

**The impact of non-curriculum-based  
interventions on the Quality of Life  
(QOL) of children and young persons  
with special educational needs and  
disabilities (difficulties)**

**By**

**Chai Leung Ho**

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**Buckinghamshire New University**

**Staffordshire University**

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## **Abstract**

This research aims to investigate the impact that non-curriculum based targeted interventions can have on the quality of life (QOL) of children and young persons (CYP) with special educational needs and/or disabilities (difficulties) - SEND.

Previous research is mostly quantitative, hence I argue the importance of collecting qualitative data from different types of participants, such as the student participants, their parents and intervention leaders. Three student participants took part in this research, alongside their mothers, and intervention leaders. This study follows an action research approach, using ethnography inspired data collection methods: participant observations, fieldnotes and semi-structured interviews.

The main themes that emerged from this research were: social well-being through peer interactions, physical well-being and emotional well-being. The findings suggest that all targeted interventions had an impact on the student participants' QOL, mostly on their social and physical well-being. The communication and interaction intervention had an indirect impact on Tony Conor's social and emotional well-being, as additional social opportunities were fostered and a friendly relationship between Tony and the intervention leader was developed through the intervention. The sensory, motor and physical intervention had a direct impact on Oli's physical and emotional well-being, as Oli took part in multiple physical activities that worked on his gross and fine motor skills and felt happier as he became thinner and that no one called him fat anymore. The social, emotional and mental health intervention had a direct impact on Gordon's social and emotional well-being, as Gordon explicitly discussed social encounters that he considered difficult or joyful emotionally throughout the intervention, while receiving coaching and mentoring with strategies. Thus, student participants unraveled some of their difficulties under these domain headings due to their specific SEND, and their perception of their QOL appeared to improve over time.

# List of Contents

Abstract.....	2
List of Contents.....	3
List of Figures.....	6
List of tables.....	6
Glossary.....	6
Acknowledgements.....	7
Author's Declaration.....	8
1 Introduction.....	9
2 Literature review.....	20
2.1 'Well-being' and QOL.....	20
2.2 Objective and subjective QOL.....	33
2.3 QOL of typically developing CYP and CYP with SEND.....	39
2.4 Measuring the QOL of CYP with SEND.....	41
2.5 Enhancing the QOL of CYP with SEND.....	47
2.5.1 Education and employment.....	47
2.5.2 Religions and Spirituality.....	50
2.5.3 Improving behaviour.....	50
2.5.4 Life coaching and person-centred action steps.....	52
3 Methodology.....	56
3.1 The definitions and ideology of a qualitative approach.....	56
3.2 Why adopt an ethnography inspired approach?.....	64
3.3 Defining action research.....	68
3.4 Reflexivity.....	74
3.4.1 Reflexivity: A personal narrative of the evolution of the methodology and chosen methods including my final position.....	75
3.4.2 The strengths and weaknesses of an insider research.....	78
3.4.3 My professional position within School H.....	80
3.5 Sample group.....	81
3.5.1 Gordon and his mother (Mrs Smith).....	85
3.5.2 Oli and his mother (Mrs Zane).....	86
3.5.3 Tony and his mother (Mrs Conor).....	87
3.5.4 Intervention leaders.....	90

3.6	Intervention overview .....	91
3.7	Data collection .....	94
3.7.1	Participant observation .....	95
3.7.2	Writing fieldnotes .....	99
3.7.3	Conducting interviews.....	101
4	My time in the field: ethical considerations.....	104
4.1	Gaining access to the field .....	104
4.2	Practitioners' own ethical reservations .....	105
4.3	Consent, confidentiality, and anonymity.....	106
4.4	Handling sensitive topics and working with vulnerable participants .....	107
4.5	The participant school .....	108
4.5.1	Formal pathway .....	108
4.5.2	Semi-formal pathway .....	109
4.6	Staff turnover in School H .....	109
4.7	Delays caused by COVID.....	110
4.8	Dual positions within School H .....	110
5	Data Analysis Procedure.....	114
5.1	Thematic analysis.....	115
5.1.1	Contextualising and decontextualising data .....	116
5.1.2	Familiarising myself with the data.....	118
5.1.3	Generating initial codes – including connecting relationships and de- contextualising where necessary .....	120
5.1.4	Identifying themes.....	125
5.1.5	Reviewing themes.....	128
5.1.6	Defining and naming themes .....	130
5.1.7	Producing the report .....	131
6	Findings.....	132
6.1	Social well-being through peer interactions.....	133
6.1.1	Participants' views on Peer Interactions .....	135
6.1.2	Playing on the console with peers .....	143
6.1.3	Playing sports with peers .....	156
6.1.4	Unkind behaviours from peers .....	163
6.2	Physical well-being .....	180
6.2.1	Student participants' views on physical Well-being .....	182
6.2.2	The impact of physical fitness on physical well-being .....	197

6.3	Emotional well-being .....	207
	Tony's emotions stemming from social and physical well-being .....	208
6.3.1	Oli's emotions stemming from social and physical well-being .....	211
6.3.2	Gordon's emotions stemming from social and physical well-being .....	212
6.3.3	The intervention impacts on Tony's emotions .....	215
6.3.4	The intervention impacts on Oli's emotions .....	217
6.3.5	The intervention impacts on Gordon's emotions .....	221
7	Conclusions.....	230
8	Recommendations for future research .....	236
	References .....	239
	Appendix 1: Interview schedule .....	266
	Appendix 2: Interview schedule .....	269
	Appendix 3: Differentiated materials .....	270
	Appendix 4: Participant consent form .....	271
	Appendix 5: Participant information sheet .....	273
	Appendix 6: Participant information sheet with visuals .....	275

## List of Figures

Figure 1 Communication and Interaction Intervention data collection overview .....	83
Figure 2 Sensory, Motor and Physical Intervention data collection overview .....	83
Figure 3 Social, Emotional and Mental Health Intervention data collection overview	84
Figure 4 Interview transcript – Gordon .....	121
Figure 5 Fieldnotes - Gordon .....	121

## List of tables

Table 1 Flanagan's (1978) QOL Domains headings and domains .....	26
Table 2 Felce and Perry (1995) QOL Domains headings and domains .....	28
Table 3 Pseudonyms and associated roles .....	82
Table 4 Coding Excel sheet .....	122
Table 5 Coding excel sheet showing the tabs, additional information on the data, highlighted quotes / notes, and initial codes. ....	123
Table 6 Coding excel sheet showing a set of new tabs and quotes moving across	124
Table 7 Coding excel sheet showing how data was first contextualised before decontextualised .....	125
Table 8 Coding excel sheet showing how codes, domain headings and local themes emerged through an interview. ....	126
Table 9 Common themes arranged by counts in a descending order .....	130

## Glossary

SEND	Special Educational Needs and Disability
CYP	Child and Young Persons
QOL	Quality of Life
C&I	Communication and Interaction
SM&P	Sensory, motor and physical
SEM&H	Social, Emotional and Mental Health
MLD	Moderate Learning Difficulties
SLD	Severe Learning Difficulties
PMLD	Profound and Multiple Learning Difficulties
ASD	Autism Spectrum Disorder
ADHD	Attention Deficit Hyperactivity Disorder
PDA	Pathological Demand Avoidance
ID	Intellectual Disabilities
LA	Local Authorities
EHC plan	Education, Health and Care Plan

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## **Author's Declaration**

I declare that this thesis and the work presented in it are my own and have been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University.
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated.
3. Where I have consulted the published work of others, this is always clearly attributed.
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work.
5. Where elements of this work have been published or submitted for publication prior to submission, this is identified and references given at the end of the thesis.
6. This thesis has been prepared in accordance with the Coventry University and Buckinghamshire New University.
7. I confirm that if the submission is based upon work that has been sponsored or supported by an agency or organisation that I have fulfilled any right of review or other obligations required by such contract or agreement.

*Chai Leung Ho*



# 1 Introduction

Before the 18<sup>th</sup> century, individuals with disabilities faced exclusion and were often considered incapable of benefiting from education. However, during the 18th century, the European Enlightenment brought about a shift in societal attitudes towards human equality and compassion. This included the belief that it was humans who should take responsibility to care for others, even strangers (Winzer, 2009).

Pritchard (1963) states that the progress towards inclusive education in the UK can be traced back to the establishment of a residential school for delinquent girls in 1851. Pritchard (1963) also highlights that the first school for handicapped boys was opened in Kensington, UK, in 1865; these boys received both boarding and education based on Christian principles for a period of three years. However, they were under the supervision of the matron and were only allowed to leave the building with her approval and were only permitted to have a visitor once every three months (Pritchard, 1963).

The introduction of the *Forster Education Act 1870* paved the way towards compulsory education for all, whereby the 'School Boards' system was introduced and subsequently, schools were built and managed in 2500 different areas (Read and Walmsley, 2006). More special schools were established between 1890 and 1914 for those who were identified as 'feeble minded' or 'mentally defected', with the intention to help them develop skills for manual occupations (Read and Walmsley, 2006).

The *Education Act 1944* then established various categories for these pupils' needs, including blindness, partial sightedness, deafness, partial hearing, delicate health, physical disabilities, epilepsy, maladjustment, speech defects, and moderate educational subnormality. The *Education Act 1944* also stated that the responsibility for education and care fell under the Local Authorities or Department of Health and Social Services respectively based on the needs of the individual.

Not until Warnock's (1978) report were these terms replaced by the widely known term 'special educational needs' (SEN, later referred to as SEND, including the disability element). The Education Act 1981 then introduced the assessment of special educational needs for children and as a result, some children became eligible to receive a statement of special educational needs (Later re-named as Education, Health and Care Plan – EHC plan); LAs were tasked to arrange a suitable special educational provision for children with a statement of special educational needs.

*The Education Act 1993* imposed a duty on the Secretary of State to publish a SEN Code of Practice, and therefore, first SEN Code of Practice came into effect in 1994, which provided practical advice to Local Authorities, maintained schools, and others on their statutory duties to identify, assess and arrange provision for CYP with SEND (Department for Education, 2001). There were significant revisions to the SEN Code of practice in 2001, which included students and parents' rights and duties with regard to their schools, particularly emphasis how they were required to be involved in the decision-making process (Department for Education, 2001). The *Equality Act 2010* outlines the protected characteristics, of which 'disability' was one of them; consequently, schools were given the legal obligation to support pupils with physical or mental disabilities by making reasonable adjustments to meet their needs. The UK Government then further published the Special Educational Needs and Disability Code of Practice: 0 to 25 years (referred to as SEND Code of Practice in this thesis) in 2014, further highlighting the focus on CYP and parents' involvement in decision-making at both individual and strategic levels. The SEND Code of Practice also calls for all practitioners to improve the outcomes of CYP with SEND, promote inclusion as a whole and pro-actively identify SEND in schools (Department for Education, 2014). Despite the series of policies launched by the UK government between 1944 and 2014, the improvement in overall the standards was minimal. For instance, the number of SEND provisions increased from 91 thousand to 101 thousand between 2007 and 2014, with the number of pupils with SEND only slightly dropping from 1.57 million to 1.49 million (Department for Education, 2014). Even within the slight improvement of ratio, special schools often have little to no autonomy over the intake of CYP with SEND based on my professional experience. Due to the varying SEND of pupils, schools are not often able to fully meet their needs through differentiation.

There were fewer substantial policies published by the UK government since the SEND Code of Practice (Department for Education, 2014), however, there were additional policies published to indirectly complement or reiterate the SEND Code of Practice. For instance, Part 3 of the *Children and Families Act 2014* further reiterates the guidelines from the SEND Code of Practice and requires local authorities to publish a 'Local Offer', which sets out the support available for CYP with SEND in their area across education, health and social care. My profession allows me to work with 18 different local authorities, and although each local authority has the information displayed on their website, the actual offerings vary. CYP with SEND and their families I worked with did not always fully find the offerings accessible due to timings, interest areas or willingness.

Supporting Pupils at School with Medical Conditions (Department for Education, 2015) calls for governing bodies of schools to make arrangements to meet CYP's medical needs at school, and that their individual healthcare plans used in schools should also reflect Section C of CYP's EHC plans, where health needs and diagnoses are outlined. Chapter 3 of the *Mental Health and Behaviour in Schools 2018* highlights the importance of the collective effort from school staff to apply early interventions to address behavioural and mental health needs for CYP with SEND, as those with severe mental health needs are also defined as having a SEN. There was a slight improvement on permanent exclusion rate of CYP with SEND, as they were over 7 times more likely to be permanently excluded compared to their typically developing peers in 2015, and were down to 5 times more likely in 2023 (Department for Education, 2015; Department for Education, 2024).

Keeping Children Safe in Education (Department for Education, 2024) is updated yearly to share safeguarding guidance with schools, and specific support measures for safeguarding CYP with SEND, including but not limited to the use of Early Help social care support mechanisms and the importance of understanding contextual safeguarding matters in relation to SEND due to their vulnerability, such as online grooming and county lines. My professional experience has taught me that more work needs to be undertaken to support with the safeguarding of CYP with SEND, as families I worked with still often feel reluctant to use Early Help support from social

services due to the underlying fear of admitting their 'weaknesses' or losing custody of their child. The vulnerability of CYP with SEND continues to put them at further risk than just education, which can include matters such as social exclusion, safeguarding risks, or not having their enrichment needs met by the local offer.

The above brief chronology provides readers with the context, policy and practice in the world of SEND, including how this group of people were perceived by society and the evolution on the support received overtime. Although the label SEND draws attention to the 'needs' of people rather than deficits, it can still be argued that the 'D' in the term 'SEND' should represent 'difficulties', instead of 'disability'. Like everyone else, people with SEND face difficulties in life. Therefore, with or without SEND, people can overcome life difficulties, and even improve their QOL with the appropriate support. Furthermore, the current SEND policies published within the last 10 years discussed above also highlight that catering for those with SEND is a priority, not only from an educational point of view, but also the support that is required to meet their medical, mental health and behaviour needs, family support mechanisms and to safeguard them with contextual knowledge. However, the statistics from the Department for Education (2015; 2024) and my professional experience indicate that more work on supporting CYP with SEND in all areas is needed, as the implementation of the mechanisms driven by the policy is not always evidently effective, which also poses the question of what level of quality of life (QOL) they perceive.

The aim of this research study is to investigate the impact that a communication and interaction based; a social, emotional and mental health based; and a sensory and physical based intervention can have on the QOL of children and young persons (CYP) with special educational needs and/or disabilities (SEND). The UK Government highlight the necessity of matching the needs of CYP with SEND through specific interventions in addition to their academic attainments outlined in the SEND Code of Practice (Department for Education, 2014). Besides the cognitive barriers to learning, the following three broad areas of need of CYP with SEND are outlined as:

- Communication and interaction
- Social, emotional and mental health

- Sensory and/or physical needs

In other words, the interventions investigated in this thesis are based on the areas of needs outlined in the SEND Code of Practice (Department for Education, 2014).

Interventions aimed at promoting the QOL of people with SEND have become more common over the last 30 years (Brown and Faragher, 2014). Brown and Faragher (2014) state that a range of interventions focusing on each QOL domain and different areas of one's self-perception can be carried out to enhance QOL. Similarly, Flanagan (1978) believes that social scientists have the ability to create social programmes can elevate the QOL of the vast majority of people in society. All student participants in this research receive a different specific intervention that falls under the areas outlined in the SEND Code of Practice, which the intervention leaders have been responsible for delivering interventions prior to the start of my research (See section 3.6 for a description of these interventions) (Department for Education, 2014). I must also stress that interventions are an addition to the student participants' regular curriculum. Having considered the possibility of interlinking QOL domains with the broad areas of need of CYP with SEND, the interventions are best delivered by professionals who have a good understanding of the student participants. Therefore, intervention leaders were recruited at the participant school (which will be referred to as School H), to be a part of this research, to allow me to examine the interventions' impact on student participants' QOL. In order to safeguard the anonymity of all the participants, pseudonyms are used in my research (Lahman, Thomas and Teman, 2023). This will be further discussed in sections 3.5 and 4.

School H is an independent day special school based in West London, which enrolls students aged 11-19 with Autism Spectrum Disorder (ASD) as well as moderate learning difficulties (MLD) and severe learning difficulties (SLD). Parents at School H do not pay a fee; all students attending School H have an EHC plan and are placed and funded by a wide range of local authorities. In line with School H's admissions policy, local authorities consult them with information of the prospective students, and often request consultation feedback within 14 working days. At the time of the research, there were 128 students enrolled. There were approximately 70 staff

members working at the school H, with 48 of them being class-based, forming a 3:8 staff to student ratio; non-class-based staff members consist of administration, senior management team and a multi-disciplinary therapy team covering Speech and Language, Occupational, Creative Arts and Talking therapy. Further information on School H will be discussed in section 4.5.

In order to achieve the aim, the following research objectives have been set:

- 1) To understand how QOL is defined by the literature and identify a working definition for this research.
- 2) To identify the student participants' views on their QOL domains
- 3) To examine the impact of non-curriculum-based interventions on student participants' QOL
- 4) To explore student participants' perspectives on their intervention experience

QOL is described as one's desires and demands of life quality and fulfilment, of which personal well-being indicates one's life quality and the concept of QOL is composed of domains that are complex and multi-dimensional (Brown and Faragher, 2014; Schalock, 2010). During the late 20th Century, Flanagan (1978) attempted to break down QOL into headings based on different life aspects:

- Physical and material well-being
- Relations with other people
- Social community and Civic activities
- Personal development and fulfilment
- Recreation

Besides the complexity of QOL and its headings, the definition of perceptions is also crucial. Brown, Hatton and Emerson (2013) believe that both objective and subjective well-being are important when conducting a research study, as what is considered to be good life qualities by society does not always equate to how QOL is

perceived by individuals subjectively. In this research study, QOL is defined as an overarching concept consisting of different domains. In sub-chapter 2.1: QOL definitions, I will further investigate the definitions of QOL and the chosen definition for my research. The term 'QOL' is used in my research as an umbrella term, which comprises different domain headings in relation to well-being in different aspects.

Eddy (2013) states that QOL has multiple definitions from different perspectives. Whilst QOL can be seen as the 'subjective nature of individual experience' under a sociological approach, it is also specifically related to one's health and illness according to the medical approach (Eddy, 2013). As mentioned by Brown, Hatton and Emerson (2013), both objective and subjective well-being is important. Whilst participants in this research have a subjective understanding and perception of their QOL, the objective QOL is always present in context. In other words, their personal perception is, inevitably, influenced by the objective 'benchmarks'. Therefore, this research has considered both subjective and objective QOL when investigating and concluding any findings. Sub-chapter 2.2: Objective and subjective QOL will discuss the views of objective and subjective QOL based on the current literature to a greater extent. The focus of this research is to assess participants' QOL based on their subjective perception, and a qualitative approach was chosen, as it enables researchers to establish individual experiences, explore individual matters and gain a greater understanding of real-life experiences (Merriam and Tisdell, 2016; Slevitch, 2011; Atkinson, 2017).

Undertaking an action research approach allows researchers to have the flexibility to plan, take actions, observe and reflect (Lazarus, 2019). In this research study, the contents or the nature of the specific interventions evolve based on the feedback and observations from the various stages. The nature of the cycles of an action research challenges the research study by presenting 'conflicting demands' to the researcher and the participant school, due to policy constraints schools might have when bringing about change (Armstrong and Tsokova, 2019). Whilst the nature of the action research could bring about conflicting demands, all participants including students, parents, school staff and leaders are given opportunities to provide their input and discuss the implications of potential ways forward during each stage of this research study. This research has also been inspired by an ethnographic approach,

whereby I, as the researcher, am involved in the interventions and engage in participant observations as a data collection method. Furthermore, during the process of thematically analysing the data from the semi-structured interviews, adaptations are made as interventions are developed as well as the interview questions and process.

In order to obtain an in-depth insight through the cycles, an ethnographic inspired approach has been adopted in this research, as it allows me to gain a first-hand understanding of participants' perspective (See Pike, 1967) from taking part in the non-curriculum based targeted interventions. Humberstone and Stan (2011) stated that ethnographers can embrace the diversity and access others' worlds and experiences. By combining the insights gained as an ethnographer as well as refinement opportunities from the action research cycles, I am aiming to enhance the quality of the investigation into the impact of the non-curriculum based targeted interventions and what effect these have on improving the QOL of CYP with SEND.

Having been a teacher in different educational settings, I have been exposed to working with CYP from different backgrounds and have understood the potential that educators have to empower one's life. According to my own professional experience, schools focussed highly on students' academic results, which led to qualifications and jobs in their wider life. However, aspects such as CYP's relations with other people, social skills, personal development and recreational opportunities were not prioritised, which affect their QOL in the wider world. In my experience, some CYP were unhappy and complained to me about feeling tired during lessons, feeling disadvantaged as their family could not provide them with branded clothing and not fitting in social groups. As important as academic attainments may be, I still believed that schools could also provide CYP with different opportunities to improve their QOL.

As a means to investigate the appropriate opportunities that CYP need to improve their QOL, I conducted a research project as part of my Master's dissertation to ascertain the most desirable skills that parents want their CYP with severe learning difficulties (SLD) to acquire at school. The findings have suggested that parents desire skills that are beyond the general academic qualifications one can attain from



schools; these included communication and domestic skills. Moreover, parents also expressed their concerns regarding their CYP's independence and accommodation. With the relevant and appropriate up-skilling, parents believed that their CYP with SLD were more likely to live their lives with less concerns and with a better quality of living (Ho, 2019). I, therefore, would like to extend the knowledge and investigate how non-curriculum based targeted interventions provided by the school can also be used as a tool to directly improve the quality of life of CYP.

Besides my personal rationale, another reason for conducting this research is that the literature relating to QOL and CYP with SEND in the field is limited. Brown and Faragher (2014) stated that the relevance of supporting and planning interventions that focus on QOL of people with SEND have increased since the mid 1980's. However, the limited literature appears to indicate that CYP with SEND have a lower QOL in comparison to CYP without SEND. Thurston, Paul, Loney, Wong and Brown (2010) suggest that CYP with SEND aged between 2-18 present a lower QOL score than their typically developing peers. Brown and Schormans (2014) point out that some CYP with SEND are at risk of experiencing maltreatment and different types of negligence emotionally, physically or sexually, resulting in a poorer QOL. Svekle, Cibule, Vetra and Eglitel (2010) have suggested that the QOL of CYP with SEND aged between 7-10 in Europe is lower than their typically developing peers. These results also indicate that the QOL of CYP with SEND is higher when exposed to a learning environment created by places such as special schools and elementary schools, rather than day care homes. Although this thesis does not aim to compare the QOL of student participants' to their neurotypical peers, previous research (Thurston *et al.*, 2010, Brown and Schormans, 2014 and Svekle *et al.*, 2010) provides readers with more context, which is also in line with my professional experience on how some CYP felt disadvantaged as their families could not provide them with branded clothing and not fitting in social groups.

Other literature suggests that 'education' could be an important element of students' QOL (Ross and Willigen, 1997; Faragher, Broadbent and Brown, 2014). Education is a key factor in improving people's subjective QOL (Ross and Willigen, 1997). The findings of Ross and Willigen (1997) suggest that participants who were 'well educated' have a better subjective QOL, as they have lower levels of emotional and

physical distress compared to the 'poorly educated' participants, where the quality of education was being determined by the years of completed formal education. Nevertheless, defining 'good' quality education based on the total time spent in education is problematic as one can never be sure how the curriculum offered by full time education is perceived by one subjectively. Faragher *et al.* (2014) propose that education helps learners engage in the wider world, as well as having positive impacts on learners' material and physical QOL. They also viewed education as a 'fundamental human development' and a differentiated life-skills curriculum is crucial in improving students' QOL with SEND.

Having noted above that CYP with SEND are more likely to have a lower QOL compared to that of their neurotypical peers, it is important to understand why this occurs. In 2017-2018, CYP with SEND were reported to have missed school 1.5-2 times more and were 2.7-5.8 times more likely to be excluded than CYP without SEND (Department for Education, 2019). In other words, CYP with SEND are more likely to have a lower subjective QOL according to Ross and Willigen's (1997) QOL theory. In addition to the theory proposed by Faragher, Broadbent and Brown (2014), that a life-skills curriculum is critical to improve the QOL of CYP, this research study primarily investigates the impact that non-curriculum based targeted interventions, not already included in the ordinary school curriculum, can have on the QOL of CYP with SEND.

The literature focusing on work enhancing the QOL of CYP with SEND is even more limited. Burgess (2014) suggests that problem solving skills and thinking skills should be embedded in the school curriculum. If CYP often displays challenging behaviour and reduced intellectual ability, their QOL can be improved if they enhance self-control by learning and rehearsing the skills to solve real life problems through adapting different aspects of school, including the curriculum (Burgess, 2014). Although it is possible that thinking and problem solving skills can be transferable and improve different QOL domains, there is no valid evidence on the effectiveness of the framework proposed by Burgess (2014). Instead of specifically focusing on problem solving and thinking skills, Faragher's (2010) case study indicated that the implementation of a personalised 'life skill' based numeracy curriculum is effective on improving the QOL of an individual with SEND (referred as intellectual disability).

Jensen (2008) points out that the transferability of a qualitative research study can be enhanced by the thorough description of the research, alongside a robust sample group that consists of participants that purposefully match the description.

Faragher's (2010) rationale for the study was to investigate how a life skill based on a numeracy curriculum could enhance the QOL of an adult with intellectual impairment. However, due to the small sample size, the severity of the cognitive impairment, chronological age, gender or specific interests of people with intellectual impairments, were not thoroughly covered. Consequently, the transferability of the findings that indicate the level of enhancement of the QOL of the participant in the case study is frail.

Instead of just proposing a range of varied curricula with the intention to enhance one's QOL, the value of my research study is that I, as a researcher, experience and learn with the participants. The planning of the specific intervention will change progressively based on the data collected ethnographically during the different action research cycles. As suggested by Burgess (2014) and Faragher (2010), the QOL of CYP with SEND could be enhanced through improved problem solving, thinking or life skills. However, since one size does not always fit all, the life experience and general understanding of participants will determine the nature, specific content, as well as the implementation of the non-curriculum based targeted interventions.

To summarise, I have decided to connect the concept of QOL and the non-curriculum aspect of education in this research study through examining the impact of the interventions that place emphasis on CYP's communication and interaction, sensory and motor skills and social, emotional and mental health needs. The data was collected using interviews and participant observation, as part of an ethnography inspired approach, and was analysed using thematic analysis. In Chapter 2, I critically evaluate the current literature on well-being and QOL, especially ones related to people with SEND. Chapter 3 and 4 illustrate the methodology undertaken in this study and my time in the field; the data analysis procedure is explained in Chapter 5. Finally, this thesis ends with the Findings, which includes the main three themes of this research – Social well-being through peer interactions, Physical well-being and Emotional well-being.

## **2 Literature review**

In this chapter, I explore the definition of QOL through critically evaluating the existing literature on QOL, then proceed to identifying the definition of QOL used in this research. Before defining QOL, I first discuss the relationship between 'QOL' and 'Well-being' by comparing the two and explain the rationale behind adopting the term QOL for this thesis, and why well-being is significant when exploring student participants' QOL. In addition, I also further critique researchers' views on objective and subjective QOL and explain how the two may naturally co-exist in research. I then explore the QOL of CYP with SEND and their typically developing peers and any discrepancies. Finally, I explore how QOL of CYP with SEND has been measured by researchers and review the findings of how the QOL of CYP with SEND can be enhanced. This chapter aims directly at exploring the first research objective set, which is to understand how QOL is defined by the literature and identify a working definition for this research.

### **2.1 'Well-being' and QOL**

Besley and Bucelli (2022) state that there was a recent growing interest in well-being, and there have been advances in understanding its determinants. Similarly, Joseph and McGregor (2020) highlight that political and public policy circles paid increased attention to the concept of well-being in recent years. On the other hand, QOL appears more 'historical' as it was more widely used in the 1970s by researchers including Flanagan (1978), Andrew and Withey (1974) and Liu (1974). Well-being is a state of being and it entails what is required for a good life, and therefore encompasses a wide range of economic and non-economic factors, but most importantly - how one experiences the quality of their life (Joseph and Mcgregor, 2020). Adopting a slightly different stance to well-being, Layard (2022) suggests that the 'typical way' to review one's well-being is through asking how satisfied they are with their lives. Personal well-being is defined as how satisfied one is with their life overall, whether they feel they have meaning and purpose in their life, and about their emotions (happiness and anxiety) during a particular period (Joseph and McGregor, 2020). Huppert (2017) suggests that the term well-being is used synonymously with other terms including life satisfaction and Quality of Life

(QOL). The above-mentioned authors suggest that there is a close relationship between well-being and the quality of one's life.

Mansfield, Daykin and Kay (2020) point out that there are overlapping and blurred definitions of well-being, dependant on the discipline of the research or reader. For instance, Elvin, Kurt, Kennedy, Sice, Walton and Patel (2023) describe well-being as a broader concept of mental health that considers strengths, one's functioning and symptoms. Regarding one's functioning, the term 'Physical well-being' is often used and investigated by medical researchers. For example, Sleight, Boyd, Klein and Jensen (2021) investigated the relationship between anxiety on physical well-being of cancer survivors; Vassou, Chrysohoou, Georgousopoulou, Yannakoulia, Pitsavos, Cropley and Panagiotakos (2023) investigated the association between cardiovascular disease risk and physical well-being. Well-being can also be interpreted in a social context as social well-being, as Bekalu, McCloud and Viswanath (2019) describe 'social well-being' as the appraisal of one's circumstance and functioning in society that are also associated with age, education and income. The income aspect of social well-being can also be interpreted as 'material well-being' and is considered as how one perceives their life to be. (Franzen and Mader, 2022).

It is clear well-being encompasses different factors and can be interpreted in multiple contexts (Elvni *et al.*, 2023; Sleight *et al.*, 2021; Vassou *et al.*, 2023; Bekalu, McCloud and Viswanath, 2019 and Franzen and Mader, 2022). Wulfovich, Buur and Wae (2022) state that QOL is more than health, as there are other factors on one's life including their work capacity, social support and physical environment; QOL also integrates one's multidimensional evaluation of their life and overall 'well-being'. Similarly, Gabor and Miklousic (2022) also refer to QOL as a term that is associated with the concept of 'subjective well-being' and defined as the overall evaluation of one's life from their perspective. The increased awareness of life satisfaction in society means that well-being indicators are used to consider how one perceives how well their life is (Maccagnan, Wren-Lewis, Brown and Taylor, 2019). As discussed above, the term well-being and QOL have a very close relationship (Joseph and Mcgregor, 2020; Layard, 2022), and appear to be used interchangeably (Huppert, 2017). Sirgy (2012, p.5) states that the concept of QOL is built on

philosophical grounds, including *'happiness, positive and negative affect, emotional well-being, life satisfaction, subjective well-being, perceived QOL, psychological well-being, and eudaimonia.'* I have decided to adopt 'QOL' for this thesis, as an umbrella terminology that describes one's overall life quality. In order to explore student participants' QOL, different well-being indicators are also used (referred as QOL domain headings), as this was the method used by Flanagan (1974), then more explicitly by Felce and Perry (1995).

Lyons (2010) states that there is not a broad consensus of the meaning of QOL as a phenomenon, or even a terminology. Romney, Brown and Fry (1994) also explain that elusive definitions as well as concepts of QOL differ when explored by divergent authoritative circles. For instance, the health field interprets QOL as a physical phenomenon, whereby it is regarded as multidimensional subjective and objective experiences and elements in the field of mental health.

The World Health Organisation (WHO) defines QOL as:

*'An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.'* (WHO, 1997, p.1).

Felce and Perry (1995) likewise believe that the 'operational' QOL definitions are diverse; fuelled by theoretical models as well as societal and individualistic perceptions. The concept of QOL is recognised as the subjective individual's values of a mixture of 'life conditions' and 'personal satisfaction'.

The Good Childhood Report (The Children's Society, 2023) describes well-being as how one is doing on an individual, community and national level, suggesting that an individual is in the centre of their well-being, even though their well-being can be seen in different contexts. People's thoughts, feeling and sense of meaning of their QOL determine their perception (The Children's Society, 2023); equally, perception is a subjective belief or opinion that can vary greatly, depending on one's understanding and life experiences. Therefore, the perception of a good QOL differs from one another. However, Landesman (1986) regards QOL as a concept that consists of both subjective and objective measures, and life satisfaction is a separate concept that is personal and subjective. Likewise, Romney, Brown and Fry (1994)

also disagree with QOL being a concept based on subjective experience, as they do not believe that QOL could be improved 'merely by lowering one's expectations'. Although Cheng (1988) also states that QOL needs to be quantified by both objective and subjective measures, he emphasises the importance of subjective QOL measures, as they can provide irreplaceable information on one's perceived well-being uniquely. Similarly, Lehman (1983) claims that QOL is a subjective matter 'ultimately' and that subjective evaluations have an immense analytical impetus to decipher QOL subjective to one's personal traits on top of objective life conditions. More specifically, Evans (1994) defines the port of call of QOL as satisfaction, regardless of whether it is general life satisfaction or satisfaction on a specific life aspect such as job, family or even leisure. Nevertheless, the long-standing debate between the importance, relevance and balance between objective and subjective QOL measure still exists.

This research study favours the stance of WHO (1997), Sirgy (2012), Evan (1994) and Felce and Perry (1995), whereby QOL should be defined by one's subjective perception. The Good Childhood Report (The Children's Society, 2022) suggests that subjective measures are crucial when evaluating how one perceives their own life and stresses the importance of self-reported subjective well-being as '*Children have the right to enjoy a good childhood, and for it to equip them with a tool to grow and transition into a good adulthood.*' (p.10) However, it does also state that objective measures are the social indicators of people's life. As a matter of fact, QOL is an extremely personal concept, and one's subjective views are all influenced by the objective measures to different extents.

Since the concept of QOL is based on one's philosophical perception, its definitions differ due to the different influential factors that determine 'good' life quality. By the 1970s, terminologies such as indicators, life domains and components were created to measure and indicate QOL (Flanagan, 1978; Andrew and Withey, 1974; Liu, 1974). In order to provide readers with greater clarity, the style of presentation is unified; all 'components', 'indicators' and 'life domains' are regarded as QOL domains. Similarly, all the headings or categories comprising the above, are referred to as QOL domain headings.

In unison, Flanagan (1978), Andrew and Withey, (1974) and Liu (1974) all proposed that a set of QOL domains is essential to explore one's QOL. However, the process of developing a set of reliable domains is controversial, as different authors have different sets of favoured criteria. For instance, material wealth and its positive association is not recognised as the sole aspect of a good QOL, and aspects such as social, economic, political and environmental health of the society indicate the well-being of a nation, and subsequently, one's individual QOL (Liu, 1974). Although the national social QOL domains can relate to an individual's QOL at an aggregate degree, Flanagan (1978) stresses the importance of the relevance of the domains as they are required to be evaluated by people when determining their QOL. Moreover, Liu (1974) emphasises the need to develop a set of QOL domains that are simple, sufficiently universal, flexible to encompass different lifestyles and adaptable to different social, economic, political and physical conditions. Based on over a hundred variables for fifty states of America and the District of Columbia, Liu (1974) developed nine QOL domains, including individual status, individual equality, living conditions, agriculture, technology, economic status, education, health and welfare and state and local governments. Although the definition of QOL is based on subjective perception, the development of a set of QOL domains enables QOL to be categorised. In other words, there need to be areas (described as domains in this thesis) for the general public to subjectively compare. By way of illustration, person A and person B could both subjectively be satisfied with the quality of the education that they received as well as their achievements, even though the former could have achieved much more than the latter. Verdugo, Navas, Gomez and Schalock (2012) state that good QOL is experienced when one's needs are met and has the opportunity to pursue enrichment that are major to one's life.

Andrew and Withey (1974) state that humans gain an overall sense of their life quality by responding to QOL domains effectively based on their role-situation and values. A complete set of QOL domains can be used as an assessment that indicates one's perceived QOL. Upon obtaining participants' affective responses of 123 items, Andrew and Withey (1974) mapped twelve life domains including yourself, family life, money index, amount of fun, house/apartment, things to do with family, time to do things, spare time activities, national government index, goods and services, your health and your job. There are similarities between the QOL proposed



by Liu (1974) and Andrew and Withey (1974), such as living conditions and house/apartment or health and welfare and one's health. However, despite having three extra QOL domains compared to Liu (1974), Andrew and Withey's (1974) focus is also much more person-based. For instance, yourself, family life or time to do things are considered as QOL domains. Moreover, the language selected to compose the QOL domain is also simpler and easier for the general public to understand. As a concept, Andrew and Withey's (1974) QOL domains appear to be more suitable than Liu's (1974), because QOL is based on one's subjective perception. The domains above, along with the flexibility to adapt to one's social, economic, political and physical condition, have provided this research study with the background knowledge of what Liu (1974) and Andrew and Withey (1974) believed was the best fit for the public back in the 1970s. More revised QOL domains based on the revolution of the needs and relevance of society will continue to be explored in the literature review.

Similarly, Flanagan (1978) attempted to define the QOL of nearly 3000 Americans through identifying their behaviours and experiences with a questionnaire, consisting of keywords such as: 'important', 'experience', 'satisfying', 'pleasure', 'harmful', 'worse' and 'trouble'. Through thematic analyses of the participants' subjective behaviours and experiences, the following QOL domains headings and QOL domains were developed. Table 1 illustrates the QOL domain headings and domains developed by Flanagan (1978):

Table 1 Flanagan's (1978) QOL Domains headings and domains

QOL domain headings	QOL domains
Physical and material well-being	Material well-being and financial security
	Health and personal safety
Relations with other people	Relations with spouse
	Having and raising children
	Relations with parents, siblings, or other relatives
	Relations with friends
Social community and Civic activities	Activities related to helping or encouraging other people
	Activities relating to local and national governments
Personal development and fulfilment	Intellectual development
	Personal understanding and planning
	Occupational role (job)
	Creativity and personal expression
Recreation	Socializing
	Passive and observational recreational activities
	Active and participatory recreational activities

The QOL domains developed by Liu (1973), Andrew and Withey (1974) and Flanagan (1984) appear to cross reference each other. For instance, the 'state and local governments' from Liu (1974) is similar to Andrew and Withey's (1974) 'national government index', which is also similar to the 'activities relating to local national governments' proposed by Flanagan (1978). However, it is evident that more QOL domains that reflect on one's welfare were developed from Flanagan's (1978) research study, which cover even more life aspects than QOL domains developed by Andrew and Withey's (1974). As an illustration, yourself, family life and things to do with family are the three QOL domains related to relationships with others developed by Andrew and Withey (1974). According to Flanagan's (1978) proposal, relationships with other people as QOL domains are divided into relationships with one's spouse, children (having and raising children), family (parents, siblings or other relatives) and friends. Since QOL domains are revised based on the needs and relevance of a specific era of society, they could vary from time to time. However, the QOL domain headings developed by Flanagan (1978) help shape the broad directions of the QOL domains.

Felce and Perry (1995) reviewed QOL indicators, domains and components from fifteen researchers and compiled a set of twenty-four QOL domains under the following headings. Table 2 illustrates the QOL domain headings and domains developed by Felce and Perry (1995):

Table 2 Felce and Perry (1995) QOL Domains headings and domains

QOL domain headings	QOL domains
Physical well-being	Health
	Personal safety
	Fitness
	Mobility
Material well-being	Finance / income
	Transport
	Housing quality
	Privacy
	Possessions
	Meals / food
	Neighbourhood
Social well-being	Interpersonal relationships
	Community involvement
Development and activity	Competence
	Job
	Homelife / housework
	Leisure / hobbies
	Education
Emotional Well-being	Positive effect
	Status / respect
	Satisfaction
	Fulfilment
	Faith / Belief
	Self-esteem

In comparison to Flanagan's (1978) QOL domain headings, Felce and Perry (1995) have split 'Physical well-being' and 'Material well-being' into two separate headings, they combined 'Relations with other people' and 'Social community and civic activities' using the 'Social well-being heading' and renamed 'Personal development and fulfilment' as 'Development and activity'. The actual QOL domains have also been slightly modified. Given the slight change in semantics, the basic areas covered by the QOL headings have not differed. Most importantly, Felce and Perry (1995) also developed an extra heading named - Emotional well-being, in contrast to Flanagan's (1978) proposal. Besides the well-being of other facets in life, Felce and Perry (1995) highlight the importance of emotional well-being as one of the overall general well-being that comprises one's QOL. Williams (1993) also specifically calls attention to the correlation between physical and emotional well-being and QOL as frustration, anger and fatigue are signs of a reduced QOL.

WHO (1997) developed the WHOQOL-100 (an instrument that measures QOL according to WHO's standards), based on lay people's and scientific experts' opinions on important life areas. QOL domain headings include: 'Physical health', 'Psychological', 'Level of independent', 'Social relations' and 'Environment'. Although the exact QOL domain heading 'Emotional well-being' is not part of WHOQOL-100, its heading 'Psychological', covers domains including feelings and self-esteem. It, once again, suggests the relevance of one's emotional or psychological well-being when considering their QOL. Despite the incline towards the medical aspect in WHOQOL-100, its QOL domain headings cross referenced the ones developed by Felce and Perry (1995). Besides semantics and the medical influence, the add-on from WHOQOL-100 is the QOL domain heading 'Level of independence', followed by domains such as mobility, activities of daily living, dependence on medical substances and medical aids and work capacity.

Also coming from the medical perspective, Grilli, Feldman, Majnemer, Coulture, Azoulay and Swaine (2006) suggested that functional independence, such as mobility and self-care abilities are correlated to the health related QOL (HRQL) of children with physical disabilities. From a functional and financial point of view, Brown (2012) also proposes that financial independence including the ability to read letters and pay bills can preserve vitreoretinal patients' QOL. Moreover, Bonk (2016)

suggests that functional independence including both physical and mental functioning has a positive impact on senior citizens' QOL. According to the literature (WHO, 1997; Grilli *et al.*, 2006; Brown, 2012 and Bonk, 2016), 'Independence' has a significant role to play in QOL, as well as the ability to self-care, handle financial matters and process challenges both physically and mentally. Consequently, independence appears to be an essential QOL heading.

Schalock and Verdugo (2002) mapped another a QOL review model, consisting of QOL domain headings: 'Emotional well-being', 'Physical well-being', 'Material well-being', 'Interpersonal relations', 'Personal development', 'Social inclusion', 'Self-determination', 'Right'. The QOL measurement model including its QOL domain headings have been verified by being replicated by Bonham, Basehart, Schalock, Marchand, Kirchner and Rumenapp (2004) and Jenaro, Verdugo, Caballo, Balboni, Lachapelle, Otrebski, and Schalock (2005) cross-culturally. Carapeto, Candeias, Franco, Grzcio, Coelho and Costa (2017) conducted a research study on the QOL and SEND, and domain headings used include 'Emotional well-being', 'Interpersonal relations', 'Material well-being', 'Personal development', 'Physical well-being', 'Self-determination', 'Social inclusion' and 'Rights'. In comparison to Felce and Brown's (1995) and WHO's (1997) QOL domain headings, there is a considerable number of duplications or similarities. Additionally, 'Right' and 'Self-determination' are also QOL domain headings in the research of Schalock and Verdugo (2002) and Carapeto *et al.* (2017). However, both QOL domain headings should have been considered QOL domains, as opposed to headings. For instance, 'Right' should come under 'Social well-being' under Felce and Perry's (1995) proposal or 'Environment' in the words of WHO (1997). Similarly, 'Self-determination' can be categorised under 'Development and activity' or 'Level of independence'. This review of the literature has shown the evolution of QOL domains and their headings since the 1970s. All the aforementioned QOL domains are bound to change over time as society evolves. For instance, 'Agriculture', as a QOL domain suggested by Liu (1974), is relatively less relevant in the 21st century. QOL domain headings such as 'Emotional well-being' and level of 'Independence' have been developed by Felce and Perry (1995) and WHO (199) since Liu's (1974) time. The above literature shows that the QOL domain headings evolved over time, however the commonly used, fundamental domain headings remained unchanged.

The research of Burckhardt and Anderson (2003) attempted to investigate the relevance of the QOL domains proposed by Flanagan (1978) when applied to participants with chronic illness. Although most QOL domains were validated by at least half of the participants, the perspective of 'importance' of certain domains varied. For instance, 'relationship with spouse' and 'health' were deemed as important by over 90% of the participants, whilst less than 40% of participants perceived 'Activities relating to local and national governments' as important. Likewise, Petry, Maes and Vlaskamp (2005) investigated the perspectives of parents and support staff of people with SEND (referred to as PMLD - Profound and Multiple Learning Difficulties) on the QOL domain headings developed by Felce and Perry (1995). Although the QOL domain headings still apply, different QOL domains were found more relevant based on these findings. For instance, 'nourishment' and 'rest' were found to be more pertinent than 'fitness'. Also, more relevant domains such as 'involvement in activities', 'influences' and 'development' replaced original domains such as 'job', 'housework' or 'education' under the QOL heading - Development and activity. Verdugo *et al.* (2012) explain that QOL is an experience of one having their needs met and having the opportunity to pursue major life enrichments, and the research from Petry, Maes and Vlaskamp (2005) shows how the QOL domains can vary based on the individual's needs. Although the student participants in my research have SEND, their needs are not as severe as the participants in Petry, Maes and Vlaskamp's (2005) research. Therefore, domains created under the domain headings for my student participants may differ.

The findings of Petry, Maes and Vlaskamp (2005) support Flanagan's (1978) point on the relevance of the QOL domains. Although researchers such as Liu (1974) and Andrew and Withey (1974) incorporated national social QOL domains, such as 'state and local government' and 'national government index' in their sets of QOL domains, the research of Burckhardt and Anderson (2003) and Petry, Maes and Vlaskamp (2005) suggest that relevance of the QOL domains can be circumstantial. Felce and Perry (1995) mention that QOL domains created do indeed extend over between different researchers. What is more, the sheer nature of, including the number of QOL domains, have been procured effectively based on conjectural evidence from individuals. To further reiterate, despite the relevance of QOL domains, they are

subject to change according to life experiences and circumstances of the individuals themselves.

This thesis will follow a mixture of QOL domain headings from the literature discussed above, mostly from Flanagan (1978), Felce and Perry (1995), WHO (1997) and Schalock and Verdugo (2002), including:

- Physical well-being
- Material well-being
- Social well-being
- Emotional well-being
- Personal development
- Level of independence

Since the language used in Felce and Perry's (1995) proposal is simpler, most QOL domain headings have been directly replicated. In addition, literature also indicated the importance of how 'Level of independence' connects to QOL (WHO, 1997; Grilli *et al.*, 2006; Brown, 2012; Bonk, 2016). Therefore, it is deemed as an essential QOL domain heading in this thesis. As I suggested above, QOL domain headings change based on individual circumstances and life experiences. I, therefore, highlight the importance of the process of student participants moderating the QOL domains that are relevant to them individually. This will be done through a robust process of semi-structured interviews following my observations. For instance, whilst participant A may consider personal safety as one of the QOL domains under the heading Physical well-being, participant B may not find it relevant at all. Although the set of QOL domains have been chosen for this research study, their specific headings vary, and different domain headings have emerged throughout the research and will be further explored with student participants.



## 2.2 Objective and subjective QOL

When reviewing the literature on objective and subjective QOL, I have identified three stances from different groups of researchers:

- 1) The group that stresses the importance of the use of subjective QOL (Andrew, Abbey and Halman, 1991; Chaturvedi, 1991; Edgerton, 1990; Kraut, 2018; Pavot and Diener, 1993)
- 2) The group that promotes objective QOL and criticise the use of subjective QOL obtained by people with SEND (Cheng, 1988; Jenkins, 1992)
- 3) The group that supports the use of both subjective and objective QOL in research (Cummins, 2005; Lyons 2010; Lysaght and Cobigo, 2014; Schalock, 1990; Verdugo *et al.* 2021)

Pavot and Diener (1993) view life satisfaction as a 'judgmental process' that includes one's self-assessment of their own QOL based on their own distinctive criteria. In order to measure the growth or deterioration of ones' QOL, conscious cognitive judgement has to be made by such individuals followed by their distinctive criteria. Correspondingly, Edgerton (1990) also criticises the use of a set of objective standards to apply to all people, as there is likely an underlying level of presumption added ethnocentrically. They both suggest that subjective perception of QOL needs to be considered, and more so, personalised. Similarly, Chaturvedi (1991, p.1) states that QOL is '*a matter for the individual alone to decide*', as well as '*an individual's subjective sense of well-being and therefore is necessarily the result of personal perception of circumstances*'. Andrew, Abbey and Halman (1991) also highlight the importance of subjective well-being as it directly affects one's QOL; the feedback from participants on their subjective well-being was used directly. Compared to many other animals, human beings have the ability to experience more sophisticated internal factors such as pleasure, intellectual, social and perceptual experiences. Consequently, in-house components counterbalance 'external goods', these include things such as position and affluence. Therefore, the quality of one's internal experiences constitutes good QOL (Kraut, 2018).

However, the credibility of the subjective views of disadvantaged people has been challenged by Cheng (1988) and Jenkins (1992). Cheng (1988) suggests that if QOL is based purely on one's subjective perception, a chronic mental patient could self-define poor QOL, and it could become a debatable statement. Similarly, Jenkins (1992) suggests that the proxy views from knowledgeable professionals on behalf of young children, people with severe disabilities and certain neurological or psychiatric patients are the better source, due to the 'unreliable' self-assessment. The stance from Cheng (1988) and Jenkins (1992) implies that the judgement made by neurodiverse people can be inaccurate due to their diagnosis. It also suggested that an objective view on such people's QOL is required for the purposes of verification due to the hierarchy of intelligence. This is a misconception between one's understanding and perception.

Young children may be asked to consume healthy foods such as fruit and vegetables as their parents intend to ensure that they are healthy and have an improved physical well-being in the long run. If the young children consistently demonstrate healthy eating, the 'objective QOL' is likely to be deemed as good. Specifically speaking, the quality of the QOL domain: Physical health, under the heading Physical well-being, will be deemed as good, according to the objective views. However, the 'Subjective QOL' can be perceived as poor, if the young children feel 'physical discomfort when eating' as a QOL domain and find eating healthily causes distress. Moreover, regardless of the young children's understanding of their parents' intentions, consuming healthy foods can still be a negative activity and have a negative impact on their emotional well-being. Whilst understanding may potentially be developed overtime, perception and subjective feelings are authentic and reliable. The example above highlights how one's subjective perception could differ completely from the proxy opinions. It also leads to another debate on how relevant and important proxy opinions can be in terms of the process of QOL measurement and be the sole measure of QOL. Coming from a different perspective, the Good Childhood Report (The Children's Society, 2022) also highlights the future sustainability when discussing QOL, regardless of its objectivity and subjectivity. Therefore, a balance has to be found between the two when gathering participants' views.

For instance, using the example above, before identifying a student participant's life quality, the important underlying question would appear to be – Are the young children aware of the positive and negative impacts of healthy eating? Emotionally, how do they feel about their parents' requests? Do they have long-term life goals that would involve being healthy, and if so, are they able to make a balanced-decision around food choices? Therefore, the answers to the research questions of this thesis are all subject to the context and circumstances, which are uncovered through a robust data collection system.

Mental Capacity Act (2005) provides principles on how one should be prescribed the ability to make decisions (p. 1-2):

- (1) The following principles apply for the purposes of this Act.
- (2) A person must be assumed to have capacity unless it is established that he / she lacks capacity.
- (3) A person is not to be treated as unable to make a decision unless all practicable steps to help them to do so have been taken without success.
- (4) A person is not to be treated as unable to make a decision merely because they make an unwise decision.
- (5) An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in their best interests.
- (6) Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Although one could argue that the SEND labels establish that participants with SEND lack the capability to make decisions, it needs to be clear that all practicable steps need to be taken and no decisions should be disregarded even if they appear unwise. Therefore, decisions and views have to be respected, as long as they are made by participants with SEND subjectively. In light of the Mental Capacity Act (Department of Health, 2005), Cheng's (1988) and Jenkins's (1992) viewpoints that the reliability of the statements and self-assessments made by participants with SEND are not debatable.

Schallock (2010) claims that subjective self-report and proxy observations and measures should both be obtained when evaluating QOL, as there could be times when the participants are not able to respond for themselves. Schallock (2010) considers proxy reports as an objective measure, and he recognises the downfalls of using proxies and how the validity could be challenged, hence providing the following guidelines (p. 8):

- 1) Persons who know the individual well should be used
- 2) Have two persons who know the individual well respond as if they were the person and then use the average score for all subsequent purposes
- 3) Assessment involving proxies should be clearly identified as another person's perspective
- 4) Analyse separately self-report from objective measures
- 5) Build the effect of proxy responses into data analysis

The main difference between Cheng (1988) and Jenkins (1992), on the one hand, and Schallock (2010) and the *Mental Capacity Act 2005*, on the other hand is that the former challenge the credibility and reliability of participants' subjective views due to their mental capacity and criticise their inability to express their views and, where the latter celebrate their ability to recognise that participants with difficulties cannot provide responses and the use of proxy views is unavoidable, and more so, as a last resort. The stance of this research is geared towards the latter. As mentioned in the introduction to this thesis, my research has considered both subjective and objective QOL. Before I could further elaborate on the practicality of balancing the two, I must clarify that all subjective data collected from participants is valid and that the judgments made will not be considered unreliable or unwise, but rather authentic. As Schallock (2010) and the *Mental Capacity Act 2005* pointed out, there are times when the participants cannot respond to questions and that practicable steps should be taken to support one with decision making. With the aim to support participants to elicit their voices on the research questions, some data collection methods have been adopted from an ethnographic approach. My approach, inspired by ethnography, consists of immersing myself in the midst of participants, actively observing them while being in the field. As a result, I can justify why my subjective

views on participants' QOL could come in as an objective measure to support the findings. This is explained in more detail in the methodology chapter.

Although Rice (1984, p. 3) defines QOL (referred as QL) as *'the degree to which the experience of an individual's life satisfies his/her personal wants and needs (both physical and psychological)'*. Rice (1984) divided QOL into two types:

Objective QOL - *'The objective quality of life is the degree to which specified standards of living are met by the objectively verifiable conditions, activities, and activity consequences of an individual's life.'* (p.3)

Perceived QOL - *'The perceived quality of life is a set of affective beliefs directed toward one's life.'* (p.4)

Although the two types of QOL above correlate to each other, 'Objective QOL' appears to be factual and concerns things that are happening in one's life, the causes, consequences and conditions. On the other hand, 'Perceived QOL' (will be referred as 'Subjective QOL' in this thesis from this point onwards) focusses on one's subjective satisfaction of their own life according to their own perception. The example of young children consuming healthy foods demonstrates how one's 'subjective' view could differ greatly from the 'objective' view. Cummins (2005) outlines the two forms of QOL:

- (1) Attributes which are objective and accepted by the public but that are also transparent and measurable, for example prevalence of properties and frequencies.
- (2) A domain that is purely subjective, existing on a personal and emotional level to an individual, substantiated by the feedback of the person in question.

Cummins (2005) further proposes that QOL should comprise both subjective and objective measures in order to be comprehensively measured, as both indicators are valid. Similarly, Lyons (2010) supports the stance of using both subjective and objective measures and states that the objective indicators consist of 'norm-referenced' measures of good life quality, where subjective indicators represent

one's perceived well-being. Furthermore, Lysaght and Cobigo (2014) believe that the environment naturally connects to how one perceives QOL subjectively and objectively. Whilst one could experience QOL subjectively by evaluating internalised expectations, the objective standards of what QOL stands for have been determined by society (Lysaght and Cobigo, 2014). Verdugo *et al.* (2012) also state that QOL is a multidimensional construct that is influenced by individual and environmental factors, which form the subjective and objective components.

Cummins (2005), Lyons (2010) and Lysaght and Cobigo (2014) believe that objective indicators of QOL are seen as norm-referenced measures or benchmarks. Davison (2001) describes objectivity as an 'evidence-transcendent' that can deny the link between subjective belief and truth. Meanwhile, subjectivity is 'sceptical' as what one believes does not necessarily correlate with reality. Davison (2001) also highlights the importance of objective views and their influence on subjective views, as one would not develop their own thoughts without understanding what others think. Despite living in the same world, one would lack the ability to gauge the thoughts of others (objective views) and lose touch with the wider world if they did not have knowledge of their own thoughts. As objective QOL is always there in context in society, it is inevitable for one to make a subjective decision or judgement without referring to them. For instance, participants cannot generate a subjective view on their material well-being without using the objective measure as a norm reference. However, to what extent participants are influenced to the norm reference, and to what extent they relate their own satisfaction or standards to the norm reference is up to their own interpretation. Therefore, one could feel greatly dissatisfied with the materials they have in life despite having significantly more than a norm-person, or vice versa. What is more, Lysaght and Cobigo (2014) recognise that the environment affects how one perceives QOL subjectively and objectively. Hence, the objective norm reference is changeable and dependant on the environment, driven by the culture and society. In order to investigate what the objective benchmarks look like for the participants in my research, it is essential to understand their world and culture. This also supports the reasoning behind the use of an ethnography inspired approach in this research study.

To conclude, although the findings of my research are drawn based on participants' subjective views on their QOL, the objective views or norm references are always in context. In contrast to the views of Cheng (1988) and Jenkins (1992), the participants' subjective views will be taken and regarded as authentic data, despite the severity of their needs. Furthermore, in line with Schalock (2010) and *Mental Capacity Act 2005*, the use of an ethnographic approach will complement the findings and elicit the voice of the participants by removing barriers. As stated by Lysaght and Cobigo (2014), the environment affects how one perceives objective QOL, and therefore, it is also worth investigating how the objective benchmarks influence participants when concluding their own subjective QOL.

### **2.3 QOL of typically developing CYP and CYP with SEND**

Ravens-Sieberer, Erhart, Wille, Wetzel, Nickel and Bullinger (2006) highlight the lack of focus on CYP's health related QOL between the early 1980s and mid-2000s, as less than 11% of the literature was devoted to CYP. Although the QOL of CYP has historically been under-researched compared to adults, there are still multiple purposes for assessing CYP's QOL. The process of assessing CYP's QOL consists of stakeholders that fall under four groups: society, health care policy, patient groups and the individuals, and they all have unique outcomes. Individuals are the stakeholders that can share their subjective perception of their QOL, the results could potentially influence the rest of the stakeholders hierarchically (Wallander, Schmitt and Koot, 2001).

Clark, Coll-Seck, Banerjee, Peterson, Dalglish, Ameratunga, Balabanova, Bhan, Bhutta, Borrazzo, Claeson, Doherty, El-Jardali, George, Gichaga, Gram, Hipgrave, Kwamie, Meng, Mercer, Narain, Nsungwa-Sabiiti, Olumide, Osrin, Powell-Jackson, Rasanathan, Rasul, Reid, Requejo, Rohde, Rollins, Romedenne, Sachdev, Saleh, Shawar, Shiffman, Simon, Sly, Stenberg, Tomlinson, Ved and Costello (2020) point out that the current threats to CYP's health and well-being are multisectoral, and that it is crucial to address the relevant domains to improve their well-being. Since CYP are the future of society, their QOL requires investment and domains should also go beyond just health and education (Clark *et al.*, 2020).

The lack of research on the CYP's QOL, including its health-related aspects, is concerning and much more work is required in this field. At a government level, the UK government urged all services working with CYP to promote, support and safeguard CYP's well-being and consider their QOL by ensuring they are active, respected, responsible, included, safe, healthy, achieving and nurtured (Children and Families Directorate, 2016). Similarly, the UK government have stated that the early experiences undertaken by CYP has a direct influence on their well-being in the future; sowing the seeds for their life to come (Parenting, Childcare and Children's Services, 2018). A set of thirty-one QOL domains were subsequently developed in order to better understand and monitor the QOL of CYP (Parenting, Childcare and Children's Services, 2018).

CYP with SEND historically received less attention and were perceived negatively by society. For instance, the present education pathway of CYP was paved from before the 18th century. CYP with SEND were deemed as 'ineducable', they then experienced very limited forms of education in the mid-18th century, and eventually received a statement of special educational needs that highlights their specific learning needs in light of receiving appropriate education (Kirman, 1947; Pritchard, 1963; Read and Walmsley, 2006; House of Commons Education and Skills Committee, 2006). Education is only one aspect of QOL, as Brown and Faragher (2014) point out that the QOL of CYP with SEND has also been overlooked until the mid-1980's.

Despite the lack of focus and oversight of the QOL of CYP with SEND, there is evidence that suggests that their QOL is generally lower than their typically developing peers (Hibbard and Desch, 2007; The Good Childhood Report, 2022; The Good Childhood Report, 2023; Schormans, 2014; Shpigelman, 2019). For instance, a council in Northwest England interviewed over 600 young people face to face. Whilst over 90% of the research participants suggested that they lived a happy life, those who self-identified as having SEND reported to have a lower overall well-being than their neurotypical peers (The Good Childhood Report, 2022). Furthermore, The Good Childhood Report (2023) suggests that CYP with SEND have poorer social and physical well-being as they are twice as likely to be unhappy



with their friends and health. All of the above show that the QOL of CYP with SEND is lower than their peers.

Hibbard and Desch (2007) highlight that the maltreatment of CYP with SEND, including the full spectrum of physical, mental, and emotional impairment, is a critical public health issue. Similarly, Brown and Schormans (2014) points out that some CYP with SEND are at risk of experiencing maltreatment and different types of negligence emotionally, physically or sexually, resulting in a poorer QOL.

Shpigelman (2019) further explains that the environmental barriers and the stigma of people with SEND often cause social exclusion and negatively impact on their psychological well-being as part of their QOL. People with SEND are in a disadvantaged group that is more vulnerable and has a poorer QOL, particularly in terms of their social and physical aspects (Thurston *et al.*, 2010; Svekles *et al.*, 2010; Totsika, Felce, Kerr and Hastings, 2010; Arias, Gomez, Moran, Alcedo, Monsalve and Fontanil 2010), which will be explored in the next section.

## **2.4 Measuring the QOL of CYP with SEND**

Even though the importance and reasoning of using subjective QOL measures have already been discussed in the last section, specific reasons for doing so have also been given by researchers, namely on the QOL of CYP (Lippman, 2007; Brim, 1975). Lippman (2007) states that adult-centred QOL domains and headings such as age-based attainment and expectations are likely to steer towards children's development. Similarly, Brim (1975) urges researchers to pay attention to children's subjectivity state, their sense of self, self-worth and their being, as opposed to 'becoming'. In order to ensure that children's well-being is the focus, instead of children's 'becoming', QOL domains and their headings need to come from children's own perspective.

In their study, Thurston *et al.* (2010) used an adapted version of PedsQL (a questionnaire that consists of QOL domain headings: physical, emotional, social and school functioning) and telephone interviews with the parents or guardians, who were the most knowledgeable (PMK) of 429 CYP with SEND in Canada. Thurston *et al.* (2010) suggest that CYP with SEND present lower QOL scores compared to their

neurotypical peers, both physically and psychosocially. Similar to Thurston *et al.* (2010), Svekle *et al.* (2010) utilised a questionnaire (KIDSCREEN) consisting of 10 QOL domain headings to assess the QOL of 34 CYP with SEND aged between 7-10 as well as their PMK in Riga. The findings suggest that there are contrasts between the views of CYP with SEND and their PMK. In comparison to the self-report from the CYP with SEND, the PMK report highly over-estimated the quality of 'moods and emotions', 'social acceptance / bullying' and 'self-perception'. The results also suggest that the QOL of CYP with SEND is generally lower than that of neurotypical children in Europe, with physical well-being, financial resources and social acceptance being the QOL domain headings with the greatest difference. The 'financial resources' QOL domain heading only indicates one's understanding of their household's financial situation, which is less relevant to one's direct life prospects, such as physical well-being and social acceptance or bullying.

Thurston *et al.* (2010) recognise as one of the limitations of their study the fact that the views of participants were not collected, and the parental proxy views could have underestimated the QOL of their CYP with SEND. However, Svekle *et al.*'s (2010) research findings suggest otherwise. In addition, the narrow demographic representation of the PMK involved in both Thurston *et al.*'s (2010) and Svekle *et al.*'s (2010) research studies also affects the validity of the proxy results. For instance, around 90% of the PMK in both research studies of Thurston *et al.* (2010) and Svekle *et al.* (2010) are mothers. Moreover, PMK in Thurston *et al.*'s (2010) study appear to come from predominantly married, working and educated mothers, leaving out the less educated, single and non-working parents, and fathers.

Similar to the findings of Svekle *et al.*'s (2010) research study, existing literature has also suggested that CYP with SEND are at higher risks of experiencing physical and health problems (McPherson, Arango, Fox, Lauver, McManus, Newacheck, Perrin, Shonkoff and Strickland, 1998; Jee, Barth, Szilagyi, Szilagyi, Aida and Davis, 2006; Szilagyi *et al.*, 2015). Other studies have also suggested that CYP with SEND are less likely to be accepted by their peers and have a higher chance of becoming a victim of bullying by their peers (Rose, Monda-Amaya and Espelage, 2010; Schroeder, Cappadocia, Bebko, Pepler and Weiss, 2014; Fink, Deighton, Humphrey and Wolpert, 2015). In addition, Wigelsworth, Oldfield, and Humphrey (2015) and

Kaufmann (2015) highlight the vulnerability of CYP with social, emotional, behaviour and mental health difficulties as they are more likely to experience bullying, unfairness and discrimination. It is also important to note that the data on poorer physical health and higher chances of experiencing bullying do not necessarily correlate to or explain the findings of Thurston *et al.*'s. (2010) or Svekle *et al.*'s (2010) study, as subjective perceptions of experiencing physical and health problems and bullying differ.

Coming from a different angle, the QOL of adolescents with Attention Deficit Hyperactivity Disorder (ADHD) and Intellectual Disability (ID) is comparable to the normative range, as participants' self-determination and autonomy hold up their positive sense of self. In addition, external factors such as income and social support also impact on their QOL (Araten-Bergman, 2015). Thus, adolescents with ADHD and ID are more likely to perceive a lower QOL compared to the normative range if they lack internal autonomy or external resources. On the other hand, Totsika *et al.* (2010) explored the QOL of adults with ID and Autism Spectrum Disorder (ASD). Their findings suggest that the lack of adaptive skills of adults with ASD as well as ID could have a negative effect on their QOL, compared to those without ASD. Understandably, due to the difference in age range of the participants and potential varying diagnoses, life experiences and level of satisfaction, the findings of Araten-Bergman (2015) and Totsika *et al.* (2010) still have a small level of transferability to this study. Furthermore, a gap in the literature has been highlighted, as the limited existing literature mostly focuses on the QOL of adults with SEND, as opposed to CYP.

Involving younger participants, Arias *et al.*'s (2017) research investigates the QOL of CYP and adolescents with ID and ASD. The findings suggest that the participants with ID and ASD present a lower QOL than those with only ID in terms of 'interpersonal relationships', 'social inclusion' and 'physical well-being'. This is supported by the American Psychiatric Association (2013), which states that people with ASD may experience difficulties interacting with others in a social context and display restricted interests or activities. Interestingly, the findings also highlight that CYP and adolescents with ID and ASD had a higher perceived quality of material well-being than those only with ID. One of the suggested reasons to support the

findings is that the social deficit and restricted interests of the participants with ASD allowing them to be satisfied with their material conditions (Arias *et al.*, 2017). The findings above oppose the stance undertaken by Romney, Brown and Fry (1994) that QOL could improve 'merely by lowering one's expectations'; it is possible that the interests of CYP and adolescents with ASD and ID require less materials than those without ASD and feel more satisfied with their material well-being.

One limitation in the research of Thurston *et al.*, (2010), Totsika *et al.* (2010) and Arias *et al.* (2017) is that proxy data was used to generate reasons. Without the subjective data from the participants directly, the results do not appear to be authentic. Moreover, even if the results are reliable, the reasoning behind them remains unidentified and can only be hypothesised. For instance, whether CYP and adolescents with ASD and ID are more satisfied with their material well-being due to their restricted interests remains unclear as suggested by Arias *et al.* (2017). Coming from a health related QOL perspective, Raven-Sieberer *et al.* (2006) state that the dilemma between the use of subjective and objective use of assessment has existed historically. However, proxy perspective should only be used as an 'emergency' source as subjective experiences and perceptions from children are irreplaceable (Raven-Sieberer *et al.*, 2006). Despite the increased accuracy and authenticity from the use of subjective report and data, Svekle *et al.*'s (2010) findings do not provide any in-depth explanations, and the following questions are yet to be answered:

- (1) Why have PMK overestimated the QOL of their CYP with SEND?
- (2) How CYP with SEND would reflect on their poorer QOL on physical well-being and social acceptance with life examples?
- (3) Why have female participants perceived to have a higher QOL than the male participants?

This shows the importance of qualitative research, as CYP with SEND would be given the opportunity to elaborate on the reasons behind their subjective QOL judgement.

Although obtaining subjective data in a QOL research study is essential, collecting this type of data can be quite difficult. Wallander, Schmitt and Koo (2001) pointed out that of the few research studies on CYP's QOL before the early 2000s, only 9%

measured their QOL based on their subjective evaluation. Jenkins (1992) described the self-assessment completed by CYP with severe SEND as 'unreliable' due to their cognitive level. A dearth in the level of functional language skills amongst a wide percentage of people with mental illness can make it challenging to acquire authentic views from them with regards to their satisfaction with life, or indeed a multitude of facts in life as outlined in the various domains (Jenkins, 1992). The quality of life of an individual with a mental illness must therefore be confined to an objective experience that is measurable and comparable to the rest of the population (Jenkins, 1992). As a result of not being able to gain reliable data from people with a mental illness, the views and ideas of others, such as close family members, have been taken into account (Felce and Perry, 1995). Thurston *et al.* (2010) highlight the difficulties when trying to ascertain the views of CYP with SEND due to their level of complexity. Furthermore, Arias *et al.* (2017) point out the lack of tools that enable researchers to capture the QOL of CYP with SEND; participants' subjective views were not collected, even though the QOL assessment instrument used in the research was designed for CYP with ID and ASD. Besides the complexity of CYP with SEND, Thurston *et al.* (2010) also demonstrated how the financial constraints in the research study acted as a barrier to obtaining subjective data. However, existing literature suggests that such barriers could potentially be removed.

Araten-Bergman (2015) utilised QOL assessment instruments that are specifically designed for people with ID; the language used was also translated by professionals. Similarly, Karande *et al.* (2012) employed the health related QOL assessment instrument designed for CYP adolescents with any chronic medical condition or disability in the participant's first language with Specific Learning Disabilities (SpLD) in order to remove barriers and ascertain their subjective QOL. Svekles *et al.* (2010) also attempted to obtain the views from CYP with SEND through the use of a QOL assessment instrument designed for both healthy and chronically ill CYP. Prior to obtaining the views from CYP with SEND on their QOL, Holburn, Cea, Coull and Goode (2007) described the purpose of the project, explaining the concept as well as the instructions to participants in order to support their understanding. Although subjective views from CYP with SEND were ascertained from participants through the translated QOL assessment instruments, the varying levels of ID and SpLD in the research of Araten-Bergman (2015) and Karande *et al.* (2012) could affect their

understanding. Likewise, the compatibility of the instrument utilised by Svekle *et al.* (2010) can also be challenged as it is designed for healthy and chronically ill CYP, as opposed to CYP with SEND. Despite the efforts put into differentiating the QOL measurement instruments developed by Araten-Bergman (2015), Karande *et al.* (2012) and Svekle *et al.*'s (2010) research studies, I would argue that the robustness of the differentiated instruments needs further improvement and has to be more tailored for participants based on their individual circumstances. The above examples show that the instruments can be differentiated (Araten-Bergman, 2015; Karande *et al.*, 2012) and the instructions can also be explicitly delivered to participants for them to gain a better understanding (Holburn *et al.*, 2007). However, I decided not to utilise these instruments as I relied on participant observations and interviews as data collection methods to explore student participants' QOL with them. Therefore, topics we covered during the data collection were all relevant to student participants and they would have a prior understanding of those aspects of their life. Further QOL related topics were also examined further through the interview conversations.

Flanagan (1978) and Felce and Perry (1995) also pointed out the importance of the relevance of the QOL domain headings. In order to assess the QOL of CYP with SEND, not only do they need to understand the instructions and concept, QOL domain headings are also required to be relevant. Ben-Arieh and Goerge (2001) question the value of traditional QOL domain headings including 'Intellectual capacity' and promote relevant and functional domains headings such as 'Civic life skills'. Similarly, Holburn *et al.* (2007) only included three relevant QOL domain headings in their research study. Moreover, short and simple questions such as 'What's working?' and 'What's needed?' were asked to accompany such relevant QOL domain headings.

Although most of the literature adopts the theory that the QOL of CYP with SEND is lower than their neurotypical peers, the findings of the aforementioned studies cannot merely be generalised based on the following reasons:

- (1) The existing literature that focuses on the QOL is limited.
- (2) The research findings do not always present the subjective QOL of CYP with SEND.

(3) The QOL assessment instruments utilised to measure the QOL of CYP with SEND are not robust and individualised enough to explore their views fully.

After reviewing the literature on the QOL of CYP with SEND, I move onto exploring literature that suggests QOL enhancement for CYP with SEND; specific research studies will be evaluated critically in the next section.

## **2.5 Enhancing the QOL of CYP with SEND**

In this section, I explore the literature that suggested ways to enhance the QOL of CYP with SEND, including education and employment, religions and spirituality, improved behaviours and life coaching and person-centred action steps. Although my research study does not aim to enhance student participants' QOL, there were some common contents covered in the non-curriculum based intervention. For instance, behaviour of a student participant was explored in an intervention. This will be explored more in the intervention overview and findings section.

### **2.5.1 Education and employment**

The idea of developing the education level and work skills, and providing more tailored work opportunities for people with SEND has been considered as a way enhancing their QOL (Faragher, 2010; Terrill and Gardner, 2010; Lysaght and Cobigo, 2014 and Schepens, Puyenbroeck and Maes, 2019). The meta-analysis of Schepens, Puyenbroeck and Maes (2019) identifies twelve themed interventions that are associated with enhancing the QOL of elderly people with Intellectual Disabilities (ID). Although the research by Schepens, Puyenbroeck and Maes (2019) is aimed at elderly people with ID, three of the twelve identified themes - 'Psychosocial support and Education', 'Increased social participation', 'Improved self-determination' and 'Interpersonal relations'. These areas are explored further when evaluating the impact of the non-curriculum based interventions as the contents cover the identified themes in some interventions.

The 'Psychosocial support and Education' theme suggests that lifelong learning opportunities for those with ID, particularly ones with more severe conditions, are

crucial for their everyday life (Schepens, Puyenbroeck and Maes, 2019). It is worth noting that the concept of 'education' indicates the acquisition of basic life skills, as opposed to higher or further education, or strictly curriculum-based learning; such life skills include: cooking, shopping or even exploring the use of cognitive devices to support participants' daily living (Schepens, Puyenbroeck and Maes, 2019). Therefore, life skill elements can also be included in the planning of the non-curriculum-based interventions.

Although the findings of Schepens, Puyenbroeck and Maes (2019) reflect on the QOL enhancement of elderly people with ID, it could be argued that aspects such as the development of psychosocial well-being and education are also beneficial from a young age. Education paves the employment pathway for people with SEND, where employment is more likely to be linked to improved material well-being, social well-being and psychological well-being than unemployment (Ross and Willigen, 1997). Likewise, Lysaght and Cobigo (2014) highlight the lower employment rate of people with ID and that employment provides one with sustainable income, consequently improving their physical well-being, psychological well-being and social exposure. Although education does not guarantee employment, and the extent of the effects employment has on the well-being of people with SEND vary, Faragher (2010) outlines the increased QOL of the participant by recording what she was able to do before the implementation of the numeracy development plan (NDP) and after. The findings suggest that the NDP provided opportunities for the participant to rehearse counting money, which is a skill that was acquired by the participant in the past. The participant showed more readiness to apply her money counting skills in a real-life context and thereby displayed an enhanced QOL. From a quantitative perspective, the set objectives outlined in the NDP could have been measured numerically and data could also be disseminated statistically to show the growth on the independence of the participant from a third-person stance. However, Faragher (2010) adopted a qualitative approach by observing the progress made by the participants during each step of the implementation of the NDP. For instance, Faragher (2010) notes that the participant was 'able to read digital and analogue' time and 'has learned to read her own weight' in step 2 of the research; the participant started to adapt to her new role as a 'fellowship coordinator' when budgeting and sorting money. Although Faragher's (2010) case study does not



illustrate the extent to which the specific life skill-based education impacted on one's employability, the upskilling of the participant demonstrates a more equipped self for life as well as employment.

In line with Ross and Willigen (1997) and Lysaght and Cobigo (2014), Kober (2010) also highlights the importance of employment in the QOL of people with ID. Furthermore, Kober and Eggleton (2005) suggest that different types of employment affect the QOL of people with ID who also have a higher functional work ability, than those with lower ability. In particular, the QOL aspects such as independence and social belonging are reported to have improved for those with ID and higher functional work ability when working in an open employment than sheltered employment, due to the increased social exposure (Kober and Eggleton, 2005). Similarly, through measuring personal outcomes, an open work environment is found to have developed areas such as self-realisation of goals, improved connections and relations with others and increased understanding of social roles (Terrill and Gardner, 2010). Although the interventions do not have a direct aim at supporting the student participants' education and employment, there are potential overlapping elements in the contents. For example, the communication and interaction intervention (C&I intervention) and social, emotional and mental health intervention (SEM&H intervention) target communication and social skills, which are somewhat relevant to the personal outcomes that can be achieved through an open work environment as Terrill and Gardner (2010) suggested.

Besides the findings from Kober and Eggleton's (2005) and Terril and Gardner's (2010) studies, more concrete evidence is required to support the theory proposed by Faragher (2010), Schepens, Puyenbroeck and Maes (2019), Ross and Willigen (1997) and Lysaght and Cobigo (2014) that education and employment can enhance the QOL of people with SEND. One might also challenge that the literature listed above does not reflect on CYP with SEND, as all participants appear to be adults. However, as mentioned above, it could also be argued that having the QOL enhancement input from a younger age increases the longevity of the benefits. It is important to note that the purpose of non-curriculum based targeted interventions does not necessarily focus on providing student participants with support on their employment or education from a curriculum point of view, rather they target the

broad areas of need of CYP with SEND: Communication and interaction (C&I), Social, emotional and mental health (SEM&H) and Sensory, motor and/or physical needs (SM&P). However, elements such as life skills education or social participation opportunities are included in the non-curriculum based interventions.

### **2.5.2 Religions and Spirituality**

Religious involvement has been considered as one of the ways to enhance one's QOL (Ferriss, 2002; Corrigan, McCorkle, Schell and Kidder, 2003 and Glicksmans, 2011). Glicksmans (2011) criticises the non-meaningful quality of life enhancement methods, such as setting objectives and goals that are based on normalisation, socialisation and community inclusion without any religious ideals. Coming from a Jewish perspective, Glicksmans (2011) proposes ritual practice as a QOL enhancement activity for people with ID, as it enables them to embrace their specific needs without feeling ashamed. Although the suggestions from the religious perspective provide conceptual ideas, they lack concrete evidence that supports the functionality of the religious perspective as well as the potential extent of the impact on one's QOL. Corrigan *et al.*'s (2003) research study, on the other hand, suggests that religion and spirituality are associated with subjective well-being of people with serious mental illness. It is worth noting that, despite the label of religions or its layer, both suggestions from Glicksman (2011) and Corrigan *et al.* (2003) suggest that the well-being of people with ID and serious mental illness are connected to activities that boost their self-worth, mental health and emotions. Much like the argument made on how coverage of the non-curriculum-based interventions do not cover education and employment, they do not cover religions and spirituality either. However, religious elements could be an area for exploration in the interventions should the conversations evolve into this area, despite this not being a particular area of interest in my research study.

### **2.5.3 Improving behaviour**

CYP with ID are more likely to have behavioural problems, which directly affect parental stress level, and consequently the development and well-being of the CYP. Therefore, interventions such as parental behaviour management training and

mindfulness-based interventions could reduce the stress of parents, and as a result, improve the development and well-being of CYP with ID (Crnic, Neece, McIntyre, Blacher and Baker, 2017). Likewise, Burgess (2014) also highlights that challenging behaviours from CYP with SEND suggest the lack of problem solving and thinking skill. However, coming from a different viewpoint, Burgess (2014) remarks that their QOL can be enhanced through increased habit of minds, including skills to manage impulsivity, think flexibly and problem solve. Without undermining the impact parental intervention could have on the QOL of CYP with SEND, Burgess's (2014) proposal of enhancing the habit of minds of CYP with SEND is more direct. Hussein (2009) investigated how the QOL of CYP with SEND can be enhanced through accessing a sensory garden, an outdoor area that provides people with a wide range of sensory experiences. Through obtaining views from the teachers and therapists of CYP with SEND, Hussein (2009) suggests that participants were encouraged to take part in physical activities and social communication when accessing the sensory gardens. Although specific case studies in Burgess's (2014) research suggested that participants were able to manage their behaviour by regulating their heightened emotions and communicating with staff members peacefully, the findings do not provide any concrete evidence on how the behaviour and QOL of CYP with SEND improved. Similar to Crnic *et al.* (2017) and Burgess (2014), behaviour support also emerged as one of the twelve themes that were associated with the QOL of elderly people with ID in the research of Schepens, Puyenbroeck and Maes (2019). However, the findings focus more on the need for consistent psychotherapy treatment and assessments provided by the medical professionals. To clarify, my research study specifically focuses on the impact non-curriculum based targeted interventions have on the QOL of CYP with SEND and all interventions are delivered in a school context.

So far, I have explored how education and employment, religion and spirituality and improved behaviours could impact one's QOL. However, I would argue that one size does not fit all, as education and employment could be the key to enhancing one person's QOL, but not necessarily another's. Therefore, focusing just one specific aspect may not 'enhance' one's QOL, and that the impact of the non-curriculum based interventions is not predictable prior to the data collection stage due to their diverse and evolving nature. Life coaching and person-centred action steps are two

frameworks proposed by Shpigelman (2019) and Brown and Brown (2004), whereby they allow the researchers to investigate the area of QOL participants desire prior to the intervention implementation.

#### **2.5.4 Life coaching and person-centred action steps**

Shpigelman (2019) introduces life coaching as an action prone intervention that enhances the QOL of individuals with ID, consisting of eight steps:

- (1) Pre-coaching
- (2) Introduction
- (3) Defining the focus of the coaching process
- (4) Identifying personal values
- (5) Identifying resources and obstacles
- (6) Envisioned future
- (7) Action plan
- (8) Review and evaluation

The robustness of Shpigelman's (2019) intervention allows for the participants to understand the rationale of the research through step 1 and 2, before the foci of the process were identified and setting action plans. Shpigelman (2019) captured the QOL enhancement in the participants through observations. The progress made by participants in each stage of the research study is reported from a first-person perspective. In the case of participant 1, Shpigelman (2019) clearly states that his desires were to 'have a romantic relationship' and to 'expand his social circle' in stage 1. In stage 2, Shpigelman (2019) acknowledges participant 1's regret for spending too much time on his studies, as he felt that his social life was jeopardised. Within stage 5 to 7 of the research study, the participant identified his personal strengths that could support him with achieving his goals, envisioned the future and set out action plans. Although there was no quantitative data to support the findings, the participant indicated a greater satisfaction on his QOL domain headings qualitatively by commenting: 'I feel good; I feel happier since I started this programme.' Shpigelman's (2019) life coaching framework allows researchers and participants to identify specific areas mutually agreed by the researcher and participants, which could be any areas,

including their education, employment or even behaviour. Shpigelman's (2019) findings suggest that the QOL of two adult participants with ID improved over the 5-month intervention period. Participants expressed their desire to develop their social and romantic relationships and to become more independent generally and financially. Upon the identification of personal desires and values, participants were coached to identify obstacles, which included being overly rational when making decisions and the lack of resilience in life. Following specific set targets and action plans, both participants indicated a greater satisfaction on their general QOL including the specific areas. This is in-line with the conclusion I drew in the last section, that a blanket approach does not fit all, as education and employment or religions and spirituality could be the key to enhancing one person's QOL, but not necessarily another's. Shpigelman's (2019) research is closer to the non-curriculum based intervention used in this research as it does not cover just one area.

Similarly, Brown and Brown (2004) proposed four person-centred action steps, where the intervention:

- 1) Begins from the place the person perceives as most important.
- 2) Follows the person's choices on how to proceed.
- 3) Encourages and supports empowerment through self-management.
- 4) Shapes interventions in such a way that work to improve the person's self-image.

Brown and Brown (2007) suggest that a participant with a physical disability expressed wishes to build up self-confidence, despite the professionals' desire to help him develop his physical and material well-being by exploring new career options. Through a person-centred approach, it was suggested that the perceived emotional well-being of the participant with a physical disability overrides other aspects of QOL, and that is where the QOL intervention for this individual should embark. Both research studies employ a multiple step approach. Shpigelman (2019) and Brown and Brown (2007) investigated their participants' QOL satisfaction and desire before implementing an intervention that is tailored to their needs. Although both Shpigelman (2019) and Brown and Brown's (2007) approach directly supports the participants with their QOL, the non-curriculum based interventions in this study focus on the three broad areas of need of CYP with SEND: Communication and interaction (C&I), Social, emotional and mental health (SEM&H)

and Sensory, motor and/or physical needs (SM&P). This means that although the elements of coverage vary based on individual circumstances and desire, the ultimate focus of the interventions will remain changed – C&I, SEM&H and SM&P.

Shpigelman's (2019) and Brown's (2007) research indicates that the concept of enhancing the QOL of people with SEND is feasible with appropriate support. Although the participants focused on specific areas of QOL domain that they desired to enhance the most, the hypothesis is that the life coaching intervention could also enhance other areas of QOL depending on the needs of the participants and the support available. Despite the small sample group and the limited varying levels of SEND, Shpigelman's (2019) research provided an insight into the possibilities of how specific interventions could positively impact on the QOL of people with SEND. One of the limitations of both the life coaching framework and person-centred action steps is that the proposed intervention appears to only cater for adults with mild to moderate level of needs, who have the ability to identify personal goals and be coached through action plans; I would challenge that participants with less understanding might not be able to engage in conversations in relation to coaching and action plans.

Despite the limited literature on the QOL enhancement of people, more so for CYP, with SEND, there are proposed areas of enhancement and frameworks that are feasible. Respectively, Crnic *et al.* (2017) and Burgess (2014) suggest that managing the behaviour of CYP with SEND can be one of the routes to enhancing their QOL, as reduced parental stress can indirectly improve the well-being of the CYP with SEND and increased habit of minds can enhance the CYP with SEND. In spite of the proposed theory above, there is lack of evidence on the actual impact on the QOL enhancement of CYP with SEND. Similarly, the impact from the emotional support that stems from spiritual or religious activities is also unclear (Corrigan *et al.*, 2003 and Glicksmans, 2011). As mentioned above, elements within the scope of the non-curriculum based interventions vary based on the circumstances and needs of the participants. Therefore, elements or discussions around behaviour or spiritual and religious activities could potentially be included, should they be deemed to be what the participants need or desire.

Whilst a technique for managing the behaviour of one particular child with SEND could work, it may not necessarily work for others. This is due to the varying levels of (1) SEND diagnosis, (2) life experience, (3) self-perception of QOL and (4) individual priority. Both Shpigelman (2019) and Brown and Brown (2007) highlighted the importance of the concept of a framework or approach; the most important QOL areas differ from one another and identifying them appears to be the most practical approach. However, limitations on such frameworks have been identified, as not all participants with SEND have the cognitive ability to identify the QOL areas that they desire to enhance. Therefore, securing participants' understanding of the purpose of the project, concept and instructions is vital (Holburn *et al.*, 2007). In this present study, the appropriate level of differentiation will be in place to ensure that participants are able to express themselves as well as to access the interventions.

In summary, there are many different QOL definitions stated in the existing literature, of which Burckhardt and Anderson (2003), Petry, Maes and Vlaskamp (2005), Felce and Perry (1995), WHO (1997) and Schalock and Verdugo (2002) provide explicit domain headings that are deemed relevant to my thesis. Further to the evaluation, I concluded the working definition of QOL using QOL domain headings as follows:

- Physical well-being
- Material well-being
- Social well-being
- Emotional well-being
- Personal development
- Level of independence

The next chapter explores the methodology and approaches deployed in this thesis, where I also justify the reasons why they are the best suited methods to meet my research objectives and answer questions that arose.

### **3 Methodology**

This research aims to explore the impact that non-curriculum based targeted interventions have on the QOL of CYP with SEND. The chosen methodology for this research is a qualitative study inspired by some ethnographic principles, with an action research approach. Although the process of my data collection involves an array of methods and approaches used in ethnographic studies including writing fieldnotes, participant observations and conducting interviews (Harrison, 2018), it is considered ethnography inspired, as, during the action research cycles, I was involved in developing and modifying some of the interventions in which the participants took part. The definition of ethnography and how my research is inspired, yet different from an ethnographic study will be explored in the sections below. As part of the action research approach, I conducted multiple sets of research cycles, whereby qualitative data is generated at different stages in this research study.

In this chapter, I first explore the reasoning behind adopting a qualitative approach, followed by an explanation as to why an ethnography inspired approach was adopted. I will also explain the action research approach undertaken and how the research cycles are presented in my research. I will also explore how I engaged in reflexivity during the research by defining my position. Finally, sampling, intervention overview and data collection methods will also be explored.

#### **3.1 The definitions and ideology of a qualitative approach**

In this section, I will justify why a qualitative approach was chosen for this research, while focussing on defining a qualitative approach and exploring the methods used by researchers to yield qualitative data. Finally, I will also explore the differences between a qualitative approach and a quantitative approach. I will highlight the features of the former and discuss the decision behind adopting it for my thesis.

Sale, Lohfeld and Brazil (2002) note that interpretivism and constructivism are the fundamental bases of the qualitative paradigm. In other words, qualitative researchers are keen to establish how individuals define their experiences, formulate words and what associations they make with regards to those words (Merriam and



Tisdell, 2016). For instance, whilst an interpretivist approach focuses on interpreting the perspectives of the meaning of the participants' reasons behind their actions, a constructivist approach allows the participants to be responsible for actively constructing and organising knowledge according to their existing knowledge and experiences (Bakker, 2010; Stauffacher, Walter, Lang and Wiek, 2006). Thus, I chose a qualitative approach because it enabled me to identify student participants' own view on their QOL qualitatively.

After meeting the first objective of my research through the reviewing of the literature, I intended to identify student participants' own views on their QOL domains headings and what they mean to them, as well as to examine their perspectives on the intervention experience and how such experience impacted on their QOL. The data collection and analysis process were straight-forward from a constructivist viewpoint, as student participants' views on their QOL domain, experience of their intervention and how they impacted on their QOL were constructed through semi-structured interviews. Using an interpretive approach was more complex, as I began to interpret student participants' perspectives from the moment I observed the interventions. Beyond the initial layer of interpretation, there were further steps, which ranged from reviewing the intervention recordings, writing fieldnotes, interviewing both student participants and their parents, producing interview transcripts, categorising data to identifying themes and sub-themes. More details on the process of data collecting and my thematic analysis process, and the data presentation are outlined in 3.6 and 5.1.6 respectively. It is, however, important to note that the data collected for my research would not have been deeply analysed and richly presented if the fundamental basis of the qualitative paradigm had not been adopted for this research.

Unlike the quantitative approach, the ontological position of a qualitative approach is not based on one existing reality or truth; the emphasis of a qualitative methodology lies on subjectivity of the individual matters from an interpretative nature, where multiple truths and realities could emerge when interpreting the data (Slevitch, 2011). Atkinson (2017) highlights that a qualitative approach is ideal for allowing one to gain a greater understanding of the mechanism of co-devised interpretations, real life

experiences, including religious and cultural practices. All data collected from student participants and their parents are an interpretation of their lived experience, and therefore the qualitative approach enabled me to further understand.

One might challenge my choice to adopt a qualitative approach for my research, as most existing research studies on the QOL of the population with SEND follow a quantitative pathway (Thurston *et al.*, 2010; Svekles *et al.*, 2010; Araten-Bergman, 2015 and Arias *et al.*, 2017). Indeed, the use of a quantitative approach in the research suggested above provides clear data presentation at first glance. For instance, Svekles *et al.* (2010) presented the data collected from the questionnaire using bar graphs, which clearly shows children and parent participants' views on their own QOL respectively. As a reader and a fellow researcher, I understood that children participants in their study scored their 'Social Acceptance (Bullying) QOL domain as the lowest (with a mean score of 24.6) and 'Parent Relation & Home Life' QOL domain as the highest (with a mean score of 50.7). However, no explanations are available for further insights to answer the 'why questions'. While I noticed a discrepancy between children and parent participants' views on 'Social Acceptance', as the mean score was 40.1 for the parents, the reasoning behind this discrepancy was not explained by the researcher. On the contrary, I use the qualitative data including quotes from interviews and observational fieldnotes, to enhance readers' understanding.

Similarly, Arias *et al.*'s (2017) study produced detailed scores under each QOL domain headings using a QOL assessment questionnaire. The use of plot graphs in their study supports the display of data on different participant groups' QOL. As part of the discussion, Arias *et al.* (2018) produced hypotheses about why participants with both ASD and ID were found to have a lower physical well-being, yet a higher material well-being score compared to those with less needs. Although all hypotheses made by Arias *et al.* (2018) were logical and based on the data collected, they were not as certain as if participants had themselves elaborated on the results, and therefore could only remain hypothesised. Arias *et al.* (2017) also highlighted the fact that the QOL scores ascertained for their research were not self-reported, but rather assessed by external observers who knew the children well, and they highlighted the urgent need for tools that capture young people's own perspective on their QOL. Moreover, Thurston *et al.* (2010) also recognised the limitation of their study as they highlighted

the difficulties to ascertain data from CYP with SEND due to their complexity and that they might not be able to express their unique life experiences. Apart from also interviewing parents, I spent time building a rapport with the student participants in the field in order to better enable me to collect meaningful data.

As mentioned in the introduction of this chapter, I included data collection methods such as writing fieldnotes, participant observations and conducting interviews inspired by ethnography (Harrison, 2018). In doing so, I obtained an in-depth insight into the student participants' lived experience and aimed to provide explanations of the findings of which quantitative studies on QOL mentioned above have not provided. Nevertheless, I do have an understanding of the disadvantages of adopting a qualitative approach, as my research is not generalisable or representative, since it includes a small sample, it does not include numerical data, or graphs that show clear results on how my participants valued their QOL and how the intervention impacted on the different QOL domains. Still, the advantages of adopting a qualitative approach allows me to present my findings in a more descriptive manner to establish how my participants define their experiences, actively construct and organise knowledge according to the participants' knowledge, and have the personal stories presented in my findings (Merriam and Tisdell, 2016; Bakker, 2010; Stauffacher *et al.* 2006). Thus, my research enables me to answer the 'why' question, which quantitative research may not be able to answer.

There are, however, QOL related research studies that adopted a qualitative approach to collect and present data (Faragher, 2010; Shpigelman, 2019). Faragher's (2010) qualitative study highlighted the importance of numeracy skills for people with SEND (referred as Intellectual Disabilities), and of planning around numeracy development. Following a systematic approach, Faragher (2010) presents the qualitative data collected by outlining the step-by-step process of the Numeracy Development Plan (NDP) and how the participants' QOL improved overtime as she demonstrated the acquisition of new functional life skills related to maths following the implementation of the NDP, which included weighing herself and applying the concept of money in different contexts. Similarly, Shpigelman (2019) captures the QOL enhancement in the participants through first examining their personal values, then exploring success and meaningful functioning within their lifestyles. With the eight steps from the life coaching

framework clearly recorded, the progress made by participants was also presented with rich texts, detailing each milestone and barrier. In comparison to the research by Svekle *et al.* (2010) and Arias *et al.* (2017), the clarity on how the QOL improved and how progress was made is admittedly less clear in the research by Shpigelman (2019) and Faragher (2010). What the latter research offer is a rich story behind each participant's journey of recognising their QOL domain headings, and particularly in Shpigelman's (2019) research, the growth. After reviewing this research, I find the studies adopting a qualitative approach more insightful, because I was able to understand the lived experience of the participants more than just interpreting numerical figures. And, therefore, I have decided to adopt the same approach and to look for the 'answers' that are missing in some quantitative studies.

On the note of answer-searching, Sale, Lohfeld and Brazil (2012) and Lapan, Quartaroli and Riemer (2015) are qualitative researchers focusing on the 'process' and 'meanings' when looking for the answers, whereby participants' unique life experiences are reflected upon as part of the research through the use of texts. As mentioned previously in the Introduction and Literature review in this paper, QOL is an individual perception of their position in life, which is also an overarching concept consisting of different domains (Andrew and Withey, 1874; Flanagan, 1987). I would suggest that qualitative data is the most appropriate to be used to capture and disseminate the 'process' and 'meaning' of participants' QOL.

Qualitative research studies focus on texts over numbers, as they include student participants' voices by asking them questions that promote reflection and insight (Lapan, Quartaroli and Riemer, 2015). Mahoney and Goertz (2006) describe qualitative researchers as detectives, as they gather information and draw conclusions based on fact finding, experience and knowledge on working with similar research studies. They further explain that not all information collected through observation weighs equally when building a conclusion, as some specific observations could contribute substantially to their viewpoint to validate a theory or even the conclusion. I fully echo Mahoney and Goertz's (2006) viewpoint as their theory is highly applicable to my thesis, from my first-hand experience in the field as the researcher. At times, the progress could appear 'slow', as the observations or interviews did not appear to directly contribute towards the research questions. However, some observations and

interviews also weighed substantially, whereas rich data could be extracted from those encounters. More will be explored in the next section, but the action research approach adopted in my research also led me to make changes to my interview schedules, which supported the data collection process. For example, I directly asked student participants questions about their views on their QOL domain headings in an interview, as the questions from the previous interviews did not yield rich enough data for analysis purposes.

After exploring the definitions and ideology behind a qualitative approach with previous studies as examples, I now discuss the differences between a qualitative and quantitative approach. Mahoney and Goertz (2006) also point out that there are some technical differences between a qualitative and quantitative approach when conducting the research, collecting and analysing the data. Apart from the utilisation of surveys, questionnaires and number collection systems, quantitative researchers also have at their disposal sophisticated mathematical models to aid the interpretation and systematic analysis of the findings. Contrarily, qualitative researchers opt for other methods, including observations and interviews as well as analysing data gathered from focus groups and discussions (Mahoney and Goertz, 2006). In my thesis, where the QOL domains of student participants are identified and explored, a qualitative approach is adopted. One could argue that any quantitative data is also likely to be derived from subjective perspectives on the student participants' lives, which are fundamentally qualitative notions. Likewise, the qualitative data collected from participants were categorised and coded, of which the frequency was tracked numerically before themes emerged. Therefore, having a balanced perspective and understanding on both the qualitative and quantitative approach.

From a qualitative researcher perspective, data is disseminated in the narrative of the first person, combining the views of both the participant and the researcher; these types of perspectives are referred to as etic and emic (Yilmaz, 2013). Mahoney and Goertz (2006) further point out that qualitative researchers attempt to identify the causes of individual matters and outcomes, whereas quantitative researchers focus on the effects of causes statistically. Because life experiences and circumstances differ from one another, I would suggest that exploring the participants' own understanding and perspectives is necessary in research on QOL. Thus, a qualitative

approach allows the participants to develop and share their experiences enabling the researchers to focus on and decipher the process and definitions behind the certain behaviours ( Sale, Lohfeld and Brazil, 2002).

While I briefly touch on the topic of sample sizes and sampling here, further justifications are provided in section 3.5. Unlike quantitative studies, the sample size in a qualitative study is also not meant to be representative of large populations, instead, qualitative research focuses on smaller, more useful samples as they allow for more in-depth descriptive data (Slevitch, 2011). In other words, as far as a qualitative approach is concerned, it is not feasible to simply generalise, as the research is diverse (Punch, 2014). Instead, working with a small group of participants allows the researcher to immerse themselves in the field and address the research problem in-depth through the establishment of close relationships developed with participants (Crouch and McKenzie, 2016). Therefore, I would argue that the small group of participants in my research allowed me to investigate the QOL of CYP with SEND in greater detail.

After explaining the differences between the qualitative and quantitative approach, and why I chose to adopt the former for my research, I now move onto discussing qualitative studies generalisability and transferability. Maxwell (2021) also recognises the issues qualitative studies have around generalisability, and that some regard qualitative research as 'incompatible' with the concept. However, transferability in qualitative research has been suggested as an appropriate alternative. While it is the researchers' responsibility to paint a full picture of the context of the research, the responsibility for transferring the information from the original study's findings to different contexts belongs to the readers (Jensen, 2008). In other words, readers are not to blindly generalise findings and adopt a generic approach, but should look to apply the findings appropriately after considering the contexts of the qualitative studies as well as their own. Consequently, the transferability of a qualitative research study can still be enhanced by the thorough description of the research, alongside a robust sample group that consists of participants that purposefully match the description, which all contribute to providing readers with a clearer understanding on what data is transferable and vice versa (Jensen, 2008). Besides the thorough description of the research, the purposefully sampled participant group that presents the research

design, limitations and delimitation of a study also enhances its transferability (Jensen, 2008). Therefore, although my research is not designed to be generalised, the findings are transferable, more so for readers who recognise themselves or their own experiences through understanding the rich description of my research as well as reasoning behind a purposefully selected sample group. More details on my sampling decisions and process are outlined in section 3.5.

Similar to the concept of transferability, Stake (1994) propounded the term 'Naturalistic generalisation', where the readers of a study should determine if such experiences can be used or understood in a new setting, following the thick description provided by the researchers. In line with Stake (1994), Hellstrom (2006) and Smith (2018) also recognise that naturalistic generalisation is a 'tacit recognition' of similarity, based on the readers' personal involvement, while the researchers are required to provide the readers contextual details and rich layers of theory that reflect on the reality of their research.

Thus, the qualitative and quantitative approaches consist of different values, beliefs and norms (Mahoney and Goertz, 2006). As there are many technical differences between conducting quantitative and qualitative research studies, the biggest differences between the approaches are the ideology and philosophical assumptions, which are beyond the research, data collection or analysis techniques (Lapan, Quartaroli and Riemer, 2015; Sale, Lohfeld and Brazil, 2002; Merriam and Tisdell, 2016; Bakker, 2010; Stauffacher *et al.*, 2006 and Slevitch, 2011). While the incompatibility in the generalisability of qualitative studies is flagged up (Maxwell, 2021), readers should focus on the transferability and the naturalistic generalisability of my research, as I provide rich and contextual descriptions of my research and sample group. I intend to close this section by reiterating that generalisations of the findings are not the aim of this research. In the next two sections, I explain ethnography, including the reasons why my research is considered an ethnography inspired approach, then define action research, including its ideology and practice during the research, as well as providing a rationale for adopting an action research approach.

### **3.2 Why adopt an ethnography inspired approach?**

This section explains what ethnography entails and why my research is inspired by ethnography. The literal meaning of ethnography is to 'write or represent a culture', with the ethnographers developing long-term engagement and commitment in the field, taking part in participants' world and culture while remaining analytical and observational (Tacchi, Slater and Hearn, 2003; O'Reilly, 2009). Atkinson (2017) argues that 'ethnography' is an important qualitative research methodology, as it is essential for decoding intersubjectivity and co-devising interpretations amongst different communities. He adds that by including themselves in the research, ethnographers are able to look for patterns, understand local relations and meanings through obtaining real life first-hand experiences when conducting the observations. Delamont (2013) describes ethnography as interchangeable with participant observation and field work, as they all mean spending long periods watching, talking to participants about their doing, thinking and saying, with the aim of understanding their world. Therefore, ethnographers are able to take a holistic approach to immerse themselves in the world under study, interpret and present the rich data collected (Atkinson, 2017; Tacchi, Slater and Hearn, 2003). I stated in the previous section that I chose a qualitative approach as it enabled me to identify student participants' views on their QOL, however, my credibility for being the 'analyst' can be challenged as I do not speak for the student. Therefore, adopting an ethnographic inspired approach helped me increase my understanding of the student participants and gain credibility.

In line with Atkinson's (2017) point on participant observations, Reeves, Kuper and Hodges (2008) state that ethnographic research studies tend to involve analysing data that is the explicit interpretation of the meanings and functions of one's actions as researchers 'get inside' the way that participants view the world. Furthermore, the product of data analysis primarily takes the form of verbal descriptions and explanations (Reeves, Kuper and Hodges, 2008). Similarly, Harrison (2018) suggests that the attribute of ethnography is the emphasis on studying, describing, representing, and theorising cultural behaviours. He further highlighted the importance of contextualising data when practising ethnography to ensure that the reasonings behind behaviours are provided to readers (Harrison, 2018). Ethnography should be referred to as a methodology, rather than a 'method' in a research study, as



ethnographers typically adopt an array of methods and approaches during the process, such as participant observations, writing fieldnotes, and conducting interviews (Harrison, 2018). In agreement with Harrison (2018) and Atkinson (2017), I have chosen to conduct participant observations, writing fieldnotes and conducting interviews in my research as a means to gain an insight into student participants' world, further details on the actual process are detailed in section 3.7.

As mentioned in chapter 2, I have highlighted the importance of subjective QOL whilst the objective measures are in the context, perceived by participants individually. However, there is a lack of subjective data sought and presented in QOL research studies, in particular, for participants who have SEND (Thurston *et al.*, 2010; Totsika *et al.*, 2010; Arias *et al.*, 2017). Jenkins (1992) refers to the self-assessment on QOL completed by CYP with severe SEND as 'unreliable' as their cognitive level is low. With a different attitude, yet experiencing similar difficulties, Thurston *et al.* (2010) also express the difficulty in ascertaining subjective data when working with CYP with SEND due to their level of complexity. Efforts in making the QOL assessment instruments more accessible for participants with SEND, such as adopting simplified language for participants with ID, translating the instrument for participants whose first is language English and thoroughly describing and explaining the purpose and concept of the research, have been made by several researchers (Araten-Bergman, 2015; Karande *et al.*, 2012; Svekile *et al.*, 2010; Holburn *et al.*, 2007). However, an ethnographic or ethnographic inspired approach would allow researchers to explore the qualitative elements, which would be valuable for QOL related studies.

Due to the complexity of the research questions, as well as the SEND of student participants, I argue that the need to adopt the data collection methods from ethnography is essential. Without the process to study the participants through different methods, it would be difficult for me, as a researcher, to confidently interpret their views and analyse the data collected. Fieldwork and participant observations, including observing and interviewing, enable researchers to understand and grasp participants' culture (Delamont, 2013) Without the inspiration of ethnography, the credibility of the process of my thematic analysis would have been affected adversely as I would not have grasped the student participants' culture as clearly and effectively. In section 3.7, I will further explore how I familiarised myself with the data collected

and used thematic analysis to support the interpretation of participants' views and how I have adapted my interview schedule upon reflection during an early stage of data collection.

After introducing the key concepts of ethnography, I now proceed to explaining why my research is not strictly considered an ethnography, rather as a study inspired by ethnography. Mixing ethnography and action research is not unheard of, as Tacchi, Slater and Hearn (2003) used the term 'Ethnographic Action Research' as a methodology and state that ethnography fits well with action research as the former supports the research in understanding how the 'community' works with the 'project'. They further suggest that the multi-method approach informs each method used, as researchers may edit the schedule of their semi-structured interview based on the observation feedback; further actions can then be planned after understanding the whole picture through the ethnographic approach (Tacchi, Slater and Hearn, 2003). I agree with Tacchi, Slater and Hearn (2003), because the techniques and approaches used in ethnography produce rich data, which can then be used to inform the action research cycle, which informs the approach I have adopted for my research. However, the action research approach I undertook has led me to make changes to some of the interventions, which also technically interfered with the setting and the culture under study. This is also discussed in section 3.4 when I outline the matters I reflected throughout this research. Strictly speaking, certain aspects of the interventions student-participants were involved in throughout the research were modified due to feedback from my research cycle. Therefore, it poses a conflict of interest and challenges the 'purity' of ethnography, as it would not have been possible to study one's culture by being a part of it while changing their life experiences with an intention. I will further explore the definition of action research in section 3.3.

In order to ascertain the views from participants, the contents, delivery and interview schedules have been differentiated for the participants, based on their level of understanding. Although the robustness of the measures is not be perfect since participants have varying levels of SEND and one size simply does not fit all, the data collection methods inspired by Ethnography enabled me to gain an in-depth understanding on participants' life circumstances, and the adoption of an action research approach also allowed me to reflect on the steps taken in the research, which

include the revision of interview schedules and the delivery of the intervention due to logistical issues discovered throughout the research.

The ethnographic approach supports action researchers to build upon notions of immersion, long term engagement and understanding local contexts holistically (Tacchi, 2015). Similarly, Bath (2009) also stated that the ethnographic approach allows the action researcher to acknowledge and interpret the dynamic situations from different perspectives by understanding participants' positions between taking actions. In my view, the interpersonal relationship gained from adopting an ethnographic approach compliments the action research cycles. Specifically, in my research study, I immersed myself into the research cycles in order to gain an insider, in-depth perspective from participants, reflected on feedback from stakeholders and reviewed action plans for the upcoming stages. However, I must reiterate that my study is considered an ethnography inspired approach due to the fundamental conflict of compatibility between my action research cycles and the principle of pure ethnography. More will be explored in the next section, where I discuss actions taken during the action research cycles and my involvement in the intervention as an overview. Nevertheless, conducting an action research could be never-ending, as the solutions found could lead to new questions; question-asking is a learning process that is never complete. Therefore, action research should be regarded as a dynamic process, rather than a fixed outcome (Ulvik and Riese, 2015; Hopkins, 2008). Similarly, Jeffrey and Troman (2004) also state that ethnographic research studies are never-ending, as the studies could develop throughout the lives of the researchers and serve as a long and episodic narrative. For the very same reason, I believe that the process of an action research is enhanced by the chosen data collection methods inspired by ethnography, as I had sufficient time to explore, investigate and discuss data collected with student participants before drawing conclusions. Although my research is not considered ethnography, the data collection methods were inspired by its principles, therefore this is an area I had to be aware of as I spent time in the field observing participants, writing fieldnotes and interviewing participants. Further details on how I reflected on my practice are outlined in section 3.4.

So far, I highlighted all the positive elements of an ethnography inspired approach, however, ethnographers encounter inevitable dilemmas on multiple occasions during

their research, which include the time before they make contact with the setting, during the actual research process or even after the work in the field is over (Roberts and Sanders, 2005).

### **3.3 Defining action research**

Action research brings about change, promotes reflection among practitioners and helps to build a better society through problem solving collaboratively in a specific context (Coleman and Lumby, 2009; Greenwood and Levin, 2007). In a similar vein, Efron and Ravid (2013) state that action research is an intentional, systematic, and purposeful 'inquiry' conducted by researchers in order to solve, understand, or advance one's practice. However, action research also consists of a great deal of flexibility, which enables researchers to creatively adapt in diverse contexts upon collaboration with participants, reflection on their own practice and digestion on feedback from other parties throughout the process (Armstrong and Tsokova, 2019). The flexibility of action research comes from its cyclic nature; the research cycle can be repeated during the inquiry, with the focus being on the same or other emerging variables during the research (Oranga and Gisore, 2023). Action researchers are not limited to using a fixed data collection method, as long as a mutual consensus is agreed prior to the research (Green and Levin, 2007). At the stage of seeking consent, I took the opportunity to introduce participant observations and semi-structured interviews as my data collection methods to all participants; I will further discuss how the information sheet was shared and differentiated to ensure participants' understanding of my methodology and research in section 4.3.

Efron and Ravid (2013) highlight 'situational' as one of the unique characteristics of action research, as action researchers always aim to understand the context of their research and the participants. Moreover, conclusions of the inquiries should be understood and interpreted within the complexities, ambiguities, and nuances of the culture of the participants (Efron and Ravid, 2013). Therefore, techniques, including ethnography-inspired techniques, are acceptable to be utilised to answer the inquiry of the action research (Green and Levin, 2007). Armstrong and Tsokova (2019) further suggest that the nature of the cycles of an action research challenges the research

study by presenting 'conflicting demands' to the researcher and the participant party, which, in my research, is School H.

Although action research is a practice-based research, it requires participants to engage both theoretically and practically. Within an action research approach, there is a theory-practice relationship, whereby both elements influence each other, and the action researchers are required to critically reflect on their practice. Action researchers will evolve through this process by making appropriate adaptations to practice and theory (McAteer, 2013).

In order for researchers, who are also known as the practitioners, to be able to evolve with the process, action research operates cyclically, whereby the findings from each cycle inform the planning and the actions for the next; it also ensures the existence of the reciprocation between the 'action' and the 'research' and between 'theory and 'practice' (McAteer, 2013). The action research cycle is also referred to as the 'learning circle', where action researchers need to 'look, think and act' as they would often start with a research question and gain knowledge that then led to a new set of questions (Koch, Mann and Kralik, 2005; Efron and Ravid, 2013). Similarly, Brassey (1998) proposes eight stages of an action research cycle:

- (1) Define the inquiry
- (2) Describe the educational situation
- (3) Collect evaluative data and analyse it
- (4) Review the data and look for contradictions
- (5) Tackle a contradiction by introducing change
- (6) Monitor the change
- (7) Analyse evaluative data about the change
- (8) Review the change and decide what to do next

With fewer stages proposed, Coleman and Lumby (2008) believe that an action research cycle consists of a general plan, followed by an action stage, then a monitoring stage and an evaluation stage before moving onto the next cycle. Although the cycle suggested by Coleman and Lumby (2008) does not have as many stages as Bassey's (1988) and proposal, they emphasised the fine steps within the monitoring

and evaluating stages, such as discussing, learning, reflecting, understanding, re-thinking and re-planning. Similarly, Coghlan and Brannick (2005) define the main steps of an action research cycle as:

- (1) Diagnosing
- (2) Planning action
- (3) Taking action
- (4) Evaluation action

In my research study, I have defined main steps of my action research cycle as:

- (1) Defining the research inquiry
- (2) Planning
- (3) Actioning
- (4) Data collection
- (5) Reviewing the current cycle and planning for the next cycle

Each stage in the cycle is equally important, even though the time spent could vary depending on the circumstances and the potential problems encountered. I intend to keep the stages simple but clear. Besides the constant reflection and reviewing platforms provided by the cycles of the action research, another advantage of adopting an action research approach is that I have the opportunity to embrace the role of a practitioner in addition to being a researcher. This means I could be a part of the research, collaborate with participants and reflect on feedback from student participants, including my very own. In addition to the role of a researcher, the 'practitioner' role in action research enables one to gain an insider stance and build up bonds of responsibility and social commitment with participants by being part of the research study and maintaining professional relationships with student participants (Zeni, 2009). For instance, I was able to share the feedback received from Oli (student participant) to Sally (Sensory, motor and physical intervention leader) with information on what specific exercises he wanted to attempt.

After considering the theory and practice guidance proposed by Nuddkewiid and Coleman (2008), MaAteer (2013), Coghlan and Brannick (2003) and Bassey (1988), I established my steps for conducting this research. I also outline how I utilised my

involvement with participants as action research during each stage to support the flow of my research. In order for readers to have a better understanding of the planning and actions implemented following the definition of the research enquiry and problems, the first two steps were combined (Defining the research enquiry and planning and actioning) in the commentary, so that matters are displayed in a chronologically fluid order.

The process of defining my research inquiry was clear, as I started my research with a clear rationale (also outlined in chapter 1), which was based on my perspective as a practitioner, having been a qualified teacher who has worked with students with SEND since 2015, as well as the review of the literature which revealed a limited number of research studies in this field. Therefore, a clear set of objectives were set for my research, by which I intended to:

- 1) To understand how QOL is defined by the literature and identify a working definition for this research.
- 2) To identify the student participants' views on their QOL domains
- 3) To examine the impact of non-curriculum-based interventions on student participants' QOL
- 4) To explore student participants' perspectives on their intervention experience

My inquiries were shared with all participants in different formats, and therefore it was clear that the participants were aware of the enquiries of my research. The initial planning and actioning steps were crucial for this research, as I first had to recruit all participants after explaining the rationale of my research to them as well as gaining approval from Executive Headteacher of School H. Following the recruitment of the participants, I proceeded to observe a series of sessions before conducting semi-structured interviews. Although I analysed the data as I collected them, in-depth analysis was conducted after each semi-structured interview. The digestion of feedback received in an action research inform the reflection on researchers' own practice (Armstrong and Tsokova, 2019). The evaluating stage before the next cycle

begins by seeking to confirm if a diagnosis and action taken were appropriate that leads to the answers (Coghlan and Brannick, 2005).

With each cycle ending after a semi-structured interview was conducted for all three student participants, my understanding of the contexts and stories improved systematically and necessary changes were made appropriately. During one of the cycles, I learned that participants' views on their QOL were still unclear, and that I would not be able to conclude my research without this research question being answered. Therefore, in January 2022, I planned to design a semi-structured interview, focusing specifically on the topic of QOL with visual support. In addition, planning and action steps also included me outsourcing intervention rooms for both student participants and leaders, in order to enable interventions to take place. During one of the final cycles, I also requested further ethical approval to allow me to interview the parents of participants. Unlike the views of Jenkins (1992), the reason I decided to ascertain proxy views was to gain further data to enable me to analyse from different sources, rather than that I deem participants' views as 'unreliable' due to their SEND (Jenkins, 1992). In section 2.2, I critiqued the use of proxy views and suggested how it could be deemed subjective. I decided to include proxy views in the data collection and findings process because I desired to see a clear picture through different perspectives. This does not indicate that participants' views are unreliable or untrue. I am in partial agreement with Schalock's (2010) views that there could be times when the participants are unable to respond for themselves. I believe that my ethnography inspired approach has enabled student participants to express their views as I am able to put things in their, as well as, my very own perspective. Instead of referring to participants as able or unable to respond themselves, I decided to use proxy views to further 'enhance' the views and findings, and aimed to obtain a clearer picture through collecting data from multiple sources. I understood that the only way for me to conclude if the proxy data in this research is credible is to first ascertain, then analyse them. Unlike the research of Thurston *et al.*, (2010), Totsika *et al.* (2010) and Arias *et al.* (2017), my research does not solely consist of proxy data. With data coming from participants directly, intervention leaders, parents and my own interpretation as a researcher, I am able to make credible interpretations when analysing the data. Following this stage, there were no significant problems



that arose during the action research cycle; all problems were resolved with minimal planning and action due to the insignificant nature. In chapter 5, I discuss the merits of analysing my data thematically and provide readers an outline of the details of my thematic analysis.

In addition to stating the reasoning behind adopting an action research approach for this qualitative research study, I also outlined each step of my action research cycle with details. As discussed at the start of Chapter 3, I will further explain the rationale and advantages of adopting some ethnographic data collection methods to enhance my research, and more importantly, why my research is inspired by ethnography, yet not considered one.

So far, I have explained why I have chosen to adopt a qualitative approach for my research study. Furthermore, I have given my reasons as to why it is more appropriate to do so through analysing the methodologies used in the current QOL studies (Faragher 2010; Shpigelman, 2019; Thurston *et al.*, 2010; Svekle *et al.*, 2010; Araten-Bergman, 2015 and Arias *et al.*, 2017). I have also explained why I consider my research study as an action research, inspired and complemented by some ethnographic data collection methods. The next section outlines the concept and purpose of reflexivity in qualitative research and how I reflected on my own practice throughout this research.

In this chapter, I have so far explored the rationale behind choosing to adopt a qualitative approach, and how the use of ethnographic data collection methods strengthened my position as a researcher in terms of understanding the participants' culture. In this section, I discussed how the use of action research cycles complemented my position further, as it allowed me to have time to reflect at different stages of the research and gain access to the rich data from the participants through the use of ethnographic data collection methods. Therefore, my final position of the chosen methodology is an ethnography inspired action research. In the following section, I explain the process that led to the adoption of this approach.

### 3.4 Reflexivity

*'Reflexivity lies at the heart of, and is fundamental to, good qualitative research.'* (Delamont, 2016, p.4)

Reflexivity is believed to be a widely established critical element that ensures the quality in qualitative research, including ethnography research (Townsend and Cushion, 2021). Guillemin and Gillam (2004) describe reflexivity as a concept that is closely associated with ethics in research, as researchers have a duty to provide the readers with the knowledge constructed. Stan also discusses (2008) the significance of reflexivity in research, as the researchers' views could be influenced by their socio-historical locations, including their personal values and interests. Guillemin and Gillam (2004) also argue that reflexivity consists of an active process of scrutinising, reflecting and interrogating of the data collected. Further to my argument on gaining credibility through adopting ethnographic inspired data collection methods, Delamont (2016) states that reflexivity in a qualitative research replaces the scientific concepts of validity and reliability, with researchers' robust concentration on understanding the effects of investigating. Throughout the research, the reflective process enabled me to make a number of changes including the definition of the methodology undertaken. Although reflexivity is deemed important in qualitative and ethnographic studies. Townsend and Cushion (2021) acknowledge that it can be a difficult concept to be implemented and can easily be subject to a conceptual slippage. This is because researchers hold different positions and stances and, therefore, operationalise and interpret things differently (Townsend and Cushion, 2021). In response to the difficulty posed with the nature of reflexivity, Stan (2008) suggests that merely being honest with oneself, as a researcher, and keeping an open mind about the reasons behind every reaction to particular situations and participants are an important practice for reflexivity when conducting research. Coming from a similar perspective, Guillemin and Gillam (2004) suggest that practices such as being sensitive to ethically important moments from different dimensions and being able develop a means of addressing, pre-empting and responding to the ethical issues if they arise, all contribute towards good reflexivity. In line with Stan (2008), Townsend and Cushion (2021) used the fieldnotes from the experience of sports coaching participants with disability to highlight the process of their reflexivity on their practice. While ethnographers should leave behind their prior knowledge and control, follow the participants' rules and

become a member of the group of participants (Ladner, 2014), Townsend and Cushion (2021) reflected on how his 'coaching role' required an acceptance of pre-existent conditions, which was to downplay the immediacy of impairment of the participants by adopting an ablest model, which was to look beyond their disability, as opposed to going into the field to follow the participants' rules and to understand their world by being a member of the group. As a result, Townsend and Cushion (2021) reflected on how the mindset adopted did not sit comfortably with him as a researcher. While keeping an open mind when collecting the data, a student participant's responses were particularly challenging to interpret. Through reflecting, further ethical approval was obtained to interview his mother for further information.

Reflexivity is an important part of a qualitative and ethnographic study, and a vital stage of field work, because researchers have the responsibility to deliver the knowledge constructed to readers with reliability and validity (Guillemin and Gillam, 2004; Delamont, 2013). Without reflexivity, researchers' views could be influenced by their own personal values and interests based on their socio-historical locations, stances, and risk creating conceptual bias when interpreting data (Stan, 2008; Townsend and Cushion, 2021). Although exercising reflexivity can be difficult, there are practices one can follow in order to reduce the barriers (Townsend and Cushion, 2021; Stan, 2008 and Guillemin and Gillam, 2004). This includes being sensitive to moments deemed ethically important, which could arise from different dimensions, being able to develop a means of addressing, pre-empting and responding to the ethical issues, and most importantly – being honest with oneself as a researcher, while keeping an open mind (Guillemin and Gillam, 2004 and Stan, 2008). In the following sections, I outline the main reflective moments throughout my research journey, the strengths and weaknesses of an insider research and my professional position with School H.

### **3.4.1 Reflexivity: A personal narrative of the evolution of the methodology and chosen methods including my final position**

The most significant reflective moment of this research occurred when I reviewed the methodology of my research. At the beginning of my research, I identified the research approach for the study as an ethnography. Therefore, I first wrote up sections on ethnography including its ideology and practices, then moved onto the

data collection process, explaining my time in the field, undertaking participant observation and semi-structured interviews. It had not occurred to me that there was a conflict of interest between me exercising the cycles in my action research and the 'purity' of ethnography. In section 3.3, I outlined the fact that the nature of the action research cycles challenges the research study by presenting 'conflicting demands' for me and School H (Armstrong and Tsokova, 2019), suggesting that there would be implementational changes put in place throughout the cycles. I also explained in section 3.3, that by implementing the changes from the action research cycles, I interfered with the life of the student participants directly. Therefore, I was unable to carry out the fundamental duty of an ethnographer, which is to write or present a culture, follow the participants' rules and become a member of the group, while remaining analytical and observational without interfering with the culture (Ladner, 2014; Tacchi, Slater and Hearn, 2003; O'Reilly, 2009).

The first realisation through reflection in relation to the conflict of interest came to light during my early-stage review, where I had a discussion with the university panel, who raised concerns about the study not being a 'pure' ethnography. Following the discussion, my decision was to 'keep' the methodology of the study as 'ethnography' as I did not design the intervention and that the participants had already been offered participation in these interventions prior to my research. Therefore, I believed that my 'lack of influence' on the intervention would have enabled me to adopt an 'ethnographic approach'. However, a year after my early-stage review, the ethical issue of me being an influential character to the intervention was mentioned by the panel. Further to the second review, I did further research into both ethnography and action research, as well as reflecting on my influence on the intervention by considering every minor change I might have made to the intervention through my action research cycles. I came to the realisation of the conflict of interest, and I decided to clearly explain and justify my methodology in Chapter 3. This highlights the full extent of the guidance provided by Stan (2008), as I was honest with myself as a researcher when reflecting on the issue the first time. Initially, I lacked the awareness to identify the conflict of interest, and I was only able to truly reflect on this matter when I exercised both elements suggested by Stan (2008) – honesty and open-mindedness. That was the moment when I embraced the

evolution of my methodology and decided on my final stance – ethnographic inspired qualitative study.

As mentioned in section 3.1 qualitative researchers work as interpretivists who aim to define the lived experiences of participants by formulating words and their association, and interpreting the perspectives of the meaning, multiple truths and realities emerged behind participants' actions (Slevitch, 2011; Merriam and Tisdell, 2016; Bakker, 2010; Stauffacher et al., 2006). I have already outlined the reason for adopting a qualitative approach, and therefore, despite the change in terminology used in my methodology, my chosen methods to collect data have not changed in the context of qualitative research theory.

There was, however, another important reflective moment that led to me including an additional data collection method – interviewing parents of student participants. Tony, one of my student participants, has sensory processing difficulties, as well as social interaction deficits and anxiety, further details on his needs are outlined in 4.8.3. Tony's behaviour during the intervention was mostly sarcastic, and his answers provided during the interviews were mostly short, misleading, and at times argumentative. Therefore, when analysing the fieldnotes and interview data, I was initially unable to extract and interpret as much information as intended. I started by reporting the data, verbatim, as the 'truth', I reflected on this situation and discussed it with my supervisors, where I was advised to consider taking advice from people who knew Tony well, as that could support with understanding his perspectives more. As with any reflexivity process, I had to pre-empt any ethical issues, and therefore I submitted a further ethical approval, outlining my intention to interview parents of student participants and intervention leaders. With the extra proxy data from relevant participants who knew Tony well, I was also able to 'decontextualise' data collected from Tony, and exercise my data analysis process credibly. I will further discuss the concepts behind decontextualisation and how it was implemented in chapter 5.

As identified in the literature review, QOL is a complex concept that is composed of multiple domain headings and domains. What is more, the SEND and communication and interaction needs of participants in this research serve as

additional barriers to QOL measuring. I have given my arguments as to why qualitative data is more appropriate to capture one's QOL than quantitative data. Through using data collection methods such as participant observation with associated fieldnotes and conducting interviews inspired by an ethnographic approach, the meanings and functions of participants' response were collected and analysed from an inside perspective. Nonetheless, I also discussed the dilemma I encountered throughout the research by highlighting two of the biggest reflective moments, concerning the definition of the methodology chosen for this research, as well as my approach to interpreting complex data extracted from Tony.

In this section, I have provided a personal narrative of the evolution of and the final position on my methodology, with more details on how my data collection methods largely remained unchanged except for the additional interviews being carried out with the rationale. The next section outlines the strengths and weaknesses that often come with an insider research, and how they were utilised and overcome.

### **3.4.2 The strengths and weaknesses of an insider research**

The historic standards of the anthropological position of a researcher associate an outsider approach with 'etic' and an insider approach with 'emic' (Madden, 2017). Fetterman (2020) further defines the outsider perspective as the external and social scientific perspective of reality, while the insider view without complementing with an outsider's standpoint would fit into the spectrum of an ethnographic study. Similarly, Stan (2008) highlighted how the insider perspective is 'at the heart of ethnographic research'. While I explained my journey to realising my research is an ethnographic inspired study, I actively worked towards gaining an insider's perspective and understanding of the student participants' worlds in an authentic manner. This section outlines the strengths and weaknesses of adopting an insider's approach and how they applied to my research.

The goal for an insider's approach is to be able to identify stories of participants' that are meaningful (Keating, 2001). In line with Keating's (2001) viewpoint, I chose to adopt and solidify my insider stance in my research as I aspired to capture and

interpret 'meaningful' data. It was mentioned multiple times in this thesis that the student participants have varying SEND, meaning their ability to express their views are affected. Therefore, the main strength of adopting an insider's approach is to increase the authenticity and credibility of my interpretation of data (Keating, 2001). Angrosino (2007) indicates that an insider should go through a process of searching for patterns, themes and regularities of behaviour within the research area.

Fetterman (2020) further points out the importance of acknowledging, recognising and accepting the multiple realities of how the individuals think and act in different ways. Following the guidance from both Fetterman (2020) and Angrosino (2007), I invested time in learning about the student participants with an open mind, observed the patterns of their world, while accepting the differences. This approach enabled me to understand the student participants' behaviours in interventions, interviews and general interactions with others, before proceeding to further analyse and eventually present the data from an insider point of view. At times, simply asking questions in interviews curiously about student participants allowed me to learn more about their areas of interest. Each student participant behaved differently and, therefore, the way I interpreted their behaviour varied. In section 5.1, I further discuss how my insider's understanding enabled me to contextualise, and occasionally, de-contextualise data. Angrosino (2007) also discusses the potential weaknesses of the insider approach, such as whether researchers would be open to 'negative evidence'. As a researcher, I experienced this dilemma from a first-hand perspective, as not all data appeared 'positive'. Tony often provided me with single-word-answers or answers that appeared to be sarcastic at times, which posed difficulties in the analysing process. Instead of challenging the difficult responses, I encouraged Tony to further elaborate on comments and viewpoints. The intention of providing the encouragement was not an attempt to 'change' the data, but rather aligned with Fetterman's (2020) stance on learning to acknowledge participants' viewpoints, as I did not believe that there was such thing as 'negative data'. Additionally, as outlined in 3.4, I also reflected on the situation and decided to collect additional proxy data to support the data analysis process while I was open to the 'negative evidence'. As a researcher, I was open to the 'negative evidence' and managed it; the so-called 'negative evidence' received from Tony either required more time to digest or additional proxy views for further analysis in this research.

To summarise, I explored the meaning, strengths and weaknesses that adopting an insider approach led to my research in this section. I will move onto discussing my position within School H in the next section.

### **3.4.3 My professional position within School H**

Besides being a researcher, I also held a senior leadership position at School H during the research period. In this section, I will discuss the advantages of having this dual role, particularly in conducting insider research. The ethical implications of this dual role will be further explored in section 4.8.

One clear advantage of my dual role was my familiarity with the school environment, including the dynamics of the learning environment during lessons and unstructured break times. This familiarity allowed me to navigate the field more easily and effectively. Additionally, I had a general understanding of the profiles of the student participants and intervention leaders. It is important to note that this initial information and perception of the students and intervention leaders served as a starting point, and I had the opportunity to gradually immerse myself in their worlds and become an insider in the research process.

However, Karnieli-Miller, Strier and Pessach (2009) also highlight the complex power relations qualitative researchers often have with their participants, who happen to be a 'client' to the researcher as well as the main data provider. Power relations often involve one party having 'power over' others; to create a balanced relationship, the concept of 'power to' must come into play, where cooperation, trust, and care are essential (Florczak, 2016). In my research, there were several power relations between me and different participants, including intervention leaders, student participants and the mothers of the student participants. A non-threatening research environment where power-equality is promoted is important for researchers to maintain power relations (Karnieli-Miller, Strier and Pessach, 2009). In order to create a non-threatening research environment with a balance between power, I referred to myself as a researcher who was keen to ascertain some information from participants



and that they had the right to agree or disagree. Throughout the research, I also balanced the power relations by actively emphasising how the student participants would have the most authentic opinion on their own QOL, while the intervention leaders and mothers of student participants would also have their expert knowledge on this topic. I will further discuss my management of the power relations, including the actions taken to manage the 'power over' and 'power to' within my research, in section 4.8.

The next section outlines the details of the sample group, including how the participants were chosen and the rationale for choosing them, advantages and disadvantages of having a small sample group.

### **3.5 Sample group**

My research consists of a total of nine different participants: three intervention leaders, three student-participants and their mothers. All research participants were recruited from School H, a school for pupils with Autism Spectrum Disorder (ASD) and other SEND. As well as being a researcher for my thesis, I also worked at School H at the time of the research as a senior leader. The ethical considerations are outlined in chapter 4, specifically in relation to my dual positions (section 4.8). In this section, I aim to define different approaches to sampling, justifying why the approaches adopted were the most appropriate at the time of the research and defend the small sample sized used. As mentioned in Section 1, pseudonyms are used to safeguard the anonymity of participants in my research (Lahman, Thomas and Teman, 2023). Wang, Ramdani, Sun, Bose and Gao (2024) suggest that anonymising participants shields them from harm and ensures their confidentiality, enabling them to freely share their viewpoints and experiences without fear of repercussions. In a similar vein, Lahman, Thomas and Teman (2023) also suggest that although the people's names are personal and reflective of their own identity and culture, the standard practice in qualitative studies is to use pseudonyms to protect them from being identified. Wang *et al.* (2024) state that employing a 'title' or 'number' (e.g., Participant 1 or Participant 2) can also effectively conceal participants' identities and prevent their re-identification, however, this do not convey participants'

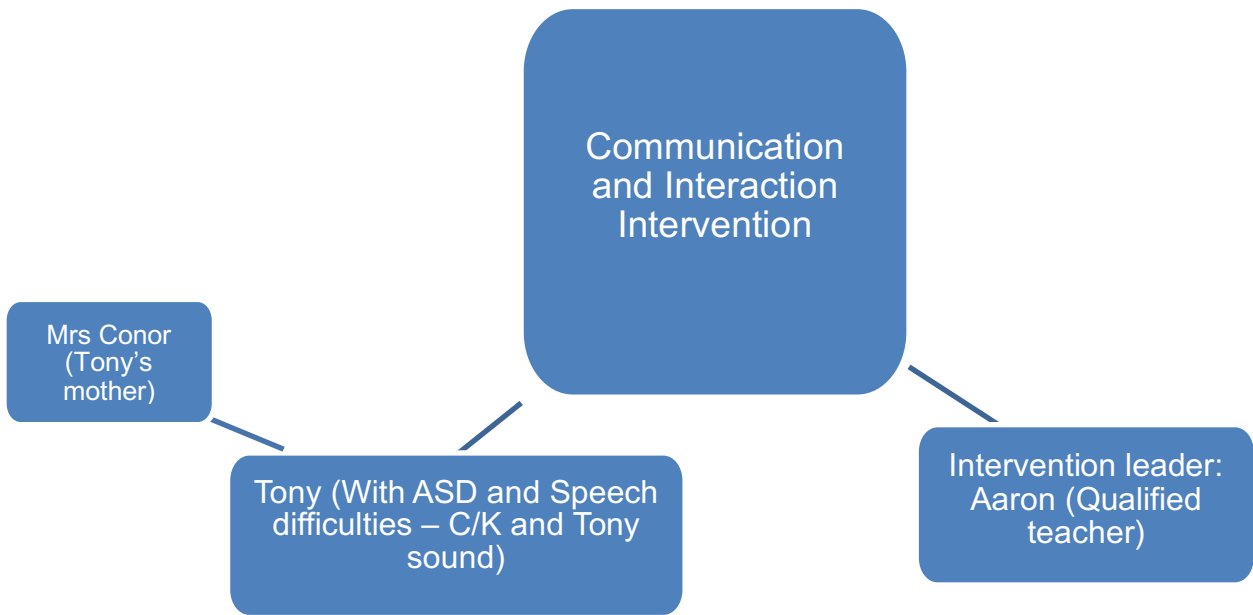
ethnolinguistic backgrounds and can appear dehumanising. Therefore, the use of titles or numbers makes it challenging for readers to empathise with participants and recognise their valuable insights as integral to the research (Wang *et al.*, 2024). Consequently, I took the decision to adopt pseudonyms to keep the ethnolinguistic backgrounds of the participants, while protecting the confidentiality and enabling readers to be able to empathise with the individual stories presented more easily.

The below table illustrates the pseudonyms and their associated roles in this research:

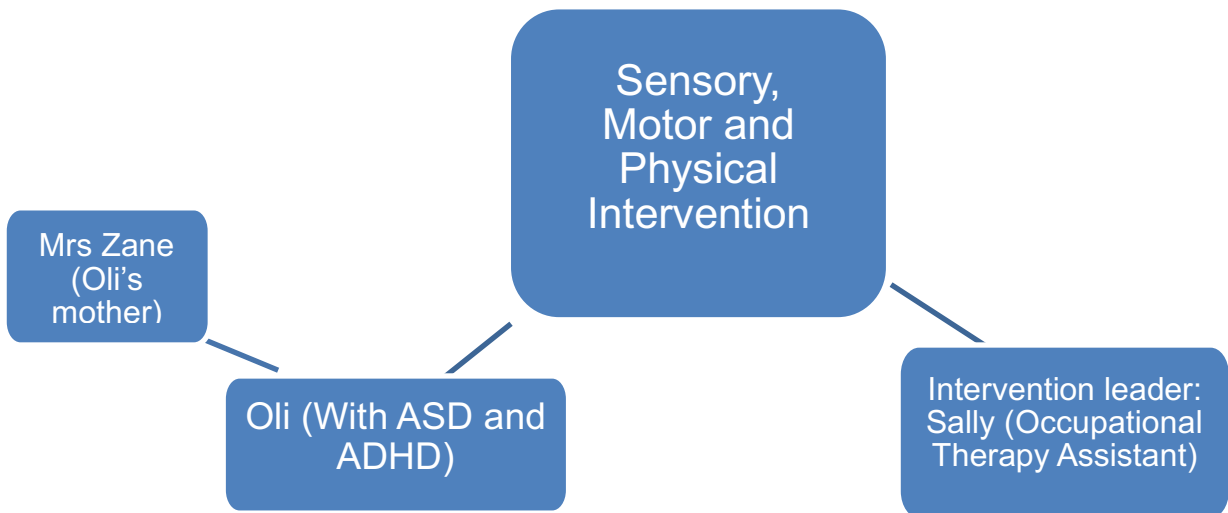
*Table 3 Pseudonyms and associated roles*

Tony Conor	Student participant
Mrs Conor	Tony's mother
Aaron	Communication and Interaction intervention leader
Oli Zane	Student participant
Mrs Zane	Oli's mother
Sally	Sensory, Motor and Physical intervention leader
Gordon Smith	Student participant
Mrs Smith	Gordon's mother
Nia	Social, Emotional and Mental Health intervention leader
Craig	Executive Headteacher at School H
Chai	Researcher

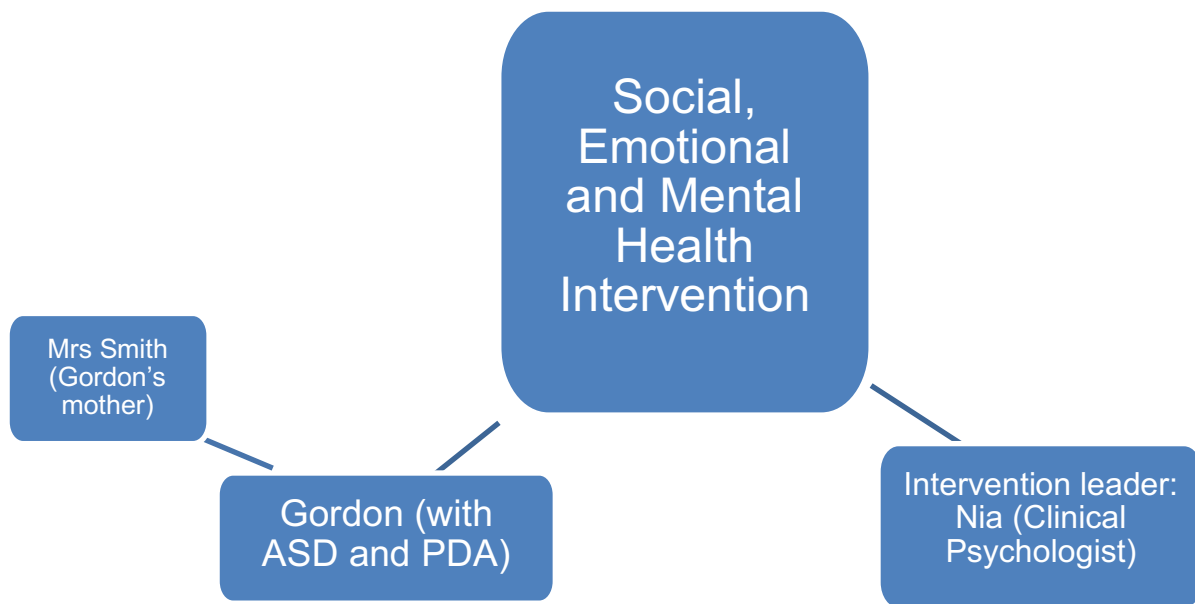
The below figures provide a brief intervention overview: Tony took part in the Communication and interaction (C&I) intervention led by Aaron; Oli took part in Sally's Sensory, motor and physical (SM&P) intervention; Gordon attended Nia's Social, emotional and mental health (SEM&H) intervention.



*Figure 1 Communication and Interaction Intervention data collection overview*



*Figure 2 Sensory, Motor and Physical Intervention data collection overview*



*Figure 3 Social, Emotional and Mental Health Intervention data collection overview*

The trustworthiness of qualitative research pertains to sample adequacy, including its composition and size (Vasileiou, Barnett, Thorpe and Young, 2018). Marshall (1996) outlines the three broad approaches to identifying a sample group for qualitative studies – convenience sample, purposeful sample and theoretical sample. Since the aim of my research is not to validate a theory, the theoretical sampling approach was not adopted in this research. Although there was an element of convenience to conduct the research at school Mrs Smith as I worked there at the time of the research, the participants were all purposefully chosen to fit the criteria of the research. A purposeful sampling approach was used when selecting the sample of this research. Purposeful sampling involves the researcher actively looking for the most productive sample group to respond to the research questions, and that the sample group have specific experiences or expertise for the research (Marshall, 1996). I made sure that the data and credibility are kept at a high quality by also adopting purposeful sampling as defined by Marshall (1996), who argues that purposeful sampling consists of the researcher actively selecting the most productive sample to answer the research questions. The student participants recruited have specific lived experiences, the intervention leaders have specific expertise and parents of student participants have both experience and expertise that are beneficial for my research, using purposeful sampling techniques.

Three participants took part in my research study: Tony Conor was from the semi-formal pathway, Oli Zane transitioned from the semi-formal pathway when moving up from Y7 to Y8 and Gordon Smith was from the formal pathway. All three student participants were in Key Stage 3 at the start of my research. All the participants in my research study can verbally communicate with me and the intervention leader at different levels. Tony required questions to be repeated to him and, at times, be presented with my own examples during interviews. Oli required more processing time and prompting than other pupils, due to his lower attention span. Whilst Gordon's verbal articulation appeared to be the most advanced, he was unable to conclude a topic and move on to another very easily during his intervention. A more detailed profile for each student participant is provided below, with information extracted from their Education, Health and Care Plan (EHCP).

### **3.5.1 Gordon and his mother (Mrs Smith)**

At the start of the research study, Gordon was in a year 7 formal class. Gordon has ASD and Pathological Demand Avoidance (PDA), he was also undergoing Dyslexia screening at the time when he joined my research. The intervention that Gordon received is based on his social, emotion and mental health, conducted by Nia. Gordon had a good relationship with his mother, Mrs Smith, at the time of the research. Mrs Smith is a working mother and she decided to transfer Gordon from his previous school to School H, as she believed that School H was a more suitable place for Gordon. Mrs Smith also actively engaged with the research and shared her insights on Gordon's life.

Gordon's behaviour at his previous mainstream school was described as challenging. His past verbal and physical outbursts had led to an exclusion from the setting and a short-term placement in a resource centre, before returning to another mainstream primary provision. Gordon lacks confidence and can refuse to do tasks assigned to him as a defence mechanism if he sees them as a demand or threat. Gordon appears withdrawn when he feels that he has been treated unfairly or when he does not witness incidents being dealt with after he has raised it with an adult. Also, Gordon struggles to accept consequences when he does not feel that he is in the wrong, if the person delivering the instructions was direct and demanding.

Gordon likes to organise things his own way and he finds it hard to accept change. For instance, Gordon once felt distressed when his work desk was swapped without his prior knowledge. Also, Gordon's learning is affected by his ASD as he requires clear instructions for him to fully understand his 'now' and 'next'. Although Gordon presents with some problem-solving capacity, he finds it difficult to transfer knowledge from one instance to another as he has difficulties with working-memory and perceptual reasoning.

Before starting at School H, Gordon attended a mainstream primary school. Due to his needs, Gordon experienced bullying in his previous school and he did not spend much time with his class as he did not enjoy the company of his peers. Whilst Gordon had become happier and identified a friendship group at School H, he still at times struggled with understanding how to socialise with peers, regulating his emotions, identifying others' sense of humour and feeling safe to speak to adults when necessary. Gordon played football with peers daily and could, at times, become involved in arguments with peers. Therefore, the primary purposes of his social, emotional and mental health session are to develop his ability to identify his feelings, differentiate positive and negative experiences, identify the elements that exist in positive experiences and understand his own behaviour, having been through traumatic events – bullying.

### **3.5.2 Oli and his mother (Mrs Zane)**

Oli was a year 8 pupil in the formal pathway at the start of my research. When Oli was in year 7, he was placed in the semi-formal pathway due to his academic ability. Oli's attention span is low, and he relies on regular prompting to start and continue a task. However, he was moved to the formal pathway in year 8, as School H believed that he would have a better peer group being in the formal pathway as Oli's social ability and interests are similar to other pupils in the formal pathway.

Oli has a diagnosis of ASD and was undergoing an Attention Deficit Hyperactivity Disorder (ADHD) screening at the start of the research. Although Oli only worked at year 1 to year 2 level for his core subjects (Maths and English), he is a very sociable pupil who shares the same interests with other pupils in the formal pathway, such as

football and video games. Oli aspires to be a cook; he is aware of the areas of improvement, such as division in Maths and not talking back to teachers when spoken to. Oli is not yet fully independent; he is still working on personal hygiene and teeth brushing and healthy eating habits, as he has a tendency to overeat.

Mrs Zane was Oli's primary carer at the time of the research, and she appeared to have a good understanding of Oli's life. Mrs Zane supported this research by having regular contacts with me and providing me with information on different aspects of Oli's life.

### **3.5.3 Tony and his mother (Mrs Conor)**

Tony is a pupil who was in year 9 at the start of my research. Tony has a diagnosis of ASD; he also has sensory issues as well as underdeveloped fine and gross motor control. Tony is hugely sensitive to smells, bright lights and excessive noise and this can cause him severe upset. In addition to ASD, Tony also has social and interaction deficits and has anxiety in general. One of Tony's preferred modes to camouflage his anxiety and socially blend in is to be sarcastic during conversations so that he does not directly answer questions and can re-direct the conversation with his sense of humour. The conscious or unconscious suppression of natural autistic responses and adoption of alternatives to disguise and compensate for one's autistic features in social context can be referred as 'Autistic masking' or 'Social camouflaging' (Pearson and Rose, 2021; Alaghband-rad, Hajikarim-Hamedani and Motamed, 2023). Based on my observation, Tony is in fact, comfortable with his masking behaviour and that it has become one of his preferred modes of communication. Tony can become highly anxious upon returning to school following a long period of absence (half-term breaks and holidays). Tony also does not attend school on the days when his stomach hurts, which his mother believes is triggered by anxiety. Tony lacks independence in most situations as he is fearful of what might happen and will always try to insist that he needs someone to be with him, even in his room at home. He can become very clingy to his mother and will complain and stress that he feels physically unwell and feels like he is going to throw up. He requires constant support for self-care including personal care, choosing appropriate clothes, getting dressed, washing, and cleaning his teeth. Tony's mother has also expressed concerns over his eating habits and attendance, as she believes that Tony does not eat enough.

The intervention that Tony received at the time of the research was targeted on the social and interaction aspects, in particular his pronunciation of the C and Tony sounds.

Mrs Conor is Tony's mother, who also worked at School H. Therefore, she interacted with Tony both at the school and at home. Mrs Conor's input was significantly important to this research due to Tony's masking behaviour, as she was able to provide me with information for me to contextualise or decontextualise raw data collected from T.

In this section, I discussed how I spent my time in the field, including the ethical implications and difficulties encountered, such as the barriers to gaining access to the field, making changes due to the staffing situations in School H and practitioners' own ethical reservations, delays caused by COVID, seeking consent from student participants and handling sensitive information. Following the explanation behind my actions in response to the difficulties, I provided readers with further information on School H and a comprehensive profile on each participant. In the next chapter, I move onto my data analysis procedure, which includes my steps taken during the action research cycle, as well as a step-by-step approach to my thematic analysis, before themes are identified.

All three student participants were selected for my research study purposefully, and also by virtue of their ability to provide detailed information due to their specific life experiences and needs. The three student participants in my research study each have specific needs that fall under the intervention coverage. Since I was a senior leader at School H, I already had some level of prior knowledge of the student participants in the capacity of learners, including their learning needs. Therefore, I was confident that all student participants would have the ability to understand the rationale of the research with differentiated materials, and support from their parents at the stage of obtaining consent. Besides the parents of the student participants, I also purposefully recruited staff members from School H as they also had an understanding of the student participants' needs and were used to working with them directly. Therefore, all participants involved in my research study are 'fit for purpose'.



According to Green and Thorogood (2004) most qualitative researchers can investigate the answer to a specific research question in interview-based studies with a sample size of 20. Britten (1995) (cited in Vasileiou *et al.*, 2018) stated that large interview studies will consist of 50 to 60 participants. Under the scrutiny of the guidelines stated above, the sample of my research study appears to be undersized. Conversely, Dukes (1984) (cited in Creswell, 2013) recommends studying 3 to 10 participants in a qualitative study for rich and in-depth data, and the suggested falls within my sample size. I was able to collect rich and in-depth data as, throughout the research, as I conducted twenty-nine observation sessions and nineteen interviews, and over sixty-five thousand words have been transcribed through interviews and fieldnotes. Thematic analysis was chosen as my main method to analyse the data to produce findings and draw up conclusions.

In addition, Creswell (2013) states that sample size in qualitative research typically includes a few individuals; Sandelowski (1996) also highlights that making sense of individual cases is the key to qualitative analysis. Although my study is not considered an ethnography, but rather ethnography inspired, Palmberger and Gingrich (2013) also suggest that the risk of decontextualising information can be prevented or minimised if the number of cases is kept at a particularly low number in fieldwork conducted in ethnography. During the process of thematic analysis in my research study, decontextualizing data can be deemed as a helpful method in terms of making sense of data and supports the construction of themes (Maxwell and Chmiel (2013). Further details on the decontextualising process will be discussed in chapter 5 - Data analysis procedure. Thus, Palmberger and Gingrich (2013) argue that having a high number of participants in ethnographic research can potentially affect the researcher's ability to concentrate on understanding the context and culture of the participants and be at risk of misunderstanding or misinterpreting information. Creswell (2013) further states that well-defined ethnographic studies are well suited to include no more than four or five case studies in a single study, given that artefacts, interviews and observations are conducted before the data collection process ends. Crouch and McKenzie (2016) also suggest that a small number of participants facilitates the close association between the researcher and the participants, which leads to validity of the 'fine-grained' and in-depth inquiry in a

research setting. Although a small sample size means that the research is not generalisable, Walsh (2003) points out that there is still indeed a large quantity of data extracted from the frequency counts of the information, which further develop the codes and themes.

As mentioned above, I conducted a large number of interviews and observations over the course of two academic years, with a small sample size. Therefore, this shows that having a small sample size is appropriate for this study, as it enabled me to explore, collect and analyse in-depth and rich information from a large quantity of notes and interview transcripts, which are required to answer the specific research questions set. Vasileiou *et al.* (2018) recommend that researchers are to be transparent about the evaluations of the sample size and apply sample size norms that are best fit for their studies. As mentioned in 3.1, in line with Jensen's (2008) views on enhancing the transferability of a research, I provided readers with a rich description on the research and outlining the purposefully sampled participant group that presents the research design, limitations and delimitation – further information on the profile of each participant is presented.

#### **3.5.4 Intervention leaders**

Nia ran the Social, Emotional and Mental Health (SEM&H) intervention, and she is a clinical psychologist, who also worked at School H. She has regular contacts with students at School H as a part of her role, but she worked closely with Gordon during the time of this research.

Aaron is a qualified teacher who was in charge of the Communication and Interaction (C&I) intervention. Aaron had experience in delivering English at School H, and had a good understanding of Tony's needs, as he was one of his teachers.

Sally is an occupational therapy assistant, who was in charge of the Sensory, Motor and Physical (SM&P) intervention. Sally had worked with Oli for a year prior to this research taking place, and therefore, she had a good understanding of him.

### 3.6 Intervention overview

In chapter 1, I highlighted that all student participants were already in receipt of a different specific intervention that falls under the areas outlined in the SEND Code of Practice, and that the intervention leaders had been responsible for delivering interventions prior to the start of my research (Department for Education, 2014). I also recruited the intervention leaders at school Mrs Smith to be a part of this action research, to allow me to examine the non-curriculum-based interventions' impact on student participants' QOL. Although I did not have a direct input on the intervention contents, the action research cycles led me to be involved in the process of adapting certain aspects of the intervention, including the environment and the interview activities.

This section provides an overview of the different interventions conducted in this research. The aim of this research is to investigate the impact that non-curriculum based targeted interventions can have on the QOL with CYP with SEND. The findings from my literature review suggest that there are a number of 'interventions' of different disciplines available to improve the QOL of CYP or CYP with SEND, including: 'Education and employment', 'Religions and Spirituality', 'Improving behaviour' (Schepens, Puyenbroeck and Maes, 2019; Puyenbroeck and Maes, 2019; Ross and Willigen, 1997; Lysaght and Cobigo, 2014; Kober and Eggleton, 2005; Terrill and Gardner, 2010; Ferriss, 2002; Corrigan *et al.*, 2003; Glicksmans, 2011; Crnic *et al.*, 2017 and Burgess, 2014), and most directly – Life coaching and person-centred action steps (Shpigelman, 2019) and the implementation of the NDP (Faragher, 2010), where interventions were specifically designed following the researcher identifying the QOL areas the participants desire to improve. However, I must reiterate that the intervention investigated in my research differs from Faragher's (2010) and Shpigelman's (2019), as the student participants were already in receipt of the specific intervention prior to the start of my research. Although there were changes made to the intervention as a part of the action research cycle, the interventions investigated in this research were not designed with the aim of improving the QOL of participants.

Instead of investigating interventions that have an obvious link to one's QOL, I have planned to investigate the impact of the interventions that are designed based on the 'needs' of participants. The interventions used in this research are in line with the areas outlined in SEND Code of Practice (Department for Education, 2014):

- Communication and interaction
- Social, emotional and mental health
- Sensory and/or physical needs

One might challenge the rationale behind this as it would seem logical to think that interventions that are designed to meet the needs of the participants would improve their QOL. However, as mentioned in chapter 1, one of my research objectives is to identify how participants view their QOL domains and what they mean to them. The fact is, the definitions of student participants' QOL were not concluded at the intervention planning stage. Without investigating the above, the areas of need can turn out to be completely irrelevant to their perception of their QOL. Therefore, it is important to stress that the interventions are designed to meet the needs of the participants, rather than to improve their QOL. Also, the interventions have no direct links to the national curriculum, and the intervention leaders planned the intervention according to the needs of the participants, then adapted the content based on feedback received in sessions and discussions with me.

Within the communication and interaction (C&I) intervention designed for Tony, the primary aim is to support him with his speech. In particular, Tony's ability to verbally distinguish between the letter sound 'T' and 'C/K'. Throughout the intervention, A, the communication and interaction intervention leader, planned and delivered a range of activities, such as word association games, sentence building activities, noughts and crosses, snap. All the activities delivered in the sessions required Tony to have to practise the targeted sounds. For instance, Aaron 'competed' with Tony, using a T/C/K consonant to form as many words as possible. Aaron also helped Tony build up his recognition of the speech sounds by playing snap with Tony, which required him to focus on listening out for the specific consonants.

While Aaron is not a specialist in Speech and Language, he is a qualified teacher who has experience of teaching pupils working from pre-national curriculum to General Certificate of Secondary Education (GCSE) level. As mentioned above, all three intervention leaders adapted their intervention based on feedback received in the sessions as well as discussions.

The social, emotional and mental health (SEM&H) intervention comprised of discussions, recognising and embracing emotions, and sharing life experiences and strategies. Nia, the Social, emotional and mental health intervention leader, is a qualified clinical psychologist. She was aware of the profile of Gordon as well as his experience from his previous school. Therefore, the aim of the intervention was to provide Gordon with a safe space to discuss his emotions, especially around peer interactions. Prior to the start of the intervention, Gordon explained to me how she had planned to spend the first few sessions to get to know Gordon and build up mutual trust. The primary activity in the SEM&H intervention is discussion, and the topics of their conversation throughout this intervention were always driven by Gordon's experience and mood. Nia also planned to support Gordon by providing him with strategies, using credible examples and to identify his own emotions.

The sensory motor and/or physical (SM&P) intervention consists of exercises that focus on core strength, and both fine and gross motor skills. Core and gross motor exercises planned and delivered included star jumps, roly-poly, navigating on balancing boards, push kicks, juggling, sit-ups, push-ups, stepping machine and more. In terms of fine motor activities, the intervention included activities such as sewing, buttoning up, puzzles and other games that require the use of fingers. Sally is an occupational therapist assistant, and she has an understanding on how one's body can operate functionally. The aim of the intervention was to develop Oli's functional skills through a range of exercises, especially with Oli being considered overweight at the start of the intervention. In the next section, I discuss my time in the field, which includes other difficulties that came to light and my approach to resolving them.

### 3.7 Data collection

In section 2.2, I discussed the importance of collecting data that is drawn based on participants' own subjective views on their QOL, with the objective views or objective references being in the context. I then further explored the different principles and guidance on how to support one with SEND to make decisions, referencing the Mental Capacity Act 2005 and Schalock (2010). It was pointed out that participants, at times, cannot respond to questions and that practicable steps are essential for supporting the decision-making process. As mentioned in section 3.2, I adopted some data collection methods inspired by an ethnographic approach, and therefore I can justify my reasoning behind why Schalock's (2010) guideline number 1, 3 and 5 are applicable to my research:

- 1) Persons who know the individual well should be used
- 3) Assessment involving proxies should be clearly identified as another person's perspective
- 5) Build the effect of proxy responses into data analysis

As mentioned above, the ethnographic data collection methods adopted in my research consist of a range of techniques including participant observations, writing fieldnotes and conducting interviews (Harrison, 2018). Furthermore, Reeves, Kuper and Hodges (2008) also highlight that ethnographic data collection techniques such as detailed observations and interviews provide empirical insight into participants' views and actions. Since QOL is a sensitive subjective as well as multi-dimensional concept, I would argue that purely applying the data collection techniques without building rapport is not enough to gain an in-depth insight.

Ladner (2014) describes the process of ethnographers applying such techniques as being in the 'field' and doing 'fieldwork' and that there are two aspects of fieldwork. The first aspect is that the ethnographers act as a research instrument, whereby they physically locate themselves with the participants, collect photographic and written notes, observe and interview participants. The second aspect is the 'walking in the shoes' of the participants notion, and this is where the ethnographers leave behind their prior knowledge and control, follow the participants' rules and become a

member of the group of participants. The latter of the two aspects develops rapport between the researcher and the participants. Although my research is not considered an ethnography, I still aimed to optimise my time in the field and collecting data. As I previously mentioned in section 3.3, the action research process posed a conflict of interest, which challenged the 'purity' of ethnography. I was, therefore, unable to merely follow the participants' rules and become a member of the group of participants, as described by Ladner (2014). Despite my research not being an ethnography per se, the data collection methods were adopted and I, in the next sections, discuss how the methods chosen were suitable for my research with an insight into the data collection process.

During the nine-month data collection period, I observed the C&I interventions on ten occasions, the SM&P on seven occasions and the SEM&H on twelve occasions. Additionally, I observed the student participants during over twenty informal instances, when they were engaging with their peers and others. Along with the twenty-one semi-structured interviews conducted, I collected a total of 65,000 words of primary data. The chronology can be found in Appendix 1, and the process of data collection is discussed in more detail below.

### **3.7.1 Participant observation**

As discussed in section 3.2, one of the methods adopted from ethnography is participant observation, which enabled me to gain first-hand experience by being part of the research myself. By doing so, participants would not have to be asked to complete a self-assessment and the varying levels of SEND would not act as a barrier, as their voices will be elicited through participant observations. Throughout section 3.1 to 3.3, I also discussed the rationale my chosen methodology is an ethnography inspired action research.

There is a difference between utilising a QOL assessment instrument and determining one's QOL based on a set of standards or statements. Consequently, I immersed myself into the world of the participants and studied them through analysing their verbal and non-verbal interactions as a researcher when conducting this research. Jeffrey and Troman (2004) state that the observations conducted in an ethnographic

study capture the dynamics, the visible, as well as the less tangible details through a range of contexts including conversations and interactions; every little piece of detail will be soaked up and analysed by researchers. Therefore, through the adaptation of an ethnographic approach, subjective first-hand data of the QOL of CYP will still be available in my research study.

As I once stated in this chapter, I believe that investing time to conduct participant observations is far more practical than inventing a QOL instrument to assess one's QOL. The UK Government highlights communication and interaction as a broad area of need for CYP with SEND, as they may have 'difficulty saying what they want, understanding what is being said to them or they do not understand or use social rules of communication' or 'difficulty with one, some or all of the different aspects of speech, language or social communication' (Department for Education, 2014, p.97). As it may not always be possible for participants with SEND to express their views verbally, I have chosen to use participant observation as one of the data collection techniques in this research study.

The three fundamental elements of my participant observations included what was being observed, how I went about observing and why the observations mattered. As mentioned earlier, I have already stated the 'why', as I outlined the student participants' limitations on communication, and therefore observing enabled me to interpret their interactions and communication with an improved understanding.

The observations were conducted in a variety of settings within the school, such as being in classrooms during formal lessons, outdoors or indoors during break and lunch time e.g. canteen, playground. Oftentimes, my observation fieldnotes summarised student participants' interactions with others including the topics of conversations, as well as their verbal and non-verbal behaviours when interacting with others. For instance, Gordon and Oli often discussed how their weekends went on Mondays and Tuesdays with their peers. Gordon and Oli would often have follow-up conversations with their peers after having communicated either in person or through playing games online during the previous weekend. Tony appeared to have fewer verbal interactions with his peers. At times, I observed Tony's teachers initiating conversations by asking



prompting questions to help him recall the information. There were also occasions where I observed student participants' decisions of engaging with other activities as opposed to human interactions. For example, Tony often ate his snacks and lunch on his own while reading a book; Gordon and Oli also have been observed watching YouTube videos with headphones on as opposed to interacting with others. The observational data collected informed the thematic analysis and the key findings of my research.

Participant observation is one of the core ways to help ethnographers understand the lived experiences of participants (Crang and Cook, 2007). Harrison (2018) describes participant observation as a 'simultaneous process that oscillates between varying degrees of participation and observation' (p.16). He further explains that participant observation harbours the perspective from the insider (participant) and the outsider (observer). Due to the complex nature of social life and how people display different behaviours under different circumstances, Reeves, Kuper and Hodges (2008) state that there are nine dimensions that need to be considered during participant observations, including:

- (1) *The layout of the location*
- (2) *The range of people involved*
- (3) *The range of activities that occurred*
- (4) *The physical objectives that were present*
- (5) *Participants' actions*
- (6) *Activities that were carried out*
- (7) *The sequence of the activities*
- (8) *The goal participants tried to accomplish*
- (9) *The participants' emotions.*

I agree with Reeves, Kuper and Hodges (2008) that the dimensions connect to participants' behaviours closely.

As part of my action research cycle, I met with the intervention leaders regularly. Details such as the layout of the location, people involved, the activities involved and the physical objects that were present affected participants' behaviours adversely. For instance, Oli's intervention was often interrupted by both staff members and students at School H walking into the session room. As a result, Oli was often distracted and lost concentration during activities. Although it was inevitable for students who were

distressed to run into the session room, the intervention leaders and I reflected on our practice and decided to put up a sign outside the door to eliminate unnecessary disruptions. Without stating a specific timeframe, Harrison (2018) also highlights the importance of the duration of time in the setting when conducting participant observations. Besides enabling the research to gain a deeper understanding of the participants, their individual circumstances and the contexts, participants also become more accustomed to the presence of the observers' presence over a long period of time with them being in the field.

Passive observation could add value to the research to a certain extent, however, this technique alone is not ethnographic. Ethnography is also complemented by clarifying the questions and conducting interviews (Ladner, 2014). Besides formal and in-depth interviews, Reeves, Kuper and Hodges (2008) state that it is not uncommon for ethnographers to probe any emerging issues or discuss and enquire about unusual events through conducting conversational interviews informally and naturally during observations. During the first two SEM&H sessions, Gordon spoke about his time playing football with his peers, describing both positive and negative feelings he had. Therefore, my assumption was that he was having difficulties with his social interaction with his peers at the time and used football as a platform to develop his social skills. Surprisingly, Gordon disclosed that playing football is not actually an interest of his and he only played it at School H because there were no other activities available. This confirms Harrison's (2018) theory on the importance of spending time on participant observations, as Gordon could express his feelings about football during further sessions. On the other hand, it also highlights Atkinson's (2017) point on how ethnographers can elementally decode intersubjectivity and co-devising interpretations amongst different communities by including themselves in the research, obtaining real life, first-hand experience.

Due to an ethical implication outlined in chapter 4, my method to conduct participant observation had to be adapted, where the use of video technology had to be employed. Gibson (2000) used video recordings in addition to participant observations and discussions in his case study on a participant who was congenitally Deafblind. The video recordings were taken when the participant was on holiday; Gibson (2000) stated the effectiveness of the use of video recordings as they prompted the

discussions between staff who worked with the participants, and it also enabled cross-checking on interpretations between him and the staff. All sessions in my research study were recorded using an iPad on an online secured platform – IRIS Connect. Once videos are uploaded onto IRIS, intervention leaders would share them with me and enable me to view and annotate the sessions remotely. One advantage of my chosen methodology is the access to rich data throughout the different action research cycles. Additionally, because the sessions were recorded, I had additional access to this rich data.

When meeting the intervention leaders, I often replay parts of the sessions on IRIS to reference notable moments that I wished to discuss further, and this enabled me to recall specific discussion points with them and review as a part of my data collection.

### **3.7.2 Writing fieldnotes**

The term ‘fieldnotes’ simply refers to the notes written during or soon after being out on the field. The form of fieldnotes range from jotting or even quick scribbled words or to detailed dialogues or narratives of observations (Harrison, 2018). The details pertaining to fieldnotes include descriptive accounts gathered through observations as well as experiences made by the researcher through active participation. Consequently, fieldnotes at times can portray underdeveloped and incomplete insights into life experiences if an observer is to immerse themselves in the midst of someone living out their ‘everyday life’, as one would (Emerson, Fretz and Shaw, 1995). Not only is it important for ethnographers to carry a notebook when being in the field, all five senses need to be utilised when documenting observations or experiences as they can be an integral aspect of painting a realistic image of reality (Harrison, 2018; Bailey, 2007). Besides creating a record of the field experiences or observations, fieldnotes also provide the context of such experiences and observations for the ethnographers to reflect on, to be challenged and inform future planning (Harrison, 2018). For instance, extra attention may have to be paid to a certain participant during the non-curriculum based interventions to produce a good amount of quality fieldnotes to support me to recall the details of the behaviours and experiences of particular participants during the interventions. Nevertheless, the process of interpretation begins as the researchers begin to write fieldnotes (Crang and Cook, 2007).

Over time, the fieldnotes I have produced for this research study have formed their own unique, natural style. All fieldnotes were typed up on my Buckinghamshire New University OneDrive account due to two main reasons. Firstly, I was able to access and edit the fieldnotes whenever I had access to a computer with secure internet connection. I found that to be more convenient than using one specific handwritten notebook. Secondly, I have learnt from my previous research experience that I could use online technology, such as keyword searching and copying and pasting direct quotes to support the analysis and write up at a later stage. During the first month of collecting data, I was overly detailed when making fieldnotes because I had access to the session recordings and revisited them frequently. However, the feedback from my supervisors suggested that the notes were overly detailed and a more general picture needed to be portrayed through my fieldnotes. Therefore, the style of my fieldnotes started to change and they became more structured. The amended structure consists of the summary of different episodes of conversation with specific topics, followed by significant quotes that highlight the mood, and both obvious and subliminal messages or even the intonation of the intervention leaders and participants. My interpretation of the different episodes was summarised in bold for differentiation purposes.

At the time of data collection, I was working full-time at School H, a part-time music tutor and a full-time father who was also expecting a second child. Therefore, time was always pressing, and I had to ensure that I made fieldnotes efficiently. There are both advantages and disadvantages of having the sessions recorded and always accessible to me. The advantages include having the opportunity to review the recordings in a very detailed manner, as well as the flexibility of doing so at my own pace. The disadvantages include the increased amount of time spent on making fieldnotes overall, as ethnographers in the field would be able to make all the initial notes during the sessions, rather than after the sessions. However, I utilised my car journeys to and from work from time to time to initially listen to the session videos, before starting to make notes; this way of taking fieldnotes worked very efficiently for me considering my personal circumstances throughout my PhD.

Since I spent an increased amount of time on making fieldnotes at the early stages, I was unable to spare time to meet up with the intervention leaders as regularly as I

had originally planned. For instance, it took me over one week to make fieldnotes on Gordon's first SEM&H session. By the time I finished making the fieldnotes, the second session was already delivered to Gordon. Therefore, I was unable to meet up with Nia until she had delivered two sessions and I had conducted two interviews with Gordon. However, the issue was resolved as I identified a more time-efficient way to make fieldnotes, and I was able to meet up with the intervention leaders between each session.

### **3.7.3 Conducting interviews**

Whilst participant observation provides the researcher with the opportunity to observe the gap between participants' verbal and non-verbal communication, interviewing gives an insight into what the participants are thinking (Ladner, 2014). Besides participant observation, conducting interviews is also regarded as one of the main methods to collect data by ethnographers (Harrison, 2018). Because participants in my research study have communication and interaction difficulties, I have explored the literature and applied a range of interview techniques in order to:

- (1) Set a comfortable atmosphere for them to express themselves.
- (2) Build up rapport with participants through having friendly conversations.
- (3) Support them to gather and express their thoughts.

The first interview conducted consisted of the same set of questions, which included questions around the participants' general likes and dislikes, aspirations and how they found the activities in the sessions in general. Following their feedback, including their understanding on the questions set, as well as findings from the observation, the specific questions asked in the interviews for each participant started to be differentiated more over the course of the data collection period. The original interview schedule and examples of how the questions differentiated over time are attached in Appendix 2 and Appendix 3 respectively.

Spradley (1979) describes ethnographic interviews as 'a series of friendly conversations', which also consist of a range of elements that usually take place in a chronological order:

- (1) Greetings
- (2) Giving ethnographic explanations
- (3) Asking ethnographic questions
- (4) Asymmetrical turn taking
- (5) Expressing interest
- (6) Expressing cultural ignorance
- (7) Repeating
- (8) Restating informant's terms
- (9) Incorporating informant's terms
- (10) Creating hypothetical situations
- (11) Asking friendly questions
- (12) Taking leave

Regarding expressing cultural ignorance, Weaver (2011) pinpoints that questions asked in an ethnographic interview are required to contain no presumption of answers in order to eliminate any potential influence on the content of answers. In order to ensure appropriate questions are asked, ethnographers need to ensure that the objectives of the interview are set out and plan questions that allow room for the interviewees to explore or even raise issues that they feel are worth discussing (Crang and Cook, 2007). Consequently, ethnographic interviews do not usually take place at the early stages of the research, as the researchers often generate better interview questions upon gathering more first-hand experience from being in the field (Harrison, 2018). Despite the importance of the elements and chronology, Spradley (1979) emphasises the term 'friendly' and the pace of introducing such elements, as researchers could turn an interview into an interrogation, where the rapport between them and the participants could be affected negatively. Similarly, Hampshire, Iqbal, Blell and Simpson (2014) also point out the importance of the interviewer having a good rapport with the interviewee, as it directly affects the level of depth of the interviews and a successful ethnographic interview could include the discussion of sensitive and intimate matters.

As mentioned earlier in this section, the value of rapport with participants is significant, as QOL is a sensitive topic. Therefore, interviews in my research study were conducted with extra care and the interview elements proposed by Spradley (1979) were introduced at an appropriate pace. There was a clear objective for each of the interviews conducted, starting with a more holistic first interview, which enabled me to understand each participant's likes and dislikes, then moving onto

discovering more in-depth details about their lives as well as their views on QOL under different domains. At the beginning of each interview, I greeted and expressed my appreciation of their support for taking part. Furthermore, I highlighted the options of asking for elaboration on questions, as well as their right to refuse to answer any questions that could cause discomfort. Throughout the interviews, I expressed a high interest in their lives and recalled aspects I observed from the sessions.

Unlike in Gibson's (2000) study, the participants in my research were able to communicate with me verbally. The use of video benefited me the same way as it did Gibson (2000), as it generated discussions between me and the participants. I was able to recall conversations that took place during the interventions and initiated conversations with the participants. For example, I recalled the conversation Gordon had with his intervention leader about his interest in boxing during his first interview and proceeded to express how boxing was our common interest. A conscious effort was also made to repeat and restate participants' answers so that they felt comfortable and listened to. Although participants have various levels of comprehension and understanding of abstract concepts, opportunities to respond to hypothetical situations or abstract questions were offered. For instance, all participants were all asked about their goals in the future as an icebreaking question. In agreement with Weaver (2011), questions prepared for the interviews do not set a presumption of the QOL of participants. In line with the views of Crang and Cook (2007) and Harrison (2018), the interviews were conducted two months after I had been in the field and the agenda of the discussions was planned according to pre-set objectives in order to plan appropriate interview questions.

## **4 My time in the field: ethical considerations**

This chapter offers an overview of the challenges and ethical considerations that emerged during the planning phase of my research study. It also addresses the process of obtaining access to the field, obtaining consent from the participant school, as well as the obstacles encountered during fieldwork and the strategies employed to overcome them. Moreover, due to the needs of the student participants, there were other ethical implications, including the process of obtaining their consent, and discussing sensitive topics and handling safeguarding information. The sections below outline the ethical implications that arose throughout the research in further details and how they were resolved and minimised.

### **4.1 Gaining access to the field**

As this research is inspired by ethnography, it was important that I spent time in the field, as highlighted several times in Chapter 3.5: Research design. Whilst Ladner (2014) described ethnographers who stay in the field as a research instrument, Reeves, Kuper and Hodges (2008) discussed how ethnographers can analyse data that is the explicit interpretation of the meanings and functions of participants' actions as they gain an understanding of how participants view the world. As my study is ethnography inspired, I also intended to spend time in the field, in order to gain an in-depth insight into student participants. Prior to starting my data collection in the field, a substantial number of ethical implications had to be resolved. The process of gaining access to the field was more complicated and it took more time (six months) than I had originally planned. The main three obstacles I had to overcome before gaining access were staff's turnover in School H, practitioners' own ethical reservations, and delays caused by COVID, an infectious disease that caused a global pandemic since 11<sup>th</sup> March 2020. A further ethical approval request was made in February 2022 and approved in March 2022, which enabled me to interview parents of student participants as well as student participants and intervention leaders.



## 4.2 Practitioners' own ethical reservations

N had reservations about my research study as she pointed out the ethical implications following her own professional code of practice. She explained that the nature of social, emotional and mental health sessions involved very deep conversations, at times revealing one's 'secrets', such as suicidal thoughts or other safeguarding concerns. Nia was worried that participants would not freely express themselves in the sessions and the objectives of the social, emotional and mental health intervention would not be met. Nia drew the attention of her line manager (referred as D), who was also the regional manager for the Senior Regional Head of Children's Clinical Services of the organisation, to which School H belonged. D shared his concern, where he felt that participants would not act the same way in the intervention if there was another party introduced, other than the intervention leader. Therefore, I invited the intervention leaders to use IRIS connect, a video-enabled professional learning platform that is securely encrypted (IRIS Connect, 2021), to film their sessions then share with me securely using the platform. D also agreed that the use of IRIS connect could eliminate the concerns he had.

When I initially prepared my ethical approval with Buckinghamshire New University in November 2020, the use of video recording was not part of the proposal. Although a lot of operational work at schools nationally, including School H, were done virtually during the first two national lockdowns (23rd March 2020 - July 2020, then 5th November 2020 - 2nd December 2020), I did not feel that the use of video recordings was necessary as England was no longer in a national lockdown at the time I had applied for my ethical approval from Buckinghamshire New University. However, having considered the suggestion from both the C and D, as well as advice from my supervisor, I re-introduced the idea to the potential intervention leaders in a meeting in February 2021, and they all agreed to take part in my research using IRIS connect. Additional ethical approval was sought for the use of the video recorded interventions, which was granted in May 2021. Gibson (2000) has outlined the advantages of using video technology in his research; however, the use of video affected the process of my fieldnotes writing, both positively and negatively, as outlined in section 3.7.2.

### **4.3 Consent, confidentiality, and anonymity**

As part of the process of seeking consent, a consent form (see Appendix 4) and a participant information sheet (Appendix 5) were sent to all student participants and their family outlining the researcher's contact information, the rationale behind the research, the involvement and how the data would be protected and anonymously used. Also, as mentioned in section 3.5, pseudonyms are used in this research with the aim of protecting anonymity while avoiding to 'dehumanise' participants and providing readers with a greater opportunity to empathise with their experiences (Lahman, Thomas and Teman, 2023 and Wang *et al.*, 2024). The arrangements on how data in a research is handled directly affects confidentiality (Ethicist, Cooper and McNair, 2015), and I ensured that personal data were anonymised and that no real names were used in my research. Ensuring confidentiality is a general ethical standard in qualitative research, however it raises controversies when the participants are more vulnerable (Surmiak, 2018). As stated numerous times in my thesis, it is difficult to ascertain participants' views due to their needs. Therefore, one of the hurdles I had to overcome was to remove student participants' barriers in understanding the information shared. In order to do so, I created a version of the information sheet with visuals, which was shared with them (Appendix 6). The information sheet outlined the information that the participant school and the public were given, and that their age, gender, and needs would be used in the research with their name being anonymised. I also consulted with student participants' form tutors at the stage of designing the differentiated information sheet to ensure that the language and visuals used were compatible with student participants' understanding in their professional opinion.

As a part of the ethical approval submission, I obtained the consent from the parents of the student participants. In addition to providing the student participants and their parents with the information sheet, I also verbally spoke to both parties to ensure that – the former showed verbal understanding of the process and had the opportunity to raise questions, and the latter were in the position to provide the student participants with information in my absence.

#### **4.4 Handling sensitive topics and working with vulnerable participants**

QOL is a topic that involves personal, and potentially sensitive matters. Furthermore, another reason to pay extra regard and due diligence during the research was that the student participants belong to a vulnerable group due to their age and SEND.

While it is somewhat inevitable to receive and potentially handle sensitive information, Liamputtong (2011) highlighted how sensitive topics could lead to offence, disapproval and discomfort to express. To minimise the chances of causing discomfort to participants, I ensured that the purpose of the research and the right to withdraw from the interview and research were reiterated throughout. Furthermore, all concerns that arose from the interventions were also investigated further, with the aim to ensure that student participants were safeguarded.

For instance, Oli and Gordon, two of the participants in my research, disclosed incidents that negatively impacted their emotional well-being within the first two months of the data collection period. In particular, Gordon revealed having suicidal thoughts and Nia explored this further with him during the session. However, we both agreed that the disclosure was not particularly alarming as School H and Gordon's mother were both aware of Gordon's past experiences and his feelings. Moreover, Gordon was simply recalling thoughts from the past, as opposed to his present feelings. Nia used the disclosure as a gateway to de-escalate and resolve negative emotions.

I also agree with Grimm *et al.*'s (2020) stance on the importance of the security of the sensitive fieldnotes, which included strategies such as using abbreviations or omitting names. In addition to the above strategies implemented to safeguard the sensitive data collected, I also stored them digitally on a password protected platform as password-protected documents.

In order to encourage student participants to elaborate on their experiences subjectively, researchers have to be willing to share their views with them in the first place (Liamputtong, 2007). Further, Schubotz (2020) highlights the benefits of the use of humour as it can break down barriers and drive a sensitive conversation dynamically. I particularly agree with Liamputtong's (2007) viewpoint, as throughout

the process, I actively listened to student participants during the interviews, and shared my opinion at times with the intent to encourage. This is because topics could be sensitive, alongside the limited understanding of, or ability to elaborate on this topic. Schubotz's (2020) method on humour was also utilised in my research as there were, at times, occasions when I created a sense of humour to lighten while driving a sensitive conversation with student participants.

## **4.5 The participant school**

School H is an independent special school that caters for 128 secondary aged pupils with Autism Spectrum Disorder (ASD) and a range of SEND diagnoses. The placements of students at School H are funded by local authorities, and students came from 13 different local authorities at the time of the research. There are 121 boys and 7 girls in total. Although all pupils have ASD, their academic ability varies due to the different levels of needs - some pupils have the ability to access formal qualifications, such as GCSEs and A-levels, whilst some were working below Y1 national curriculum level, i.e. Pre-verbal and pre-numeral levels, at a secondary school age at the time of the research. Pupils were divided into two streams in School H: the formal and the semi-formal pathway, of which I explain below:

### **4.5.1 Formal pathway**

Pupils categorized in the formal pathway are often ones who have mild learning difficulties (MLD), and can access the National Curriculum (Year 1 levels onwards) when they enter Key Stage 3 (Y7 - Y9). Pupils in the formal pathway are likely to be able to obtain formal qualifications such as GCSEs, BTEC and A-levels, and will access jobs in the future that require such qualifications. The learning style for pupils in the formal pathway mirrors mainstream education, where pupils attend specialist foundation subjects and are required to go to different classrooms. When pupils progress to Key Stage 4 (Y10 – Y11) and Key Stage 5 (Y12 – Y13), School H supports the pupils with their external work experience in preparation for their adulthood.

#### **4.5.2 Semi-formal pathway**

Pupils identified as being in the semi-formal pathway often have higher needs and severe learning difficulties (SLD). The approach used when working with pupils in the semi-formal pathway is relatively kinaesthetic, 'hands on' and repetitive. All their lessons are designed to be based on life-skills, as opposed to being driven by academic qualifications. School H has its very own facilities, such as the school garden, printworks shop, admin workshop and café, where pupils in the semi-formal pathway increasingly access internal work experience when they are at Key Stage 4 and Key Stage 5.

#### **4.6 Staff turnover in School H**

After my research was first approved by the ethics board in December 2020, I first introduced my research to the Executive Headteacher of School H (referred to as Craig in this study) in person, whereby he approved verbally. The study was officially approved by Craig in January 2021, after he reviewed all my supporting documents. As I received the official approval from Craig, I also began to approach the speech and language therapist, occupational therapist and clinical psychologist to introduce the study and invite them to take part as intervention leaders. They all agreed to become the intervention leaders in my study.

As the leader of the social, emotion and mental health intervention (referred to as W) informed me of her departure of her role in School H, she recommended that I contact another member (referred as Mrs Smith) of the clinical team in School H, who was the assistant psychologist. Although Mrs Smith had agreed to take part in the research, I soon found myself in the same situation as she also informed me of her decision to work for a different organisation and leave School H. The original social, emotional and mental health intervention lead suggested I approach a different member of the team, who is also a clinical psychologist (referred to as Nia). The process of identifying a leader for the SEM&H intervention took approximately two months.

## **4.7 Delays caused by COVID**

Following the discussions with C and D, I re-submitted my ethical approval application, which was approved in March 2021. Due to the COVID pandemic, I was unable to easily meet and explain the research to Craig, and the research study was therefore only approved in May 2021. Also due to the restrictions caused by COVID (social distancing and essential journeys only) at the time of obtaining consent from participants' parents, I had to adapt my method of gaining consent from participants' parents. Instead of meeting parents face-to-face to explain every step of the research in detail, I had telephone conversations, shared all relevant documents, including the consent form and sought their consent via email.

Whilst I was attempting to gain consent from participants' parents, I also was responsible for providing the intervention leaders with training on how to set up, access and share videos on IRIS connect. Again, due to the social distancing restrictions, I only managed to deliver the training sessions with the leaders individually. By June 2021, consent from all the participants involved was sought, and I was finally at the stage of starting my data collection.

## **4.8 Dual positions within School H**

One ethical implication that arose was due to the positions I held at the participant school – a senior leader as well as a researcher. In section 3.4.3, I referenced Karnieli-Miller, Strier, and Pessach (2009) and discussed the common practice for qualitative researchers to democratise power relations. I highlighted the importance of creating a non-threatening research environment with power equality by actively valuing everyone's expert knowledge and understanding in the topic. As a researcher, my focus was on seeking information rather than asserting expertise, ensuring that the information sought belonged to the participants' domain. Similarly, Florczak (2016) emphasises the balance between having 'power over' participants and enabling them to have 'power to'. In addition to acknowledging participants as experts, I placed a strong emphasis on their 'power to' share information from the outset of the research, through their participation in interventions, observations, and

interviews. Moreover, the level of immersion researchers have in the culture significantly impacts power dynamics in qualitative research studies (Florczak, 2016). While I held 'power over' aspects such as research design and interview schedules, I actively allowed participants to have 'power to' take the lead as I strived to immerse myself in their culture. Participants had the autonomy to refuse interviews and drove conversations based on their preferences, leading to a more equitable balance between 'power over' and 'power to' in my research. Karnieli-Miller, Strier, and Pessach (2009) also suggest that managing power relations involves different stages such as recruitment and data collection. Participants must fully comprehend the purpose of the research, volunteer willingly, while researchers must protect anonymity and prevent harm. In section 4.3, I detailed how I tailored information sheets to meet participants' needs and ensure their full understanding of the research rationale before deciding to participate. Additionally, I used pseudonyms to safeguard anonymity. These measures were consistently applied throughout the research to prevent any imbalance in power relations with participants due to my dual roles within School H.

Being a colleague of the intervention leaders could cause a conflict of interest as the capacity of my full-time role involves having expectations from the intervention leaders. For instance, if a student is not engaged in the learning due to specific social and interaction difficulties, I would be involved in liaising with the intervention leader and requesting feedback in terms of the improvement of the student, presuming a certain extent of growth on the social and interaction skills through the intervention. However, the nature of qualitative research inspired by an ethnographic approach involves the researcher gaining an understanding of and establishing the way participants define their own experience by gathering evidence whilst being in the field of the research (Atkinson, 2017; Mahoney and Goertz, 2006 and Merriam and Tisdell, 2016). With the research method chosen, it will be a case of me, as a researcher, immersing myself in the world of the participants. Therefore, I tried not to make presumptions and expectations about what the interventions could be during the research as the aim of study was to purely investigate its impact on participants' QOL.

On the other hand, one of the main features of action research is collaboration, where the researcher and participants and other parties discuss, reflect and go about making changes through the different cycles (Armstrong and Tsokova, 2019; Lazarus, 2019). When explaining the aim of the research to staff members who led the interventions at School H, I officially re-introduced myself as a researcher and that my role was to collaborate with them through involving them in every step of my action research. During the start of most communication that I had with the intervention leaders in the first three months, I purposefully reminded them of my role. Therefore, I have managed to maintain my researcher status in this study and collaborate with them as co-researchers who feedback to me and help me reflect on my practice, as opposed to only work colleagues.

Similarly, participants in this study also knew me as a school staff member as opposed to a researcher. My research role was made clear to participants from the start when the information sheet explaining this research was sent to them; it was also reiterated from time to time and before the start of each interview was conducted. During a Research Colloquium event, I was prompted by a senior staff member at my university to think about the potential conflict of interest of having dual positions further. I, therefore, have noticed that the senior leader position I held would inevitably affect students' QOL as that was one of the underpinning roles of my job. Whilst it is unavoidable for me to have to deliver both positive or negative news to students or their parents as a senior leader of School H, I needed to clearly and objectively note down the possibility of how participants' QOL could have been affected positively or negatively by their senior leaders at school. For instance, Gordon, one of the participants in my research study, openly talked about how I supported him to resolve conflicts between him and his classmate in a meeting, and how he subsequently felt better about attending school. Nia, the session leader, acknowledged that and further prompted Gordon to think about how the senior leader managed to resolve the conflicts, with the aim of prompting Gordon's autonomy to self-solve conflicts and mirror the strategy used in that meeting. I have accepted my dual roles in this research, and that it would be possible for my senior leader role at School H to have an impact on participants' QOL. However, any child who attends a school would have the opportunity to interact with their senior leaders and me having dual roles should not be detrimental to the development of the



participants. In fact, during my research study, I have prompted participants and intervention leaders to focus on the impact that a senior leader could have on their QOL, as opposed to the impact that I, as a researcher, could have. The example above suggests that Nia tried to highlight the transferability of the strategy used in the meeting, rather than focusing on my dual roles.

## 5 Data Analysis Procedure

In this chapter, I explain the procedure of my data analysis with examples of each stage. Similar to Stan (2009), I also found this stage of my research difficult for the same reason, which was that I needed to work on a way to analyse data I have collected, as the guidance or advice from the current literature is ambiguous. For instance, Harrison (2018) highlights the importance of data contextualisation and ensuring that the reasonings behind behaviours are provided to readers. Moreover, Reeves, Kuper and Hodges (2008) suggest that the production of data analysis predominately takes the form of verbal descriptions and explanations.

As mentioned in section 3.7.2, I initially had difficulties making fieldnotes efficiently before starting to review the session videos effectively and utilise my car journeys. As suggested by Jeffrey and Troman (2004), I understood that every little piece of detail of the research, both tangible and less visible details, would be soaked up and analysed by researchers. However, I did not expect that the process of data analysis commenced in conjunction with my data collection in my research.

Before writing the fieldnotes, I had initially listened to the session videos during my car journeys and had already internally analysed and understood the general context and contents. With the prior knowledge, I then noted down the general topics of the conversations or activities, with specific dialogue recorded verbatim and my interpretation on the pupil's views and situations. However, the progress of my analysis continued both actively and passively. On an active level, the semi-structured interviews allowed me to discuss and elaborate on matters that emerged from their interventions or unanswered questions further with participants. Additionally, meeting intervention leaders regularly allowed me to understand the participants, the sessions and specific behaviours better. For instance, Oli showed unusual behaviours in one of the sessions and Sally (intervention leader) suggested the reason was that Oli was distressed because of an incident at the time. On a passive level, my dual role enabled me to physically see the participants during weekdays as they attended school. Therefore, information that ranges from pupils' change in behaviour, home environment to changes in their individual safeguarding

concerns was fed back to me. With the information passed onto me due to my school role, my interpretation and analysis of the intervention observation and semi-structured interview would be affected.

In line with Butler's (2015) thought process, when writing and engaging with the transcripts, I also felt that my opinion of the verbatim dialogue changed as I gained further insights. From that point onwards, as a researcher, I started the process of exploring the data more whilst analysing. As Reeves, Kuper and Hodges (2008) mentioned, ethnographers analyse data that is the explicit interpretation of the meanings and functions of participants' actions as they gain an understanding on how participants view the world. Apart from the observations, I also believe that my understanding of how participants perceive the world has grown through the process of transcribing the interviews from audio forms to text, which in turn, has made my interpretation more explicit. To conclude, the process of the data analysis of my research started as the fieldnotes writing had begun, and the data was analysed both actively and passively. The next sub-chapter outlines the steps that I took to during the analysis process.

## **5.1 Thematic analysis**

In this section, I discuss the process of thematic analysis and its advantages. I also explore the concept of de-contextualising and justify the use in my research study, as well as explaining the reasoning behind the choice of using thematic analysis as a data analysis method.

In the 1970s, thematic analysis was used inconsistently. However, it is widely used as a method in qualitative analysis due to its accessible and flexible nature (Braun and Clarke, 2006; Braun and Clarke, 2014). Thematic analysis involves searching, identifying, analysing, coding, categorising, summarising, reconstructing and reporting common patterns or themes emerged through a set of interviews, focus groups or a range of texts (Braun and Clarke, 2006; Maxwell and Chmiel, 2013; Vaismoradi, Turunen and Bondas, 2013). Boyatzis (1998) highlights the challenge when conducting a thematic analysis, and it is that researchers need to extract the

high quality, raw data from the given themes in a way that does not negate from the insights provided.

When thematically analysing data, researchers code contents that address the research questions by carefully identifying patterns in the raw data and then proceeding to categorise it as a means of elucidating the data. Therefore, patterns emerged in the data are often labelled with codes units, of which they are not exclusively used as some patterns could fall into multiple codes (Joffe and Yardley, 2014). Codes provide a snapshot of the principal ideas shared by the participants, and can also act in a manner that makes reference to the existing literature. As my research study consists of over twenty-nine observation sessions and nineteen interviews, and over sixty-five thousand words have been transcribed through interviews and fieldnotes, I considered thematic analysis my main method to analyse the data to produce findings and draw up conclusions.

### **5.1.1 Contextualising and decontextualising data**

In chapter 3, I highlighted the risk of decontextualising data proposed by Palmberger and Gingrich (2013), and that keeping the number of participants low is a way to avoid it. Maxwell and Chmiel (2013) have a different view on decontextualisation; they state that the process of coding produces a like-for-like method of approach that allows for close-connection ordering, one that can reinstate the original contextual structure categorically is referred as 'decontextualising'. The process of identifying themes would involve data to be decontextualised to a certain extent, and although there is a need to keep the relationship between the codes and the original raw data, there is also a need to analyse the contextual and de-contextual relationships.

Joffe and Yardley (2014) further elaborated that through the process of analysing data, patterns emerge which can then be drawn upon in a clear and quiescent manner, both of which are exploited during thematic analysis. As I stated in section 2.2, my stance is in opposition to Cheng (1988) and Jenkins (1992), in that the self-assessment of people with additional needs could seem 'unreliable'. The approach to decontextualisation suggested by Maxwell and Chmiel (2013) is an important

element of the thematic analysis of my research, as data gathered may not be comprehensible without the in-depth understanding of the contexts, due to the complexity of the QOL concept and the SEND of the participants. This way, their opinions can be elicited by having their thoughts in any form and gathered by me directly and indirectly. Therefore, in addition to generating codes and themes merely based on data from the original context, it is crucial to ensure that the relationships and connections are made based on generic relationships and out of the original context when necessary.

Although Palmberger and Gingrich (2013) also stress the importance of preventing de-contextualisation, it is worth highlighting that ethnographers act as a research instrument and walk in the shoes of participants whilst observing, writing fieldnotes and conducting interviews (Harrison, 2018; Ladner, 2014). I would argue that ethnographers have the ability to decontextualise data when analysing it thematically due to their understanding on the participants. According to Joffe and Yardley (2014), thematic analysts have to draw upon both manifest and latent themes when interpreting the data, and as an ethnographer, I believe that the less tangible data would be soaked up and understood both contextually and de-contextually and presented in my research.

Secondly, as stated above, participants were unable to compartmentalise their views on QOL due to their needs and the complexity of the concept of QOL, so decontextualisation can be seen as a means to elicit their views in my research study. Autistic masking relates to general social practices and involves suppression of identity (Miller, Rees and Pearson, 2021), and therefore it is likely that one with ASD can disguise and compensate for their autism features to socially 'blend in' (Alaghband-rad, Hajikarim-Hamedani and Motamed, 2023). In my research, Tony deployed autistic masking techniques by appearing sarcastic and avoiding the conversation topics by giving 'difficult' answers. As a researcher who has an in-depth understanding on the participants' needs, I fully appreciate the need to decontextualise data during the process of thematic analysis.

Because thematic analysis could be conducted in multiple forms, resulting in various products, Braun and Clarke (2006) have created a systematic guide for researchers who conduct thematic analyses. However, they also emphasise that the guidelines differ from rules, as researchers are supposed to apply flexibility and adapt it to fit their research studies:

- (1) Familiarising myself with your data
- (2) Generating initial codes – including connecting relationships and de-contextualising where necessary
- (3) Searching for themes
- (4) Reviewing themes
- (5) Defining and naming themes
- (6) Producing the report

The sections below highlight my experiences and adaptations made through each phase, as well as strategies put in place to support the process of thematic analysis in my research.

### **5.1.2 Familiarising myself with the data**

Researchers are likely to have gained knowledge of their data and even have gathered initial analytical thoughts if the data have been collected through interactive means, and it is crucial that researchers immerse themselves in the data and be familiar with the content, both in-depth and in-breadth (Braun and Clarke, 2006). An ethnography consists of multiple interactive means to collect data, including participant observations, writing fieldnotes and conducting interviews (Harrison, 2018). Through the process of collecting data, as described by Ladner (2014), I also attempted to act as a research instrument by walking in their shoes in order to build a rapport with them. This demonstrates how the use of thematic analysis benefits my ethnographic research study, even an ethnography inspired study such as mine.

As part of familiarisation with the data and searching for meanings and patterns, it is vital that researchers read the data repeatedly and in an active way before the process of coding, as multiple truths and realities could emerge when interpreting

data in a qualitative study (Slevitch, 2011; Vaismoradi, Turunen and Bondas, 2013). As mentioned in section 3.7, I utilised my car journeys to and from work to initially listen to the session videos before making fieldnotes. The same method was adopted to support the write up of the interview transcripts. Besides being in the interview room with participants during the actual interviews, this is the very first step of me familiarising myself with the data. Furthermore, I made notes and transcribed the interview in a working environment with minimal distractions, which enabled me to gather analytical thoughts of the data and gain a further understanding. Through the process, I had the opportunity to replay, rewind the recordings and re-listen to certain details.

Interviews in ethnographic studies are a series of friendly conversations and small, yet significant steps such as expressing interests, cultural ignorance, restating informant's terms and creating hypothetical situations are all included (Spradley, 1997). The initial interviews conducted with participants were not as in-depth as I expected them to be. Without more in-depth data, the rest of the steps could be difficult to carry out. Therefore, I reflected on my interviewing techniques and reviewed the schedule as part of the first step of my thematic analysis. I have noticed that the participants and I established a strong rapport, with me understanding their personal circumstances through observations and them showing me trust. However, all three participants had difficulties on compartmentalising their thoughts and expressing their feelings at times due to the complexity of the concept of QOL. Having reviewed the data from the fieldnotes and transcripts, I have decided to create hypothetical situations. Questions such as: 'If you could have anything in life, what would you have?', 'What does an acceptable life look like?', 'What does a bad life look like?', 'What do you have in real life?' and 'Are you satisfied with what you have?' were explored in the fourth interview onwards. With the hypothetical questions, participants were able to articulate a good life, acceptable life and a bad life before reflecting on their current situation.

### **5.1.3 Generating initial codes – including connecting relationships and de-contextualising where necessary**

Coding and sorting by code as a mechanism for sorting the data collected descriptively and creating an order of the data based on similarity, and by doing so, data would be divided to give greater clarity and details (Maxwell and Chmiel, 2013; Joffe and Yardley, 2004). Throughout this stage, there were different levels of 'sorting', including categorising data, arranging them in a chronological order, and clearly stating the different nature of the data and its origins. Although Palmberger and Gingrich (2013) are in favour of the use of computer programmes as an assistive measure to support with the data sorting process, I have decided not to pursue the route. It was mainly because sorting the data solely, and manually, enables me to have the opportunity to further familiarise myself with the data and to be able to draw credible conclusions based on my in-depth knowledge and interpretation. In addition, I did not want to risk losing the authenticity of the data when transcribing data due to the participants' speech and social deficit. Finally, I feared that the computer programmes would not have the ability to de-contextualise certain comments made by participants, and they have no understanding of the participants.

Having said the above, I did deploy technology throughout this stage as all data was transcribed onto online Microsoft documents, mostly being Word and Excel. Three main documents were produced following the transcribing process mentioned in the section above – interview transcripts (Figure 4), fieldnotes (Figure 5) and coding excel sheets (Table 3).



**First interview – 14:50 – 14:57 Wednesday 14<sup>th</sup> July 2021**

C: Good morning G. Thank you for doing the interview with me. Just before we start, I would like to let you know that if you have any questions about the questions that I'm going to ask, feel free to ask me. And also, feel free to not answer anything if you don't feel comfortable answering them, okay? Are you ready?

G: Yeah.

C: First question. What do you like in general?

G: I like Xbox. I like watching my games. I like watching YouTube. I just like to play. Fun stuff, like basketball.

C: So, there is a gaming side and a physical side?

G: Yeah, I don't like football too much.

C: Okay. So, you don't like football too much? So, what do you like about the gaming stuff and what do you like about the physical sport stuff?

*Figure 4 Interview transcript –Gordon*

Participant G

**First session observed: 1st July 2021 (36 minutes)**

N started the session by observing how the IRIS recording platform blacks out the screen, explaining that: 'We sort of to have C in the room.' and asking if G felt alright.

G smiled and responded by saying: 'It's alright.'

N then explained that: 'If you didn't feel alright about it, then we would, we had talked about it hadn't we? We would think about what to do then wouldn't we? Because that is really important as well.' G nodded. N then further said: 'And also, I want to say thanks to you again, for being so patient. Because we were trying to get it (camera) working weren't we? And we had some little thing that kept coming up and we couldn't make it work, so you had to go back to music (lesson) even though you were thinking...emmm not sure if I wanted to be in music. So you went back there and I said 'if I could get it sorted out we would have the session now, otherwise it would be in the afternoon'. And you were trying to help me as well. You had some ideas about how to get it working.'

G smiled and said: 'Yeah. Did you finally find C?' N: 'I did. I needed Kief to sort it out.' G asked: 'Where was he?' N responded: 'He was (thinking) near the large playground.' G: 'I had a feeling he'd be there.'

N: 'Did you? You were right! (pointing her finger at him)'

After the initial introduction, N started the session officially.

N smiled and said: 'So... It's very nice to meet you in a session.'

G smiled, nodded, and said: 'Nice to meet you.'

*Figure 5 Fieldnotes - Gordon*

Table 4 Coding Excel sheet

Nature	Mode	Date	Quotes / Notes	Code	Category / Domain headings	Local theme
DQ/A	I	14/07/2021	Gordon: like Xbox. I like watching my games. I like watching YouTube. I just like to play. Fun stuff, like basketball.	Xbox; watching games; watching YouTube; play fun stuff - basketball	Physical Health [Sports (Basketball)]	Physical Health
DQ/A	I	14/07/2021	Gordon: Yeah, I don't like football too much.	Dislike football	Physical Health [Sports (Not football)]	Physical Health
DQ/A	I	14/07/2021	And the physical side is just fun in general like basketball, you learn how to do the cool tricks. Rugby is just like you can tackle.	Basketball - tricks; Rugby - tackle	Physical Health [Sports (Basketball & Rugby)]	Physical Health
DQ/A	I	14/07/2021	Gordon: Yeah, I like boxing a lot.	Boxing	Sports (Boxing)	Physical Health
DQ/A	I	14/07/2021	I'm getting really good. My mum has got me into a class. A kickboxing class.	Kickboxing	Physical Health [Sports (Kickboxing)]	Physical Health

The first two documents are straight forward, with the interview conversations being transcribed in a verbatim manner and my fieldnotes consisting of direct quotes from the interventions, my interpretation and discussion notes with the intervention leader. The draft coding sheet is created based on the data presented on both interview transcripts and fieldnotes.

The first form of categorisation took place when I arranged them by the QOL domain headings when being entered into the Coding excel sheet based on the nature of the information. Table XX illustrates the different tabs representing different QOL domain headings at the bottom of the document. In addition to forming a chronological order for the data, I have also recorded the nature of the data, such as direct questions and answers (DQ/A) and interpretation (I), as well as the mode of the data, including Interview (I), fieldnotes (FN) or interview with parent. The process of categorising the data enabled me to re-examine the data, and once all the data were moved across from the interview transcripts and fieldnotes accordingly, I started to analyse them, take out the keywords and key phrases and generate some initial codes.

*Table 5 Coding excel sheet showing the tabs, additional information on the data, highlighted quotes / notes, and initial codes.*

Nature	Mode	Date	Quotes / Notes	Code
			<p>N then asked G how he felt about today, of which he said he was tired and happy. N showed sympathy as she mentioned that the tiredness is expected at this time of the year. N also told G how proud of him she was, with the fact that he was honest, stopped feeling frustrated and made a change. G was nodding and acknowledging most of the time when N was talking to him about sleep and tiredness. G did, in the end, laughed and jokingly said he was still tired after N pointing out the fact that he wasn't yawning as much.</p> <p>N: 'Let's think about how you are feeling?'            G: 'Tired and Happy.'            N: 'Can you remember what zones they are?'            G: 'Tired is blue and happy is yellow I think?'            N: 'I think the tiredness is expected at this time of the year.'            N: 'I am really proud of you for being so honest with me last week. It must have been very frustrating for you for feeling tired yet wanting to play with your friends. On the way here as well, you told me you had given up coffee. This is huge!'            N: 'Rather than feeling frustrated with the situation or cross with me. You were assertive; you told me that you made a change and you have stopped drinking coffee.'            N: 'You have really changed your behaviour as you started to look after yourself more. You are not yawning so much either.'</p>	Tired and happy; given up coffee
FN	Q + D	18/11/20	G: 'I am still a bit tired.' (Then laughed)	

Physical well-being   Material well-being   Social well-being   Emotional well-being   Personal development   Independence   Comments referencing session

Any direct quotes or interpretations that are related to the participants' intervention have also been highlighted in yellow, and then moved across to a set of new tabs that focus on the impact the interventions had on the participants, as illustrated in Table 5. This stage does have a certain level of overlapping element with the previous stage, as I familiarised myself with the data through moving and categorising data before generating the codes. Coates, Jordan and Clarke (2021) suggest that once the researchers have completed the coding of the transcript, similar coded ideas will form discrete themes and it is possible for subthemes are to emerge following a more critical analysis (Coates, Jordan and Clarke, 2021). Although this and the previous stage were time consuming, I also managed to build an extremely solid foundation for my data analyse process and was ready to proceed to the next stage and to search for themes.

Table 6 Coding excel sheet showing a set of new tabs and quotes moving across

Nature	Mode	Date	Quotes / Notes
DQ/A	FN	27/05/2021	O then initiated a conversation in this intervention for the third time. He asked S: 'Will we be doing this again? After a week?' S answered: 'Do you mean after half term?' O said: 'Yes, after half term.' S asked: 'Do you like the sessions?' O smiled and said: 'Yes, I love the sessions.' S proceeded to bounce the basketball to O. As O was catching the ball, he continued the conversation by saying: 'Especially with you. Because you are my favourite OT teacher.' S responded: 'Aww. Thank you, O, and I enjoy having sessions with you. I am seeing you getting so much stronger. Can you feel it? Not getting so tired?' O said: 'Yes.'
I	FN	27/05/2021	During the whole conversation, S and O were bouncing the ball to each other. The moment O said yes to S question in relation to his strength, he made an effort to bounce the ball to her with more force, as if he was to show her how strong he was. S then moved the mat closer to O, and said: 'So the best way to get a star jump is when you have got yourself nicely balance, so that you are there.' As soon as S finished her sentence, O jumped down, his star jump was much improved compared to his last one. S raised her voice and said: 'Yes, exactly! That was fantastic!' O just quickly went back to the start, jumped down and did a good start jump again. S: 'Perfect, you are getting very confident with the star jump.'
DQ/A	FN	27/05/2021	The first kick out was good. S said: 'Good. We are going to do five of these.' The second kick out was not as good as O kicked out too soon. O said: 'I suck at this. I need to get into position.' S said: 'Exactly, let's get the position right.' O then got himself into position and kicked again for the third time, that was the most powerful kick so far. The forth and fifth kick were equally good. S then asked: 'Shall we do one more?' O said: 'Yeah.' The sixth kick was also a great success.
			C: Let's talk about getting fitter than usual. That leads onto my next question; it is about the sessions that you are having with S.... What did you think about the activities that you had to do? O: Oh well they are definitely a lot of fun. I really enjoy working with S. I find them a little bit too easy. I am. I'm going to tell her to make them a bit harder for me.

As mentioned in section 5.1.1, there is a need to decontextualise data. Table 6 shows a conversation between participants Tony and Aaron (intervention). Factually, Tony's response to questions raised by Aaron regarding his enjoyment of the session is merely above average, as he used the term 'kind of'. However, contextually speaking, I interpreted his answer as slightly more passionate about the session than he described, as he carried on explaining what he did, and had a joke with Aaron about him always winning when it was not always the case. When I took a step further to decontextualise the data here, I realised his passion towards the sessions was far greater than passionate. Through the work in the field, spending time with Tony and even people around him, I became aware that he went through a long period of absence due to COVID, and was socially rejected by his peers when he returned as his cough continued. Without Tony explicitly mentioning it, I was aware that he had had a very difficult period of time and his social interactions including having conversations or playing games with others were even less frequent than usual. Therefore, I concluded that he was grateful and excited to have spent his time with Aaron during the session, as he had the opportunity to play games and speak to Aaron. According to Joffe and Yardley (2014), the data obtained from this

interview conversation could also be considered 'latent', and it was discovered due to decontextualising. Although this example below does not show how decontextualising the data could draw the conclusion to the opposite direction, it helped me strengthen my findings. As mentioned in 5.1.1 and in accordance with Harrison (2018) and Ladner (2014), I am able to prove that I have the ability to credibly decontextualise data as an ethnographer.

*Table 7 Coding excel sheet showing how data was first contextualised before decontextualised*

N	16/12/2021	<p>A: 'Before we finish T, I just want to ask you a few questions about our sessions. Let's start off with today's session. Did you enjoy today's session today?'  T: 'Kind of.'  A: 'Okay, I will take that.'  A: 'What about the way you pronounce the words? Does the strategy help?'  T: 'I speak more clearly.'  A: 'We have done a few games now to develop your speech, which one has been your favourite?'  T: 'Noughts and crosses because I always win.'  A: 'Well, that's interesting because you didn't always win.'  T: 'I always win.'</p>	Kind of, speak more clearly, I always win
N	16/12/2021	<p>A started off the session by reminding T of the technique that he could use to technique with his speech. A told him they would be playing noughts and crosses as they did before in session 5. T pronounced the word 'Table' very clearly. A won the game and showed the whiteboard to the camera; T pushed the board down and accused A of 'cheating' with a smile on his face. When pronouncing the word 'Cake', T found it harder. With the support provided by A, T said the word aloud in with much clearer speech. T won the second game and was very proud of himself. He told A he wouldn't have won had he not cheated. The third game ended with a tie.</p> <p>A: 'I am going to use "cat". What are you going to use?'  T: 'Emm not sure.'  A: 'What is this? (Whilst pointing at the table)'  T: 'Table'  A: 'Would you like to use this word?'  T: 'Yeah'  A: 'Straight win that was.'  T: 'You're cheating.'  A: 'I did not. I won fair and square.'  T: 'You cheated.'</p>	

### 5.1.4 Identifying themes

As Braun and Clarke (2006) stated, the nature of thematic analysis consists of steps such as searching, identifying, analysing, categorising, summarising, reconstructing and reporting common themes. Once all the initial codes were produced, I started

the process of identifying themes. As straightforward as it seemed, the level of complexity of the data was overwhelmingly rich. Spradley (1997) highlighted the importance of the significant steps in interviews, which is also referred as ‘friendly conversations’, including expressing interests and cultural ignorance. The ethnographic interview techniques in this research were particularly important as the in-depth data slowly emerged through those ‘friendly conversations’, and it would be uneasy if the researcher did not express their interest or cultural ignorance.

Table 7 shows an example of my interview with Tony, of which he first briefly talked about how he would ‘go with the flow’ when spending time with friends and family, then slowly expressed his desire in somewhat fulfilling his material well-being and personal development plan whilst discussing a topic on social well-being. During the coding process, I first identified keywords or phrases, then highlighted the multiple domains headings in addition to social well-being, before identifying the local themes – Family interactions and Peer interactions.

*Table 8 Coding excel sheet showing how codes, domain headings and local themes emerged through an interview.*

Quotes / Notes	Code	Domain headings	Local theme
Chai: How about when you're with friends or family. Would you do anything specific with them? Tony: No, just go with the flow. Chai: Whatever they suggest, you just go in there? What would you not do with your friends or family? Tony: Not spend my money. Chai: Not to spend your money with them, so they spend money with you? Tony: Yeah, I get them to buy things and, see, this is why it's good to spend time with them. They can then buy things for you. Chai: That's brilliant. Tony: It's a business plan.	Out with family, go with the flow, not spend my money, good to spend time with them, buy things for you	Peer and family interactions [Spending time with friends and family; go with the flow; not spend money]	Family interactions  Peer interactions

In line with Sandelowski (1996), I also believe that making sense of individual cases is crucial to my analysis. Therefore, I attempted to search for ‘local’ themes, which are matters that are deemed to be important to the individual participants. However, local themes at this stage could well only reflect on an individual’s life perspectives; I needed to then filter down to local themes that are shared across all three

participants, which I refer them as 'common themes' in this research. At this stage, 26 local themes in total were identified. However, before proceeding to defining the themes for my research and explore the individual stories from participants, common themes across all three participants needed to be identified at the next stage when reviewing the themes.

### **5.1.5 Reviewing themes**

Following the identification of the themes, I now outline the process of reviewing them. Walsh (2003) pointed out the fact that the large quantity of data and frequency counts of the information develop the codes and themes. As I explored the sample size used in my research in section 3.5, I clarified by stating that the small sample size works in my favour as it allows me to explore, collect and analyse such in-depth and rich information. In the previous section, I stated that 26 local themes were identified. Through the process of elimination, 16 out of the 26 local themes were shared across all three student participants and were identified as common themes, despite the smaller sample size. However, some of the common themes were less frequently mentioned with less details and stories behind them. Therefore, a further process of elimination was required. At this stage, I further considered the frequency of occurrence of each common theme (see Table 8). Unlike quantitative studies, my research focuses more on individual participants' life experiences and pays less attention to statistics and frequency (Mahoney and Goertz, 2006). However, I felt that this further process of elimination required the use of statistics and frequency. Table 8 illustrates my process of arranging the common themes based on the frequency. However, that was solely a starting point as frequency does not necessarily represents the level of importance of each common theme.

During this stage, I revisited some research studies with a larger sample size, including Schepens, Puyenbroeck and Maes (2019), Burgess (2014), which identified 12 significant themes. However, I am fully aware that there are no 'official' criteria for me as a researcher when selecting the themes. Both sets of 12 themes emerged in the research studies mentioned above consist of an in-depth level of information. This suggested to me that the sample size and the frequency should not be the 'criteria' when reviewing the themes, instead, it is the information and stories behind each common theme that truly matters. Therefore, I believed that it was essential that I revisit each common theme and how they emerged through my coding and theme searching progress outlined in 5.1.3 and 5.1.4. Harrison (2018) emphasises how ethnographic interviews do not take place during the early stages of the research, and that the better interview questions would be generated throughout the research as participants started to be studied. Through revisiting the



data, I managed to re-study each participant's story behind each common theme, and was able to identify six themes that I deemed significant in all of their lives. They happen to be the top six themes emerged by frequency. I also want to highlight that, numerically, the discrepancy between the 6<sup>th</sup> (Personal development: Improving physical well-being) and 7<sup>th</sup> (Independence in society) most mentioned common themes is by 8 counts; however, when analysing the stories behind the common themes, the richness and depth of between the two themes varied greatly. Hence, I was able to eliminate some other common themes and conclude the 6 most important common themes. After this stage, I progressed to officially defining and naming the themes emerged thus far. Following this process, I identified the two main themes as - (1) Social Well-being: Peer interactions and (2) Physical Well-being: Physical Health.

Table 9 Common themes arranged by counts in a descending order

Common themes	
Physical health	Total 78
Physical safety	Total 9
Physical appearance	Total 6
Console	Total: 37
Career prospect	Total: 12
Money	Total: 14
Peer interactions	Total: 92
Family interactions	Total: 31
Interactions with staff	Total: 55
Improving physical wb	Total: 31
Emotion regulation	Total: 8
Future career planning	Total: 22
Improving independence	Total: 4
Independence in society	Total: 23
Looking after oneself	Total: 21
Independence at school	Total: 6
Common themes by frequency	
Peer interactions	Total: 92
Physical health	Total: 78
Interaction with staff	Total: 55
Consoles	Total 37
Family interactions	Total: 31
Improving physical wb	Total: 31
Independence in society	Total: 23
Future career planning	Total: 22
Looking after oneself	Total: 21
Money	Total: 14
Career prospect	Total: 12
Physical safety	Total 9
Emotion regulation	Total: 8
Physical appearance	Total 6
Independence at school	Total: 6
Improving independence	Total: 4

### 5.1.6 Defining and naming themes

I initially did not consider this stage meaningful compared to the others. This is because all local themes, common themes, and selected common themes were already given a name from the very beginning. Therefore, 'defining' and 'naming' the selected themes seemed to be a redundancy. However, it was good practice that I reviewed the defined and named themes and once again, revised the stories behind. Although the common themes were identified by frequency at this point, I had to consider the actual name of the themes. Since my research is inspired by ethnography, and that an ethnographic approach embrace the diversity and access others' worlds and experiences (Humberstone and Stan, 2011), I had to re-think the name of the main themes rather than using 'Peer interaction' and 'Physical health'

purely because they were the two most frequently topics that were spoken about according to my spreadsheet. Without losing the authenticity of the lived experience while also discussing findings that are relevant to those common themes, I chose to identify the first two main themes as Social well-being through peer interactions and Physical well-being. Student participants' social well-being is evidently orientated to their peers' aspect, however, student participants touched on the topic of physical health, improving physical well-being, safety and appearance. All these elements are somewhat related, and therefore having Physical well-being as the second theme enabled me to explore the lived experience in-depth. Finally, Emotional well-being is identified as the final theme. Although 'emotional regulation' seems to be the only Emotional well-being related common theme emerged in my spreadsheet, everything that student participants discussed and encountered includes emotions. Besides the discreet connection between Emotional well-being and other common themes, there is also a clear link between student participants' Emotional well-being and their perspectives on their intervention experience.

### **5.1.7 Producing the report**

The production of the report comprises the write up of chapter 6 of this thesis. I outline each theme with relevant literature to provide readers with a background and contexts, before moving onto discussing what each theme and sub-theme means to the student participants. This step was the most complex, as themes and sub-themes both had to be revisited to ensure authenticity of the stories. The report produced in chapter 6 also directly meets the research objectives and provides readers with the answers to enquires raised, as student participants' views on their QOL domains are explored, and the impact of the intervention as well as student participants' experience of them are also discussed. These questions are all answered through exploring the three main themes.

## 6 Findings

As outlined in chapter 5, all the data collected were reviewed and analysed through a robust thematic analysis process. In this chapter, I explore the findings collected through reviewing the two main themes and their sub-themes. In order to provide readers with contextual information, I also included a range of data – interview transcripts, conversations between me and both student and parent participants, and observational data.

As stated in Chapter 1, the following research objectives are set for this thesis:

- 1) To understand how QOL is defined by the literature and identify a working definition for this research.
- 2) To identify the student participants' views on their QOL domains
- 3) To examine the impact of non-curriculum-based interventions on student participants' QOL
- 4) To explore student participants' perspectives on their intervention experience

In chapter 2, I review the literature on QOL and explore its definition and domain headings. I particularly investigated the literature by Felce and Perry (1995), WHO (1997), Schalock and Verdugo (2002), and concluded that the following domain headings in my thesis:

- Physical well-being
- Material well-being
- Social well-being
- Emotional well-being
- Personal development
- Level of independence

Further in section 2.2, I clearly stated that the findings of the thesis are drawn from participants' personal views on their QOL subjectively. However, I also explicitly explained the objective views, or so-called norm references are in the context, which

drives participants to form their own opinions. This chapter focuses on exploring the second research objective in the thesis. In short, the meaning of these domain headings mean to the student participants.

As detailed in chapter 5, the cycle of the action research and the process of thematic analysis were comprehensive. The former was crucial in the sense of shaping the research and making adjustments to ensure of research objectives are met. The latter enabled me to systematically categorise, code, and finally theme the key points of this research from the sixty-five thousand words collected through interviews and fieldnotes. There were numerous stories under each QOL domain heading uncovered from each participant through the data collection process, and many links between the domain headings and themes were also identified. Three themes were identified: social well-being through peer interactions, physical well-being and emotional well-being, and each theme is presented alongside student participants' personal stories, which also justify the significance of the themes.

## **6.1 Social well-being through peer interactions**

Flanagan (1978) suggests that social programmes could elevate the QOL of people in society. During the same period, Andrew and Withey (1974) and Liu (1974) also showed an interest in investigating the social elements in society, as they believed that they affect one's QOL. 'Socially' speaking, Flanagan (1978) developed the domains: 'Activities related to helping or encouraging other people' and 'Activities related to local and national governments', whereas Felce and Perry (1995) developed the following domains: 'Interpersonal relationships' and 'Community involvement'. Pragmatically, the two sets of domains are not too dissimilar. Through the thematic process, I concluded that 'Social well-being through peer interactions', is the most important and valued matter to all three student participants, which also had a direct impact on their QOL.

The findings of my research do not indicate that student participants were concerned about their social involvement at a larger scale such as national government or community involvement, as suggested by Flanagan (1978) and Felce and Perry (1995). The two very possible reasons are 'Age' and 'Needs'. Firstly, Flangan's

(1978) research demographics were just shy of 3000 American adults aged 30+, 50+ and 70+, and participants in the research of Felce and Perry (1995) resided in supported accommodation, aged 19-67. The three student participants were all aged 14 during the data collection period, hence it is probable that their perception of the importance of social involvement compared to older participants would differ. Similarly, the needs of my participants are different compared to the neurotypical participants and participants in supported living in the research of Flanagan (1978) and Felce and Perry (1995) respectively.

Across all three student participants in my research, the general desire is to make friends and to be able to have a positive social experience with peers. The findings are unsurprising as there were some indications of this from the literature review in chapter 2. Svekle *et al.* (2010) included CYP aged 7-10 with SEND in their research and suggested that the 'social acceptance' aspect of their social well-being is lower than their typically developing peers. Arias *et al.* (2017) also stated that the 'interpersonal relationships' and 'social inclusion' aspect of participants with ASD and ID are lower than participants with only ID. Although I have no intention of comparing the QOL between my participants and neurotypical participants, the research studies above indicate that the higher needs the participants have, the lower their social well-being. The Good Childhood Report (2022) highlighted the importance of seeing friends, family and being able to do hobbies when investigating the impact COVID-19 had on CYP aged 10-17, as the suggested findings are the biggest negative impacts found in the participants lives. The Good Childhood Report (2023) further stated that CYP with SEND are about twice as likely to be unhappy with their friends, compared to their typically developing peers.

However, my findings suggest that socialising and engaging in hobbies with friends are complex matters as student participants gained both positive and negative experience from such activities. Moreover, one of the student participants (Tony) expressed his desire to be alone on different occasions. The next sections explore what 'peer interactions' means for student participants, playing on the console with peers, playing sports with peers and unkind behaviours from peers, and the impact the interventions have on the student participants under the different sub-themes.

### 6.1.1 Participants' views on Peer Interactions

All three student participants were in year 9 at the time of the research. As mentioned in section 3.5, Oli and Gordon accessed the formal pathway whereas Tony accessed the semi-formal pathway at School H during data collection. As one of the two starting points, I believed that interviewing student participants directly by initiating a conversation on their views of friends was important. In addition, when presenting the findings, I have also combined the interview data with my own observations to gain a more in-depth understanding of perspectives. During the interview, both Oli and Gordon highlighted the importance of having good friends and have discussed the impact of having bad friends. Oli suggested that good friends were people who he could share happiness and feelings with. Oli further mentioned that friendship was a two-way relationship as he was keen on supporting his friends when they were in need; Oli also described how he would comfort others and vice versa, which can be seen in his statements below:

*Oli: '...having friends is a really good social thing, like to have to have good friends. Not bad ones that treat you like rubbish.'*

*Oli: 'I define a good friend as someone like you can have a laugh, you can, you can tell them how like your day has been going on, how and what you've been doing. You know, like, basically all of that stuff, like, you can tell a good friend on what you've been doing.'*

*Oli: '...you can have 5, 10, 15, probably 100, but I, I reckon that probably the highest amount you can have is probably 10 friends... probably 1, like best friend.'*

*Oli: '...so if, if you're down they (friends and family), they always know what to do to cheer you up...usually when I'm sad I have a cup of tea to like, make me happier and it always does.'* (Fourth interview with Oli, 18th January 2022)

*Oli: '...so say if somebody said... if somebody like told me... if someone told me like someone passed away that that makes me quite sad because I know how it feels. They, they can, they can always tell me anything and they can tell anyone else and, but most, most of the time they come to me...I know how it feels, because I've had a lot of family*

*members passed [sic] away.'* (Fifth interview with Oli, 23rd February 2022)

Similar to Oli, Gordon also valued the quality of his friends over quantity as he stated that around five to six friends are enough. Gordon elaborated on his ideal social life, which consisted of talking and going out with people such as dining out, including both friends and family, as he stated in the extract from one of the interviews with him below:

*Chai: 'And next one is social well-being. [Me reading his writing out loud] So talking to people, going out with friends and family...Tell me little bit more...'*

*Gordon: 'Going out for a meal.'*

*Chai: 'You know, talking about it in order to have a good life, you say going out with friends. How many friends?'*

*Gordon: 'Five... six. around that.'* (Fourth interview with Gordon, 17th January 2022)

Despite what appeared to be an eloquent conversation between Tony and I, the depth of the answers was absent as Tony was not able to justify his responses. Tony showed that he valued friends in life and placed the emphasis on the quantity aspect. Tony provided me with a total number of 556 friends when discussing quantity. Although the number provided was precise, I have only perceived it as that Tony values a large quantity of friends. Unlike Oli and Gordon, Tony did not go into details of having friends with good qualities. Instead, he focussed on discussing the idea of popularity and strategically 'gaining' more friends through friends. Tony also mentioned that not having friends, communication and not having a phone were the definitions of poor social well-being. He felt that not having a phone could lead to one missing out socially, which can be seen from the interview quotes below:

*Chai: 'In order to have a good life, you said you need to have lots of friends... How many friends?'*

*Tony: 'Yes... because that's how you become popular. 556.'*

*Chai: '... what would you do with your friends if you had a lot of friends.'*

*Tony: 'Get more friends.'*

*Chai: '...then what would you actually do with your friends?'*

*Tony: 'To get some more friends through my friends.'*

*Chai: '...you have written 'no friends, no communication, no phone.'*



*Tony: 'No phone being the worst one... Otherwise, you would be left out of the group.'* (Fourth interview with Tony, 17th January 2022)

Melchior, Barry, Cohen, Plancoulaine, Bernard, Milcent, Gassama, Gomajee and Charles (2022) state that the use of screen-based media has increased since the start of COVID-19. It was also pointed out that CYP with a diagnosis of ASD are more exposed to screens, and that they are likely to be related to worse outcomes neurodevelopmentally, which includes disengagement in play and interactions with others, as well as physically inactiveness. Interestingly, Tony's main reason for wanting or needing the phone was that he would not be left out of the group. Therefore, it appears that Tony's use of mobile phone supports his engaging in play and interactions with others. Howard and Sedgewick (2021) investigated the communication mode preferences in the ASD community, who found that the participants preferred to communicate using text message, face to face and instant messenger when communicating with friends. Furthermore, the qualitative data shows that participants disliked communicating with others over the phone as they required thinking time to respond and the sensory factors including noise in the background could be overwhelming. On the other hand, some preferred communicating using written methods such as texts and instant messages, which are more structured and that they could go back and revisit the information shared. Although Tony did not specify how he would utilise his phone to stay in the group, the modes of communication from Howard and Sedgewick (2021) are all possible. Throughout the research, I observed the participants on many occasions. However, the conversations between the student participants and their peers when they first returned from the summer holiday were the most noteworthy as their teachers allowed them to have extra time to socialise during the first days of school. My fieldnotes suggest that the nature of the conversations between all three student participants and their peers are not too dissimilar, however the broadness and the depth differed greatly, with Gordon and Oli providing details in conversations and Tony being quiet and observational.

My observational data on Tony is aligned with his own views on the importance of the quantity. It also provided context and explanation, as Tony showed a higher level of satisfaction when involved in a larger group conversation about his experience over the summer holiday, which is evident in the extract below:

*'A classmate of Tony's asked him how his summer was, and he responded with mostly short answers such as "playing games" and "not much". As more classmates arrived, Tony switched to a more observational role in the conversation as he mostly observed and listened to the extended conversations, where others shared what they did over the summer holiday with more details. Although Tony stopped contributing to the conversation by making comments, he looked as though he was enjoying the company of his friends'* (Fieldnote, conversation between Tony and his peers, 6th September 2021)

It appears that Tony was comfortable in a larger social context, even though his role in a social context appeared to be more passive. Based on other observational data and interviews, it seemed that Tony was uncomfortable being at the centre of the attention. Interactions observed and interviews data often consisted of dismissive or diverted conversations: *Chai: 'Can you tell me somethings that might have happened [...]?' Tony: 'No.'* (Second interview with Tony, 22nd October 2021); *Chai: 'In a recent session [...] Can you describe that more?' Tony: 'Pass.'* (Third interview with Tony, 30th November 2021); *Chai: 'I don't know if I understand what that is, Tony.' Tony: 'It means what it means.'* (Fourth interview with Tony, 17th January 2021).

Tony showed discomfort when being at the centre of the attention in more than one context. The interview quotes above showed his behaviours during one-to-one conversations with me directly, and the fieldnotes below show how he behaved in a similar manner when communicating with one of his peers:

*'Tony and a classmate of his stayed indoors during a wet break. I have seen Tony and this particular classmate of his interact on many more occasions in a slightly larger context. Tony appeared much quieter than usual when it was just him and the other classmate. Tony was asked a few questions including what he was going to have for lunch and what his plans were during the weekend, and Tony appeared dismissive by saying "not much" to both*

*questions.*' (Fieldnotes, conversation between Tony and one of his classmates, 4th November 2021)

Tony was unable to suggest substantial reasons behind why he preferred quantity over quality, nor could he point out why he appeared more comfortable in a larger social setting. In fact, there is no evidence showing that Tony was even aware of his social presentation in both small and large social settings. However, Howard and Sedgewick's (2021) findings provide an insight into how his participants with ASD feel about being in a face-to-face social context who preferred to have more thinking time when communicating with others. Participants with ASD prefer to have more time to compose their responses to others so that their words have the intended effects, some suggested that they struggle with the speed of verbal communication and there is no expectation of an immediate response when using alternative modes of communication, such as texting and instant messaging.

Although the observational data does not directly suggest how much Gordon and Oli value the quality of their friends as they suggested in the interview, it does highlight that they are both keen on contributing to a conversation with their peers. Moreover, both Gordon and Oli were comfortable in a social context with their friends, and demonstrated appropriate social skills such as turn-taking and keeping the conversation within a topic:

'Gordon returned back to his form-classroom from the summer holiday. He was the first one to arrive and looked tired. As his classmates started to arrive, Gordon started to talk about what he was doing over the summer holiday. He talked about spending money on the game currency and getting different 'skins' [outfits] in Fortnite<sup>1</sup>. He also talked about how he didn't spend all of his money on the skins, but also Funkopop<sup>2</sup> toy figures [Marvel superhero characters]. All classmates including Oli appeared to be jealous of the holiday Gordon had. Although not as articulate, Oli waited for his turn and also talked about the amount of time he spent playing games and getting new

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<sup>1</sup> Fortnite Battle Royale (Fortnite) is a player-versus-player game that can be played online and offline.

<sup>2</sup> Funkopops are small figurines renowned for their exaggerated features.

dinosaur toys over the summer holiday.’ (Fieldnote, conversation between Gordon, Oli and their peers, 18th September 2021).

Bowen Reavis and Findley (2013) attempted to assess the preferences for social interaction in their participants with ASD. One out of the six participants showed a clear preference for social interaction as he made a clear effort to engage. However, the rest of the participants showed that social interaction was a neutral stimulus as their preference was unclear. Similarly, Nuernberger, Smith, Czapar and Klatt (2012) also investigated the preference for social interaction in children with ASD. The findings are not dissimilar to Bowen Reavis and Findley (2013) in the sense of the lack of consistency. Although all three student-participants showed their preferences in social interactions, the preferred stimuli were all different. While Oli and Gordon are comfortable in contributing to a conversation with their peers using social skills, Tony prefers to be in a large social situation and be passive. Although Gordon and Oli appeared similar in the sense of social ability and preferences, there are still fine differences in what they really prefer. For instance, Gordon’s interest is to collect Funkopop superhero toy figures, however Oli’s toy selection is dinosaurs. While it is not my intention to investigate the social preferences of student participants in my thesis, the findings still clearly show that all three student participants had their own unique way to find comfort through interacting with peers socially. While Oli and Gordon were likely to simply engage in a conversation or discussion with peers socially, Tony waited for the opportunity to become passive in a conversation. Having spent time with Tony and observed him during my time in the field, I understood that Tony generally spends time on his own during structured play time. There were occasions when I observed him interacting with peers and adults, with the adults taking the role in supporting and fostering interaction opportunities. This suggests that Tony’s social ability and interaction skills are less advanced than Oli’s and Gordon’s. Having learnt that the quantity of friends matters to Tony, it suggests to me that he craves friendship. Tony is not at the stage of distinguishing the quality of friends as he desired to purely make friends at the time of the research. Although Tony stated friends were essential for a good life, he was also the only participant who discussed having time being alone. Despite expressing his preference on having alone time, Tony also explained that friends make him happy in life. Although

Tony could not articulate when he preferred to spend time with peers and alone, he suggested that playing games when alone was a preference. When I further explained my view on how I preferred to be alone generally, Tony described my preference as 'mean'. This suggests that Tony values both peer interactions and alone time, however, the extents of him wanting to interact with peers and be alone are unclear. This can be seen from the quotes below:

*Chai: 'So you say "I like to spend time with my friends and with my family and sometimes I'd like to spend time alone". So when do you prefer to spend time with friends and families and when do you prefer to spend time on your own?'*

*Tony: Whenever I want to.*

*Chai: 'Do you live a happy life?'*

*Tony: 'Yes.'*

*Chai: 'What in your life makes you happy?'*

*Tony: 'Pass.'*

*Chai: 'Do friends in your life make you happy?'*

*Tony: 'Yes.'*

*Chai: 'I personally don't like to spend time with friends and families a lot myself. I like to spend time on my own.'*

*Tony: 'Right. You're just being mean.'* (Fifth interview with Tony, 2nd February 2022)

Whilst Tony's social ability is not fully developed, his idea of friendship and conditions to fulfil in this area seem to be simpler than Oli. For example, Tony did not specifically mention the quality of his friends, and he was also satisfied spending time on his own. Although I mentioned that Oli values quality over quantity in terms of friends, he also stated that having bad friends is better than not having friends at all as being alone makes one feel upset. It suggests that Oli's higher social ability may lead to more opportunities to feel upset due to friends. His views are presented below:

*Chai: '...what is worse, having bad friends or not having friends at all?'*

*Oli: '... No friends I would say... they're just gonna feel like they're nothing... they just feel alone...very, very upset.'* (Fourth interview with Oli, 18th January 2022)

Both Oli and Gordon discussed the implications of having 'bad' friends. For instance, Gordon made the link between social well-being and material well-being as he explained how socialising with the wrong people could affect one's material well-being, career prospects. Gordon also touched on how one should avoid socialising with the wrong people and how it is connected to their emotional well-being, as he felt that one tends to display 'silly' behaviours such as stealing when they are unhappy. On the other hand, Oli stated that 'bad' friends make one down:

*Gordon: '...don't be like messing with the wrong people...it's like people you know who are not gonna be like, silly. Or be like, get in trouble... like stealing'*

*Chai: 'And so if someone steals it means...'*

*Gordon: 'They're probably not happy.'*

*Chai: 'So people who are not silly or the ones that do not get in trouble, what kind of effect or influence might they have on you?'*

*Gordon: 'Get a job.'* (Fourth interview with Gordon, 17th January 2022)

*Oli: '...they (bad friends) just make you feel really down. Like they don't really support you that well, they just tease you.'* (Fourth interview with Oli, 18th January 2022)

The findings suggest that both Oli and Gordon share a similar view on friendship, which is the importance of quality. On the contrary, Tony focusses more on the quantity of friends due to the different social level and experience. However, it appears that Tony is more used to being on his own due to his social ability and as a result, his view on friendship is also affected. For instance, he can cope with being alone, despite not articulating when he prefers to be alone and when he prefers to be with friends. On the other hand, Oli shows that he is unable to cope with being alone, despite his higher social ability. Even though Oli can outline the negative emotional impact 'bad' friends have on one, he still prefers to have 'bad' friends over being alone. Selfhout, Branje, Delsing, Bogt and Meeus (2008) recognise the beneficial

effects of high friendship quality amongst people. They also pointed out how different types of internet use could serve as a means for one to communicate and its advantages and disadvantages on one's friendship quality. Although Efeoglu and Sen (2022) share the same stance on how the quality of friendship is considered a crucial factor that affects one's well-being, they have a different take on those potential 'disadvantages' that different communication means could bring to a friendship. It was believed that besides positive functions such as providing others with emotional security, help or being a reliable alliance, negative features including conflict and competition are also unmissable elements in a friendship. However, there must be more positives than negative in a relationship for it to be deemed high-quality. Therefore, one can learn and grow through these experiences (Efeoglu and Sen, 2022). Although I do not have a stance on certain 'advantages' or 'disadvantages' created by the quality of friendships, all three participants' life experiences were affected by friendships with different qualities, and that they responded to the matters which then led to potential changes in their life journey. These stories will be explored in the following sections.

So far, my findings have shown student participants' idea of good social well-being, of which both Oli and Gordon clearly value the quality of their friendship. Through the process of unravelling stories from the sub-themes, which include playing console with peers, Playing football with peers and Unkind behaviours from peers, I will also evaluate the social conflicts each participant encountered through peer interactions over the course of the research to different extents.

### **6.1.2 Playing on the console with peers**

Playing on the console appears to be the most popular activity across all three student participants. Without using the same adjective, all participants describe playing on the console as fun. Furthermore, both Oli and Gordon made a link between playing on the console and its emotional impact. However, playing on the console is not always a positive experience as Oli and Gordon both suggested how arguments took place when playing on the console with peers, which can be seen in the extracts below:

*Oli: 'Playing games keeps me happy and calm.'* (Third interview with Gordon, 30th November 2022)

*Gordon: 'The gaming side is like relaxing and fun.'* (First interview with Gordon, 14th July 2021)

*Chai: 'Okay. Why do you like to watch YouTube or play video games? What do you get from it?'*

*Tony: 'It's good entertainment.'* (First interview with Tony, 12th July 2021)

*Oli: 'They (playing on the consoles) are just very, very fun... we do have a lot of arguments sometimes... it's very negative when we play together on Xbox, console and stuff like that.'* (First interview with Oli, 12th July 2021:)

*Gordon: '...played my game with my friend. He annoyed me there as a joke.'*

*Chai: 'Were they serious arguments? Did they get resolved?'*

*Gordon: 'Yeah no, not serious at all. Yes, they did.'* (Second interview with Gordon, 21st October 2021)

Throughout the research, I also observed that playing on the console with peers was a popular way to interact with peers as student participants had regular discussions with their peers on this topic:

'Just as playtime was finishing, Oli and Gordon headed back to their classroom with the rest of the class from the MUGA (Multi Use Game Area). Oli and Gordon were both talking about how they had to complete certain missions on Fortnite in order to get the Halloween skins. One of the peers made a comment about how pointless it was to gain the Halloween skins as they didn't affect the players' attributes. The rest of the group laughed it off, carried on talking about how well the skins looked cosmetically and ignore the comment made by the peer.' (Fieldnote, conversation between Gordon, Oli and their peers, 21<sup>st</sup> October 2021)

'Unusually, Tony contributed to a conversation, but Tony was passionately defending the value of the PlayStation 5 that came out almost a year ago and justified why it was hard to get hold of. Tony agreed that the Xbox Series X had better graphics compared to the PlayStation 5, however the latter had



Spider-Man: Miles Morale as an exclusive game, which the Xbox Series X did not have.’ (Fieldnote, conversation between Tony and his peers, 24<sup>th</sup> November 2021)

Although the observed conversations between the student participants and their peers did not turn into arguments, they certainly fostered opportunities for them to share their unique opinions on a topic that they were passionate about – consoles. Before moving onto exploring the conflicts student participants experienced through playing on the console, it is also important to note that they have different levels of involvement when it comes to playing on the console, ranging from having little involvement to playing with friends until late at night.

For instance, Tony did not discuss his experience playing on the console with peers. However, in an interview, Tony articulated the kind of peer and family interactions relating to the console he would encounter; how he could encourage them to fund their activities so that Tony could spend his spare money on console games:

*Chai: ‘...Would you do anything specific with them (friends and family)?’*

*Tony: ‘No, just go with the flow... not spend my money... I get them to buy things and, see, this is why it's good to spend time with them. They can then buy things for you... It's a business plan.’*

*Chai: ‘So does it happen a lot then?’*

*Tony: ‘Yes, yes, and then I do end up spending my spare money on games.’ (Fifth interview with Tony, 2nd February 2022)*

In addition to just playing on the consoles with peers, Oli extended this common interest to a different level, as he recognised the discussions with friends on consoles and games he had with his peers. This can be seen in the quote below:

*Chai: ‘Do you play (on the consoles) with friends?’*

*Oli: ‘I do play with friends’*

*Oli: ‘I just talked to them about like how they're getting on. We love to... talk about games like on how new games are probably gonna be released.... I played with them on Xbox. Sometimes I mainly play with them on Xbox...’ (Third interview with Oli, 30th November 2021)*

Out of all the student participants, Gordon's desire to play on the console with peers appeared to be the strongest as playing on the consoles with peers takes up a big portion of Gordon's time. On occasions, there were discussions between Gordon and Nia during the SEM&H intervention about the balance between his console playing pattern, which concerns another main theme - Physical well-being, as Gordon would stay up and play on the console with his friends until the morning:

*Gordon: 'Sorry I am not a morning person... I play on the Xbox with my friends until late...I mean I played for as long as I wanted with my friends.'*

*Nia: 'So what time was that?'*

*Gordon: 'I played all night with my friends, until 5.'*

*Nia: 'Wow, that's really late'*

*Gordon: 'I normally have a lay in on a Sunday, until 11 or midday.'*

*Nia: 'How do you feel at school on Monday?'*

*Gordon: 'I am normally alright at school in the mornings, I am just not a morning person... I don't fall asleep in lessons. I try to stay awake. I know that I need to learn to get a good job and earn good money.'*

*Nia: 'It is about balance isn't it. You want to have that contact with your friends, you also want to have that life goal in mind.'* (Seventh SEM&H session, conversation between Gordon and Nia, 11<sup>th</sup> Nov 2021)

Through interviewing Tony, I was unable to conclude how much Tony enjoyed playing on the console with peers. Mrs Conor (Tony's mother) confirmed that Tony often played on the console by himself or with his parents. There are occasions where Tony would be playing with peers, such as having friends over to his house or vice versa, and those arrangements not frequent:

*Chai: Does Tony normally play games on his own or with friends?*

*Mrs Conor: 'On his own or with myself or Tony's father. If we have friends over or went to a friend's house then he would do.'*

*Chai: 'How often does he play on his own and how often does he play with friends?'*

*Mrs Conor: 'Only if an arrangement of parents/families meeting so maybe once/twice a month.'*

*Chai: What friends does Tony play with?*

*Mrs Conor: 'Children of parents' friends.'* (First interview with Mrs Conor, 4th September 2022)

This confirms that Tony does not often play on the consoles with his peers, and this could suggest that Tony is a very particular teenager, and he likes to play life-stimulated games in a fantasised way where he would understand and enjoy. As mentioned in chapter 2, individuals with ASD may experience difficulties interacting with others in a social context and display restricted interests or activities (American Psychiatric Association, 2013). Researchers' stance appeared to have come from a concerned aspect. For instance, Nuernberger *et al.* (2012) mentioned how CYP with ASD could experience aloneness that seemingly isolates them from the outside world. Similarly, O'Connor (2016) also pointed out how the impaired social interactive ability of CYP with ASD could cause areas of concern such as self-harming, aggression or other inappropriate communication initiations or responses. While the concerns might be valid for some people with ASD, the social situation for Tony appeared very different. Based on my observation, Tony has shown none of the concerns suggested by O'Connor (2016). Although Tony was somewhat 'experiencing aloneness' and 'isolated from the outside world', Tony did not appear to be unhappy about spending time alone; in fact, he showed his ability to cope with being alone.

Besides being able to cope with spending time alone, not being completely compatible with his peers from a console-play perspective is another reason as to why Tony mentioned playing on the console alone more frequently during one of our interviews:

*Chai: '...when you spend time on your own, what do you do?'*

*Tony: 'Stuff! How am I meant to remember? I don't even remember what I had for breakfast?'*

*Chai: 'Would you play games or would you...'*

*Tony: 'Obviously I will play (console) games. Who doesn't play games?'*

*Tony: 'Yeah, (I'll) make it (Minecraft) better.'*

*Chai: 'In what sense? Like graphics, the structure of a game, the rules?'*

*Tony: 'They are not rules. They are modes.'*

*Chai: 'What game modes would you create?'*

*Tony: 'One mode only, if you die in Minecraft, you die in real life... That is their choice.'*

*Chai: 'I personally wouldn't play it...'*

*Tony: 'I'll make them sign a contract so they know they're giving up their life by signing.'* (Fifth interview with Tony, 2nd February 2022)

Having said the above, playing life-simulation games in a fantasised way does not equate to incompatibility with peers. For instance, Gordon also enjoys playing fantasy games. However, he has paid particular attention to making money through trading cars, which appeared more mainstream compared to Tony's fantasy. Although Career prospects and Money from Material well-being is not identified as a theme in this thesis, Gordon has evidently shown his passion towards wanting to become a mechanic and earning money through games. Gordon also further explains the types of activities he does when playing one of his games, which includes trading cars, going on heists and mutual car appreciation. Gordon is aware of the violent nature of the game, however, and has also stated that he avoids them and shown his online safety awareness, which can be found from the conversation that took place during an SEM&H<sup>3</sup> session:

*Gordon: 'I spent all my money on this car in the game. Then I had to sell it. I sold it for 170k.'*

*Nia: 'Is it real money or money that you earn through the game?'*

*Gordon: 'It is money earned in the game, but sometimes you have to go on heists or rob the bank... I only get my friends to bring their car to my lobby and have a chat. We look at each other's cars. Some have got bigger tyres.'*

*Nia: '...Are you exposed to the aggressive or violence side of things?'*

*Gordon: '...I am not tapping into the violent side.'*

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<sup>3</sup> Social, emotional and mental health

*Gordon: 'Yeah that's fine. I control my party so I allow people to come in and show off their cars. If people are not being very nice and blow our cars up then I will just kick them out of the party. I have done that before.'* (Eighth SEM&H session, conversation between Gordon and Nia, 18th November 2021)

To summarise, all three student participants enjoy playing on the console. However, their console related involvements differ greatly, and the difficulties they experience also vary. As mentioned above, there is a lack of consistency in terms of the social preferences for people with ASD (Bowen Reavis and Findley, 2013 and Nuemberger *et al.* 2012). Whilst Tony struggles with identifying and stating when he prefers to play alone and when to play with peers, his preferred game playing way is not compatible with others. Whilst there are concerns in relation to how the lack of social interaction could cause concerns such as being isolated from the outside world, self-harming, aggression or other inappropriate communication initiations or responses, Tony has not shown signs of any of the concerns above at the time of the research. Although his preferred game playing way is not compatible with others, he still appeared to be able to cope with the idea of playing alone.

On the other hand, Gordon and Oli both appeared to have very few difficulties in playing on the console with peers, despite the occasional conflicts. Gordon's imbalanced game-playing routine is also posing problems in his life. However, these problems concern his physical well-being, which will be discussed in theme 2 The reason why this must be discussed is because there is a conflict of interest in Gordon's well-being, socially and physically. In line with the Good Childhood Report (2021), the sustainability for the future also counts when measuring one's well-being.

As mentioned in section 3.6, the primary aim is to support Tony with his speech with specifically planned activities. Therefore, no direct impact links were made. However, in light of Tony struggling to identify and state his preference, the intervention provided Tony plenty of opportunities to state preference or answer questions and elaborate on them, with occasional scaffolding provided by Aaron, which can be found below:

*Aaron: 'Well, unsurprisingly, I won the first game. Would you like a rematch?'*

*Tony: 'Yes, I'll start first!' (Said loudly) (Seventh C&I session, conversation between Aaron and Tony, 11th November 2021)*

*Aaron: 'So how do you feel in general, Tony, about the sessions we have had? How have they made you feel?'*

*Tony: 'Okay.'*

*Aaron: 'Do you feel that they have gone well?'*

*Tony: 'Yeah' (Eighth C&I session, conversation between Aaron and Tony, 19th November 2021)*

*Aaron: 'Before we finish Tony, I just want to ask you a few questions about our sessions. Let's start off with today's session. Did you enjoy today's session today?'*

*Tony: 'Kind of.'*

*Aaron: 'Okay, I will take that.'*

*Aaron: 'What about the way you pronounce the words? Does the strategy help?'*

*Tony: 'I speak more clearly.' (Nine C&I session, conversation between Aaron and Tony, 16th December 2021)*

Similarly, there is not a direct impact on Tony understanding his choice of games and how he would like to play them. However, Tony was exposed to different types of games other than console games and it is possible that Tony has broadened his game choices when socialising with others.

*Aaron: 'Are you any good (at playing snap)?'*

*Tony: 'Yes I am.'*

*Aaron: 'What usually happens when I play?'*

*Tony: 'You cheat. And you would get disqualified. You always cheat and I always catch you.' (Third C&I session, conversation between Aaron and Tony, 1st July 2021)*

*Aaron: 'Can you perhaps tell me which games or activities that we have done so far that you've enjoyed the most?'*

*Tony: 'This one' (Pointing at the die)*

*Aaron: 'This one? Why?'*

*Tony: 'Don't know.'*

*Aaron: 'But you have clearly chosen this one – what makes it more fun?'*

*Tony: 'It's because you can roll it.'* (Eighth C&I session, conversation between Aaron and Tony, 19th November 2021)

*Aaron: 'We have done a few games now to develop your speech, which one has been your favourite?'*

*Tony: 'Noughts and crosses because I always win.'*

*Aaron: 'Well, that's interesting because you didn't always win.'*

*Tony: 'I always win.'* (Nine C&I session, conversation between Aaron and Tony, 16th December 2021)

As for intervention impact on how Gordon and Oli handle impacts when playing on the console with peers, there is a varied degree of positive reinforcement. Similar to Tony's intervention, Oli's intervention does not have any direct links to playing console games with peers, as games played were always delivered in a face-to-face method. The structure of both interviews can be found in below fieldnotes:

*'A started off the session by reminding Tony of the technique that he could use to technique with his speech. Aaron told him they would be playing noughts and crosses as they did before in session 5... Tony won the second game and was very proud of himself. He told Aaron he wouldn't have won had he not cheated. The third game ended with a tie.'* (Fieldnote on Tony and Aaron's interaction when playing a game, Ninth C&I intervention, 16<sup>th</sup> Dec 2021)

*'Before Oli and Sally continued with 3-D puzzle number (Angry bird) two, Oli took out a slingshot and shot accurately at certain places on the table and knocked his completed puzzle... Oli also moved from sitting opposite Sally to being right next to her during the last game... When they finally finished the last game, which took over 20 attempts collectively, Oli jokingly said that he would choose a different game next time as it was too stressful. Sally acknowledged and agreed.'* (Fieldnote on Oli and Sally's interaction when playing a game, Fourth SM&P intervention, 11<sup>th</sup> November 2021)

However, like Tony, Oli was also exposed to playing different games during the intervention and had the opportunity to interact with Sally when playing games that developed his motor skills, such as ball games, bodyweight games or board games. In all those instances, playing those games led to a positive outcome, which was demonstrated through the conversations that took place during a semi-structured interview and Oli's SM&P<sup>4</sup> intervention:

*Chai: 'You said you used to get frustrated building the Angry bird models and playing the game – how do you feel about that now?'*  
*Oli: 'Yeah. I have actually gotten better with building now. I can start building now. I have got more creative.'* (Third interview with Oli, 30th November 2021)

*Sally: 'Let me have a go... whoops... my reflexes are not very good.'*  
*Oli: 'I want to get to at least 30.'*  
*Sally: 'We have got a minute or so, then I want you to play one final game.'*  
*Oli: 'I need to concentrate, I need silence' (with an animated tone)*  
*Sally: 'Oh okay silence, sorry sorry.'* (Throwing her hands up in a mock surrender)  
*Device: 'You have scored 30.'*  
*Oli: 'Oh yeah! Thirty!'* (Sixth SM&P session, conversation between Sally and Oli, 20th Jan 2022)

Although I did not have the opportunity to observe how Oli interacted with his peers when playing on the console, I witnessed the growth in Oli's confidence when playing face-to-face games with others during school through my observations:

*'Oli was asked to be one of the two team leaders in a P.E. lesson and picks his teammates. Although Oli appeared a bit shy at the start, he managed to complete the task and formed his team.'* (Fieldnote, instructions given to Oli in a lesson, 26<sup>th</sup> November 2021)

*'A prospective pupil visited Oli and Gordon's class and stayed for the day. As the prospective pupil arrived, Oli approached him, introduced himself and told him what games he liked to play. Oli then invited the prospective pupil to join him and to play the target throwing game. He appeared very confident.'*  
(Fieldnote, instructions given to Oli in a lesson, 24<sup>th</sup> January 2022)

Unlike the C&I<sup>4</sup> and SM&P intervention, there were direct discussions between Gordon and Nia, the SEM&H intervention leader, during their intervention on playing

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<sup>4</sup> Communication and interaction



on the console with peers. For instance, Nia also recognised how Gordon chose to block people who were rude to him on social media and games, and to stay in his own 'bubble'; she subtly suggested that Gordon had to let people in one way or another, however he needed to be careful who he let in:

*Gordon: 'As he is not my friend (on the Xbox), he doesn't pop up.'*  
*Gordon: 'I just want to be in my own bubble, with no other people in it.'*  
*Nia: '...you want to have friends as well. So you sort of want to be very careful who you let in.'* (Second SEM&H session, conversation between Nia and Gordon, 8th July 2021)

Although people with SEND enjoy using the internet, there are risks involved such as extremism, online radicalisation and grooming (Caton and Landman, 2022). Nia raised a very valid point in the conversation above, which was also in line with the risks that Caton and Landman (2022) proposed on risks of people with SEND using the internet, as she emphasised the importance of carefully letting strangers online into Gordon's world. However, throughout the conversation, Nia also balanced the social element by emphasising that having friends was important, and that the central principle was to be careful about handling friendship online, and who to let into Gordon's world. Also, in line with Selfhout *et al.* (2009) and Efeoglu and Sen (2022), Nia also recognised the benefits of having friends as well as the central principle about being careful who Gordon lets into his world online, Nia suggested that avoiding meeting people online was not a solution for Gordon.

Whilst acknowledging the fun aspect and checking if Gordon was exposed to the violence and aggression of a game, Nia also ascertained his consent to speak to his mother to ensure that she was aware of the nature and the risks of the game, as well as the people Gordon plays with. The conversation mentioned above took place during an SEM&H session, and is presented below:

*Nia: 'Oh, I see. What is the age restriction?'*  
*Gordon: 'It's fine. It's an 18.'*  
*Nia: 'Why do you think it's an 18?'*  
*Gordon: 'Its violence?'*  
*Nia: 'Yeah, the violence is the worry though.'*  
*Gordon: 'I only get my friends to bring their car to my lobby and have a chat. We look at each other's cars. Some have got bigger tyres.'*

Nia: *'Oh okay. So for you it's about the cars and how you modify them? Are you exposed to the aggressive or violence side of things?'*

Gordon: *'No, I don't really do those things.'*

Nia: *'Sorry I don't mean you, I mean if you have been watching other people do violent or aggressive things?'*

Gordon: *'No not really.'*

Nia: *'Does your mum know if you're playing it?'*

Gordon: *'Yeah, she does. She knows that a lot of people my age play that game.'*

Nia: *'Does she know much about the game?'*

Gordon: *'Yes she knows that I am not tapping into the violent side?'*

Nia: *'You wouldn't mind me checking in with your mum about this?'*

Gordon: *'Yeah that's fine. I control my party so I allow people to come in and show off their cars. If people are not being very nice and blow our cars up then I will just kick them out of the party. I have done that before.'*

Nia: *'Who are these people that you play with?'*

Gordon: *'Some are my friends and some are people I don't know.'*

Nia: *'That's sounds really fun.'*

Gordon: *'I enjoy buying and selling things there. Sometimes I sell things but don't get my money back.'* (Eighth SEM&H session, conversation between Gordon and Nia, 18th November 2021)

Despite the mixture of experiences student participants encountered under all three sub-themes, the general consensus was that they were all satisfied with their social well-being. While Tony was satisfied with his social well-being, but not having it on the top of his QOL domain heading list, both Gordon and Oli rated their social well-being as their highest domain headings of all, which can be seen from the interview quotes below:

Chai: *'PlayStation and material well-being, so material well-being. So you are the most happy with your material well-being. What's your second most satisfied aspect?'*

Tony: *'There isn't one.'*

Chai: *'There isn't one, so physical and social well-being...They are on a par?'*

Tony: *'Yeah.'*

Chai: *'But you're still happy with them in general?'*

Tony: *'Yes.'* (Fifth interview with Tony, 2<sup>nd</sup> February 2022)

*'Chai: Social well-being you prefer to have friends. You have mentioned a few friends here at school and then some friends outside of school, of which one of them you were going to visit as well.'*

Gordon: *'Yeah.'*

*Chai: 'Are you satisfied with all three aspects here? Or are you dissatisfied with them?'*

*Gordon: 'I'm satisfied by all of them.'*

*Chai: 'If you were to choose one out of three that you're the most satisfied with, what would you say?'*

*Gordon: 'Probably with friends.'*

*Chai: 'So you're most satisfied with their social well-being in terms of their life, so so far you are saying that you're having good life.'*

*Gordon: 'Yeah.'*

*Chai: '...but you're the most satisfied with their social well-being so far?'*

*Gordon: 'Oh yeah, I'd talk to them (friends) about my nice animals and pets as well.'* (Fifth interview with Gordon, 22<sup>nd</sup> February 2022)

*Chai: 'So would you say you are satisfied or dissatisfied with your social well-being?'*

*Oli: 'Oh, I'm definitely satisfied with my social well-being.'*

*Chai: 'So out of the three things we've talked about, physical well-being material well, being social well-being, which aspects are you the most satisfied with in your life?'*

*Oli: 'I would say, I would say, social well-being, because I, I do talk to a lot of people.'* (Fifth interview with Gordon, 23<sup>rd</sup> February 2022)

Although parents and school professionals acknowledge the role of playing online games and the benefits of internet use, they also have concerns about the online risks when their children access online games (Caton and Landman, 2022).

Therefore, Nia's concerns were valid and the conversation above showed a high level of trust and respect between her and Gordon, as she was confident to inform Gordon of her decision to speak to his mother about the potential explicit contents he might be exposed to, and that Gordon was also comfortable with the suggestion. So far, I have explored the student participants' emotional experiences of playing on the console with peers, and how they all have discussions with their peers about console games. While Oli and Gordon often played on the console with peers, Tony appeared to have some form of incompatibility with his peers when it comes to playing games with his peers due to his particular imagined rules. Although it seems concerning that some people with ASD are isolated from the outside world due to their lack of social interactive ability (Nuenberger et al. 2012; O'Connor, 2016), it does not appear concerning for Tony, as he appeared to be coping well with the idea of playing on the console on his own. Moreover, Bowen Reavis and Findley (2013) and Nuenberger *et al.* (2012) suggest that the social preferences for people with

ASD vary, and that the idea and importance of socialising also means something different to people with ASD. So far, this has been the case for the student participants in my research. Although the C&I and SM&P interventions did not have a direct impact on this sub-theme for Tony and Oli, there were direct conversations regarding the online safety aspects between Nia and Gordon during their intervention. Unlike playing on the console with peers, which often took place in a home environment, the next sub-theme focuses on playing sports with peers. Due to the nature of the sub-theme, there was also more observational data from the field.

### **6.1.3 Playing sports with peers**

Besides interacting with peers through consoles, playing sports with peers appeared as another sub-theme as I discovered participants' stories behind through interviewing and observing. Although playing sports is a physical activity, which is also related to another theme - 'Physical well-being', I intend to outline the social aspects of playing football with peers instead of the physical aspect. First and foremost, Oli was the only participant who actually enjoys playing sports with peers, football in particular, and the other two participants feel otherwise about it. Like the console, football is also a common discussion topic for Oli and his peers. Oli described playing football with his peers as a positive experience:

*Oli: I like to have fun with my friends. I like to play football. Yes, stuff like that.*

*Chai: 'How about playing football with friends at school? Do you find that a positive or negative experience?'*

*Oli: 'I am I find it quite a, well, I... I find it quite a positive experience.'*

*Chai: 'Why is that?'*

*Oli: 'I don't really know.'*

*Oli: 'And we talk about football. We talk about football a lot.' (First interview with Oli, 12th July 2021)*

As mentioned above, both Gordon and Tony feel differently about playing sports with peers. In a semi-structured interview, Tony mentioned that he did not enjoy the

subject Physical Education (P.E.) including sports-related activities, without further explanation:

*Chai: 'What don't you like in general?'*

*Tony: 'P.E.'*

*Chai: '...Can you explain why you don't like it?'*

*Tony: 'I just don't like it.'*

*Chai: '...Are there any particular activities in PE that you don't like?'*

*Tony: 'Not really.'* (First interview with Tony, 12th July 2021)

Although Tony was unable to elaborate on why he did not enjoy P.E., Mrs Conor shared her views on the reasons behind this. Mrs Conor believed that Tony's previous school experience was considered traumatic as he did not receive the appropriate level of support and hence, he does not have positive association with P.E. as a subject. As for playing sports with peers, Mrs Conor explains that football is not an activity Tony would desire to take part in, however, he would take part in game-based activities in the park. The final element Mrs Conor suggested that explains why Tony does not enjoy playing sports with peers is multi-dimensional. First, she believes that there is a negative association with his previous school experience. In addition, Mrs Conor believes that Tony is aware of his sports competency and that his performance is below his typically developing peers, and as a result, the lack of resilience in him has caused him to give up on the idea. Mrs Conor confirmed the information above through a semi-structured interview:

*Chai: 'Tony said that he doesn't like P.E. - What do you think?'*

*Mrs Conor: 'He definitely does not like P.E.!'*

*Chai: 'Why doesn't he like P.E. or sports?'*

*Mrs Conor: 'I think it stems from some traumatic experiences when he was in mainstream school and the staff would not help him to get changed into/out of his P.E. kit. On more than one occasion I picked him up from school and he was in just his underwear in the classroom as he had "refused" to get dressed. Even now Tony still needs help on some days with getting dressed due to his fine motor skill delays. I do not think he has any positive association with P.E.'*

*Chai: 'How would he feel about playing football / sports with his peers?'*

*Mrs Conor: 'This is not something he would chose to do or enjoy – he would play in the park with family/family friends outside of school though but I have only seen him play football with family.'*

*Chai: 'What do you think is stopping him from playing football / sports with his peers?'*

*Mrs Conor: 'Negative association with PE. Also I think as he gets older, he is aware that he is not as good at these kind of activities as his peers are. He would always chose to not do something he thought he was not good at rather than have a try.'* (First interview with Mrs Conor, 4th September 2022)

Similar to my observation on Tony's general peer interaction, he preferred to be passive in a larger social setting. On one particular occasion, I observed how staff members at school Mrs Smith eventually managed to encourage Tony to join in a dodgeball match:

'During activity week, staff at school Mrs Smith created multiple activity stations for students. Tony was sitting on the bench in the sports hall while the others were taking part in the dodgeball match. I also joined in as students invited me to do so. After each game, staff invited Tony to join but were rejected. After the fourth game, staff members changed their tactics and encouraged Tony to join again by telling him that it would be the best opportunity to hit staff with a ball without consequences. The competitive nature of the conversation successfully motivated Tony and he took part in the end. Although he did not stay in the game for long before getting hit by a ball, I was impressed and surprised that Tony took part.' (Fieldnote, dodgeball match during activity week, 19<sup>th</sup> July 2021)

Traumatic experiences are likely to have negative effects on the well-being of people with SEND on a significant scale, and they are likely to lose a sense of safety and trust. Therefore, trust is considered an essential element of one's healing and sense of safety following an episode of traumatic experience (Calveley, 2022; Katherine and Sarah, 2022). I believed that Tony became more and more comfortable with the idea of playing dodgeball as he had already seen how the game worked on three occasions. With familiar staff members' relentless invites, I also believed that Tony managed to build up a sense of safety in joining the game. The single observation above does not suggest that Tony enjoys playing sports with peers or vice versa, but it acknowledges Tony's journey of recovering from his previous traumatic experience, which led him to associate negative emotions with P.E., a platform that would ordinarily allow him to socialise with his peers through playing sports.

Gordon initially claimed that he did not enjoy playing football with his peers due to social reasons as well as his competency in playing football. However, Gordon also claimed that he played football due to a lack of options. Gordon disclosed his feelings towards football in a semi-structured interview:

*Chai: 'What don't you like in general?'*

*Gordon: 'Football, and people being rude to me.'*

*Chai: 'And what don't you like about football?'*

*Gordon: It's just too 'tackly'. Everyone is better than me. I don't know. I don't like football. Oh yeah, they call me a trash player... That's why I don't like playing it.'*

*Gordon: 'I asked Na (P.E. teacher) to take me to the P.E. cupboard but there is no basketball or rugby balls. All the rugby balls are kicked over the fence.'* (First interview with Gordon, 14th July 2021)

However, my observational data suggest that Gordon might not have been able to fully express his feelings towards playing football with his peers, as he was observed laughing and smiling when playing football with peers on different occasions:

*'Oli picked Gordon to be in his team and they played. All students focussed well during the football match and there was laughter from everyone including Oli and Gordon.'* (Fieldnote, P.E. lesson, 26<sup>th</sup> November 2021)

*'During lunch, Gordon played football with peers in the same key stage. Gordon was the goalkeeper and managed to save a few shots throughout the game. Although Gordon's team lost the match in the end, Gordon appeared proud as he smiled after saving those shots from the opponents' team.'* (Fieldnote, Gordon playing football with his peers during lunch, 4<sup>th</sup> January 2022)

It appears that Gordon was, overall, unable to deal with the conflicts arisen due to football in a positive manner and his overall feelings towards football are affected negatively. Gordon's feelings towards football were very discreet and personal as his mother also perceived it differently, which can be seen in the quote below from a semi-structured interview:

*Mrs Smith: '...I try and protect Gordon in certain aspects of life, but then in other aspects I want him, I want him to be able to enjoy all different sports, not just football.'* (First interview with Mrs Smith, Gordon's mother, 30th March 2022)

Encountering arguments and conflicts when interacting with peers also applied to Oli. Oli was aware of his lack of football competency, however, his approach to dealing with this matter appeared to be different from that of Gordon. Whilst Gordon appeared to have negative feelings about football and stopped enjoying it as much, Oli confirmed his awareness of his lack of football competency of playing football and ability to apply self-regulation techniques when dealing with conflict during two separate semi-structured interviews:

*Oli: Oh well, we have a back garden, quite a big one. I play football with my sister. I'm quite rubbish, she, she always beats me.* (First interview with Oli, 12th July 2021)

*Chai: 'Do you find things stressful in life in general?'*

*Oli: Like general? Football mainly. It's quite hard. This kid A, he keeps on bossing me around and telling me what to do. I get quite annoyed with him.*

*Chai: 'What can you do if you find things stressful in life?'*

*Oli: Probably take a deep breath and walk away.* (Third interview with Oli, 30th November 2021)

Although both Oli and Gordon appeared to enjoy playing on the consoles with peers, Oli's perspective suggests that his console experience was generally more negative than interacting with peers in real life. It appears that Gordon's situation was the opposite. Gordon's experience of playing on the console with peers is generally



more positive than playing football with peers, as he showed a good understanding of online safety and more slightly advanced interpersonal skills. Oli's views on this from a semi-structured interview can be seen below:

*Chai: Okay, so in comparison to playing with friends on the console, would you say playing football with friends it's more positive than playing with them on the console?*

*Oli: Yes.*

*Chai: Why is that?*

*Oli: I don't really know. (First interview with Oli, 12th July 2021)*

Earlier in this chapter, I explored the importance of having more positive experiences than negative features in friendships in order to label them as high-qualified using the definition by Efeoglu and Sen (2022). Whilst having conflicts with peers is inevitable, Wied, Branje and Meeus (2007) stress the importance of understanding other's position and feelings following conflicts, through applying conflict resolution skills, including problem solving, conflict engagement, withdrawal and compliance. In other words, playing sports as well as playing on the console with peers might have caused conflicts between Oli, Gordon and their peers respectively, but they could be seen as important life lessons. Once conflicts with peers are resolved, they would be likely to experience less negativity in friendships and be successful in gaining high quality friendships.

On the note of playing football being a more positive experience than playing on the console with peers, I am able to suggest a credible reason that explains this. The times when Oli played football with his peers were structured at School H. During my research, I visited the school Multi Use Game Area (MUGA) when Oli was playing football with peers on multiple occasions. Staff members at school Mrs Smith were on duty and would play with pupils during these structured breaks. I have observed conflicts arising and being resolved by staff members directly or through coaching:

*'Oli was playing football with his peers during lunch. Players in Oli's team kept on missing their shots and people in the team were getting frustrated and started to insult each other. Although Oli did not initiate any negative conversations, he responded with negative comments as others were being*

*rude to him. The staff on-duty reminded them to focus on the positive side, as they still had 15 more minutes and that there was still time for them to do better if they were unhappy with their performance.'* (Fieldnote, Oli playing football during lunch time, 23<sup>rd</sup> November 2021)

Therefore, it appears that Oli was taught and coached to resolve conflicts caused by football. Although I am unable to comment on the level of supervision Oli receives when playing on the consoles with his peers or his ability to resolve conflicts caused by playing on the console with peers, Oli did mention that there were a lot of arguments when he played with peers. Therefore, I believe that this is a credible interpretation that Oli has a better time playing football with peers as he received more supervision on handling conflicts. The support from staff at School H also extends to Gordon, however, his response towards the staff's support was generally different due to his experience. Tony's struggle to play sports with his peers appears to be complex, the two fundamental reasons are – he does not enjoy sports, and he does not enjoy playing sports with peers. The former is explained by his traumatic experience, and the latter is explained by his sports competency and his lack of resilience.

Besides Tony's previous traumatic experiences, which led him to avoid P.E. and be less exposed to playing sports with others less, Mrs Conor (Tony's mother) also stated how Tony would avoid taking part in an activity that he did not feel he was good at. However, there were plenty of opportunities for Tony to play games with Aaron (C&I intervention leader) during the intervention and losing was inevitable when playing the games. Whilst Tony managed to develop his resilience through losing a game and demanding a rematch, he also had the opportunity to witness how Aaron approached the idea of losing.

*Aaron: 'Well, unsurprisingly, I won the first game. Would you like a rematch?'*

*Tony: 'Yes, I'll start first!' (Said loudly)*

*Aaron: 'How might someone use tape in everyday life?'*

*Tony: 'The man needed some tape to fix something.'*

*Aaron: 'Okay, let's place one more so that I can get some revenge'*

*Tony: 'No!' (Seventh C&I session, conversation between Tony and*

*Aaron, 11th November 2021)*

Further SEM&H intervention impact on conflict resolution is discussed in the section below when I explore how Gordon dealt with unkind behaviours as a sub-theme. Although the C&I intervention does not support or factor in any sports opportunities for Tony in any means, an indirect impact on Tony from his C&I intervention was found. In this section, I have discussed how playing sports with peers means something different to each of the three student participants, as well as the impact of their intervention. Both Oli and Gordon face different problems when playing sports with peers due to a lack of competency in playing football, whereas Tony avoids playing sports with peers generally due to his past experiences. All three interventions had a different impact on each of the students/ For instance, Oli was shown how to regulate himself through breathing, and he demonstrated his ability to apply the technique learnt in a hypothetical situation. Gordon was coached through the process of understanding and analysing emotions. On the other hand, although the impact was not direct, Tony's C&I intervention fostered opportunities for him to play games and potentially lose, which helped him build up his resilience in attempting to undertake activities that he might not be good at. Although I have evaluated the positive and negative aspects of playing on the consoles and playing sports with peers so far, in the next sub-theme - Unkind behaviours from peers, I will explicitly discuss the unpleasant experiences of student participants due to from the unkind behaviours from peers.

#### **6.1.4 Unkind behaviours from peers**

Social acceptance, social inclusion and interpersonal relationships are the three sub-themes that emerged in the research of Svekle *et al.* (2010) and Arias *et al.* (2017). Although Gordon, Oli and Tony have varying levels of social skills, it appears that all three student participants experience difficulties with social acceptance and handling interpersonal relationships with their peers at the time of the research. In the previous sections, I discussed how conflicts arose from playing on the console and football with peers. Unlike the previous sub-themes, this sub-theme illustrates the general unkind behaviours from peers without a specific reason in common between the participants.

For instance, Oli spoke about how others were being unkind on multiple occasions as his peers made fun of him due to his physical appearance, which can be seen in the quotes below from our first semi-structured interview:

*‘Oli: I don’t like people making fun of me. I don’t like people poking my belly... It happens quite a bit.’*

*Oli: ‘I get really wound up, honestly. I honestly get really wound up.’*

*Oli: ‘R does it (poking Oli’s belly) pretty much every single time...’* (First interview with Oli, 12th July 2021)

During my time in the field, I also observed how Oli’s physical appearance was critiqued through small gestures without any verbal comments:

*‘Oli’s class was heading to the science lab for their lesson. Oli walked in the front and other students were behind him. Two students were whispering while pointing at Oli, then they started to rub their stomach and laughed. Oli was not aware.’* (Fieldnote, Oli walking to science lab with his classmates, 11<sup>th</sup> October 2021)

CYP with SEND are more at risk of being overweight and their body shape can affect their self-esteem and social well-being, and that social network can be used positively (Lee, Brown, Leung, Chen, Louie, Chen and Lee, 2019). For instance, one could promote positive self-esteem and social well-being through exploring identity, sharing positive stories in weight reduction and learn to respect each other (Lee *et al.*, 2019). Although a social network could provide support with this issue, Oli appeared to have experienced taunting behaviour from his peers in his situation. On the other hand, it appears that Gordon and his peers struggled to distinguish the boundaries and differences between receiving genuine jokes and intentionally unkind comments. During the intervention observation, Gordon discussed an incident involving him being called names and receiving a negative comment on his appearance by his peers:

*Nia: ‘How was school?’*

*Gordon: 'It's good... I do still have some problems though. With R, he still talks to me and calls me names.'*

*Gordon: 'A was being rude to me. He's just like... he's just being rude.'*

*Nia: 'Is it just to you or to everybody else as well?'*

*Gordon: 'It's to everybody else as well.'*

*Nia: 'I think we are aware of that. I think you should keep an eye on it. He might be having a difficult time, so perhaps try to understand other people too.'* (Ninth SEM&H session, conversation between Gordon and Nia, 25th Nov 2021)

I also gained some first-hand experience observing Gordon's struggle with jokes and unkind deeds, as he and the peer who offended him at the time both came to me as a senior leader. I offered to have lunch with both of them and listen to both sides of the story. The discussion I had with the two CYP showed that it all appeared to have been a misunderstanding, and that Gordon appeared to have been the first one to make fun of his peer, who was only responding to the initial 'joke'. This caused Gordon to become embarrassed as he realised that the incident was simply an exchange of insults between friends, without any ill feelings from his peer. This is evident in the extract below:

*'Gordon was clearly still upset with his peer as he was called names by his peers; he was fixated with the idea that his peer was deliberately being offensive towards him. However, his facial expression and demeanour changed when his peer told his side of the story, that Gordon was actually the one who called him names first as a joke and he was simply joking back. Gordon looked embarrassed at first as he could not remember how the incident started, and then relieved as he found out there were no ill feelings towards him from his peer. (Fieldnote, having lunch with Gordon and his peer, 25<sup>th</sup> June 2021)*

Lin, Keysar and Epley (2010) state that Theory of Mind (ToM) is an essential function to explain and predict actions of others; one uses their ToM to predict others' behaviour as they have the capacity to reason about others' mental states (Taylor,

Gonul, Alexander, Zuberbuhler, Clement and Glock, 2023). Taylor *et al.*, 2023). ToM can also be understood as the ability to tune into other people's thoughts, wants and emotions (Lecce, Ronchi and Devine, 2022) Heyes and Frith (2014) argues that ToM is necessary for understanding other's minds, which is essential for social interaction. The research of Baron-Cohen, Leslie and Frith (1985) also suggests that people with ASD lack ToM, and therefore their social stimuli might be absent. Consequently, I believe that the lack of ToM explains why Gordon was unable to explain his peer's action towards him. Therefore, Gordon was feeling victimised, and was fixated on the idea of his peer being unkind towards him. However, once Gordon gave his peer an opportunity to justify his actions, he felt and behaved differently as he understood his peer's perspective as well as the full picture. Based on the data analysis, it shows that both Oli and Gordon have experienced unkindness from peers and are on the journey of learning how to resolve this. Whilst the unkind behaviours Oli and Gordon both received are both in the form of unkind comments, they did not experience total social exclusion.

Although Tony has not spoken about the unkind behaviours he experienced during his intervention, unkind behaviour – precisely speaking, social exclusion, was observed when he was around his peers. At the time of the research, COVID-19 remained a disease that worried the nation. A varying level of protective measures were issued by the government, such as social distancing, self-quarantining and wearing protective face masks. Tony, unfortunately, developed a chest infection that affected his attendance and breathing from November 2021 until the end of the data collection for this research study. Therefore, Tony had episodes of coughing during the days when he returned to school Mrs Smith from his absences. The physical response from his peers was mainly socially distancing. Social distancing was one of the protective measures set for COVID-19, however, Tony's peers decided to socially distance themselves from him even after they were made aware of the fact that Tony had not contracted COVID-19 at the time.

In chapter 2, it was already identified that CYP with SEND, especially those with more severe needs struggle with social acceptance (Svekle *et al.*, 2010; Arias *et al.*,

2017). In addition to the already disadvantaged social life, the impact of COVID further affects CYP with ASD. This is because people with ASD thrive on routines and receiving external support, and rigorous social distancing rules caused detrimental disruptions (Kumazaki, Muramatsu, Yoshikawa, Haraguchi, Sono, Matsumoto, Ishiguro, Kikuchi, Sumiyoshi and Mimurai 2021; Vasa, Singh, Holingue, Kalb, Jang and Keefer, 2021). While measures such as social distancing were essential to prevent the spread of COVID, CYP with ASD also lost opportunities to develop their communication skills (Kumazaki *et al.*, 2021; Vasa *et al.*, 2021). While the incident appeared to have been caused by a justifiable action from Tony's peers, as they could have had their own anxiety towards COVID, Tony experienced further social isolation from his peers. Although Tony did not discuss the incident or his feelings about this, he appeared to have experienced a period of social exclusion throughout the research and his emotional well-being was affected as he appeared quieter than usual and had more absences due to anxiety rather than just his chest infection.

Besides Tony, it is obvious that both Oli and Gordon's emotional well-being were affected by the negative comments from peers. Although Oli's kind nature was outlined earlier in the chapter when describing his ideology of the role of being good friends, a more negative side of his interpersonal skills was unravelled when discussing responses and actions towards unkind comments. In addition, Oli's experience also leads my findings to another main theme - Physical well-being (will be discussed in section 6.3), as Oli revealed that he wanted to become physically healthier and not wanting to be made fun of was the reason. Oli's escalation in behaviours caused by his peers' unkind words is apparent in the extract below, from a semi-structured interview:

*Chai: 'How do you respond to that when people make fun of you and poke your belly?'*

*Oli: '...I push them away most of the time. "*

*Oli: 'I just ignore him. But when I get to the next level, I'd say shut up but don't swear at him.'*

*Chai: 'Has it (Oli's belly being poked) got anything to do with you wanting to get fitter?'*

*Oli: 'Yes, they definitely do say "you have to lose some weight, mate. You are too chunky to do anything." That's honestly what they say to me.'* (Second interview with Oli, 21st Oct 2021)

Gordon, on the other hand, also suffered emotionally from the unkind behaviours from peers. However, the 'peers being unkind' to Gordon caused a lot of emotional fluctuations. The reasons why I chose to use the word 'fluctuations' is because Gordon's emotions were affected by the above adversely, to the extent that he was questioning whether he wanted to attend school H. For instance, Gordon felt less desire to attend school due to negative social experiences in June 2021, however felt positive about his peer interactions between the end of October 2021 and early November 2021. It was partly because Gordon accepted that 'name calling' is a mutual joke and no longer took offence to it during this period. When Gordon was able to process his peers' behaviours as a joke, he was able to digest it and consequently feel positive about his school experience. The quotes from the semi-structured interviews below show Gordon's emotion fluctuations:

*Gordon: I want to come in more often.*

*Nia: Why is that?*

*Gordon: People aren't being rude to me.*

*Nia: 'We talked about how you felt about coming into school back in June when we first started out session. Can you remember how you were feeling then?'*

*Gordon: 'I couldn't really be bothered about coming in.'*

*Nia: 'How are you feeling now about coming into school?'*

*Gordon: 'I like coming into school now. No one is being mean to me. No one is bullying me.'* (Fifth SEM&H session, conversation between Nia and Gordon, 07th Oct 2021)

*Nia: 'We talked about how you felt about coming into school back in June when we first started our session. Can you remember how you were feeling then?'*

*Gordon: 'I couldn't really be bothered about coming in.'* (Sixth SEM&H session, conversation between Gordon and Nia, 04th November 2021)



*Chai: 'And how's things at school since you have come back?'*

*Gordon: '..better. A lot of people have stopped, like, being rude to me... I have not had any stress when I got home because someone stepped on my shoes... Yeah. I still don't like people being rude to me. But if it's my friends, then we joke about and we call each other names.'* (Fourth interview with Gordon. 17th January 2022)

Despite Gordon's view on name calling with friends mutually, being called names continued to be somewhat a problem for Gordon, as another incident took place in February 2022, where Gordon discussed the fact that his peers called him a racist, and that Gordon generally received rude comments on a weekly basis. Besides being called names, and somewhat similar to Oli's experience, Gordon's physical appearance was also criticised by peers at school H. The experiences are shown below from conversations that took place in a semi-structured interview and a SEM&H session:

*Gordon: 'As like earlier, they're calling me racist, and all that when I wasn't being racist... Yeah like why are you doing that?'*

*Chai: 'How often are people rude to you?'*

*Gordon: I, like, sometimes a lot, a lot.*

*Chai: 'Let's try to quantify this...'*

*Gordon: 'Yeah. It does happen on a monthly basis, like a weekly basis.'* (Fifth interview with Gordon, 22nd February 2022)

*Gordon: '...he just commented on my shoes and said they're ugly... I just walked away. He also shouted at me when he was on the bus. He shouted "Nice high heels... they (staff at school H) weren't really doing anything about it. They were just standing there and talking.'* (Ninth SEM&H session, conversation between Gordon and Nia, 25th Nov 2021)

As mentioned above, people with ASD lack ToM, and are less likely to explain and predict actions of others (Lin, Keysar and Epley, 2010; Baron-Cohen, Leslie and

Frith, 1985). Although I was unable to unravel every single incident at the time of the research and determine if those unkind behaviours were purely Gordon's own perception or otherwise, the data suggests that Gordon's emotional well-being was adversely affected by unkind behaviours. According to Mrs Smith, (Gordon's mother), Gordon even changed his outlook as his likes and dislikes for clothing were criticised by peers. Furthermore, Mrs Smith raised concerns about Gordon changing his behaviour to improve his social acceptance, which can be seen below:

*Mrs Smith: '...obviously like his clothes and shoes, because he had been bullied in the past because of the items he liked that obviously other children didn't like...so Gordon prefers to wear tracksuits and trainers, and so we have lots of them in the house.'*

*Mrs Smith: '...I'm actually quite worried that he's going to be in the class with these specific children that he ain't gonna get no learning done because all he's going to be trying to do is, he's trying to prove that he's this tough person and I, I don't want him to be that kind of person.'* (First interview with Mrs Smith, 30th March 2022)

People with ASD are in need of social competence as they are presented with peer influence and social expectations, which could fester in different forms such as face-to-face confrontation or social manipulation (Khemka, Hickson and Mallory, 2016). Although there is no evidence to suggest that Gordon's peers pressured him into changing his behaviours or likes and dislikes, it is clear that Gordon was still influenced by his peers.

Regarding peer influence, Oli also received some pressure and some form of 'disapproval' from his peers on a romantic relationship that he had with a female student (SW) in addition to the physical appearance critique. During our first interview, Oli first reported that he was taunted by his peers because he liked a girl: '*They make fun of me that I like the girl at school. I like a girl at school...*' (First interview with Oli, 12th July 2021). During an SM&P intervention, Oli shared the news about his romantic relationship with Sally (The SM&P intervention leader) and he appeared to be excited as he expressed his desire to care for her; it was also noted that Oli appreciated SW's understanding nature, suggested that he prefers to interact with people who have a good and well demonstrated ToM ability.

*Oli: ‘...the weird thing is, it’s not weird, she (SW) likes me too... She is a bit down recently. I am gonna give her my number on Friday, so I said she can call, call, me when she’s down... I am doing a nice thing. I want to care for her [...] Oh yeah, specific reasons that she liked me, so I was handsome, which I get, I tell myself this everyday [...] She is very pretty, smart, and yeah she is understanding as well.’ (Sixth SM&P session, conversation between Oli and Sally, 18th November 2021)*

Following Oli’s conversation with Sally, he confided in me in an interview that the criticism received from his peers stems from the fact that SW was older than him. The criticism appeared to have been disheartening and frustrating for Oli, as he claimed that SW was older and liked him and there was nothing he could do about that. Unlike his response to the unkind comments received about his appearance, Oli showed a more mature approach when discussing the criticism received about his relationship with SW during a semi-structured interview:

*Oli: ‘...My friends said that I can’t like her because she is older than me. I’d say she is 5 years older than me. But yeah. But the thing is she likes me as well. So there’s probably not much I could do about that.*

*Chai: ‘So how did you feel about them saying that to you?’*

*Oli: ‘Well they can’t stop me from liking someone. It’s mainly Gordon. He keeps on telling me that I can’t like her because she’s 5 years older than me. But she likes you as well. What’s wrong about that?’ (Third interview with Oli, 30th November 2021)*

During an interview at a later stage, Oli also showed how he adjusted his social skills by adapting to different conversation topics:

*Oli: ‘...we (Oli and SW) have really been talking a lot.... she doesn’t really like that (games) much [...] Well I actually don’t talk about games that much, I just talk about like how I like my life and I guess just movies and football.’ (Fifth interview with Oli, 23rd February 2022)*

Oli has shown his resilience and perseverance here, as he continued to pursue his romantic relationship despite the unkind comments received from his peers. People with ASD struggle with social interaction due to their restricted interests and activities (American Psychiatric Association, 2013) However, Oli even took the opportunity to

make social adjustments when communicating with SW, to allow a more fluid conversation between them with common conversational topics.

All three student participants experienced some form of social exclusion. Whilst Tony received his social exclusion by simply not being included by his peers, Oli and Gordon both were somewhat rejected by their peers as they received criticism. In terms of the intervention impact, I would argue that the communication and interaction intervention had a direct impact on Tony. Firstly, the aim of the intervention is to improve the speech of Tony. It is evident that Tony's speech improved over my data collection period as shown through the fieldnotes and interviews.

Besides the difficulties with social interaction due to their restricted interests and activities, people with ASD also struggle in social conversations due to their lack of ability in asking questions (American Psychiatric Association, 2013; Koegel, Koplen, Koegel and Koegel, 2021 and Rogers, Hayden, Hepburn, Charlifue-Smith, Hall and Hayes, 2006)

Language acquisition including the use of spoken language plays a pivotal role in increasing social engagement; effective teaching strategies consisting highly motivating social games and object activities are commonly used to support speech and language acquisition (Koegel *et al.* 2021; Rogers *et al.*, 2006). Although Tony's improved speech may not spontaneously resolve the problem of social exclusion he was experiencing, the improved speech has a direct impact on his communication and interaction with peers in the long run. Without in-depth elaboration, Tony showed his recognition on the intervention impact on his speech through semi-structured interviews and conversations with Aaron during the C&I intervention, which can be seen below:

*Chai: '...What did you think about the activities you were doing?'*

*Tony: 'Okay.'*

*Chai: 'Are they helpful?'*

*Tony: 'Yeah.'*

*Chai: 'Okay. How do you feel? Do you feel that you are progressing?'*

*Tony: Yeah.*

*Chai: ‘...I just want you to think about how taking part in the activities in the sessions make you feel...?’*

*Tony: ‘It’s been helping me.’*

*Chai: ‘In what sense?’*

*Tony: ‘Helping with my speech.’ (First interview with Tony, 12th July 2021)*

*Aaron: ‘How do you think you have developed your Tony and C/K sound?’*

*Tony: ‘Developed well.’*

*Aaron: ‘Has anything helped the development of the sounds?’*

*Tony: ‘Yeah, holding my finger down.’*

*Aaron: ‘And when you press it down, it helps you to do what?’*

*Tony: ‘Yes, helping with my pronunciation and speech.’ (Eighth C&I session, conversation between Tony and Aaron, 19th November 2021)*

*‘...A talked about how much he was proud of Tony for following the strategy provided and how much clearer his diction had become...’ (Eighth C&I session, fieldnotes, 19<sup>th</sup> November 2021)*

*Aaron: ‘What about the way you pronounce the words? Does the strategy help?’*

*Tony: ‘I speak more clearly.’ (Ninth C&I session, conversation between Tony and Aaron, 16th December 2021)*

As mentioned in 4.8.3, Tony masks his conscious or natural response by being sarcastic and deflective. In chapter 5, I explored the risks of decontextualising data when handling a large participant group (Palmerberger and Gingrich, 2013), as well as Maxwell and Chmiel’s (2013) different take on how decontextualising data can be useful. I mentioned how student participants could potentially struggle with compartmentalising their views due to their needs and the complexity of the concept of QOL, and therefore decontextualising data could be seen as a means to elicit their views. As I have already explored how Tony’s answers in semi-structured interviews could be short and lack depth due to his social needs, Tony also suppress his conscious responses through autistic masking as a cope mechanism. Therefore, decontextualisation was crucial when it came to analysing the data collected from Tony. Despite the positive verbal feedback given by Tony about his improved speech, Tony also at times provided me with sarcastic comments, which can be seen below from a semi-structured interview:

*Chai: 'Has the improved pronunciation helped you express yourself better... so you, say if you are happy or upset, you want to talk to someone about it about certain things?'*

*Tony: 'Why would I want to talk to anyone?'*

*Chai: 'I don't know...'*

*Tony: 'I talked to myself.'*

*Chai: 'OK, you said that the technique with you holding your tongue down has helped you with your pronunciation and speech when you spoke to Aaron last time. Has your improved pronunciations helped you in life?'*

*Tony: 'No. I'm still I'm still living life.'*

*Chai: '...with a clearer speech in life; what are the advantages or disadvantages?'*

*Tony: 'There's no advantages.'*

*Chai: '...tell me how these sessions that you've been having with Aaron have been impacting on your quality of life in general...?'*

*Tony: 'Yes, I am awesome.'*

*Chai: '...Did the sessions make you even more awesome?'*

*Tony: 'No. Because I'm just awesome... I am already and 100% awesome?'*

*Chai: '...Could you not be 105% awesome?'*

*Tony: 'There no such thing as 105%, you can't go above 100%.'* (Fifth interview with Tony, 2nd February 2022)

The conversation above was decontextualised and interpreted as Tony recognised the positive impact the intervention had on his speech, however struggled to accept or admit this to me due to his needs. In addition to the improved speech, I have discovered another direct impact the communication and interaction intervention has on Tony in relation to this sub-theme. In the previous sections, I discussed how broadening Tony's experience on playing games with Aaron would indirectly impact on Tony in relation to the sub-theme: Playing on the console with peers. As Aaron continued to explore different games and activities with Tony, they started to build up a good rapport. I can conclude that the positive interaction between Aaron and Tony was crucial for Tony at the time of the research.

As mentioned above, during the pandemic people missed out on their routines and external support and hence lost opportunities to develop their communication skills (Kumazaki *et al.*, 2021; Vasa *et al.*, 2021). Although Aaron and Tony were not friends, they built up a good relationship with positive functions one could find in a high-quality friendship, such as emotional security and being a reliable alliance (Efeoglu and Sen, 2022). Tony has not confided in Aaron with any emotional burdens, however Aaron was consistent and reliable for Tony. Although the positive

interaction between Aaron and Tony could not replicate the absent interactions between Tony and his peers, the continuous positive reinforcement and exposure enabled Tony to continue to work on his interpersonal skills during this period in his life, when he was socially excluded.

Through interviewing and observing, it has become apparent that Tony and Aaron have a good relationship. Tony appears to have struggled more to admit that he had a good relationship with Aaron, over the improvement on his speech, as there were no verbal comments on how good Tony's relationship was with Aaron. However, through de-contextualising, I re-interpreted Tony's 'neutral' to 'negative' feelings towards Aaron. Words and phrases such as 'kind of' and 'I am not...' were used when asking about his enjoyment of the session and how good his relationship with Aaron was; however, they were all interpreted as camouflage:

*Aaron: 'Before we finish Tony, I just want to ask you a few questions about our sessions. Let's start off with today's session. Did you enjoy today's session today?'*

*Tony: 'Kind of.'*

*Aaron: 'Okay, I will take that.'* (Ninth C&I session, conversation between Tony and Aaron, 16<sup>th</sup> December 2021)

*Chai: 'You are bonding Aaron very well.'*

*Tony: 'I'm not bonding with him. Where did you keep that idea from?'*

*Chai: 'You managed to beat him playing naughts and crosses.'*

*Tony: 'That's it he's still trying to cheat.'* (Fifth interview with Tony, 2nd February 2022)

Despite the 'neutral' and 'negative' responses, a series of on-going 'accusations' were also exchanged between Aaron and Tony. The deficit in language skills in people with ASD can potentially affect their flexible thinking and understanding of humour and punchlines that can be interpreted in more than one way (Emerich, Creaghead, Grether, Murray and Grasha, 2013; Samson and Hegenloh, 2010). Humour is seen as an important tool in social interaction as a process of relationship building and expressing indirect messages (Emerich *et al.*, 2013; Samson and Hegenloh, 2010). Although there is no evidence to suggest that Tony acquired the skill to be humorous or understand jokes prior to the start of his C&I intervention, the

sessions provided him with opportunities to display and even develop this social quality of his. Tony believed that he was better at playing games than Aaron, and used a humorous way to indirectly express his belief. The games played in the intervention brought out the competitive nature of both Aaron and Tony, where they would mutually joke about cheating and being the loser.

*Aaron: 'Are you any good?'*

*Tony: 'Yes I am.'*

*Aaron: 'What usually happens when I play?'*

*Tony: 'You cheat. And you would get disqualified. You always cheat and I always catch you.'*

*Aaron: 'It is because I won five times in a row, you thought something was not right. I didn't cheat but let's agree to disagree.'*

*Tony: 'You chucked some cards on the floor!'*

*Tony: 'You cheated!'*

*Aaron: 'That's okay that you lost today. We can play again. Today's session is all about teaching you to be a good loser.'* (Third C&I session, conversation between Tony and Aaron, 12<sup>th</sup> July 2021)

*Tony: 'That's it he's still trying to cheat.'*

*Chai: 'He's still trying to cheat, but you managed to beat him, so you have got more out of just speech?'*

*Tony: 'No I haven't.'*

*Tony: 'I have beat him before.'*

*Chai: 'You walked out of the session with a victory. Didn't you walk out of the session with a victory?'*

*Tony: 'I always walked out with a victory.'* (Fifth interview with Tony, 2nd February 2022)

All the examples above suggest how good the rapport between Aaron and Tony is. As mentioned above, I am aware that the good rapport and the positive interaction between Aaron and Tony do not replicate the absent peer interactions, however, Aaron provided Tony with emotional security and being a reliable ally, which are positive functions that can be found in a high-quality friendship (Efeoglu and Sen, 2022). Furthermore, the intervention allowed Tony to continue to directly develop his interpersonal skills through the interaction opportunities fostered, including the use and understanding of humour.

On the other hand, the sensory, motor and physical intervention has also had a direct impact on Oli relating to this sub-theme: unkind behaviours from peers. Oli



experienced criticism on his physical appearance and his relationship with his older girlfriend. In response to the criticism Oli received on his physical appearance, the aim of the intervention directly related to this as Oli had progressively become fitter, and therefore led to the reduced taunting from peers. Oli also indirectly confirmed the effectiveness of the intervention on helping him lose weight when stating how his partner did not notice his transformed physique, as it can be seen in the quote below:

*Chai: '...You mentioned a few things...Not liking people poking your belly, not liking people calling you fat...So tell me if the sessions affected the situation with the belly poking and name calling situation?'*

*Oli: 'Uh, yeah, it's definitely, definitely has helped...I have told R to stop doing it and he stopped doing it (poking Oli's belly).'*

*Chai: 'Yeah, let's focus on how the sessions have affected the situation.'*

*Oli: 'I'm definitely getting a bit more slimmer and no one calls me fat anymore.'*

*Chai: 'OK, that's, that's good and tell me if the sessions affect your relationship with SW.'*

*Oli: 'Not really, she, not really she doesn't not, she doesn't really notice me getting slimmer.'* (Sixth interview with Oli, 29th March 2022)

The SEM&H intervention also has direct impacts on Gordon relating to this sub-theme, as it supported Gordon with his emotional regulation strategies throughout Gordon's negative experiences from his friendships this will be further explored under theme 3.

So far, I have outlined what 'Peer interactions' mean to all three participants through outlining their views on social well-being and friends, identifying and elaborate sub-themes including 'Playing football with peers', 'Playing on the console with peers' and 'Unkind behaviours from peers'. As mentioned at the start of this section, the general consensus across three participants is to gain friends that are trustworthy and to be able to have a positive social experience with peers.

The theme 'Peer interaction' appears to play an important part across all three participants' life. As mentioned at the start of the chapter, the findings from my research indicate that participants are not concerned about their social involvement in a larger scale, as suggested by Flanagan (1978) and Felce and Perry (1995). In

summary, all three student participants desire friends and a positive social experience. Whilst Oli and Gordon focus more on the quality of friends, with Oli being specifically descriptive, Tony focuses more on the quantity of friends. This can be explained by the fact that Oli and Gordon both have experienced unkind behaviours from peers, and therefore, in their opinion, the quality of friends matters more. Whereas Tony's interpersonal skills are less advanced, and that purely gaining friends is his desire. This was reflected by his comments on how he planned to make more friends through friends.

Since my research does not aim to compare the QOL or the social well-being between CYP with SEND and their typically developing peers, my research findings cannot be compared to Svekles *et al.* (2010) and Arias *et al.* (2017). However, my findings do suggest that all three participants experience difficulties with social acceptance, social inclusion and interpersonal skills to a certain extent. All three participants struggle with different peer interaction elements to varying degrees. For instance, Oli was at the stage of exploring friendship through football and consoles at the time of the research. In addition to the conflicts arising from the peer interactive activities above, he also struggles with handling criticism on his romantic relationship and his physique. Whilst he handled the former more maturely, he reacted more negatively towards the latter. Tony naturally had fewer unscaffolded peer interactions due to his social skills. Moreover, he experienced further social exclusion due to a chest infection. Although he did not express dissatisfaction with his experience, his social well-being was affected negatively. Finally, Gordon struggled with handling conflicts caused by playing football and unkind behaviours from peers due to his understanding of social boundaries more than conflicts caused by playing on the console with peers due to his advanced e-safety skills. Moreover, Gordon was also socially rejected by peers from his previous school and School H, due to his level of social boundaries being incompatible with peers at times and his fashion preference being criticised.

It is clear that there are impacts from each intervention, despite some being direct and vice versa. Since none of the interventions focus solely on playing on the console with peers, there were less direct impacts found in the interventions. However, the

discussion-based nature of the SEM&H intervention covered conversations on Gordon's experience in this respect and hence direct impacts were easily identified. On the other hand, the self-regulation strategies and emotion labelling exercises from the SM&P and SEM&H intervention respectively also contributed towards empowering Oli and Gordon when dealing with conflicts arisen from playing football with peers. Although the underlying reasons behind why Tony does not enjoy playing sports with peers are complex, he managed to build up his resilience through experiencing the process of winning and losing during the intervention. Finally, all three interventions are found to have direct impacts on participants when discussing the last sub-theme – Unkind behaviours with peers. The aim of the S, M&P intervention is to improve the physical health of Oli, and therefore, it affected Oli's social well-being as he received less criticism on his physique following his body transformation. Similarly, The aim of SEM&H intervention is to provide Gordon with a safe space to discuss his emotions, especially around peer interactions, and therefore, it directly contributed towards Gordon's ability to handle unkind behaviours from peers. It is certainly worth noting that the good rapport between Tony and Aaron, and Oli and Sally was also a key factor in this instance. Whilst Tony was experiencing unkind behaviours from peers, Aaron continued to support him to build up his speech to equip him for future peer interactions. At the same time, Aaron also managed to build up positive social interaction with Tony during the absence of peer interaction in his life at the time of the research. In a similar manner, Oli also felt comfortable to confide in Sally and discussed his relationship with SW and how his peers were being unkind – it enabled Sally to have the opportunity to acknowledge his feelings and respond to him. Therefore, I can conclude that the initial aims of the intervention play a key role in the impact on the participants' QOL. Furthermore, having a good relationship between participants and their respective intervention leader can also foster extra opportunities to explore or even develop further 'unplanned' areas, which could lead to further impacts on participants' QOL. A few links between 'Peer interaction' and the next theme – Physical well-being, were made, including some participants' football competency as well as Oli's desire to get fitter. In the next section, I will highlight connections between the background literature on Physical Health of CYP with SEND and the participants, explore their views on physical health and elaborate on the main theme through discussing the sub-themes that emerged as the impacts from the interventions.

## 6.2 Physical well-being

As discussed in chapter 2, Physical well-being has been regarded as a QOL domain in the current literature (Flanagan, 1978; Felce and Perry 1995; WHO, 1997; Schalock and Verdugo, 2022; Rice, 1984). Not only has the literature widely used physical well-being when discussing QOL, Rice (1984), Bonk (2016) and Williams (1993) also highlighted its importance. For instance, Rice (1984) simply identifies QOL as one's physical and psychological wants and needs. Similarly, Bonk (2016) suggests that people with less physical ability experience limited/reduced functional independence and overall QOL. Williams (1993) highlighted the importance of physical well-being, alongside emotional well-being in one's life quality as those who experience frustration, anger and fatigue have poorer QOL. My findings related to Williams's (1993) stance; for instance, Gordon's social activity (console playing pattern, as discussed in section 6.2.2) directly concerns his physical health, and he was therefore made aware of the balance between his social and physical well-being, as well as his emotional well-being.

The literature suggests that the physical well-being and social well-being of CYP with SEND are similar, as they are both lower than average (Svekle *et al.*, 2010; Thurston *et al.*, 2010 and Arias *et al.*, 2017). The findings of the research of Svekle *et al.* (2010) and Thurston *et al.* (2010) suggest that the physical well-being of CYP with SEND is lower than their neurotypical peers. Arias *et al.* (2017) highlight that the physical well-being of CYP with higher needs is worse than participants with less complex needs. The Good Childhood Report (2023) also stated that CYP with SEND were about twice as likely to be unhappy with their health compared to their typically developing peers.

As stated in section 6.2, when exploring the first theme, the aim of my research is not to compare CYP with SEND to their typically developing peers. Rather, my findings indicate student participants' views on the importance of Physical well-being and their desire to improve it through different platforms due to different reasons. However, Gibbs and Priest (2010) acknowledge that people with SEND have higher rates of obesity than their neuro-typical peers. Messent, Cooke and Long (1998) investigated the lifestyle of 24 adult participants with mild and moderate learning

difficulties, and the results have shown that over 50% of the male participants and over 70% of the female participants were overweight. Patience (2018) pointed out that adults with SEND are considerably more likely to be obese. In addition to the health element from being obese, Lee *et al.* (2019) also highlight the importance and effectiveness of achieving a healthier weight and body image through understanding the rationale behind regular exercising in daily life and practising physical activities such as aerobic and anaerobic exercises and exploring different sports. This is especially relevant to Oli, as his physical appearance also directed affected his social well-being. Weight management is an individual process, and exercising and dieting are two key elements that promote the success of the goal (Patience, 2018). Messent, Cooke and Long (1998) further identify the sustainability of different exercises, as cycling on an ergometer, treadmill and running track are not generally sustainable. Exercising to control the weight with people with SEND should be tailored to the preferences and needs of the individuals, which promotes enthusiasm and regularity (Messent, Cooke and Long, 1998). Following the discussion on the first sub-theme of this theme, where participants reviewed their physical well-being, another sub-theme emerged as the desire and plans to improve physical fitness (as opposed to health), which will be explored in the following sections.

McPherson *et al.* (1998), Jee *et al.* (2006) and Szilagyi *et al.* (2015) point out that CYP with SEND are more likely to experience physical and health related issues. Brown and Schormans (2014) suggest that CYP with SEND are at risk of physical negligence and hence poorer QOL. Hibbard and Desch (2007) explain that maltreatment of CYP with a range of spectrum including physical impairment is a critical issue. Despite the literature mentioning cases of maltreatment or negligence, throughout this research, student participants have not disclosed any forms of maltreatment or negligence and therefore, it was not an area I focussed on. The next sections first explore the student participants' views on Physical well-being and the impact of physical fitness on physical well-being. Moreover, I will also outline the impact the interventions have had on the student participants under each sub-theme.

### 6.2.1 Student participants' views on physical Well-being

There is a clear mutual consensus when all student participants expressed their views on physical well-being. The stance from all three student participants is in line with Patience (2018), as they discussed the importance of having a good diet as a means to maintain physical health, and that healthy eating plays an important role in maintaining good physical well-being. Gordon and Oli both articulated their views by suggesting the types of food required in order for one to keep their physical well-being. Whilst Tony did not suggest what a healthy or unhealthy diet consisted of, he shows an awareness that unhealthy diets cause poor physical well-being, without further elaboration. Student participants had similar perspectives on what physical well-being entails, mostly related to healthy eating. This can be found below from the interview quotes:

*Chai: '...what defines healthy food?'*

*Oli: 'I usually eat quite a lot of fruit like apples and bananas... like vegetables. Or fruit. Yeah, quite a lot of healthy food like a roast dinner or something.'*

*(Fourth interview with Oli, 18th January 2022)*

*Chai: 'Can you tell me a little bit more about ...being healthy...?'*

*Gordon: 'Healthy like. In well shape and not eating stuff I shouldn't? Maybe healthy eating?'*

*Chai: 'OK, let's start with first one - eating.'*

*Gordon: 'Well'*

*Chai: 'What do you mean by eating well?'*

*Gordon: 'Healthy stuff, you know...salads.'* (Fourth interview with Gordon, 17th January 2022)

*Tony: '...unhealthy diets.'*

*Chai: 'What would happen to someone if they have an unhealthy diet? What is going to happen to your body?'*

*Tony: 'Nothing.'*

*Chai: 'Nothing? Why would it be a bad life?'*

*Tony: 'It just is.'* (Fourth interview with Tony, 17th January 2022)

The feedback from most student participants was again, in line with the guidance from Patience (2018), as Tony and Gordon also discussed how fitness and exercising are another key factor to good physical well-being in addition to having a good diet. Similar to the discussion regarding diets, Tony expressed his views by stating that exercise is important for one in order to have good physical well-being.

However, no further elaboration was made on the stance, which is evident in the interview quotes below:

*Chai: 'Can you talk about what good physical well-being looks like?'*  
*Tony: 'Just exercise.'*  
*Chai: 'Anything in particular? Like football? Basketball?'*  
*Tony: 'No.'*  
*Chai: 'So why do you think lots of exercises lead to good physical well-being?'*  
*Tony: 'It just does.'*  
*Chai: 'What does exercising do to one's body?'*  
*Tony: 'How am I meant to know?'* (Fourth interview with Tony, 17th January 2022)

In comparison, Gordon was more articulate as he describes how one needs to stay in shape to maintain good physical well-being and lifting weights and exercising more often were some activities that he mentioned. In section 6.2.4, I discussed a range of unkind behaviours all student participants encountered, and highlighted that the self-esteem and social well-being of people with SEND can be affected by being overweight (Lee *et al.*, 2019). Although Gordon has not disclosed such an experience before throughout the research, he felt very strongly about staying in shape. To conclude, being strong and avoiding being unfit or overweight is Gordon's idea of being physically healthy, which is shown in the quote below:

*Chai: 'When you say, say in shape, do you mean like physically? Like you can see if someone is in shape, or you feel like you're in shape? Or both?'*  
*Gordon: 'Oh like stay [sic] in shape.'*  
*Chai: '... How in shape are we talking about here?'*  
*Gordon: 'I don't know.'*  
*Chai: '...Like what would you say if someone is in shape? What should that person be able to do?'*  
*Gordon: 'Like lifts [sic] weights, exercise more often... if they're like really strong, then they should lift heavy.'*  
*Chai: 'How unfit are we talking about...?'*  
*Gordon: 'Fat.'*  
*Chai: 'Fat, define fat.'*  
*Gordon: 'Um, someone who eats a lot. Haha, I don't know...I've never been fat.'* (Fourth interview with Gordon, 17th January 2022)

In section 6.2.4, I discussed how Oli was taunted by his peers due to his physical appearance (his protruding stomach), how he changed his attitude from escalating his behaviours to respond to his peers in October 2021, to handling the situation more positively after realising the impact from the SM&P sessions in March 2022. On

the contrary to Gordon's stance, Oli described poor physical well-being could be caused by under eating, such as one not having food and as a result feeling sick and hungry. It appears that Oli's stance of physical health has been affected by his own experience when his physical appearance was taunted, which can be seen in the interview quotes below:

*Oli: '...I push them away most of the time. "*

*Oli: 'I just ignore him. But when I get to the next level, I'd say shut up but don't swear at him.'* (Second interview with Oli, 21st Oct 2021)

*Oli: 'Uh, yeah, it's definitely, definitely has helped...I have told R to stop doing it and he stopped doing it (poking Oli's belly).'*

*Oli: 'I'm definitely getting a bit more slimmer and no one calls me fat anymore.'* (Sixth interview with Oli, 29th March 2022)

*Oli: 'You're basically like sick and you have no food...so basically, if you're sick and, and you're like really hungry...it's a bit like hungry sick...if there's no food in the house... that's not really gonna help your system.'* (Fourth interview with Oli, 18th January 2022)

So far, all three student participants' views on physical well-being are in line with Patience (2018) and Messent, Cooke and Long (1998), as the topic around diet was discussed when asked about physical well-being. Tony and Gordon moved onto discussing further on physical exercise as another means to maintain physical health. Further to discussing their views on physical well-being, student participants also shared their review on their physical well-being, which ties into the next sub-themes including their 'Plans and desire to improve physical well-being and 'Emotions stemming from physical well-being. In section 2.2, when I discussed the topic on objective and subjective QOL, I also explored Schalock's (2010) stance on how subjective self-report and proxy observations and measures should both be obtained when reviewing their own QOL. In chapter 3, I gave justification as to why having proxy report was important as a part of my reflection on this research. The proxy data was found to be useful when collecting data for this theme, as the parent of the participants provided further insights into the physical health of participants.



It appears that all three participants' perspective on their interviews indicates that they perceived that they had good physical well-being at the time of the research. They also suggested the reasons why they believe they have a physically healthy life and also in line with their views on what good and bad physical well-being represents. There were slight discrepancies from my observation in the field. Therefore, the proxy data was another means to support with the information gathering and the data analysis process. For instance, Tony believes that he eats healthily as a means to maintain his physical well-being, which can be seen in the quotes below:

*Chai: 'So how is your physical well-being? ...So you say that I eat quite healthily... So what do you eat?'*

*Tony: 'Eat healthily.'*

*Chai: 'What food do you eat?'*

*Tony: 'Healthy food.'*

*Chai: 'Give me an example.'*

*Tony: 'Food.'* (Fifth interview with Tony, 2<sup>nd</sup> February 2022)

My observations from the field suggest that Tony's eating was minimal during lunch breaks, which was different to what he claimed in his interview with me. I observed him spending time reading a book during lunch when he was in his classroom when the weather was rainy, and on another occasion, I observed him eating limited amounts of food when in the lunch hall with the rest of his peers. This can be seen from the observational fieldnotes below:

*'Following the wet-break, the weather was still rainy so all pupils stayed in their class to have lunch. Tony had his eyes on his fictional book during lunch for the whole time, however, he did not eat much at all. He spent his lunch time reading rather than eating, and his lunch was mostly untouched, with him having a bite in between 2-3 pages of his fiction.'* (Fieldnote, conversation between Tony and one of his classmates, 4th November 2021)

*'The lunch hall was very busy with school staff heating up lunch and pupils socialising while eating. I saw Tony sitting with one of his friends at his table and looking at his lunch for a prolonged period of time. I stood in the corner to observe for about 5 minutes, and he only took 2 bites of his food so far – he*

*was not eating much.*' (Fieldnote, Tony's activities during lunch time, 4th February 2022)

Further to my observations, I also interviewed Mrs Conor (Tony's mother) about Tony's physical health condition, who stated that she did not agree with Tony regarding his healthy eating habits, as he often did not eat. Also, somewhat in line with Tony's self-evaluation, Mrs Conor suggested that Tony was aware of the definition of healthy and unhealthy, however, she believed that Tony was not very healthy. Mrs Conor's proxy views can be seen in the semi-structured interview quotes below:

*Chai: 'What's Tony's views on physical health?'*

*Mrs Conor: 'He is aware of what is healthy and unhealthy. He is also aware that he is not very healthy!'*

*Chai: 'What doesn't Tony do enough to maintain his physical health? Why is that?'*

*Mrs Conor: 'Eating limitations is the main area of concern...'* (First interview with Mrs Conor, 4th September 2022)

From the above, it is evident that Tony is aware of the importance of healthy eating in relation to maintaining physical well-being. Despite his claim of eating healthily, he was unable to provide further details. In addition to the information provided in section 3.5.3 on Tony's profile, my observations and Mrs Conor's interview both suggest that Tony limited the amount of food he ate. It appears that the guidance provided from Schalock (2010) on the use of proxy report is beneficial to this research, as I was able to unravel another layer beyond Tony's perspective on his own physical health. Similar to Tony, Oli also suggested that he is a healthy individual with a healthy diet. He provided me with more information on the outlook of his diet, which mainly included fruits. His stance can be seen from the extract below:

*Oli: 'I do usually eat watermelon quite a lot, and apples, bananas... I would say I'm pretty healthy.'* (Fifth interview with Oli, 23rd February 2022)

Mrs Zane (Oli's mother) agreed with Oli that he was healthy by indicating that she did not see any issues with his physical well-being. Mrs Zane also revealed that she educated Oli about the importance of healthy eating as she states in the extract below:

*Chai: '...would you say he's having a good, average or bad... (physical) well-being?*

*Mrs Zane: 'Good, I don't see any issues with it to be honest.'*

*Mrs Zane: 'Well... I've tried to explain to Oli that... your physical well-being has got a lot to what you put into your body to start with...'* (First interview with Mrs Zane, 27th March 2022)

Unlike Tony's perspective on his eating habits, which contrasted with his mother's views, Oli and Mrs Zane's views were in line, and they both believed that Oli had healthy eating habits. As explored in theme 1, Oli received negative comments from his peers about his physical appearance and had worked on this aspect through his intervention, and it also appears that Oli was more aware of the impact eating could have on one's physical well-being and maintained a healthy diet. Similar to Tony and Oli, Gordon also confirmed that he had a healthy diet. However, out of all three student participants, Gordon was able to provide me with the most information on foods and their nutritional values, as he was able to highlight how he could gain protein from eating chicken and the function of protein in a contextual way, which is highlighted in the quote below:

*Chai: 'How you feel about your physical well-being?'*

*Gordon: 'Very healthy, doing healthy things, and living great.'*

*Chai: 'Do you think you are very healthy? ... What do you eat in order for you to say you eat well?'*

*Gordon: 'Protein... Chicken.'*

*Chai: 'And what does protein do?'*

*Gordon: 'Build muscles.'* (Fifth interview with Gordon, 22nd February 2022)

My observations also suggest that Gordon has a protein heavy diet. On two occasions when I observed him in a context of eating, he chose to have chicken, with him telling me the rationale behind choosing to eat chicken during one of the observations:

*'Gordon and his peer were invited to have lunch with me as they wanted to resolve the [sic] conflicts. When I asked Gordon what toppings he would like on his pizza, he smiled and told me chicken was his choice.'* (Fieldnote, having lunch with Gordon and his peer, 25<sup>th</sup> June 2021)

*'The lunch hall was packed with students from Key Stage 3 formal department, they were all eating very quickly as everyone appeared to be ready for their lunch activities after their lunch is finished. Gordon had a chicken sandwich, and I asked him if it was enough for him, he responded by saying that it was a quick and easy protein heavy lunch. (Fieldnote, Gordon in the lunch hall before his football time, 24<sup>th</sup> January 2022)*

From a proxy point of view, Mrs Smith's (Gordon's mother) perspective also falls in line with Gordon's own perspective and my observations of Gordon's eating habits, as she felt that Gordon had a healthy food intake. In fact, through the interview quotes, Mrs Smith stated that she thought that Gordon's physical well-being was way above average:

*Mrs Smith: 'He has, uh, a healthy food intake... I think his physical well-being is on the top end.'* (First interview with Mrs Smith, 30th March 2022)

So far, all three student participants identified themselves as having a healthy diet. However, my observations and proxy feedback suggest otherwise for Tony, due to his limited food intake. All other data sources complement Oli and Gordon's evaluation of their eating habits. Besides a healthy diet, exercising was also deemed as another way to maintain one's physical health according to the student participants. Comparing Tony's views on his eating habits, Tony clearly identified that he did not do a lot of exercise. He further explained that he did 'fun' activities instead of exercising, without specific examples. Messent, Cooke and Long (1998) argue that exercising should be tailored to the preferences and needs of the individuals with SEND. Consequently, although Tony may have not considered the 'fun' activities as exercising, some of these activities could be seen as a form of exercise. This can be found in the below interview quotes:

*Chai: 'So you say... "I don't do a lot of exercise." ...So what do you do?'*

*Tony: 'Stuff.'*

*Chai: 'What stuff?'*

*Tony: 'Something that is fun.'* (Fifth interview with Tony, 2<sup>nd</sup> February 2022)

In theme 1, I explored how some student participants used sports as a means to socialise with their peers. Tony revealed that he did not like P.E., then Mrs Conor

further explained that Tony did not have positive feelings associated with P.E. due to his previous traumatic experience:

*Chai: 'What don't you like in general?'*

*Tony: 'P.E.'*

*Chai: '...Can you explain why you don't like it?'*

*Tony: 'I just don't like it.'* (First interview with Tony, 12th July 2021)

*Mrs Conor: 'He definitely does not like PE... it stems from some traumatic experiences when he was in mainstream school... I do not think he has any positive association with PE.'* (First interview with Mrs Conor, 4th September 2022)

Through further conversations with Mrs Conor, a clearer picture was portrayed, as Tony would engage in sports activities as long as they were things that he would enjoy, such as swimming, walking, playing in the park or playing football with friends and families. In addition, Mrs Conor also suggested that Tony's exercising pattern was inconsistent as he would take sports to an extreme, which exceeded his capacity, as she explains in the quote below:

*Chai: 'What's Tony's views on physical health?'*

*Mrs Conor: 'He is aware of what is healthy and unhealthy. He is also aware that he is not very healthy!'*

*Chai: 'Does Tony do anything to maintain or improve his physical health? If so, what does he do?'*

*Mrs Conor: 'When in the right mind set, he will choose to do physical activities, sometimes to an extreme, for example cycling on the exercise bike for an hour, swimming until he is shaking with exhaustion... He will happily swim, go for a walk with friends and family.'*

*Mrs Conor: '...he would play in the park with family/family friends outside of school though but I have only seen him play football with family.'* (First interview with Mrs Conor, 4th September 2022)

Similar to what Messent, Cooke and Long (1998) suggested, interests and preferences are important when it comes to exercising, and Tony also has the ability to choose to take part or not based on his interests and preference. Despite Tony's engagement with different forms of exercising, it appears that he did not always know his limits. From my observation, Tony decided to join in a group dodgeball game with persuasion from staff at School H. It also appeared that the nature of the

exercise did not interest him as much as the social element, which brought out his competitive nature. Despite not staying in the dodge ball game for an extended period of time, Tony did take part. This can be found in the observational fieldnotes below:

*'...staff members changed their tactics and encouraged Tony to join again by telling him that it would be the best opportunity to hit staff with a ball without consequences. The competitive nature of the conversation successfully motivated Tony and he took part in the end. Although he did not stay in the game for long before getting hit by a ball, I was impressed and surprised that Tony took part.'* (Fieldnote, dodgeball match during activity week, 19<sup>th</sup> July 2021)

While Tony's exercise habits are more complex, due to his previous experience and the lack of awareness of his limits, both Oli and Gordon demonstrated an interest in exercising. Oli stated that he was satisfied with how active he was. Meanwhile, he was also very reflective and stated that he only played football, as he either disliked other sports or never tried them:

*Oli: '... I would say I'm always active and I love to play football quite a lot. Most of the other sports I don't really play like basketball, tennis, cricket, golf well, I have never played golf in my life...'*

*Chai: Are you satisfied with how active you are?*

*Oli: 'Yes I am.'* (Fifth interview with Oli, 23rd February 2022)

Through interviewing, Mrs Zane also agreed that Oli did not have an issue with his physical well-being and that he liked playing football. However, Mrs Zane also felt that Oli could benefit from more physical exercises. This can be seen below:

*Mrs Zane: 'He likes playing football...'*

*'Mrs Zane: '...So in order to change how you appear to somebody, your physical well-being, you have to change sometimes what you do, as in you do more exercise.'* (First interview with Mrs Zane, 27th March 2022)

Oli felt that he did not like other types of physical activities other than football, and that Mrs Zane believed Oli could benefit from taking part in more physical exercises. However my observations suggest that Oli was introduced to and willing to try different physical exercises, as he showed an open-mindedness to a range of activities, including both fine and gross motor skills based exercises. In addition, he asked for further opportunities and challenged himself on two occasions observed, which can be seen from fieldnotes below:

*'...Although Oli hasn't fully grasped the concept of the specific muscle groups he's working on, he certainly shows an understanding on parts of the routine through predicting, and he also certainly enjoys the sessions as he stated...'* (Fieldnote, first SM&P intervention, 27<sup>th</sup> May 2021)

*'...Sally managed to work on his fine motor skills and used the step machine and the resistance bands attached for Oli to work on his gross motor skills. Oli really enjoyed the finger exercise...'* (Fieldnote, Sixth SM&P intervention, 20<sup>th</sup> January 2022)

*'Oli responded to Sally's suggestion about the abdominal muscles very positively. It was a short session, but Oli managed to complete all tasks. Oli particularly enjoyed the kick out as he asked to have one more go after he was asked to have his final go.'* (Fieldnote, Seventh SM&P intervention, 2<sup>nd</sup> March 2022)

*'Oli showed good resilience in this session, as he didn't always succeed when trying the exercises. With certain tasks, he exceeded the expectations by challenging himself further.'* (Fieldnote, Eighth SM&P intervention, 24<sup>th</sup> March 2022)

It appears that, further to the evaluation from both Oli and Mrs Zane, Oli does have a good attitude towards trying different exercises. Although Oli felt that he did not enjoy taking part in most exercises, he did show an interest in the exercises he took part in during his intervention. On the other hand, Gordon clearly outlined his workout routine he followed to build muscles, which complemented his protein-heavy eating

diet. Gordon articulated with details as he mentioned the tailored exercises he did to work on specific muscle groups, which can be seen in the interview quotes below:

*Gordon: ‘(I am) very healthy, doing healthy things...’*

*Chai: ‘... How are you very healthy?’*

*Gordon: ‘Being well and staying fit.’*

*Chai: ‘What do you mean by staying fit? How often do you exercise?’*

*Gordon: ‘Three times a week.’*

*Chai: ‘What exercises do you do?’*

*Gordon: ‘Bicep curls, push ups, sit ups.’*

*Chai: ‘Any particular muscle groups? That you're building up?’*

*Gordon: ‘Biceps, and my triceps.’* (Fifth interview with Gordon, 22nd February 2022)

During an observation, I also witnessed Gordon’s attitude towards fitness as he showed resilience during one of his P.E. sessions, where he had to adapt his skills to an exercise that he was not very used to. Instead of complaining about the change of activity due to the weather, Gordon took the challenge seriously and showed perseverance throughout, which is evident from the fieldnotes below:

*‘Due to the rain today, Gordon’s P.E. lesson was moved from outdoor to indoor, and the lesson plan subsequently changed from competing in football to indoor Gaelic football. Most students complained about the lack of intensity of Gaelic football at first, however, they looked exhausted after just the first 5 minutes. The P.E. teacher told students to transfer their football passing and positioning skills to their Gaelic football, where Gordon worked hard to adapt and did not give up easily. His team won in the end, and he scored most of the goals.’* (Fieldnotes, Gordon taking part in a Gaelic football match during P.E., 4<sup>th</sup> March 2022)

In line with Gordon’s own perception and my observations, Mrs Smith also emphasised the amount of exercises Gordon managed on a regular basis. It also appeared that Gordon’s diet provided him with the required energy for his exercise habits, which can be seen below from the interview quotes:

*Mrs Smith: ‘He enjoys working out in the gym. He enjoys going out on bike rides.’*



*Mrs Smith: ‘...He gets lots of exercise because he has got so much energy to burn.’ (First interview with Mrs Smith, 30th March 2022)*

So far, all three student participants’ perspectives combined with my observations and the proxy views have provided me with a clearer picture of the quality of the physical well-being.

Firstly, there are discrepancies between Tony’s own perception and my observations as well as Mrs Conor’s proxy views provided. Where Tony felt that he is somewhat healthy due to his eating habits and recognised his downfall as exercising, Mrs Conor suggested that both aspects are negatively affecting Tony’s physical well-being as he was not eating enough, and his exercising routine was inconsistent. My observations suggest that Tony has the ability to join in sport activities, when they are aligned with his interests. Whilst Oli and Mrs Zane both agreed that Oli’s physical well-being is generally good, Mrs Zane still believed that Oli needed to exercise more. However, based on my observations, it appears that Oli’s enthusiasm towards exercising and trying new exercises was not noticed through both Oli and Mrs Zane’s reflection as Oli took part in all the exercises enthusiastically. Mrs Smith’s perception complements Gordon’s own views, as his diet and exercise routine provide him with good physical health. My observation also further suggests that he showed good resilience on an occasion when he was asked to take part in a sport activity he was less familiar with. I now move onto exploring the impact each intervention had on the student participants in relation to the evaluation of their physical health.

As mentioned in section 3.6, the SM&P<sup>5</sup> intervention provided Oli with ample opportunity to reflect on his physical well-being through challenging his fitness on a regular basis, and therefore had a direct impact on Oli. In addition to the exercises undertaken in the intervention, Sally also regularly provided Oli with feedback as well as opportunities to self-assess his own progress. Therefore, Oli has gained a better understanding of his own physical well-being through exercising in the intervention and feedback given. The evidence is shown below from the conversations that took place during the interventions:

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<sup>5</sup> Sensory, motor and physical

*Sally: 'I would like to have a baseline, so that I know how many you can do and I can set you some goals. Let's see if we could start with 10.'*

*Oli: '10, sure.'*

*Sally: '1, 2, 3, 4 and stop. How was it?'*

*Oli: 'It was good.'*

*Sally: 'Do you think you can do another 2?'*

*Oli: 'I can do 3 more if you want.'*

*Sally: 'Okay, 5, 6, 7, 8, 9 and 10. Amazing! Would you like to turn around and do some squeezing?'* (Eighth SM&P session, conversation between Oli and Sally, 24th March 2022)

*Sally: 'Let's move onto doing some balancing'*

*Oli: 'Yeah sure.'*

*Sally: 'Hold on for 5 seconds before rolling back.'*

*Oli: 'I am good for longer.'*

*Sally: 'Whoops, you collapsed.'*

*Oli: 'Yeah my arms are weak.'*

*Sally: 'Let's climb back up using your arms slowly. Now hold on for 3 seconds.'* (Fourth SM&P session observed, conversation between Oli and Sally, 11th Nov 2021)

*Sally: 'Good. We are going to do five of these.'*

*Oli (after completing all five repetitions): 'I suck at this. I need to get into position.'*

*Sally: 'Exactly, let's get the position right...Shall we do one more?'*

*Oli: 'Yeah.'* (Third SM&P session, conversation between Oli and Sally 24th June 2021)

Unlike the SM&P intervention, the aim of the SEM&H <sup>6</sup>intervention focuses on interpersonal and social skills. Although the topics around physical well-being were unrelated to Gordon's own reflection areas – dieting and exercising, as the discussions took place in the SEM&H sessions were focused on sleep and caffeine in-take from coffee, the intervention appears to have had a clear and direct impact on Gordon's physical well-being. In theme 1, I already briefly discussed how Nia influenced Gordon to think about the conflict of interest between his desire to maintain his social well-being and his physical well-being, which can be seen in the conversation between Gordon and Nia below during the intervention:

*Nia: 'We talked about sleep previously didn't we, how is it going?'*

*Gordon: 'It has been regular, apart from Saturdays.'*

*Nia: 'What happened on Saturdays?'*

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<sup>6</sup> Social, emotional and mental health

*Gordon: 'I play on the Xbox with my friends until late... until 5.'*

*Nia: 'Wow, that's really late'*

*Nia: 'It is about balance isn't it. You want to have that contact with your friends. You also want to have that life goal in mind. Because who knows where you are going, where your friends are going – the main thing is to look after you. You are running your own show.'*

*Nia: 'I just want to say that staying up until 5am is really really late.'*

*Gordon: 'Is it really?' (Smiling) (Seventh SEM&H session, conversation between Gordon and Nia, 11th Nov 2021)*

In addition, Gordon also revealed the extent of his electronics usage and how that also affect his sleep pattern. These conversations concerning Gordon's physical well-being led to in-depth conversations between Gordon and Nia. For instance, Nia explained why engaging in the use of electronics just before bedtime could cause fatigue in the long run. Gordon attempted to resolve the issues arisen from sleeping late by offering coffee as a solution, which then further led to Nia explaining why coffee was not appropriate for Gordon, due to his age. Although there were clear aims behind each conversation between Nia and Gordon, the atmosphere appeared relaxed when the main messages were conveyed. Therefore, I can conclude that Gordon has had ample opportunities to explore his own physical well-being as well as receiving feedback from Nia. This can be seen from the conversation between Nia and Gordon below:

*Gordon: 'Yeah. I have not slept well.'*

*Nia: 'When you use electronic devices, your brain cells work. So perhaps it's not the best idea using the devices just before going to sleep. The trouble is that we have got a really old-fashioned brain, and it doesn't manage when we keep moving the sleep time around... I would really like to encourage you to have the same sleep every day and wake up at the same time every day. I know it sounds tedious and annoying, but it will really help you, especially when you are doing so well at school.'*

*Gordon: 'I can have a coffee. '*

*Nia: 'It might be better for adults, but coffees are probably not very good for people your age. I really appreciate you being so honest. I am not here to tell you off. I want to help you get the best out of your day. When you are tired, you just don't have that control.'* (Fourth SEM&H session, conversation between Gordon and Nia, 30th September 2021)

*Nia: 'Do you remember me telling you that coffee isn't very good for people your age. (Meanwhile, Nia joking stared at Gordon when he was cheekily trying to get his coffee out from his bag.)'*

*Nia: We all have a coffee, but we can't use that to replace sleep. Sleep is such an important thing to have, that can't be replaced.*

*Gordon: Yeah, so I am always tired in the morning. (Fifth SEM&H session, conversation between Gordon and Nia, 07th Oct 2021)*

In addition to exploring his own physical well-being, Gordon also had the opportunity to reflect on his own routine and habits to improve his physical well-being. On the topic of Gordon reducing the coffee intake, he has shown progress through slowly adapting to a new lifestyle after receiving the advice, which was also recognised by H. Although the balance between playing with friends on the console at night and having a good sleep pattern has not been improved drastically, Gordon has acknowledged the concept and has shown that he was slowly working towards a healthier lifestyle, which is evident from the interview quotes below:

*Chai: '...and you guys also talked about coffee.'*

*Gordon: 'Coffee. I, I have [...] I mean, cut down the coffee.' (Fifth interview with Gordon, 22nd February 2022)*

*Mrs Smith: 'I think he only has one cup a day and that's in the morning for his breakfast.'*

*Mrs Smith: The coffee is, is really... he would smile at me and go [sic] "N would go mad if she knew I was having this coffee", Then I would ask him if he really needed this, then he'd be like "No, I'm alright". (First interview with Mrs Smith, 30th March 2022)*

*Chai: '...it (sleeping late) affects how healthy you are and if you don't sleep very well, you wouldn't be very healthy... you said to Nia that that's something you're still working on, but your weekdays ones are good.'*

*Gordon: 'Yeah.'*

*Chai: 'So is that what you have chosen. To play with your friends over a good night's sleep'*

*Gordon: 'Yeah. I just want to play with my friends.'*

*Chai: '...there is no right or wrong answers...'*

*Gordon: Yeah, I've just been playing with my friends... when I like, they come off, and I normally fall asleep. Then I wake up at like oh maybe ten or nine.'*

*Chai: 'Yeah, so you have actually cut down the coffee? You're still sleeping late on Saturday Sunday?'*

*Gordon: '...yeah, because I'm playing my mates online.'*

*Chai: 'Well, that's it, but you have acknowledged it as a work in progress.'*

*Gordon: 'Yeah' (Fifth interview with Gordon, 22nd February 2022)*

Despite the clear impact on both Gordon and Oli from their intervention, there was no direct or indirect impact made on Tony's physical well-being through his C&I<sup>7</sup> intervention. This is because the aim of the C&I intervention is to support Tony to develop his speech, and therefore, the intervention coverage does not include elements such as discussions in relation to eating or exercising, hence no impacts were found on Tony under this sub-theme from the intervention. So far, I have discussed the participants' views on their own physical well-being combining my observational data and data from interviews with participants' mothers/parents. Furthermore, I investigated the impact each intervention had on the student participants under this sub-theme. In the next section, I move onto discussing the desire and plans the student participants had to improve their physical fitness, before proceeding to explore the impact the interventions had on them.

### **6.2.2 The impact of physical fitness on physical well-being**

As mentioned in the last section, weight management is an individual process, with dieting and exercising being two key elements (Patience, 2018). Furthermore, it is essential that people with SEND identify their preferences and interests in order to produce a sustainable exercise plan Messent, Cooke and Long (1998). The section above explored what the student participants think about the impact that the interventions have had on their physical well-being. In this section, I discuss the student participants perceptions of how physical fitness may have impacted on their physical well-being. Unlike some other sub-themes, the stories behind each participant vary adversely. As both Gordon and Oli have different reasons and plans to improve their physical well-being, whereas Tony does not show the same level of desire.

At the time of the research, Gordon had more of a desire to improve his physical fitness, and he wanted to 'be' fit. For instance, Gordon spoke about how he boxed as he wanted to be rewarded and to prove otherwise to people who told him he could not fight in the past. In addition, boxing practice also appeared to be a regulation strategy for Gordon, as he mentioned how he would box with his father when feeling angry. This is shown below through a conversation during the intervention:

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<sup>7</sup> Communication and interaction

*Nia: 'What would you want from it?'*

*Gordon: 'A bunch of medals, trophies, stuff like that. Rewards.'*

*Nia: 'Do you think wanting that is related to past experience?'*

*Gordon: 'Probably. People in the past told me you can't even punch or you can't even fight. I don't like that. I can punch, but I just don't want to.'*

*Gordon: 'I box with dad when I am angry as well.'* (Third SEM&H session, conversation between Gordon and Nia, 16th September 2021)

As far as plans are concerned, Gordon had plans to improve his physical fitness and his plans involved the support from his parents. He planned to practise boxing with his father, and when his father was not around, he planned to improve his boxing skills through using some boxing equipment. This can be found from a conversation that took place during his intervention below:

*Gordon: 'I box with dad when I am angry as well.'*

*Gordon: 'My mum has ordered some boxing things and my dad hang them up, because he is not always here. I can practise my punches'* (First SEM&H session, conversation between Gordon and Nia, 1st July 2022)

In addition, Gordon also planned to use the gym or weights as a platform to improve his physical fitness. During an interview with Mrs Smith, she also confirmed that Gordon enjoyed working out in the gym. Gordon also described how he also moved on from boxing to lifting weight as a way to improve his physical fitness, which can be seen below from the interview quotes and the conversation extract:

*Mrs Smith: '...He enjoys working out in the gym.'* (First interview with Mrs Smith, 30th March 2022)

*Gordon: 'I have a speed ball at home; I can do it super-fast. It is super hard to do. I came off boxing and started lifting weights. I could lift 20kg with one hand, with my back straight. I do it safely though.'* (Third SEM&H session, conversation between Gordon and Nia, 16th Sept 2021)

Rather than 'being' fit like Gordon, Oli desired to 'look' fit instead. The reasons behind Oli's desire were also due to his social experience, as Oli told me that his

goal was to get fitter and he wanted to look fitter. It was because he wanted his peers to not have a reason to say unkind things to him about his weight and wanted to eliminate the possibility, which can be seen in the quote below:

*Chai: 'What are your goals?'*

*Oli: 'I definitely want to get fit. More fit than usual...'*

*Chai: 'Has it got anything to do with you wanting to get fitter?'*

*Oli: 'Yes, they definitely do say "you have to lose some weight, mate." "You are too chunky to do anything." That's honestly what they say to me.'*

*Chai: 'Do you think then R would stop picking on you if you don't have a belly?'*

*Oli: 'Yes, definitely.'*

On another social aspect, Oli also brought up the fact that he wanted to get fit, he then subsequently found a romantic partner. Oli may have wanted to become fitter for the sake of his relationship with So; he explained that he wore a jumper to hide his 'belly'. It appears that Oli also planned to become fitter because he intended to look physically fit in the presence of his romantic partner, which is evident through the interview quotes below:

*Oli: '...On 1<sup>st</sup> January 2021, I said I wanted to get fit, then find a girl who likes me, which I did... Do you know So?'*

*Chai: 'When you said like, what do you mean by that?'*

*Oli: 'Like in a 'crush' way. I have a crush on her (So) and she has a crush on me too.'*

*Chai: 'Right, I see. Is that why you wanted to get fit?'*

*Oli: 'Well, yeah not exactly, I just wanted to get fit. It's personal.'*

*Chai: 'How do you think your belly affects you? Or your relationship with others like So?'*

*Oli: 'Not really, it doesn't really affect my relationship with So. It is because I wear quite a thick jumper, not a thin one. So that you don't exactly notice my belly that much.'* (First interview with Oli, 12th July 2021)

It appears that the reasons behind the desire to improve physical fitness for Gordon and Oli are complex. However, their social experience was the common factor, and both participants attempted to ease their frustration through improving their physical fitness. There are further similarities between the two student participants, as both Oli and Gordon had plans to improve their physical fitness and both plans involve the support from people around them. For instance, Oli expressed how certain physical

activities in the intervention were not challenging for him, and hence suggested a specific core exercise he wanted to try with Sally on another occasion through his interviews with me:

*Oli: '... I find them a little bit too easy... I'm going to tell her to make them a bit harder for me.'* (First interview with Oli, 12th July 2021)

*Oli: We do like wall pushes. We do, I think I do squeeze a lot of stuff like I go like that to just try, I mean, I, I just want to like, you know, do those crunches?* (Fifth interview with Oli, 23rd February 2022)

Again, similar plans were found between Gordon and Oli, as they both planned to use the gym or weights as a platform to improve their physical fitness. For instance, Oli stated that he would like to attend the gym as an avenue to become fitter, and specifically, building muscles. This can be found in the interview quotes below:

*Oli: '...one of my goals for this year, probably go to the gym.'*

*Oli: '... I want to go to the gym and and like I I would say get a bit more fit... and to build muscles.'*

*Chai: So you want to go to gym? You want to build muscles.'*

*Oli: Oh yeah, definitely, definitely.* (Fifth interview with Oli, 23rd February 2022)

Oli's plan to go to the gym to work out was also confirmed by Mrs Zane (Oli's mother), as she revealed in an interview that Oli planned to go to the gym with his father when he reached 14:

*Mrs Zane: 'He's enjoying sports a lot more. He likes playing football and he's mentioned to me that he wants to start going to the gym with his dad when he's 14.'* (First interview with Mrs Zane, 27th March 2022)

So far, the findings suggest that both Gordon and Oli's desire to improve their physical fitness stemmed from social reasons. Oli was motivated by his peers' negative comments as well as his desire to maintain a physically fit image in the presence of his romantic partner. Both student participants planned to improve their physical health with some support from adults around them and through working out



in the gym. As much as Gordon and Oli were highly motivated in doing so, the findings suggest otherwise for Tony. As mentioned in the last section, Tony has shown an awareness of the definitions of healthy and unhealthy, and also discussed how he ate healthily but did not do a lot of exercises. Mrs Conor agreed with the former, that Tony was aware of the definition, however she believed that Tony was not very healthy and that Tony was aware of it, which can be found from the interview quote below:

*Mrs Conor: 'He is aware of what is healthy and unhealthy. He is also aware that he is not very healthy!'*

In 6.2.4, when discussing the desire for Tony to play sports with his peers, Mrs Conor revealed Tony's awareness of his lack of sports competency and that it is the reason why he would choose not to take part in activities that were not his strength, which can be seen in the quote below:

*Chai: 'What's Tony's views on physical health?'*

*Mrs Conor: '...Also I think as he gets older, he is aware that he is not as good at these kind of activities as his peers are. He would always choose to not do something he thought he was not good at rather than have a try.' (First interview with Mrs Conor, 4th September 2022)*

However, Tony also disclosed in an interview that he was satisfied with his physical well-being. Having analysed the information gathered, it appears that Tony had no desire or plan to improve his physical well-being, mostly because he lowered his expectations on these areas - Tony gave up the idea of furthering his physical fitness mainly because he is aware of the lack of competency.

*Chai: '...so physical and social well-being... They are on a par?'*

*Tony: 'Yeah.'*

*Chai: 'But you're still happy with them in general?'*

*Tony: 'Yes.' (Fifth interview with Tony, 2nd February 2022)*

To conclude, Gordon and Oli had the desire and plans to improve their physical fitness through different platforms. On the other hand, Tony had no intention in doing so due to his lack of competency in fitness as the baseline. It appears that Tony had the desire in other areas, largely related to consoles; Tony also had the ability to make plans as he revealed how he planned to make money. However, because he was uninterested in his physical fitness, he had no desire and plan to improve in this

area. So far, I have explored this sub-theme by exploring each student participant's personal stories. I now move onto discussing the impact of the intervention they received on this sub-theme.

I discussed the nature of the SM&P intervention in section 3.6, which was to support Oli with his functional skills through exploring exercises. As mentioned above, Oli mentioned that he wanted to improve his physical fitness through doing crunches during Sally's intervention, which shows that he utilised the SM&P intervention to plan to improve his physical fitness. This can be found below from my interview with Oli:

*Oli: '...What's one of those called, like, like so, so how you laying [sic] your backing you? You like put, your head up yeah crunches!'*

*Chai: 'Did you do that with S?'*

*Oli: 'Uh, no. I actually kind of want to.'* (Fifth interview with Oli, 23rd February 2022)

On top of the discussion Oli had with Sally, I also had a conversation with her about Oli's desire to improve his physical fitness. Through reflecting on Oli's progress, Sally consequently was inspired to implement two more effective exercises that could support Oli to develop his abdominal muscles as that was what Oli had in mind when mentioning crunches, where Oli responded with enthusiasm when the abdominal targeted exercises were introduced to him and appeared resilient. My fieldnotes include evidence of Sally implementing abdominal exercises Oli's interventions following my discussions with her on Oli's preferences:

*'Discussion with Sally: Sally talked about how strong Oli had become. Instead of doing crunches, kick out would have been more effective for him as it worked on his abdominal muscles, as well as accuracy of his kicks. More importantly, Oli really enjoyed the competition side of the exercise and his strength could be visualised by how far he kicks the ball.'* (Fieldnote, Seventh SM&P session, 2<sup>nd</sup> March 2022)

*Sally: '...we will do some exercises that work on your low abdominal muscles, because I know you have spoken to C about that.'*

*Oli: 'Yes!'*

*Sally: 'Now, I would like you to get into a sitting position, Oli. Feet together and kick the ball... Do you remember when we first started, you couldn't get your feet up in the air very well, but now you can kick really high. Last one?'*

Oli: *'No, I want to do one more.'* (Seventh SM&P session, conversation between Oli and Sally, 2<sup>nd</sup> March 2022)

Sally: *'Shall we try some sit ups later today and see how many you can do?'*

Oli: *'Yeah sure.'*

Sally: *'I will set it up while you are having your last go.'*

Sally: *'I would like to have a baseline, so that I know how many you can do and I can set you some goals. Let's see if we could start with 10.'*

Oli: *'10, sure.'*

Sally: *'Do you think you can do another 2?'*

Oli: *'I can do 3 more if you want.'* (Eighth SM&P session, conversation between Oli and Sally, 24<sup>th</sup> March 2022)

With Oli's proactiveness on utilising the SM&P intervention, as well as Sally's reflection on the intervention and Oli's receptive attitude towards the changes. It is evident that there were direct impacts on Oli from the SM&P intervention. Although the plans outlined from the SM&P did not come with measurable targets, the objective was clear, which was to improve Oli's physical fitness and his core strength. Oli's action plan here is also in line with Lee *et al.*, (2019), Patience, 2018 and Messent, Cooke and Long (1998), where he used Sally, as his social network, to identify an exercise plan. Oli was keen about working on his core muscles and therefore, the exercises suggested by Sally were appealed to Oli and he continued to be enthusiastic.

I discussed how the SEM&H intervention provided Gordon with the opportunities to understand and discuss his physical well-being. Although Gordon's perception of his physical well-being was focused on dieting and exercising, he already had the opportunity to discuss how sleep and his caffeine consumption affect his physical health. There is also a direct impact on Gordon from the intervention, and it predominantly lies on Nia supporting G' to develop his understanding on his plans to improve his physical fitness and potential implications. For instance, Gordon spoke about his desire to practise boxing and his reasons behind, however, he was also aware of the implications as he could sustain serious injuries. Although Gordon moved on from boxing to weightlifting, there are still potential risks of injuries. Nia spoke to Gordon about the potential risks of injuries when Gordon discussed weightlifting with her, which can be seen below:

*'Through the quick conversation with Nia to review Gordon's progress, I felt that Nia was proud of the maturity in Gordon. When asked about her opinion*

*on Gordon lifting instead of boxing, she felt that it was less dangerous but weightlifting also comes with its risks, which they briefly discussed in their intervention.'* (Fieldnotes, discussion with Nia, 22<sup>nd</sup> September 2021)

Unlike the other advice received from Nia, Gordon appeared to be slightly disheartened about the comments made by Nia on weightlifting, and had decided to carry on lifting weights as he felt appropriate and safe, which can be found in the interview quotes below:

*Chai: ...you said you'd like to lift weights and exercise. Have you had any discussions with Nia about that?*

*Gordon: Yes.*

*Chai: Tell me more.*

*Gordon: Nia has said I'm not to lift, to like, heavy weights.*

*Chai: Why not?*

*Gordon: Because it's like, she said, it's like, my age. It's like lifting like you need to be a certain age to lift a certain weight.'*

*Chai: Yeah, and how do you feel about that?'*

*Gordon: I was a bit upset.'*

*Chai: Why?'*

*Gordon Because I couldn't lift my weights. I was like, used to...'*

*Chai: So, did you actually lift less than after?'*

*Gordon: I, I still carried on lifting the weights I was carrying because I could, I could lift them and I could carry...'* (Sixth interview with Gordon, 28th March 2022)

The above information shows that there is an indirect impact on Gordon's physical well-being following the SEM&H interaction. Although Nia validated Gordon's maturity on his awareness of safety around his plans to improve his physical fitness, Gordon already had the plans in mind and mentioned them to Gordon through a conversation. Gordon's desire and plans to improve his physical fitness was not fostered, nor enhanced, through the intervention. In fact, Gordon was slightly disheartened by Nia's advice on the safety aspect on his plans to weightlift, and decided to carry on with his plans.

In terms of the C&I intervention, there were plenty of opportunities for Tony to work on his under-developed speech. However, the coverage of the intervention does not include discussions or activities on physical health or fitness. As mentioned early in this section, Tony does not have desire or plans to improve his physical fitness, and

had lowered his expectations on this area as he gave up the idea of furthering his physical fitness because of his awareness of the lack of competency and therefore, it would be a leap to conclude any impacts the C&I intervention had on Tony under this sub-theme. So far, I have outlined each student participant's plans and desire to improve their physical fitness, or the lack of desire and plans in Tony's situation. I then discussed the impact each intervention had on the student participants, ranging from having direct impacts Oli received from the SM&P intervention, to the indirect impacts the SEM&H intervention had on Gordon, and finally the minimal to no impact C&I had on Tony under this sub-theme.

In line with the literature (Flanagan, 1978; Felce and Perry 1995; WHO, 1997; Schalock and Verdugo, 2022; Rice, 1984), physical well-being is also regarded as a significant area for the student participants in this research, as it means different things to them in multiple contexts. Unlike Arias et al. (2017) and Svekles et al. (2010), I did not compare the student participants' physical well-being with their neurotypical peers. However, it was evident that all three student participants were aware of the quality of their physical well-being, and they had a different attitude towards their physical well-being. For instance, Tony avoided to develop in this area, whereas Gordon and Oli's desire and plans to develop it following different life experiences. Mrs Conor suggested that this was the case for Tony, and that this was also the reasons for him to not have a particular desire or plans to develop his physical fitness. As Tony chose to give up the idea of developing this area in his life, he channelled his expectations and feels satisfied and happy with his physical well-being. Although Tony was not keen on developing his physical well-being due to the lack of ability, Gordon and Oli both used their interest to build up their physical fitness, which is similar to Messent, Cooke and Long (1998) stance on enthusiasm and regularity of exercising. In line with Lee et al.'s (2019) views on the connection between weight, body image and exploring different sports, Oli was dissatisfied with his body image as his physical appearance directly affected his social and emotional well-being (this will be explored further in theme 3), which led him to exploring different physical activities with Sally.

Although Brown and Schormans (2014) and Hibbard and Desch (2007) suggest that CYP with SEND are at risk of physical negligence and maltreatment, my research

findings suggest otherwise. All three student participants' parents showed a good level of understanding of their child's physical well-being, regardless of the level of satisfaction. In fact, Mrs Smith described how Gordon exercised regularly as he had energy to burn. Similarly, Mrs Zane tried to explain the relationship between healthy eating, exercises and physical health. Despite the more complex underlying concerns, Mrs Conor was aware of Tony's downfall as she pointed out his limitation and irregular yet extreme exercising pattern.

Unlike the first main theme identified, the interventions were proven to be less impactful in this area, particularly with the C&I interaction as no impact was made on Tony due to its limited coverage. On the other hand, the SM&P intervention was still found to be somewhat impactful as it fostered opportunities for Oli to evaluate his physical health, work on targeted muscle group and feel happier due his body transformation. Since Gordon's stories emerged from this main theme and its sub-themes were largely related to his social life, including his balance between socialising with friends and sleep, how his physical fitness and boxing competency were often connected to social situations, the SEM&H intervention was also found to have a mixture of direct and indirect impacts on Gordon. In-depth discussions and debates took place between Gordon and Nia during the intervention about his physical health; emotions validation and strategies were also shared with Gordon in order to promote physical health, as well as emotion regulation.

So far, I have discussed the two main themes, which were proven to be connected in different ways in participants' lives. In terms of the intervention impact, most were found directly or indirectly made on the participants. Back in chapter 3, I emphasised the fact that my research was not designed to be generalised, rather for readers to transfer the findings or to follow a naturalistic generalising approach, as they have developed an understanding on the description of my research as well as my sample group. The third and final theme is emotional well-being, which is a theme that occurred discretely in the background. In the next section, I explore student participants' emotional well-being through their physical and social well-being and experience, as well as their experience throughout their intervention.

### 6.3 Emotional well-being

As discussed in chapter 2, Felce and Perry (1995) created an extra QOL domain heading in addition to Flanagan's (1978) Emotional well-being, and it consists of: positive affect, status, respect, satisfaction, fulfilment, belief, faith and self-esteem. Student participants showed fewer emotional states related or triggered by belief or faith, however, all the other QOL domains under emotional well-being were relevant to their lived experience throughout the research. According to the literature, CYP with SEND are at higher risk of experiencing maltreatment and emotional neglect as a public health issue, and this results in a poorer QOL (Brown and Schormans, 2014; Hibbard and Desch, 2007).

The findings of Ross and Willigen (1997) suggest that 'well educated' people are likely to gain on-alienated work and higher income, resulting in less psychological distress. Although the student participants' academic levels are not as developed compared to their neurotypical peers, Ross and Willigen's (1997) findings are not applicable to my research as my student participants were not at full-time employment age at the time of the research. It was somewhat suggested that lower income creates psychological distress (Ross and Willigen, 1997), and this is not applicable to the student participants either as they received financial support from their family due to their age at the time of the research. However, Wigelsworth, Oldfield, and Humphrey (2015) and Kaufmann (2015) both highlighted that the vulnerability of CYP with social, emotional, behaviour mental health difficulties as they are more likely to experience bullying, unfairness and discrimination, and this appears to be more relevant to my research. Evidently, all three student participants' emotional well-being was affected by their social experiences according to the data collected. An emotion is characterised by a short and affective state, and this short duration of emotion leads to short-term changes in one's emotional states (Pozas and Letzel-Alt, 2023). Therefore, many stories, conversations and observations are referenced in the following sections, as each experience student participants encountered formed short-term emotional suggest how their emotional well-being was impacted. The Good Childhood Report (2023) indicated that CYP with SEND are 'unhappy' with their social and physical well-being, as they are twice as unhappy with their friends and health, compared to their typically developing peers. In line with

my findings, most emotions from student participants were captured when I explored their social and physical related matters and discussions, as well as their emotional state throughout the interventions.

### **Tony's emotions stemming from social and physical well-being**

In section 6.2, I discussed student participants' social well-being and I pointed out that Tony liked the idea of 'gaining' friends without further elaborating on a functional reason for having friends. Without further justification, Tony also mentioned that not having friends, communication and a phone would lead to poor social well-being. Throughout the research, Tony was also often unable to provide clear reasons for his views on his emotional well-being, which can be seen below:

*Chai: 'Are you happy?'*

*Tony: 'Yeah.'*

*Chai: 'What is making you happy?'*

*Tony: 'I don't know.'*

*Chai: 'So you are not unhappy?'*

*Tony: 'No.'* (Second interview with Tony, 22<sup>nd</sup> October 2021)

*Chai: 'How are you feeling in general?'*

*Tony: 'Okay.'*

*Chai: 'Do you live a happy life?'*

*Tony: 'Yes.'*

*Chai: 'What in your life makes you happy?'*

*Tony: 'Pass.'* (Third interview with Tony, 30<sup>th</sup> November 2021)

*Chai: 'What makes you happy?'*

*Tony: 'Stuff.'*

*Chai: 'What is stuff?'*

*Tony: 'Stuff.'*

*Chai: 'I think you've talked about exercising, game consoles and having lots of friends. Do these things make you happy?'*

*Tony: 'Maybe.'* (Fourth interview with Tony, 17<sup>th</sup> January 2022)

*Chai: 'Emotional well-being is about how happy you are. So you say you're happy all the time. You like being at school and having fun.'*

*Tony: 'I like being at school when I'm having fun.'*

*Chai: 'When you're having fun, so what do you do to have fun at school?'*

*Tony: 'Stuff.'* (Fifth interview with Tony, 2<sup>nd</sup> February 2022)

From the above, we can see that Tony felt that he was generally happy, but was unable to suggest why. In section 6.2, I also explored that Tony displayed discomfort



when being at the centre of the attention and discussed how people with ASD could prefer different social stimuli, to have more thinking time when communicating and also experience aloneness that seemingly isolates them from the outside world (Howard and Sedgewick, 2021; Nuemberger *et al.*, 2012; Bowen Reavis and Findley, 2013). Despite using the above research to justify that Tony had a good social well-being as someone with ASD who did not have many friends and was along at the time of the research, there is also evidence to show that Tony had an understanding of the social norm and possibly be emotionally conflicted. For instance, Tony 'disapproved' my own experience on how I preferred to be alone and described my behaviour as 'mean', which can be seen in the interview notes below:

*Chai: I personally don't like to spend time with friends and families a lot myself. I like to spend time on my own.*

*Tony: Right. You're just being mean.* (Fifth interview with Tony, 2<sup>nd</sup> February 2022)

I would argue that Tony was feeling emotionally uneasy about his desire to be alone sometimes socially, as he perceived the social norm as being with friends and families. Therefore, my statement about my social preference was disapproved by Tony.

Further to suggestion from Wigelsworth, Oldfield, and Humphrey (2015) and Kaufmann (2015), that CYP with social, emotional, behaviour mental health difficulties are more likely to experience bullying, unfairness and discrimination, I explained in section 6.2 that Tony experienced a prolonged period of social distancing from his peers, the emotional impact was unfounded from this particular experience. However, there is also evidence that Tony felt emotionally satisfied with his social life, as his hobbies and understanding fit with the 'norm', which can be found below:

*Chai: 'What else do you use your phone for? To the point that you think it would be poor socially without a phone?'*

*Tony: 'You can't chat on Twitter.'*

*Chai: 'You can chat on Twitter, so do you chat on Twitter at the moment?'*

*Tony: 'Everyone does.'* (Fourth interview with Tony, 17<sup>th</sup> January 2022)

*Tony: 'Obviously I will play games. Who doesn't play games?'*

*Chai: 'I don't.'*

*Tony: 'How?'*

*Chai: 'I'm not interested in games.'*

*Tony: 'You're not staying with the trend then.'* (Fifth interview with Tony, 2<sup>nd</sup> February 2022)

*Tony: 'Be a social media manager for Mr Beast.'*

*Chai: 'Who is Mr beast?'*

*Tony: 'Did you really just ask who's Mr Beast?'*

*Chai: '(Bursting into laughter) Yes I did.'*

*Tony: 'You know, just a normal guy with 89 million subscribers.'* (Fifth interview with Tony, 2<sup>nd</sup> February 2022)

As mentioned, Tony often used sarcasm or distractions to avoid answering questions. Despite the vagueness of the answers, Tony showed satisfaction when discussing his feelings around his social as well as physical well-being, which can be found in the interview quotes below:

*Chai: '...so physical and social well-being...They are on a par?'*

*Tony: 'Yeah.'*

*Chai: 'But you're still happy with them in general?'*

*Tony: 'Yes.'* (Fifth interview with Tony, 2<sup>nd</sup> February 2022)

As mentioned in the physical well-being theme (see section 6.3), Tony's expectations on his physical well-being were lower due to his previous experience and a lack of competency. Therefore, he appeared to be emotionally satisfied with his overall physical well-being. When further investigating the emotions stemming from physical well-being and social well-being, Tony continued to be vague. For instance, Tony did not disagree when it was suggested to him that exercising and having friends would make him happy. Although there was no direct indication that Tony's social well-being and physical well-being made Tony emotionally happy, Mrs Conor confirmed that he was happy to engage in certain exercises, such as swimming or going for a walk, which can be found below from the interview quotes:

*Chai: 'What makes you happy?'*

*Tony: 'Stuff.'*

*Chai: 'I think you've talked about exercising, game consoles and having lots of friends. Do these things make you happy?'*

*Tony: 'Maybe.'* (Fifth interview with Tony, 2<sup>nd</sup> February 2022)

*Mrs Conor: He will happily swim, go for a walk with friends and family.* (First interview with Mrs Conor, 4th September 2022)

### 6.3.1 Oli's emotions stemming from social and physical well-being

In line with Williams (1993), physical well-being is proven to be linked to one's emotional well-being as two of the participants experienced negative emotions due to the physical aspects of their life. However, according to my findings, physical health alone did not cause those feelings; social interactions also contributed to participants' emotional well-being. My research also suggests that the feelings are not always negative as suggested by Williams (1993), as participants also experienced positive feelings due to their physical well-being.

As mentioned in the physical well-being theme, Oli found reasons to improve his physical fitness stem from social interactions with his peers, as well as his intention to maintain a physically fit imagine in the presence of his romantic partner. However, the emotions arose from the Oli's journey varied greatly. The first two emotions identified from this issue were frustration and dissatisfaction, which led to negative behaviours such as using pejorative verbal language and pushing others away, which can be seen in the interview quotes below:

*Chai: 'How do you respond to that when people make fun of you and poke your belly?'*

*Oli: 'I get really wound up, honestly. I honestly get really wound up... I push them away most of the time.'*

*Oli: 'I just ignore him. But when I get to the next level, I'd say shut up but don't swear at him.'* (First interview with Oli, 12th July 2021)

In addition, it also appears that Oli felt embarrassed about his weight as he, on occasions, contradicted himself. For instance, he stated that he did not know the reason and that he wanted to lose weight because he had had his 'belly' for some time. When, in fact, he knew the reason behind wanting to lose weight. This is evident from the interview notes below:

*Chai: 'Why would you want to get rid of it (belly)?'*

*Oli: 'Oh, I don't know it's. Oh no, I just want to get rid of it.'*

*Chai: 'Why do you want to get fitter?'*

*Oli: 'I don't know, it's just because I've had like a, I, I would say I, I've actually probably had like a gut for a couple years like a like a big belly.'* (Fifth interview with Oli, 23rd Feb 2022)

Other than the negative emotions identified above, such as frustration, dissatisfaction and embarrassment, hopefulness was identified in an interview. It appears that Oli also felt hopeful at times, as he believed that he would feel happy when he looked fitter physically, which can be seen from the interview extract below:

*Chai: 'How do you think you would feel if you didn't have the belly anymore?'*  
*Oli: 'I would feel really happy about it. I would feel really really happy about it I am not gonna lie.'*  
*Chai: 'And why do you think you'd feel happier?'*  
*Oli: 'I don't know. It's because I have had a belly for a few months now. Actually, I have had a belly for a few years now.'* (Second interview with Oli, 21st Oct 2021)

About four months later, Oli's hopeful feeling turned into reality as the taunting stopped and that no one called him 'fat' anymore. Although Oli did not confirm whether he actually felt happier, the sense of negative emotions was no longer identifiable, which can be seen from the extract from the interviews below:

*Oli: 'I I don't like when I I don't like getting picked on... In fact he always used to call me fat. I would say and he always used to whack my belly... actually this has stopped.'* (Fifth interview with Oli, 23rd Feb 2022)

*Oli: 'I'm definitely getting a bit more slimmer and no one calls me fat anymore.'* (Sixth interview with Oli, 29th March 2022)

### **6.3.2 Gordon's emotions stemming from social and physical well-being**

Unlike Tony and Oli, my findings suggest that most emotions caused by physical and social well-being, or situations in Gordon's case, appeared to be negative. However, it was also observed that Gordon took pride in his actions when handling a situation with his physical ability. Historically, Gordon found himself in a lot of social situations that involved physical fights and threats, which led to a range of emotions. Gordon predominantly discussed two groups of people, with the former being his ex-schoolmates who he dealt with in the past, and the latter being a group of strangers

who he was dealing with at the time of the research. Despite the high level of confidence Gordon showed when discussing his physical fitness and his boxing ability, Gordon experienced anger when dealing with social situations which challenged him physically. This can be found from the quotes extracted from the intervention below:

*Gordon: 'I was walking down the park with J. There were some travellers there. And they said – What are you drinking monsters for? They tried to start a fight. I carried on walking away with my friends from my old school.'*

*Gordon: 'He started punching me. I wasn't even in the mood for a fight'*

*Gordon: 'I was not in the mood that day. I picked him up, threw him to the ground and he ran out of the toilet. He left the school and he never messed with me again. He was a year 4 kid and I was in year 6, I am not going to fight him.'*

*Gordon: 'I was probably mad. I wanted to kill them all. I had all these feelings and emotions in my head.'* (First SEM&H session, conversation between Gordon and Nia, 1st July 2021)

Furthermore, fear was identified when Gordon encountered physical and negative social situations. Other emotions were also identified when he was physically confronted by two of his ex-schoolmates. For instance, fear was identified when Gordon felt that he was physically incapable of handling two situations. Gordon also mentioned how he entered a 'fight or flight' mode when his adrenaline kicked in when physically confronted, which can be seen from the fieldnotes and conversation extracts below:

*Gordon recalled an incident that started with another pupil kicking his ball away, and Gordon ended up getting hurt as he retaliated. Gordon then revealed that he did not fight back because he knew he would get hurt even more.* (Second SEM&H session, fieldnote, 8<sup>th</sup> July 2021)

*Gordon: 'I just didn't want to fight back because I know he is older than me, and he will just beat me up. It's annoying; I have had it all my life.'* (Second SEM&H session, conversation between Gordon and Nia, 8<sup>th</sup> July 2021)

*Gordon: My adrenaline will start kicking in. It's like I am going to have to fight or I just don't know what's going to happen.* (Fourth SEM&H session, conversation between Gordon and Nia, 30<sup>th</sup> September 2021)

Although the emotions caused from the above situations were not directly related to Gordon's physical fitness, his physical well-being was impacted. Furthermore, there are also other emotions caused directly by Gordon's physical ability. For instance, it

appears that Gordon was feeling proud when discussing how he managed to handle a situation physically. Gordon also reflected on incidents where he also felt proud of making the correct decision by stepping out of a situation, which can be seen below:

*He also appeared proud about the fact that he managed to 'fight off' a pupil from his primary school. (Fieldnote, First SEM&H session, 1<sup>st</sup> July 2021)*

*Gordon started to talk about another incident, where he was harassed by a group of strangers and wishing he had done a '1 on 1'... Gordon stated that he wanted to fight him but was in a dilemma as it would be a lose lose – if he lost the fight, he would be hurt, but equally, if he won the fight, he could get hurt by others afterwards. (Fieldnote, Third SEM&H session, 16th September 2021)*

*Gordon: It is a wise decision because I avoided fighting others. (Fieldnote, Fourth SEM&H session, 30<sup>th</sup> September 2021)*

Besides the above, Gordon also appeared to experience embarrassment when discussing the way he handled a physical incident. Furthermore, in section 6.2, I outlined Gordon's understanding of body building and food nutrition. In contrast with Oli, Gordon's aim was to gain as opposed to lose weight. However, Gordon expressed that his inability to gain weight caused sadness. Moreover, based on Gordon's tone in the conversation, it appeared that he was actually experiencing embarrassment due to not being able to gain weight, despite being knowledgeable in this area, which can be seen in the extract from an interview below:

*Gordon: I feel embarrassed and a bit ashamed because I would think 'should I have fought them instead?'. (Fourth SEM&H session, conversation between Gordon and Nia, 30<sup>th</sup> September 2021)*

*Gordon: 'I've always been healthy. I couldn't, I can't gain weight, sadly.'  
Chai: 'Sadly?'*

*Gordon: 'I honestly I can't. I will eat any, anything, and not gain weight.' (Sixth interview with Gordon, 28th March 2022)*

So far, I have outlined the emotions arisen from student participants' physical fitness. Although most emotions highlighted appeared to be negative, there were also positive emotions identified. For instance, Oli showed hopefulness among his frustration, dissatisfaction and embarrassment. Likewise, Gordon showed pride while feeling anger, fear and embarrassment. Tony felt satisfied with his physical well-being overall without revealing other emotions, despite have experienced social

exclusion due to his physical health at the time of the research. Following the unravelling of the student participants' emotions through social and physical well-being related stories, I now move onto discussed the emotional impacts caused by the intervention they received.

### 6.3.3 The intervention impacts on Tony's emotions

Tony initially showed a level of discomfort during the first two C&I<sup>8</sup> sessions; he was not his usual self as there was no conversation re-direction or sarcasm. Through having discussions with Aaron, he also confirmed that he decided to deliver shorter sessions to gauge Tony's level of tolerance. This can be found from the fieldnotes below:

*'Tony behaved slightly differently in this intervention...he appeared uncomfortable and anxious during the intervention, he was not sarcastic, and he did not try to re-direct the conversation with his sense of humour... Although I speak to Tony on a regular basis and have a general understanding on Tony's needs, I feel that I saw another side of him during this intervention.'* (Fieldnotes, first C&I intervention, 14<sup>th</sup> June 2021)

*'...I had a discussion with Aaron and explored his views on his delivery and Tony's responses and behaviour. Aaron explained that he deliberately delivered a short session, as he wanted to gauge the level of tolerance Tony has... Aaron also felt that Tony was anxiety during the intervention...'* (Fieldnotes, discussion with Aaron, 18<sup>th</sup> June 2021)

Although Tony appeared anxious during the first few sessions, he was able to state that he found the intervention useful. Particularly, Tony discussed how the C&I intervention supported him with his speech. This can be found in the interview quotes below:

*Chai: '...about the sessions that you have been having with Aaron. What did you think about the activities you were doing?'*

*Tony: 'Okay.'*

*Chai: 'Are they helpful?'*

*Tony: 'Yes.'*

*Chai: 'Do you feel that you are progressing?'*

*Tony: 'Yeah.'*

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<sup>8</sup> Communication and interaction

*Chai: ‘...I just want you to think about how taking part in the activities in the sessions make you feel outside of your session.’*

*Tony: It’s been helping me... helping with my speech.’* (First interview with Tony, 12<sup>th</sup> July 2021)

Tony also evidently became more comfortable with the C&I intervention, as he appeared to show more confidence overtime. At times, Tony also seemed to show a level of satisfaction as he smiled and joked with Aaron during the sessions. This can be found in the fieldnotes below:

*‘...compared to the first session, Tony appeared more confident and assertive, based on his increased amount of eye contact and his quicker responses.’* (Fieldnotes, second C&I session, 25<sup>th</sup> June 2021)

*‘...he (A) asked if Tony enjoyed playing snap before and who he played with. Tony told Aaron that he enjoyed playing it and he played it with his whole family. When asked about whether he’s good, Tony confidently said yes. Aaron then asked Tony if he knew what would often happen when he played. Tony said Aaron would cheat. Aaron and Tony had a friendly debate on this topic and they both smiled and laughed throughout.’* (Fieldnotes, third C&I session, 1<sup>st</sup> July 2021)

*‘A started the session introducing what needed to be done – reading words that start with either Tony, K or C. Tony looked confident as he smiled...’* (Fieldnotes, fifth C&I session, 21<sup>st</sup> Oct 2021)

*‘A also agreed with my stance. Tony is slowly becoming more confident as well as clearer when pronouncing the C/K...’* (Fieldnotes, tenth C&I session, 17<sup>th</sup> Jan 2022)

It appears that Tony became increasingly confident and comfortable as he slowly became more sarcastic and deployed his misdirection techniques in conversations later in the research. This can be found in the interview quotes below:

*Chai: ‘So we previously talked about your sessions with Aaron. How are you getting on with them these days?’*

*Tony: ‘Good.’*

*Chai: ‘What have you been doing with him?’*

*Tony: ‘I don’t know.’*

*Chai: ‘How are you finding those words and making sentences.’*

*Tony: ‘Okay.’* (Second interview with Tony, 22<sup>nd</sup> October 2022)

*Chai: ‘In a recent session, you said that you think the sessions have gone well. Can you describe that more?’*

*Tony: ‘Pass.’*

*Chai: ‘Do you remember what you said to A?’*

*Tony: ‘No.’*



*Chai: 'Would you like me to remind you?'*

*Tony: 'No.'* (Third interview with Tony, 30<sup>th</sup> November 2022)

*Chai: '...I want to ask you about how the sessions.'*

*Tony: 'Did you just have to keep asking the same thing?'* (Fifth interview with Tony, 2<sup>nd</sup> February 2022)

Although Tony became more comfortable and used his preferred social communication method by being sarcastic and deflective, he confirmed that he found the intervention helpful, in particular with his speech.

Moreover, it appears that Tony was confident in the session and showed satisfaction as he was observed to have smiled and joked during the intervention.

#### **6.3.4 The intervention impacts on Oli's emotions**

Unlike Tony's feedback, Oli's perspective on his experience on the SM&P<sup>9</sup> intervention was very clear, as he stated that he found the intervention fun, helpful and enjoyed working with Sally (SM&P intervention leader) on numerous occasions. Oli also showed respect towards Sally (SM&P intervention leader), as he was willing to speak to her and voice his opinion on how easy he found things, which can be seen in the interview notes and fieldnotes below:

*Chai: 'What did you think about the activities that you had to do (in the intervention)?'*

*Oli: 'Oh well they are definitely a lot of fun. I really enjoy working with Sally.'* (First interview with Oli, 12<sup>th</sup> July 2021)

*Chai: 'So we previously talked about your sessions with Sally. How are you getting on with them these days?'*

*Oli: 'Really fun. It's actually really really fun.'* (Second interview with Oli, 21<sup>st</sup> October 2021)

*Sally: 'How was your session today?'*

*Oli: 'It was good.'*

*Sally: 'How did you find it?'*

*Oli: 'Oh it was lovely.'* (Fieldnotes, Conversations between Oli and Sally during the Seventh SM&P intervention, 2<sup>nd</sup> March 2022)

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<sup>9</sup> Sensory, motor and physical

Besides expressing that the intervention was fun, Oli also showed an awareness of how the intervention had an impact on him in different areas, which can be seen below from the interview quotes:

*Chai: 'So, one of your goals it's to get fitter. Do you think your sessions are going to help you?'*

*Oli: 'Definitely. Definitely, a lot.'* (First interview with Oli, 12<sup>th</sup> July 2021)

*Chai: 'I would like to ask you to tell me about how the sessions with Sally impacted on your physical well-being?'*

*Oli: 'Uh, definitely. Definitely like being more relaxed like stop being a bit more.'*

*Chai: '... have the sessions impacted on your personal development?'*

*Oli: '...yeah, definitely, definitely.'*

*Chai: 'Final question now, have their sessions impacted on your independence.'*

*Oli: 'And yeah. Oh yeah. Oh yeah. they do definitely help me do more listening. They do help. They do definitely help me listen a bit more. They help me get a bit more calm.'* (Fifth interview with Oli, 23<sup>rd</sup> February 2022)

In addition to Oli's enjoyment and his awareness of the impact of the intervention, Oli also expressed that he enjoyed the intervention being delivered by Sally specifically, despite experiencing some difficulties during the sessions including the change of room or activities being too easy. However, it also appears that Oli had a respectful relationship with Sally, where he was able to voice his opinion and provide Sally with feedback on one occasion. Oli also showed an appreciative attitude towards the intervention as he expressed that he would like the intervention to carry on in the future. The above can be found in the interview quotes below:

*Oli: 'I find them (activities) a little bit too easy. I am, I'm going to tell her to make them a bit harder for me.'* (First interview with Oli, 12<sup>th</sup> July 2021)

*Chai: I am aware that the room has changed. How do you feel about that?*

*Oli: Yeah. It's alright. I was kind of used to having the big space. I am actually used to having the big space I am not gonna lie.*

*Chai: Has it impacted your sessions?*

Oli: Um.. Not really, but I did prefer having all the open space. (Second interview with Oli, 21st October 2021)

*Chai: 'Tell me about the, the feelings you have for the session.'*

*Oli: 'Yeah I I do really appreciate someone giving me these sessions. I would say...'*

*Chai: 'Would you like to continue in the future?'*

*Oli: 'Yes, I would definitely like to continue in the future.'* (Fifth interview with Oli, 23<sup>rd</sup> February 2022)

As mentioned in the first theme, Oli experienced conflicts when socialising with his peers and he was offered strategies to regulate his emotions during the SM&P intervention. Sally uses deep pressure and breathing techniques during the sessions to help Oli relax, managing to suggest as a strategy when needing to regulate his emotions and take himself out of an unpleasant situation, which is suggested to be an emotional regulation tool that helps people control their mood and emotion (Jerath, Beveridge and Barnes, 2018; Jerath, 2015). Following practice opportunities during the intervention, Oli managed to apply the techniques to his daily life and was able to discuss how helpful this was to him. The regulation strategy being applied to Oli and his testimony were captured and presented through a mixture of conversations that took place during the intervention and my interviews with Oli below:

*Sally: 'Tell me when (to stop). More pressure?'*

*Oli: 'More.'* (First SM&P session, conversation between Oli and Sally, 27th May 2021)

*Sally: 'Ready for some squishing? Breathe in... and breathe out. How are you feeling now?'*

*Oli: 'I am good.'*

*Sally: 'Is your ankle better now?'*

*Oli: 'Yes it's better.'* (Sixth SM&P session, conversation between Oli and Sally, 18th November 2021)

*Chai: 'What can you do if you find things stressful in life?'*

*Oli: 'Probably take a deep breath and walk away.'* (Third interview with Oli, 30th November 2021)

*Chai: '...tell me about how the sessions with Sally impacted on your physical well-being?'*

*Oli: Yes, yes, definitely, without question, they have been brilliant...definitely like being more relaxed like stop being a bit more... I get really hyper, it helps you relax.'* (Fifth interview with Oli, 23rd February 2022)

Deep breathing is a self-regulation technique that can attenuate hyper arousal and help one become more relaxed; it also has positive effects on stress and mood swings (Jerath, Beveridge and Barnes, 2019). In contrast, rapid breathing leads to excitation of one's nervous system, therefore, deep breathing can also be used as treatment for stress, anxiety, depression and emotional disorders (Jerath *et al.* 2015). Breathing exercises were regularly worked on during the SM&P. Not only did Oli find it helpful in general as it helped him relax when feeling 'hyper', he also managed to generalise this skill as he suggested that he would walk away from a stressful situation in life while taking a deep breath. While Oli does not have emotional disorders, he showed his ability to apply techniques learnt and practised in his SM&P session to deal with potential conflicts from playing sports with peers.

Although Oli responded maturely towards the criticism on his girlfriend being older, his emotional well-being was still affected. In terms of the actual aim, there appears to be no direct links between the intervention and the emotional impacts Oli experienced at the time of the research, arisen from the sub-theme. However, similar to Aaron, Sally also provided Oli with emotional security and acted as a reliable ally, which are the positive features often found in high quality friendship (Efeoglu and Sen, 2022). In light of the good relationship between Oli and Sally, he confided in Sally about his romantic relationship with SW including troubles and received Sally's acknowledgment, which was beyond the original aim of the intervention:

*Oli: 'Will we be doing this again? After a week?'*

*Sally: 'Do you mean after half term?'*

*Oli: 'Yes, after half term.'*

*Sally: 'Do you like the sessions?'*

*Oli (smiled): 'Yes, I love the sessions...especially with you, because you are my favourite OT teacher. (First SM&P session, conversation between Oli and Sally, 27th May 2021)*

*Oli: 'I am also seeing SW. The weird thing is, it's not weird, she likes me too.'*

*Sally: 'Oh that's amazing. It's good to have a friendship like this.'*

*Oli: 'I mean it's not friendship... She is a bit down recently. I am gonna give her my number on Friday, so I said she can call, call, me when she's down.'*

*Sally: 'Oh okay.'*

*Oli: 'I am doing a nice thing. I want to care for her.'*

*Sally: 'Oh, that's nice... It's making me very happy that you are happy about it. It has given you something to look forward to...did you tell her the good qualities about her?'*

*Oli: 'Yeah. She is very pretty, smart, and yeah, she is understanding as well.'*

*Sally: 'Yeah being understanding is very important isn't it.'* (Sixth SM&P session observed: 18<sup>th</sup> November 2021)

It appears that the SM&P intervention had a clear impact on Oli's emotional well-being, stemming from his personal feelings towards the intervention as well as his long-term emotional regulation skills. Furthermore, it created opportunities for Oli to speak to Sally about the targeted exercise he wanted to try, which can be seen from the interview fieldnotes below:

*Sally: 'Well, looking at how strong that core is. How is your stomach?'*

*Oli: 'I feel more on my back if I am honest.'*

*Sally: 'Yeah this works on both your tummy and your back.'* (Eighth SM&P session, conversation between Oli and Sally, 24<sup>th</sup> March 2022)

Besides the discussion opportunities Oli was offered, he also felt the benefits of the intervention as he acknowledged that he became slimmer, since no one called him 'fat' anymore. As mentioned above, Oli experienced hopefulness as he believed he would feel happier when his peers stopped taunting him. Therefore, it appears that the SM&P's direct impact on Oli's physical fitness also affected his emotions positively and indirectly. This can be found from the interview quotes below:

*Chai: 'So tell me if the sessions affected the situation with the belly poking and name calling situation?'*

*Oli: 'Uh, yeah, it's definitely, definitely has helped. Uh, I have told R to stop doing it and he stopped doing it.'*

*Chai: 'Yeah, let's focus on how the sessions have affected the situation.'*

*Oli: 'Yeah, yeah, yes, yes, it definitely has.'*

*Chai: 'In what way?'*

*Oli: 'I'm definitely getting a bit more slimmer and no one calls me fat anymore.'* (Sixth interview with Oli, 29<sup>th</sup> March 2022)

### **6.3.5 The intervention impacts on Gordon's emotions**

Similar to Tony, through the initial interviews and observations, Gordon appeared to be anxious about his intervention. However, Gordon also recognised the impact of the intervention and it appears that he was comfortable with and trusted Nia, and

that the intervention made him 'good'. This can be seen from the interview quotes below:

*Chai: 'So, in terms of the sessions that you're having with Nia, what do you think about the sessions?'*

*Gordon: They are good. I like to talk about what's going on.*

*Chai: '... Nia spoke about agreeing with you what she might be sharing... to ensure that you are safe. How do you feel about that?'*

*Gordon: 'I've not expressed myself in a long time, I've just kept myself in. But for her to tell other people, it's a bit nerve-wracking, I'm a bit nervous. I am happy for her to tell mum, and maybe Ta (Gordon's form tutor). Because it's just like sometimes when no one does anything about it.'* (First interview with Gordon, 14<sup>th</sup> July 2021)

*'Although Gordon hasn't explicitly mentioned it, he really trusted Nia as she believed in his stories... as the first session back from the summer holiday, Gordon spoke about a lot of things that happened during the holiday as well as the start of the school term. Gordon used the opportunity to let Nia know of his right decision made... Gordon is certainly becoming more mature as well as more trusting towards Nia.'* (Fieldnotes, reflection following the third SEM&H session, 16<sup>th</sup> September 2021)

*Chai: 'Yeah, now tell me how you think the sessions have been impacting your life...'*

*Gordon: 'They are making me good because I've been ignoring people.'* (Fifth interview with Gordon, 22<sup>nd</sup> Feb 2022)

*Chai: 'You told me that you feel good in general when I asked you about your emotional well-being, can you talk to me about how the sessions have impacted on your emotional well-being and how you feel?'*

*Gordon: 'I mean happy throughout the sessions. They made me feel like, happy when I've been upset.'* (Sixth interview with Gordon, 28<sup>th</sup> March 2022)

Similar to Oli, Gordon also showed an appreciative attitude towards the interventions. Gordon also felt that his life would be different without the SEM&H<sup>10</sup> intervention as he would have no one to tell his life stories to. When asked what he

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<sup>10</sup> Social, emotional and mental health

would say to Nia during an interview, Gordon simply responded with a 'thank you', to show his appreciation. This can be seen in the interview quotes below:

*Chai: 'How would your life be different if you didn't attend the sessions with N?'*

*Gordon: I don't know. It'd probably not be the same because I will have no one to tell these things to.'* (Third interview with Gordon, 1<sup>st</sup> December 2021)

*Chai: 'If you were to say anything to Nia, what would you say to her?'*

*Gordon: 'Thank you.'* (Sixth interview with Gordon, 28<sup>th</sup> March 2022)

As discussed in the first two themes, and in line with Wigelsworth, Oldfield, and Humphrey (2015) and Kaufmann (2015), Gordon felt a great deal of unfairness in life due to his social experiences and interaction with former peers and peers at School H at the time of the research. Instead of focusing on providing Gordon with physical strategies to support with his emotional regulation, Nia firstly emphasised the process of labelling emotions in the SEM&H intervention. Furthermore, when exploring conflicts related topics with Gordon, Nia also started to validate emotions focused on the principle and the moral aspect of whether one enjoys doing certain things and how it is decided.

*Gordon: '...Now it's J, D and L (another three pupils, who is not part of this research)...they are all being mean. J is in my class. I was playing football and I kicked the ball, not towards him but the goal. And by accident, the ball curved. You can't stop a ball curve, can you?'*

*Nia: 'Yes, yes, yes.'*

*Gordon: 'So like the ball hit him on his knee, and he went like "ouch". I told him "sorry, sorry, sorry". He then said "what's wrong with you", and he just screamed at me, picked up the ball and screamed at me... and he hit my shoe.'*

*Nia: 'Okay...Oh so that sounds...yeah, what sort of feelings did you have about that? I have also got this (a feeling chart) prepared for the session. How did you feel?'*

*Gordon: (He identified J's feelings, pointed at one of the faces) 'He's always mad at me. Every time I kick the ball towards him. I am not doing that on purpose, I swear on my life. I don't even care if the ball goes near him, but then when the ball goes near him, he just kicks it at me on purpose.'*

*Nia: 'Right, okay, okay. How are you feeling then?'*

*Gordon identified his feelings: 'I am a bit angry, and I am a bit upset.'*  
*N prompted Gordon and said: 'So that's kind of in the red zone?'*

*Gordon said: 'I am angry (pointing to the red zone), and sad (pointing at the blue zone)' (First SEM&H session, conversation between Gordon and Nia, 1st July 2021)*

*Nia: 'It is amazing you didn't (fight back), because they were trying to get a reaction and you just stayed chilled. With your friends, you carried on walking did you? That's impressive Gordon. We go into fight flight mode; but you didn't, you carried on walking.'* (First SEM&H session, Nia's response to Gordon, 1<sup>st</sup> July 2021)

*'Gordon was upset for two reasons. Firstly, he hit his peer with the football and felt that he overreacted, and secondly, he ended up losing football time for the rest of his day. Nia acknowledged and redirected Gordon to identify his own feelings, which he did. Nia then supported Gordon's emotional literacy by prompting him to use the terminologies shown on the visuals. It was inspiring to watch Gordon seemed to have wanted acknowledgement on the fact that his peer overreacted and that him losing football for the day was unfair. However, Nia purely listened to Gordon's account of the events, then guided him to thinking about his own emotions. Although Gordon did not get the responses that he seemed to have wanted, he appeared to have calmed down after having the conversation with Nia.'* (First SEM&H session, fieldnotes, 1st July 2021)

*Nia: 'Do you play football still?'*

*Gordon: 'No I don't play it anymore. I don't like it.'*

*Nia: 'That's okay if you don't like it. If you are not playing because other people are not making it a nice experience, then that's not okay.'* (Ninth SEM&H session, conversation between Gordon and Nia, 25th Nov 2021)

People with ASD are likely to find it challenging to label emotions and demonstrate social reciprocity, and a lack of emotional identification and labelling can disrupt one's emotion regulation (Morie, Jackson, Zhai, Potenza and Dritschel, 2019). The process of emotion coaching consists of labelling and validating feelings, showing empathy and showing appropriate negative emotions. Children including those with behaviour disorders are more likely to display more positive patterns of peer interaction after becoming more emotionally coached (Dunsmore, Booker and



Ollendick, 2013). Although there were no physical self-regulation techniques explored in the SEM&H intervention, Nia went through the process of emotion coaching with Gordon, to allow him to explore his feelings with her supporting him by encouraging him to label his emotions, making him understand that it was acceptable to dislike football if he genuinely disliked it, but was unacceptable if it was due to others making his experience unpleasant.

As Gordon became more comfortable, there were many more conversations leading to Nia offering Gordon advice or strategies. Throughout the sessions, Nia often explored the story with Nia and gathered the facts before offering advice, which can be seen below through the conversation that took place in the SEM&H intervention:

*Gordon: ‘...he still talks to me and calls me names.’*

*Nia: ‘Have you reported to staff members?’*

*Gordon: ‘No, the lunch ladies were on duty, but they weren’t really doing anything about it. They were just standing there and talking. The lunch ladies were literally standing by the gate chatting.’*

*Nia: ‘Were there no other teaching staff on duty in the playground?’*

*Gordon: ‘No, just the lunch ladies.’*

*Nia: ‘Do you remember what he said to you?’*

*Gordon: ‘I can’t remember, he just commented on my shoes and said they’re ugly.’*

*Nia: ‘What did you do?’*

*Gordon: ‘I just walked away. He also shouted at me when he was on the bus. He shouted “Nice high heels”, then L said the same to me?’*

*Nia: ‘Did you remember what you did then? Did you walk away too? Or did you react?’*

*Gordon: ‘I reacted.’*

*Nia: ‘Can you remember what you did or said to them?’*

*Gordon: ‘Nah I can’t remember. I am tired.’*

*Nia: ‘The thing I am going to say is, the more you don’t react, the better it is for them as they may not bother.’ (Ninth SEM&H session, conversation between Gordon and Nia, 25th November 2021)*

It is obvious that Gordon also experienced negative feelings toward some staff members at School H at times, as he felt that they were not taking the appropriate actions to support him. Based on my understanding of Gordon, he struggles to stay rational and resolve conflicts when feeling emotionally dysregulated. Another incident which took place in December 2021 also suggests that Gordon lacks the ability to resolve conflict with peers, stemming from another peer being rude to him. The lack of ToM could indicate how Gordon was unable to predict the actions of his peers, including how he perceives others and his ability to understand. The inability to process inferences adequately results in poor comprehension and furthermore, people without the ability to share feelings and anticipate others' behaviours and actions are at risk of being 'in their own world' (Zhou, Zhan, and Ma, 2019; Keysar and Epley, 2010; Tirado and Saldana, 2016). Gordon, to a certain extent, was in his own world. More so, he was in a vicious cycle as he was unable to process the behaviours he experienced from his peers due to his lack of ToM. Again, following a sequence of exploring and facts gathering in a session, Nia proceeded to explain to Gordon that he might not be the only person on the receiving end and the concept of understanding the actions of others, which can be seen in the quotes below:

*Gordon: 'A was being rude to me. He's just like... he's just being rude.'*

*Nia: 'Is it just to you or to everybody else as well?'*

*Gordon: 'It's to everybody else as well.'*

*Nia: 'I think we are aware of that. I think you should keep an eye on it. He might be having a difficult time, so perhaps try to understand other people too.'*

*Gordon: 'Sometimes it's just to me too.'*

*Nia: 'Now I am aware of Aaron's behaviour, I will look into that as well. He is a new pupil and a lot of things might be going on in his life too so he might need more help. I want to let you know that staff are actively trying to help pupils so things are not just left there.'* (Tenth SEM&H session observed, conversation between Gordon and Nia, 9th December 2021)

Besides labelling and validating emotions, offering advice and emotional regulation strategies directly, Nia also coached Gordon's emotions, where Gordon was prompted to think and understand more about his emotions when processing unkind behaviours peers with more autonomy. Nia put extra emphases on coaching Gordon to think about his positive experience and she used these opportunities to celebrate with him, which was evidenced in multiple sessions:

*Nia: 'How are you feeling about coming into school these days?'*

*Gordon: 'Obviously I am tired. Wanted to act as if I was sick, so that I can chill out and relax.'*

*Nia: 'How did you used to feel when you needed to come in?'*

*Gordon: 'Blue zone.'*

*Nia: 'To a degree you are saying that you are still in the blue zone. Is there any difference between how you used to feel and how you feel now about coming into school?'*

*Gordon: 'I want to come in more often.'*

*Nia: 'Why is that?'*

*Gordon: 'People aren't being rude to me.'* (Fifth SEM&H session, conversation between Gordon and Nia, 07th October 2021)

*Nia: 'We talked about how you felt about coming into school back in June when we first started out session. Can you remember how you were feeling then?'*

*Gordon: 'I couldn't really be bothered about coming in.'*

*Nia: 'How are you feeling now about coming into school?'*

*Gordon: 'I like coming into school now. No one is being mean to me. No one is bullying me.'*

*Nia: 'What were the things that you had done that made a change?'*

*Gordon: 'I told the teachers. I told my mum.'*

*Nia: 'It must be a very hard and brave thing for you to do, especially because you have talked about how not helpful you found your previous school.'*

*Nia: 'What was the other thing that you talked about, another thing that helped you.'*

*Gordon: 'Oh yeah, coming to the sessions.'*

*Nia: 'Again, that's a big thing to do as you didn't know me and didn't know how I could be helpful.'*- (Sixth SEM&H session, conversation between Gordon and Nia, 04th November 2021)

*Nia: 'How does it make you feel, now that you talk to people about your feelings?'*

*Gordon: 'Yeah I am myself, and calm.'*

*Nia: 'I think it's good that you are saying that you are calm... This is really good that you trusted us. This is all your hard work. This isn't something easy as you had a negative experience. You really deserve to feel calm at school.'*

*Gordon: 'Thank you.'* (Tenth SEM&H session observed, conversation between Gordon and Nia, 9th December 2021)

In order to encourage Gordon to react to incidents in a positive way when others pose physical threats towards him, Nia also used a slot machine as an example to demonstrate how one would eventually give up on something following a number of unsuccessful attempts. Nia was aware of the fear Gordon was going through due to the uncertainty caused by a threatening situation, however, Nia attempted to rationalise

the thought process of the perpetrators and helped Gordon create more certainties. This can be found in the conversations that took place in the intervention below:

*Gordon: My adrenaline will start kicking in. It's like I am going to have to fight or I just don't know what's going to happen.*

*Nia: Do you know what a slot machine is? Let's use that as an example. What would winning look like to them?*

*Gordon: Giving them a reaction.*

*Nia: Exactly! What would happen it's like you putting in money into the machine every time you choose not to react to them?*

*Gordon: They would leave me alone. (Fourth SEM&H session, conversation between Gordon and Nia, 30<sup>th</sup> September 2021)*

Emotions aside, Nia also guided Gordon to think about the consequences the perpetrators would suffer, to highlight the emotions of others. Nia also highlighted to Gordon that dealing with uncomfortable feelings takes strength and guided him to think about how wise and mature those decisions were, despite feeling embarrassed initially. The input from Nia support Gordon to increase his emotional resilience, which could potential enable him to handle negative emotions in the future. The coaching occasions were evident from the intervention conversations below:

*Gordon: 'I just didn't want to fight back because I know he is older than me, and he will just beat me up. It's annoying; I have had it all my life.'*

*Nia: 'What did the teacher do about that?'*

*Gordon: 'Nothing. I got a detention.'*

*Nia: 'What did the boy who kicked you get?'*

*Gordon: 'I don't remember. I think he got a minor, minor, consequence.'*  
(Second SEM&H session, conversation between Gordon and Nia, 8<sup>th</sup> July 2021)

*Nia: Would you take your boxing out of the boxing ring? Or would you say I will keep it in the right place? (Third SEM&H session, fieldnote, 16<sup>th</sup> September 2021)*

*Gordon: I feel embarrassed and a bit ashamed because I would think 'should I have fought them instead?'*

*Nia: The short term impact on you is that you might feel embarrassed. That's the thing about bullying, it brings out those embarrassed feelings. What you did was that you walked away. Short term, you felt really uncomfortable. But long term, you feel... how do you feel now?*

*Gordon: It is a wise decision because I avoided fighting others.*

*Nia: Do you think that it was a mature decision?*

*Gordon: Yeah*

*Nia: It is really not easy. It takes a lot of strength to not react. All those feelings are very uncomfortable. You have to carry those feelings aware from*

*you.* (Fourth SEM&H session, conversation between Gordon and Nia, 30<sup>th</sup> September 2021)

To conclude, both Tony and Gordon started their intervention feeling anxious, but improved their confidence over time, whereas Oli openly discussed how emotionally comfortable he was with his intervention and the Sally (intervention leader). All three interventions offered varying degrees of emotional impact, with the C&I intervention offering some additional opportunities for Tony to play games and grow in confidence and the SM&P and SEM&H intervention focussing on different strategies on emotional regulation.

## 7 Conclusions

In chapter 2, I explored the different definitions of QOL through critically analysing the current literature, and the general consensus is that QOL is an umbrella terminology that comprises of different well-being domain headings in life. Therefore, a set of domain headings including Social Well-being, Physical Well-being, Material Well-being, Emotional Well-being, Personal Development and Independence were identified. The literature review suggests that the general QOL of CYP with SEND is lower than their typically developing peers, with more specific evidence suggesting that physical well-being, mental / psychological well-being (referred to as emotional well-being in this thesis) and social well-being. There are different interventions trailed by researchers to improve the QOL of CYP with SEND, which included elements from an educational, religious, behavioural and coaching point of view. However, neither of them is directly applicable to my research as the elements within the scope of the non-curriculum based interventions vary based on the circumstances and needs of the participants. In other words, elements or discussions around behaviour, or spiritual and religious activities could potentially be included in the intervention, should they be deemed to be what the participants need or desire.

Chapter 3 outlined the rationale behind undertaking action research using a qualitative approach that is inspired by ethnography. The research included three student participants, their mothers and their intervention leaders, who were also staff members of School H. The interventions observed were Communication and Interaction (C&I), Sensory, Motor and Physical (SM&P) and Social, Emotional and Mental Health (SEM&H).

In comparison to most literature related to QOL and SEND, my research is one of the very few examples that is purely of a qualitative nature. Most existing research studies on CYP with SEND fail to tell the participants' stories. My research follows the action research cyclical approach, which provided me with more opportunities to reflect and collect qualitative data. My research follows the action research cyclical approach, which provided me with more opportunities to reflect and collect

qualitative data, allowing for an in-depth understanding of the participants' experiences. Engaging in reflexivity led to major changes to my research, which included the refinement of methodology, from an ethnographic study to an ethnography inspired research, due to the conflict between my role as the researcher and my role within the school. The other major change to my research following the reflective process led to asking for additional ethical approval for the use of proxy view: i.e. the parents of the student participants, and more research on how to utilise decontextualisation when understanding and presenting the data.

Through the process of data collection which included conducting participant observation and semi-structured interviews, I gained an in-depth understanding of the student participants' experiences of QOL. Additionally, the advantage of having a small sample group and recruiting all participants purposefully allowed me to also understand the student participants' world. The 65,000 words of primary data collected over nine months covered ten occasions of the C&I interventions, seven occasions of the SM&P interventions, twelve occasions of the SEM&H interventions, over twenty informal instances, and twenty-one semi-structured interviews.

In chapter 5, I discussed the data analysis procedure in great detail following a thematic analysis framework, which included: contextualising and decontextualising data, familiarising myself with the data, generating initial codes, identifying, reviewing, defining and naming themes, before the report production process. Throughout the process of data familiarisation and meaning or pattern searching, it was vital to read the data repeatedly and in an active way before the process of coding, as multiple truths and realities could emerge during data interpretation. I previously explained how I utilised my car journeys to and from work to listen to the audio of the intervention session videos to familiarise myself with the data, before fieldnotes. Secondly, I discussed how I deployed technology, i.e. Microsoft documents, and stored the interview transcript and fieldnotes, which I then compiled into a coding excel sheet. Within the coding excel sheet, tabs were created and named QOL domain headings, where relevant data collected from interviews and fieldnotes would be categorised under each domain heading. However, the steps so

far were not enough to meet the research objective, as I intended to identify their views on their QOL domains under the headings. Felce and Perry (1995) suggest that the QOL domains created extend over between the researchers, meaning I would have to understand and interpret the story of each participant and extend the understanding on their QOL domains. Under each domain heading, I further coded the data by the domain headings and drafted to 'local themes' after making sense of the individual cases (Sandelowski, 1996). Out of 26 local themes identified, 16 of them shared commonly between all three student participants. Out of the 16 common themes, three main themes were subsequently formulated – social well-being through peer interactions, physical well-being and emotional well-being.

In Chapter 6, I discussed the findings and outlined the sub-themes under each main theme while unravelling the student participants' stories, highlighting the impact of each intervention. Social well-being played a significant part in the life of all student participants, as they all valued friendship. Tony appeared to believe that the number of friends was important, while student participants Gordon and Oli both seemed to value quality friendships and were keen to play on the console with their peers. Nonetheless, they all faced negative experiences in this area to different extents, which include unkind behaviour, such as receiving negative comments from their peers on their sports competency, appearance, choice of having a romantic relationship with someone older and social exclusion.

Secondly, physical well-being was identified as another main QOL domain heading for the student participants of my research. There is a clear mutual consensus when exploring all student participants' views on the definition of good physical well-being, such as having a balanced diet and regular exercise routine, with different levels of description. The impact of physical fitness also appeared as a sub-theme, as Gordon and Oli both had a desire to improve their physical fitness due to different reasons and Tony lacks motivation due to his understanding of his physical ability.

Finally, both social and physical well-being appeared to be strongly linked to student participants' emotional well-being, as there are strong feelings attached to each



domain and story. Although Tony does not show emotions conventionally due to his learning needs, the findings suggest that he appeared to be happy with his life. Tony displayed discomfort during social situations and felt uneasy about his preference to be alone. Despite the lack of physical ability compared to the other student participants, Tony appeared content with his physical Well-being as he merely expects less from himself. While social and physical Well-being caused both Oli and Gordon negative emotions including feeling frustrated and embarrassed, they also motivated them to better themselves by setting specific goals, as they did not enjoy feeling the way they did.

The C&I intervention had an indirect impact on Tony's over social well-being and emotional well-being, while having little to no impact on his physical well-being. The C&I intervention provided Tony with a platform to play targeted games with Aaron, and consequently, Tony experienced both winning and losing through the intervention. It was crucial for Tony as he experienced social exclusion at the time of the research, and not only did the intervention provide him with social opportunities, it also developed his speech in readiness for future peer interactions. Throughout the intervention, it was observed on occasions that Aaron was 'accused' of cheating his way to win, and there was a positive emotional connection between Tony and Aaron as they play their games. However, there was no mention of physical activities or any related conversations throughout the intervention, Tony's physical well-being.

Similar to the C&I intervention, the SM&P intervention also had an indirect impact on Oli's Social well-being as it provided Oli with some opportunities playing games with Sally. The impact on Oli's Social well-being as Oli discusses his social difficulties with Sally throughout the sessions, despite the aim of the session being in the physical aspect. The SM&P intervention had a direct impact on Oli's physical well-being as it provided him with the opportunities to exercise and better himself physically. Overall, Oli also utilised the intervention to share both his uneasy and positive feelings with Sally, and therefore, it suggests that the SM&P had a direct impact on Oli's emotional well-being.

A strong impact on Gordon's social and emotional well-being was demonstrated within the SEM&H intervention, as Gordon explored his feelings from his social encounters with Nia on a regular basis, both positive and negative. The feedback Nia received through direct mentoring or coaching led him to reflect and make informed decisions, which evidently improved his mood overall as well as his self-autonomy. While the SEM&H intervention's focus was not on Physical well-being, there was still an indirect impact found on Gordon through the intervention, as there were in-depth discussions on physical health relating to sleep between Nia and Gordon. Appropriate solutions to support physical well-being including the consumption of coffee, and health and safety when exercising were also discussed and Gordon started to change his lifestyle positively following his evaluation.

Both Gordon and Oli also recognised the impact of the intervention and were grateful as they showed an appreciative attitude. For instance, Gordon expressed how the SEM&H intervention impacted on his emotional well-being, and how it made him become 'good'. Similarly, Oli stated how the intervention impacted on his physical well-being, personal development and level of independence respectively. Moreover, Gordon felt that Nia was the only person he could speak to and stated that he would say 'thank you' to her for the intervention experience. Oli, similarly expressed that he would like the intervention to continue after the research as he found the intervention fun. Oli also enjoyed S' delivery of the intervention and described her as his 'favourite' teacher.

Overall, all interventions had a positive impact on the QOL of the student participants. Having regular conversations and communication throughout the interventions provided student participants with opportunities to explore their QOL domain headings. Specific examples including physical exercises, interacting through games and evolving conversations with specific coaching and strategies offered also demonstrated impacts on their QOL. However, it is also worth noting that the receptiveness of the student participants and their interests and motivation must also be taken into consideration. As discussed in section 3.1, my research findings are not to be generalised. Rather, readers have to consider the transferability or the

naturalistic generalisability of my research findings, as they read through the in-depth description of the research study as well as sample group.

Therefore, the findings do not specifically demonstrate the effectiveness of the interventions, but this research does suggest that the student participants' QOL did appear to be positively impacted by the tailored non-curriculum based interventions. Additionally, the research shows that having regular conversations and communication during the interventions encouraged the exploration of student participants' QOL.

Beyond the research conclusions, my thesis brings contribution to knowledge in the larger context of the QOL of CYP with SEND. Existing literature suggests that the QOL of CYP with SEND is lower than their typically developing peers, particularly in QOL domain headings including social, emotional and physical well-being (Schormans, 2014; Shpigelman, 2019; The Good Childhood Report, 2023). In a similar vein, the three themes coincided with the QOL domain headings the literature drew attention to, as they were the most frequently discussed and observed areas over the nine-month-research period. My thesis also provided context on how student participants unravelled some of their difficulties under these domain headings due to their specific SEND, and how their perception of some of these domain headings improved overtime through the interventions.

## 8 Recommendations for future research

In my methodology chapter, I have justified the size of my sample group by explaining the choice of using a purposeful sample, the quality of the in-depth data produced and clarifying the difference between transferability and generalisability. Future researchers may want to consider adapting their interventions based on the finding of my research, if their aim is to investigate the effectiveness of enhancing or positively impacting one's QOL.

Future researchers should consider the different needs of their participants and how their SEND could affect their perception of these areas, as well as the impact of any intervention implemented. From an educational point of view, the independent school inspection framework (Independent Schools Inspectorate, 2023) also began to put a heavier emphasis on children's overall QOL by inspecting the coherence of schools' provision on supporting children's physical, emotional, social and economic well-being, as well as their mental health. Researchers in the field of education can also consider the findings of my research and apply appropriate contextual transferability and review their QOL-related practice.

The first main recommendation is in relation to the overall duration of the data collection period for research studies in QOL of CYP with SEND. The data collection period for my thesis lasted nine months, which enabled me to gain an insight into each participant's experiences, which also covers the intervention leaders and the student participants' mothers, on the research enquires. However, future research could explore participants' experiences over an even more extended period of time, which could include different phases of life, which may affect their perception of participants' QOL. For instance, the national curriculum changes by year group or key stage, meaning the young people's learning contents change and their perception of QOL as a concept can be affected. Secondary school students are also exposed to sex education as opposed to only relationship education. Furthermore, secondary school aged students also receive careers guidance as part of their school offer. As a result, CYP's perception of the concept of QOL as well as their evaluation is very likely to change due to these milestones they are exposed to

during their school life. An extensive period of research will also enable the action research cycles to continue to develop, where the researcher and participants would be provided platforms to discuss, reflect and go about making changes (Armstrong and Tsokova, 2019; Lazarus, 2019). Therefore, future research studies with extended action research cycles can capture the potential evolvement of their participants' perception towards their life, as well as the longevity of the impact of the intervention. Future research could potentially focus on CYP's QOL within one certain key stage, which lasts from 2 to 3 years, to critically evaluate the findings and stories of their research, while explaining the rationale behind the extended data collection period clearly to the participants.

Future research could also include a variety of proxy data collected. As already stated, I decided to include the use of proxy views from the student participants' mothers, upon reflection due to the difficulties I encountered when analysing data, and the proxy data collected provided me with further understanding of student participants' life from different perspectives. Further research could include a variety of proxies who may provide an even more in-depth understanding of the. For instance, besides the mother of the student participants, more proxy views such as fathers and even other staff members who have a good understanding of the student participants, could be collected and utilised. Although some studies reflect on possible discrepancies between participants' self-reporting and the proxy views (Thurston *et al.*, 2010; Svekle *et al.*, 2010), I already justified that my research does not sole rely on proxy views and indeed the proxy data complements and enhances the richness of the analyses. Therefore, future research should consider collecting a wide range of proxy research to elevate the data analysis and presentation process. In order to achieve this, the question of 'who knows you well, and in what context?' can be asked during one of the early interviews. Further recruitment of participants can be arranged based on the proxies list, where specific and contextual questions can be directed to.

With the above ways forward, I hope to see that matters around one's QOL are explored on different scales, both nationally and globally. You only live once, and

therefore, the experience of QOL can be seen as everything that one has. Hence, I urge all researchers to pay extra attention to this area and share extended knowledge in this valuable research area.

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## Appendix 1: Interview schedule

Data collection chronology for Tony	
Date	Type of data
14 <sup>th</sup> June 2021	First C&I session observed
25 <sup>th</sup> June 2021	Second C&I session observed
1 <sup>st</sup> July 2021	Third C&I session observed
12 <sup>th</sup> July 2021	First interview conducted (With Tony)
14 <sup>th</sup> July 2021	Fourth C&I session observed
19 <sup>th</sup> July 2021	Fieldnote: Dodgeball match during activity week,
6 <sup>th</sup> Sept 2021	Fieldnote: Conversation between Tony and his peers
21 <sup>st</sup> Oct 2021	Fifth C&I session observed
22 <sup>nd</sup> Oct 2021	Second interview conducted (With Tony)
4 <sup>th</sup> Nov 2021	Fieldnote: Conversation between Tony and one of his classmates
5 <sup>th</sup> Nov 2021	Sixth C&I session observed
11 <sup>th</sup> Nov 2021	Seventh C&I session observed
18 <sup>th</sup> Nov 2021	Eighth C&I session observed
30 <sup>th</sup> Nov 2021	Third interview conducted (With Tony)
16 <sup>th</sup> Dec 2021	Nineth C&I session observed
17 <sup>th</sup> Jan 2022	Fourth interview conducted (With Tony)
17 <sup>th</sup> Jan 2022	Tenth C&I session observed
4 <sup>th</sup> Feb 2022	Fieldnote: Tony's activities during lunch time,
5 <sup>th</sup> Feb 2022	Fifth interview conducted (With Tony)
4 <sup>th</sup> Sept 2022	Interview conducted (With Mrs Conor / Tony's mother)

Data collection chronology for Oli	
Date	Type of data
27 <sup>th</sup> May 2021	First SM&P session observed
10 <sup>th</sup> June 2021	Second SM&P session observed
24 <sup>th</sup> June 2021	Third SM&P session observed
12 <sup>th</sup> July 2021	First interview conducted (With Oli)
18 <sup>th</sup> Sept 2021	Fieldnote: Conversation between Gordon, Oli and their peers
11 <sup>th</sup> Nov 2021	Fourth SM&P session observed
18 <sup>th</sup> Nov 2021	Fifth SM&P session observed
21 <sup>st</sup> Oct 2021	Fieldnotes: Conversation between Gordon, Oli and their peers
21 <sup>st</sup> Oct 2021	Second interview conducted (With Oli)
11 <sup>th</sup> Nov 2021	Fieldnote: Oli and Sally's interaction when playing a game

23rd Nov 2021	Fieldnote: Oli playing football during lunch time
26th Nov 2021	Fieldnote: P.E. lesson
26th Nov 2021	Fieldnote: Instructions given to Oli in a lesson
30 <sup>th</sup> Nov 2021	Third interview conducted (With Oli)
18 <sup>th</sup> Jan 2022	Fourth interview conducted (With Oli)
20 <sup>th</sup> Jan 2022	Sixth SM&P session observed
24 <sup>th</sup> Jan 2022	Fieldnote: Instructions given to Oli in a lesson
23 <sup>rd</sup> Feb 2022	Fifth interview conducted (With Oli)
2 <sup>nd</sup> Mar 2022	Seventh SM&P session observed
24 <sup>th</sup> Mar 2022	Eighth SM&P session observed
27 <sup>th</sup> March 2022	Interview conducted (With Mrs Zane / Oli's mother)
29 <sup>th</sup> March 2022	Sixth interview conducted (With Oli)

<b>Data collection chronology for Gordon</b>	
<b>Date</b>	<b>Type of data</b>
1 <sup>st</sup> July 2021	First SEM&H session observed
8 <sup>th</sup> July 2021	Second SEM&H session observed
14 <sup>th</sup> July 2021	First interview conducted (With Gordon)
16 <sup>th</sup> Sept 2021	Third SEM&H session observed
18 <sup>th</sup> Sept 2021	Fieldnotes: Conversation between Gordon, Oli and their peers
30 <sup>th</sup> Sept 2021	Fourth SEM&H session observed
7 <sup>th</sup> Oct 2021	Fifth SEM&H session observed
21 <sup>st</sup> Oct 2021	Fieldnotes: Conversation between Gordon, Oli and their peers
21 <sup>st</sup> Oct 2021	Second interview conducted (With Gordon)
4 <sup>th</sup> Nov 2021	Sixth SEM&H session observed
11 <sup>th</sup> Nov 2021	Seventh SM&P session observed
18 <sup>th</sup> Nov 2021	Eighth SM&P session observed
25 <sup>th</sup> Nov 2021	Ninth SM&P session observed
26th Nov 2021	Fieldnote: P.E. lesson
1 <sup>st</sup> Dec 2021	Third interview conducted (With Gordon)
9 <sup>th</sup> Dec 2021	Tenth SM&P session observed
4th Jan 2022	Fieldnote: Gordon playing football with his peers during lunch
13 <sup>th</sup> Jan 2022	Eleventh SM&P session observed
17 <sup>th</sup> Jan 2022	Fourth interview conducted (With Gordon)
20 <sup>th</sup> Jan 2022	Twelfth SM&P session observed

24th Jan 2022	Fieldnote: Gordon in the lunch hall before his football time
22 <sup>nd</sup> Feb 2022	Fifth interview conducted (With Gordon)
28 <sup>th</sup> March 2022	Sixth interview conducted (With Gordon)
30 <sup>th</sup> March 2022	Interview conducted (With Mrs Smith / Gordon's mother)

## **Appendix 2: Interview schedule**

### **First interview**

C: Good morning XXX, thank you for taking part in the interview. If you don't feel comfortable answering any questions, just let me know and I'll move onto the next one or stop. Okay, are we ready to start?

C: Thank you. First question, what do you like in general? (With follow-up questions)

C: Okay. Second question then. What don't you like in general? (With follow-up questions)

C: Moving onto the next question. What things do you think are important?

C: Okay. So, the next question is about the sessions that you have been having with A. What did you think about the activities you were doing?

### **Third interview**

C: Good morning XXX, thank you for taking part in the interview...

C: How are you feeling in general?

C: In a recent session, you said that you think the sessions have gone well. Can you describe that more?

C: How do you think reading the T and C/K sound clearer help you in life?

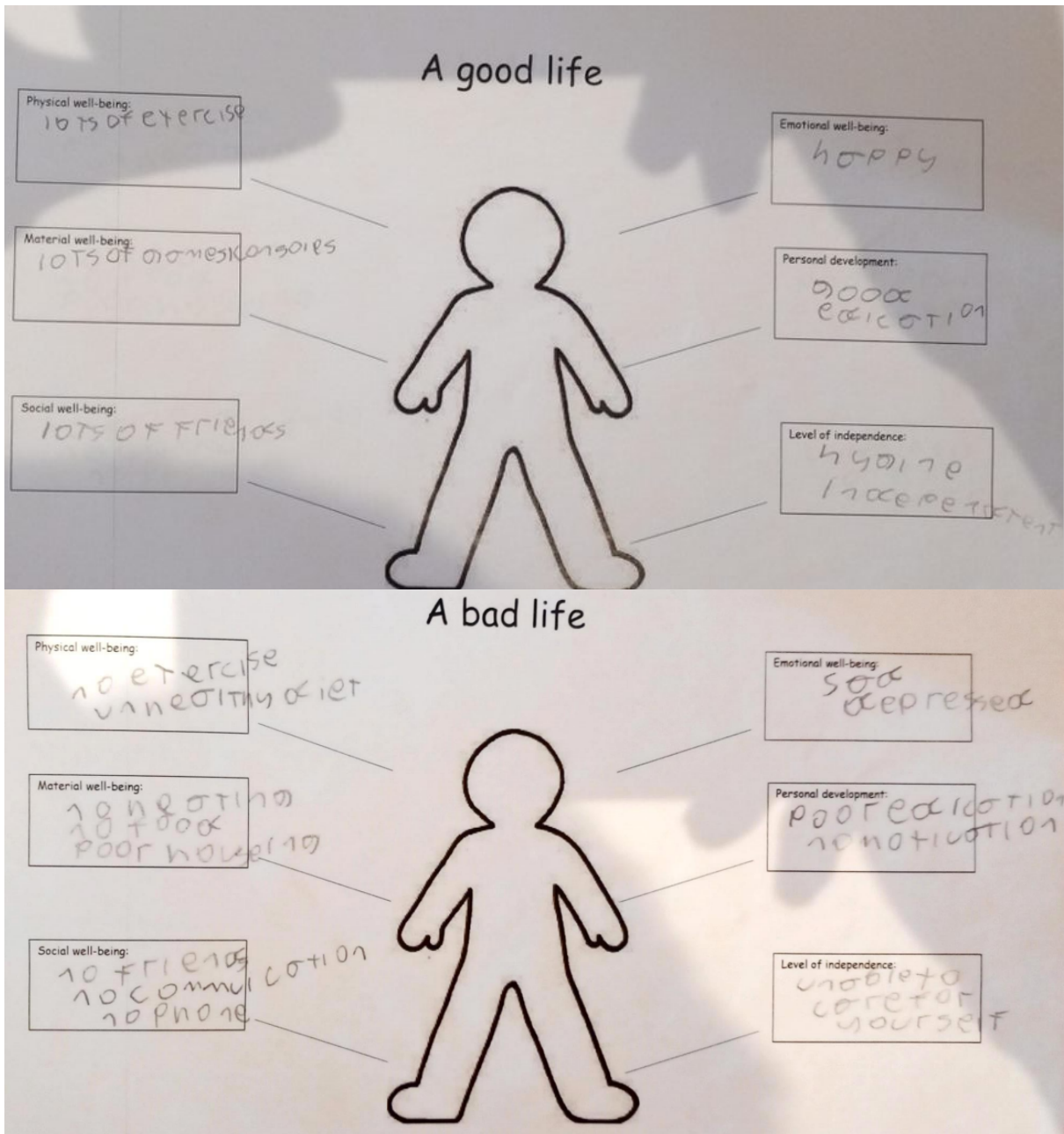
C: Has your social life been affected by your development in your T & C/K?

C: Do you live a happy life?

C: What in your life makes you happy?

C: What more would you like to have in your life?

### Appendix 3: Differentiated materials



## Appendix 4: Participant consent form



Informed Consent for Action Research: the impact that non-curriculum based targeted interventions can have on the quality of life (QOL) of children and young persons (CYP) with special educational needs and/or disabilities (SEND).



Please tick the appropriate boxes

### 1. Taking part in the study

I have read and understood the study information dated \_\_\_\_\_, or it has been read to me. I have been able to ask questions about the study and my questions have been answered to my satisfaction.

I consent voluntarily to be a participant in this study and understand that I can refuse to answer questions and I can withdraw from the study at any time, without having to give a reason. I can withdraw my data up until \_\_\_\_\_ which is the final date before data is analysed.

I understand that taking part in the study involves taking part in specific non-curriculum based targeted interventions and be interviewed by Mr Chai Ho (Kief). Notes will be taken by Mr Chai Ho (Kief) during the intervention observations. Interviews will be recorded via voice recordings and will then be transcribed as texts.

I understand that interventions are filmed using IRIS Connect, a secure online platform. The video recordings will be kept available for Mr Chai Ho (Kief) to view at the capacity as a researcher during the course of his PhD study. Once the course Mr Chai Ho's PhD study is complete, \_\_\_\_\_ School will own the videos for internal use.

### 2. Use of the information in the study

I understand that the information I provide will be used for reports for Hillingdon Manor School internal use and Mr (Kief) Chai Ho's published doctorate thesis.

I understand that personal information collected about me that can identify me, such as my name or where I live, will not be shared beyond the study team.

I consent to the processing of my personal information for the purposes of this research study. I understand that such information will be treated as strictly confidential and handled in accordance with current UK Data Protection legislation.

I agree that my information can be quoted in research outputs.

*Adapted from the LBDS model consent form April18*

### 3. Future use and reuse of the information by others

I give permission for the interview transcripts that I provide to be used for future research and learning. E

### 4. Signatures

\_\_\_\_\_  
Name of participant [IN CAPITALS] Signature Date

\_\_\_\_\_  
Name of the parent or carer [IN CAPITALS] Signature Date

\_\_\_\_\_  
Name of researcher Signature Date

### 5. Study contact details for further information

Mr Chai Ho (Kief)

07 [REDACTED]

[C\[REDACTED\]@bucks.ac.uk](mailto:C[REDACTED]@bucks.ac.uk)

Dr Ina Stan & Dr Maurice Gledhill

[I\[REDACTED\]@bucks.ac.uk](mailto:I[REDACTED]@bucks.ac.uk) & [M\[REDACTED\]@bucks.ac.uk](mailto:M[REDACTED]@bucks.ac.uk)



One copy to be kept by the participant, one to be kept by the researcher



## Appendix 5: Participant information sheet



### Participant information sheet

PhD research study: *Action Research: the impact that non-curriculum based targeted interventions can have on the quality of life (QOL) of children and young persons (CYP) with special educational needs and/or disabilities (SEND).*

#### Who is conducting the research project?

My name is Chai Ho (Kief) and I am a PhD student from Bucks New University. My research study is supervised by Dr Ina Stan and Dr Maurice Gledhill. This study has been reviewed and approved by the Ethic Committee Panel at Bucks New University.

#### What is the study about?

This research project investigates the impact that non-curriculum targeted based interventions can have on the quality of life (QOL) of children and young persons (CYP) with special educational needs and/or disabilities (SEND) at [REDACTED]

#### What will it involve?

The research will involve students from [REDACTED] to participate in non-curriculum targeted based interventions and be interviewed regularly to explore the impact the interventions have on their QOL. There are three types interventions used in this research – Social and interaction, Sensory, motor and physical and Social, emotional and mental health. Activities used in the Social and interaction group consists of board games and discussions that focus on the receptive and expressive communication. During the Sensory and motor interventions, participants will explore activities that focus on fine and gross motor skills, such as obstacle course, building activities and physical activities. In addition, discussions on how their body reacts to different feelings and experimenting with different de-escalation activities are also explored in the Sensory and motor interventions. The Social, emotional and mental health interventions facilitate activities such as discussions, counselling and cognitive behaviour therapy that focus on one's sense of self, social habits, likes and dislikes and ways to manage problems by changing the way one thinks and behaves.

Over the course of two academic years, twenty interviews will be conducted each participant and they last around twenty minutes. Please note that all participants can opt out of the project without any given reason.

### What information will [REDACTED] and the public have?

Once the research study is complete, I will provide [REDACTED] with a report, summarising the findings. They will be shared between staff members within the school, with the aim of promoting good practice. Since this is a PhD research study, the complete thesis will be published and be available in The British Library. You can request a copy of the findings. This will include **anonymous** information on:

- The contents of the interventions
- Observations on participants' behaviour throughout the interventions
- The interview analysis

### Is there anything more I need to know?

The legal basis that would be used to process your personal data will be performance of a task in the public interest. The legal basis used to process special category personal data will be for scientific and historical research or statistical purposes/explicit consent.

Your personal data will be processed so long as it is required for the research project. Although personal data such as participants' age, gender and SEND diagnoses will be displayed in this research study, no real names of people or institutions will be used to ensure anonymity and confidentiality.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact Bucks New University in the first instance at [dpofficer@bucks.ac.uk](mailto:dpofficer@bucks.ac.uk)

### How will you be safeguarded?

I have had a recent Disclosure Barring Service check (previously known as a Criminal Records Bureau check) and I have had safeguarding training (Level 3). Should there be any safeguarding concerns during any point of this research, the school safeguarding procedure will be followed and relevant designated safeguarding leads or officers will be informed.

### Further questions

If you have further questions about this research, please do not hesitate to contact my or my supervisors at: [REDACTED] I am happy to discuss the study in more detail via email, phone or through a meeting at your convenience.

## Appendix 6: Participant information sheet with visuals



### Participant information sheet

PhD research study: *Action Research: the impact that non-curriculum based targeted interventions can have on the quality of life (QOL) of children and young persons (CYP) with special educational needs and/or disabilities (SEND).*

#### Who is doing this research?



- My name is Chai Ho (Kief). \_\_\_\_\_



- I study at Bucks New University.



- My university says it is ok to do this research.

**What is the research about?**

- Quality of life means how you feel your life is, whether you are happy about some things or unhappy about other things.



- I want to see if interventions at school change your quality of life.



What will I need to do?



- You will go to interventions and take part in activities.
- You might play board games, exercise or discuss in the interventions.



- You will have a 20-minute-interview with Kief 10 times a year.



- It is ok if you want to quit.

### What information will your school and the public have?

- The school will get a report of this research.



- The public can also see a copy of this research in the library.

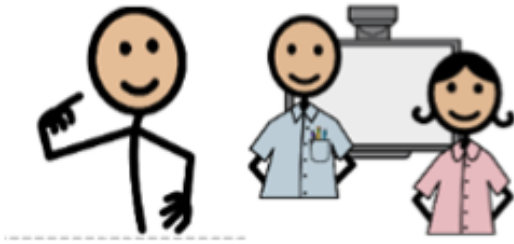


### What else do I need to know?

- Your age, gender and needs will be used but your name **will not** be used in this research.



- Only Kief and his teachers at University can see your information.



- Kief will speak to your school if he is worried about your safety.



- Remember you won't need to answer all the questions if you are uncomfortable



- Remember you can quit whenever you want.



- You can speak to Kief's University if you are worried about your personal information being unsafe.



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Please speak to Kief, his teachers or his university if you have my more questions

██████████ [@bucks.ac.uk](mailto:██████████@bucks.ac.uk)  
██████████ [@bucks.ac.uk](mailto:██████████@bucks.ac.uk)  
██████████ [@bucks.ac.uk](mailto:██████████@bucks.ac.uk)  
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