcher will next go over the interviewing process and how it will be audio recorded for data collection and analysis. The researcher will advise the participant to ask the researcher to restate or repeat any questions that may not be clear to them. The researcher will explain that some of the questions and replies to the questions may have an emotional impact because the study will focus on the lived experience of autism and how individuals' social needs are and/or are not satisfied. The researcher will explain that if a participant gets upset or wants to pause the interview at any time, it can be facilitated. The researcher will approximately take 30-40 minutes and will then ask the participant are they ready to start the interview.

#### Proposed Questions –

1. Can you introduce yourself and explain how you are associated with the Rainbow Club Cork Centre for Autism?
2. Can you tell me what you think are the unique social needs of individuals with autism and how they differ from those who are not diagnosed with autism, if so, based on your experience?
3. Can you tell me how, locally and/or nationally, the social needs of autistic children, teenagers, and young adults are currently fulfilled and not fulfilled?
4. Can you tell me if there are any current enablers that help people with autism's social skills on a personal or professional level? This could include professionals, public sector organisations, or others.
5. Can you tell me, based on your own experience, what current barriers prevent children, teenagers, and young adults with autism from having their social needs met and being included in society, and in what way does the Rainbow Club help such?
6. Could you describe what autism social inclusion means to you?
7. In your opinion, do you believe there are enough services in society for people with autism?
8. Can you tell me, based on your own experience, about the services provided by the RCCCA and how they help to fulfil the social needs of individuals with autism?

9. Can you tell me, in your experience, what have been the most supportive services provided by the RCCCA, and what potential opportunities or gaps in service provision could the Cork Rainbow Club could address in the future?

Once all questions are answered the de-briefing phase of the interview will commence. The de-briefing phase will allow the researcher to explain what will happens with the data, how it will be stored, and how their data will be analysed in order to determine the study's outcomes. The debriefing session will also allow for a discussion with the participants to evaluate how they are feeling after completing the study questions and if they require any additional supports, e.g. counselling and/or access to parent support groups. The researcher will work closely with Karen O'Mahony and staff of the RCCCA throughout the project and will ensure that participants are provided with supports if needed. The debriefing session will also be utilised to discuss the procedure of withdrawing from the research, as well as the timelines for doing so. The researcher will then thank the participant for taking part in the study and provide her contact email address details, in case there are follow up questions after the interviewing process.